Talking about personal recovery in bipolar disorder: Integrating health research, natural language processing, and corpus linguistics to analyse peer online support forum posts

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to all those who helped me along the way

für alle, die mir unterwegs geholfen haben

Abstract

Background: Personal recovery, 'living a satisfying, hopeful and contributing life even with the limitations caused by the illness' (Anthony, 1993) is of particular value in bipolar disorder where symptoms often persist despite treatment. So far, personal recovery has only been studied in researcher-constructed environments (interviews, focus groups). Support forum posts can serve as a complementary naturalistic data source.

Objective: The overarching aim of this thesis was to study personal recovery experiences that people living with bipolar disorder have shared in online support forums through integrating health research, NLP, and corpus linguistics in a mixed methods approach within a pragmatic research paradigm, while considering ethical issues and involving people with lived experience.

Methods: This mixed-methods study analysed: 1) previous qualitative evidence on personal recovery in bipolar disorder from interviews and focus groups 2) who self-reports a bipolar disorder diagnosis on the online discussion platform Reddit 3) the relationship of mood and posting in mental health-specific Reddit forums (subreddits) 4) discussions of personal recovery in bipolar disorder subreddits.

Results: A systematic review of qualitative evidence resulted in the first framework for personal recovery in bipolar disorder, POETIC (Purpose & meaning, Optimism & hope, Empowerment, Tensions, Identity, Connectedness). Mainly young or middle-aged US-based adults self-report a bipolar disorder diagnosis on Reddit. Of these, those experiencing more intense emotions appear to be more likely to post in mental health support subreddits. Their personal recovery-related discussions in bipolar disorder subreddits primarily focussed on three domains: Purpose & meaning (particularly reproductive decisions, work), Connectedness (romantic relationships, social support), Empowerment (self-management, personal responsibility). Support forum data highlighted personal recovery issues that exclusively or more frequently came up online compared to previous evidence from interviews and focus groups.

Conclusion: This project is the first to analyse non-reactive data on personal recovery in bipolar disorder. Indicating the key areas that people focus on in personal recovery when posting freely and the language they use provides a helpful starting point for formal and informal carers to understand the concerns of people diagnosed with bipolar disorder and to consider how best to offer support.

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TL;DR[1]: Thank you to the people with lived experience of bipolar disorder who shared their experiences publicly online and privately with me, to my supervisors, my family, and friends. Without you, I could not have written this thesis.

Pursuing this PhD has been both a professionally and personally challenging and rewarding endeavour. I am deeply grateful for all the fortunate circumstances and supportive beings that contributed to the success of this POETIC journey.

Purpose & meaning

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Optimism & hope

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Empowerment

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[1] Authors of longer Reddit posts often provide a 'Too long; didn't read' (TL;DR) as summary.

Travel

Having come full circle, Cardiff has been the first and last conference location on my PhD journey in the past four and a half years. In between I got to visit exciting and beautiful places such as Manchester, Florence, Hamburg, London, Bertinoro, and Philadelphia, and it probably would have been more had it not been for the pandemic. I would like to acknowledge the generous support from the UCREL centre, as well as the Lancaster University DHR, FHM, and postgraduate college travel funds who enabled me to spread the word about personal recovery in bipolar disorder around the world.

Identity

Being a (PhD) student has been a large part of my identity but not the only one. My colleagues at tooz know me as their organization talent and I thank them for making it so enjoyable to earn my living after my funding had run out but the research had not. 😉 A big shout out to the Proud@ZEISS community for making life on the Ostalb more colourful. I am also a mindfulness and yoga practitioner, pianist, and dancer and I bow to the teachers and communities who have been sharing their wisdom, skill, and joy with me so generously, the sangha of the Felsentor Zen centre for maintaining a beautiful sanctuary on a Swiss mountain, the Center for Mindful Self-Compassion, the mindfulness teachers Jack Kornfield & Trudy Goodman, my yoga teachers Adriene, Travis, and Ernst, my piano teachers Silvia Maurer and Silke, my tap dance teacher Ray Lnych and his Brooklyn Tap Gang, the Lancaster Lindy Circle, BluesKitchen Stuttgart, and my friends from the Black Forest, *obrigada*.

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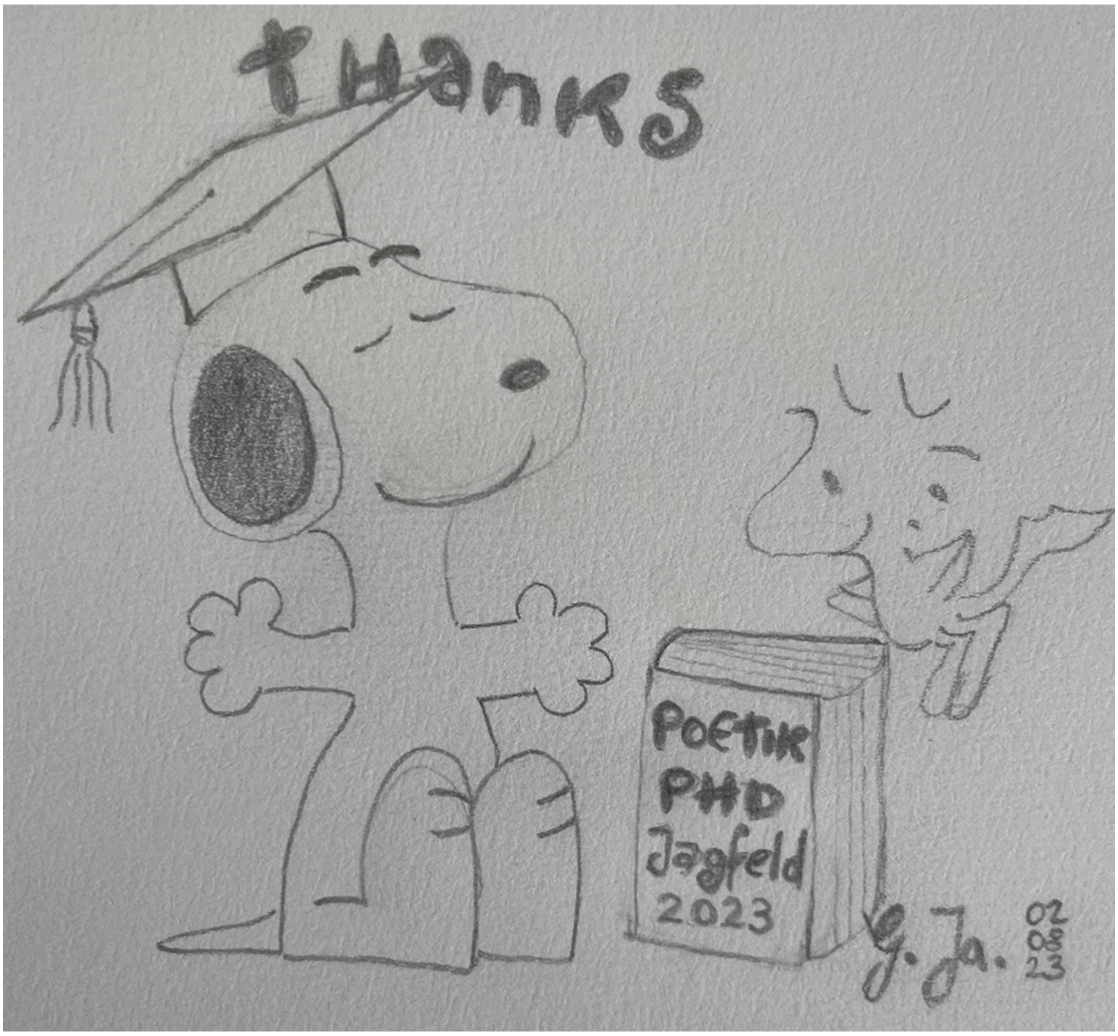
Glorianna Jagfeld Aalen, August 2023



Author’s declaration

Student declaration

I declare that this is my own work and has not been submitted in substantially the same form for the award of a higher degree elsewhere. I have submitted the following chapters of this thesis for peer-reviewed publication:

- Chapter 4: ‘Personal recovery in bipolar disorder: Systematic review and “best fit” framework synthesis of qualitative evidence – a POETIC adaptation of CHIME’ – published in Journal of Affective Disorders 2021;292.
- Chapter 5: ‘Understanding who uses Reddit: Profiling individuals with a self-reported bipolar disorder diagnosis’ – published in Proceedings of the Seventh Workshop on Computational Linguistics and Clinical Psychology: Improving Access at NAACL 2021.
- Chapter 6: ‘Posting patterns in peer online support forums and their associations with emotions and mood in bipolar disorder: exploratory analysis’ – at the time of thesis submission under review at PLOS ONE.
- Chapter 7: ‘How people with a bipolar disorder diagnosis talk about personal recovery in peer online support forums: corpus framework analysis using POETIC’ – at the time of thesis submission under review at JMIR Medical Informatics.

The following two publications were created as part of the project but are not included as parts of the thesis:

- Initial proposal for the project (peer-reviewed):

  Jagfeld Glorianna. ‘A Computational Linguistic Study of Personal Recovery in Bipolar Disorder’. In: Proceedings of the 57th Annual Meeting of the Association for Computational Linguistics: Student Research Workshop.; 2019:17-26.
- Protocol for the POETIC review (not peer-reviewed):

  Jagfeld Glorianna, Jones Steven, Lobban Fiona, Marshall Paul. ‘Lived experience of personal recovery in bipolar disorder: a systematic review and “best fit” framework synthesis of qualitative evidence’. PROSPERO 2019 CRD42019136978.

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Statement of authorship

The following authorship statements detail the contributions of all co-authors to each multi-authored manuscript. The PhD candidate, Glorianna Jagfeld (GJ), was the principal author of each chapter. Professor Steven Jones (SHJ) was the project's primary supervisor and Professor Fiona Lobban (FL) and Professor Paul Rayson (PER) were co-supervisors. Paul Marshall (PM), Dr. Ryan Boyd (RLB), Dr. Rob Davies (RD), and Chloe Humphreys (CH) contributed to research in this thesis and are co-authors of one chapter each. The following details the author contributions to each chapter:

Chapter 4: Personal recovery in bipolar disorder: Systematic review and "best fit" framework synthesis of qualitative evidence – a POETIC adaptation of CHIME by GJ, FL, MP, SHJ

GJ, SHJ, and FL designed the review and GJ wrote the protocol. GJ conducted literature searches, screening, and quality appraisal, with double-checking by PM. GJ coded all articles with auditing by FL and SHJ. GJ, FL, and SHJ interpreted the results. GJ wrote the first draft of the manuscript and all authors contributed to and have approved the final manuscript.

Chapter 5: 'Understanding who uses Reddit: Profiling individuals with a self-reported bipolar disorder diagnosis' by GJ, FL, PER, SHJ

Authors, GJ, FL, PER, SHJ had substantial contribution to the conception and design of the study. The principal author (GJ) primarily undertook the tasks involved in conducting this quantitative study with natural language processing methods, including applying for ethical approval, data collection, designing and conducting the manual annotation, implementation and application of natural language processing methods, analysis and writing up the manuscript. PER provided input on the evaluation and acted as second annotator in the manual annotation. FL, PER, and SHJ critically revised the manuscript for important intellectual content and provided input and reflections on interpreting the findings of the study.

Chapter 6: 'Posting patterns in peer online support forums and their associations with emotions and mood in bipolar disorder: exploratory analysis' by GJ, FL, RD, RLB, PER, SHJ

GJ led on the study design, supported by SHJ, FL, and PER. GJ collected the data, conducted the statistical analyses, and drafted the manuscript. RLB provided expert guidance on the Linguistic Inquiry and Word Count analysis and RD on the statistical analyses. All co-authors provided guidance throughout this study and commented on the draft manuscript. All the authors approved the final manuscript. SHJ, FL, and PER obtained the funding for this study.

Chapter 7: 'How people with a bipolar disorder diagnosis talk about personal recovery in peer online support forums: corpus framework analysis using POETIC' by GJ, FL, CH, PER, SHJ

GJ led on the study design, supported by SHJ, FL, and PER. GJ collected the data, conducted the analyses, and drafted the manuscript. SHJ and FL audited the analyses (PR relevance of posts, framework analysis of concordance lines). CH double-coded the PR relevance of posts and reviewed the paraphrasing of selected quotes. All co-authors discussed and agreed on the results, commented on the draft manuscript, and approved the final version. SHJ, FL, and PER obtained the funding for this study.

Co-author certifications

The signatures below provide certification from the other authors that the stated contributions to the thesis are accurate, and they grant permission for the candidate to include these manuscripts in this thesis.

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1 Introduction

‘You can't fix yourself out of a mental health issue. You can't wake up and say, *Today I'm not being depressed*! It's a process to get well, but there is recovery.’ (Trudeau, 2017)

Margaret Trudeau is a Canadian author, actor, photographer, and social advocate for people living with bipolar disorder, mother of Canadian prime minister Justin Trudeau, and former wife of former Canadian prime minister Pierre Trudeau. In her memoir ‘Changing My Mind’ (2011) she shares her personal experience of living with bipolar disorder.

1.1 Motivation and overview

People who experience marked mood fluctuations – episodes of depressed or elevated or irritable (hypomanic or manic) mood – causing distress and significant impairment in social or occupational functioning meet the criteria for a bipolar disorder (BD) diagnosis according to current diagnostic manuals in Western mental health (MH) systems (American Psychiatric Association, 2013; World Health Organization, 2016). BD is often associated with a decreased quality of life (Ishak *et al.*, 2012) and high risk of suicide (Novick, Swartz and Frank, 2010; Pompili *et al.*, 2013; Plans *et al.*, 2019). With the lifetime prevalence for bipolar spectrum disorders ranging from 0.1% (India) to 4.4% (US) (Merikangas et al., 2011), this causes a large burden for global populations (He et al., 2020) and makes BD prevention and treatment important tasks for society. However, a substantial group of people with a BD diagnosis also shows positive outcomes, a high level of functioning (Akers *et al.*, 2019), and increased desirable psychological characteristics such as spirituality, empathy, creativity, realism, and resilience (Galvez, Thommi and Ghaemi, 2011).

BD symptoms often persist despite treatment (Goldberg, Garno and Harrow, 2005) and even symptom-free individuals often do not regain full social and occupational functioning (Strakowski *et al.*, 1998; Tohen *et al.*, 2003). Therefore, in current Western MH systems, some people living with BD never achieve clinical recovery (Forster, 2014; NICE, 2014; U.S. Department of Health and Human Services: The National Institute of Mental Health, 2016), which is defined in terms of reduced symptom severity and improved socio-occupational functioning (Torgalsbøen, 1999; Liberman and Kopelowicz, 2002). People with lived experience of severe MH issues have been advocating for a different notion of recovery based on individually-defined criteria and self-reported life satisfaction (Deegan, 1988; Anthony, 1993). Personal recovery (PR) (Slade, 2009) is ‘a way of living a satisfying, hopeful and contributing life even with the limitations caused by the illness’ (Anthony, 1993).

A body of qualitative and quantitative research has shown the importance of PR for individuals diagnosed with BD (Jones, Lobban and Cook, 2010; Mansell *et al.*, 2010; Jones, Mulligan, *et al.*, 2013; Jones *et al.*, 2015; Morrison *et al.*, 2016b; Tyler *et al.*, 2016; Murray *et al.*, 2017), but most PR research has focused on psychotic disorders (Van Weeghel *et al.*, 2019). A meta-review of conceptualisations of PR in severe MH issues concluded: 'Striking gaps in our knowledge relate to how PR processes take place in people with mood disorders' (Van Weeghel *et al.*, 2019).

Additionally, previous research on PR in BD has mainly involved small samples and only used structured data collection methods such as semi-structured interviews, focus groups, and questionnaires. With these methods, researchers have an important influence on data production, which can lead to interviewer bias (Briggs, 1986). Naturalistic data collection, where 'participants are not aware that they are being studied' (Fielding *et al.*, 2016) offers a counterbalance to structured settings but requires careful consideration of ethical issues (see Section 3.4). Online posts written by people outside a research context are a form of naturalistic data and can offer potential insights into 'an experience as it is lived rather than as it is enacted in the researcher constructed environment' (Seale *et al.*, 2010, p. 600). Indeed, a systematic review suggested considering first-hand accounts by individuals with lived experience of severe MH issues from blog posts, tweets, and discussion forums as a critical step for PR research (Stuart, Tansey and Quayle, 2017). Online posts by people with lived experience of BD are easily accessible and available in large quantities. For example, nearly 9K unique user accounts posted in May 2020 on the public online discussion platform Reddit in the four largest BD-specific subforums[2]. The number of posts in these forums increased from 45K posts in January 2019 to 54K in January 2020.

Some health researchers have analysed online posts by people with lived experience of BD, although not in relation to PR (e.g., Vayreda and Antaki, 2009; Mandla, Billings and Moncrieff, 2017; Sahota and Sankar, 2019). Most of these approaches were qualitative manual analyses of small samples. Natural language processing (NLP) (e.g., Jurafsky and Martin, 2009) provides methods to process and extract information from large amounts of language data. Additionally, corpus linguistics (e.g., McEnery and Hardie, 2011; Rayson, 2015) provides a mix of qualitative and quantitative methods to analyse large amounts of language data that can go beyond analysis of small samples feasible with traditional qualitative research methods. Analysing online posts by people with lived experience of BD via a combination of health research, NLP, and corpus linguistic methods may have the potential to advance the understanding of PR in BD.

Figure 1 summarises the conceptual framework (Miles and Huberman, 1984, p. 33; Creswell and Plano Clark, 2018, Section 2.3) for this thesis. The following sections cover the core concepts related to BD (Section 1.2), PR (Section 1.3), and language analysis (Section 1.4), each concluding with a critical summary. Section 1.5 closes this chapter by situating this thesis in the context of previous work, stating the aim and research questions (RQs), and outlining the thesis structure.

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[2] r/bipolar, r/BipolarReddit, r/bipolar2, r/bipolarSOs

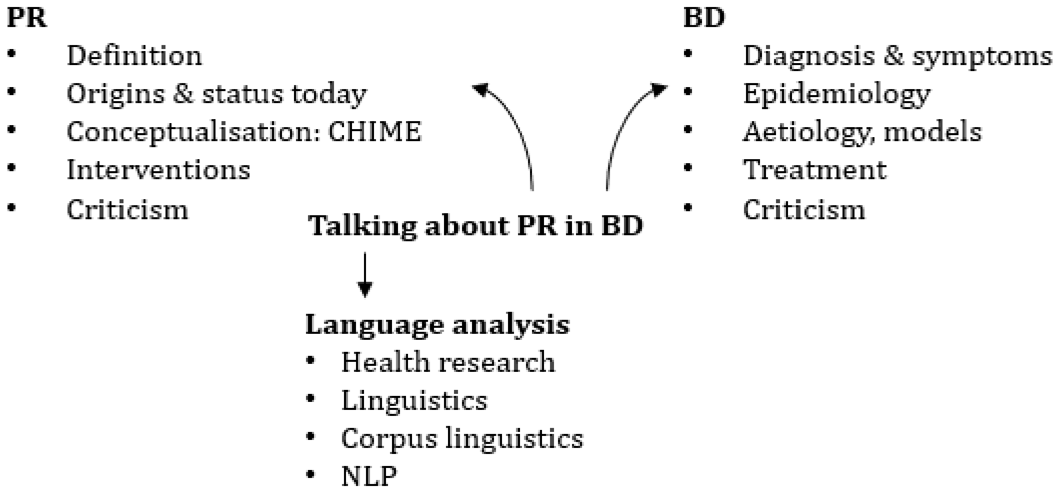

Figure 1 Conceptual framework of this thesis

1.2 Bipolar disorder

This section outlines the diagnosis of BD, the symptoms, epidemiology (distribution, causes, and risk factors of the diagnosis in the population), main treatments, and the debates around these aspects. It draws on clinical guidelines[3], systematic reviews and meta-analyses, and large international multi-site studies. Only where such pooled evidence is not available, it cites individual studies. It concludes by justifying the view on BD in this thesis.

1.2.1 Diagnosis and symptoms

Descriptions of extreme mood experiences exist at least since antiquity (Goodwin *et al.*, 2016) as reflected in the Greek and Roman terms *mania* for elated and *melancholia* for low mood (Baldessarini *et al.*, 2015, p. 3). The concept of BD as a diagnostic entity in Western psychiatry traces back to Kraepelin's (1921) distinction between affective and non-affective psychosis. The former, he called manic-depressive psychosis, which maps to the current concepts of BD and unipolar psychotic depression, and the latter dementia praecox, nowadays called schizophrenia or psychotic disorder. Kraepelin believed in biological causes for psychotic experiences. This contrasted with the Freudian view that MH problems arise from the unconscious, which dominated Western psychology throughout most of the twentieth century (Trede, 2007).

Today, Western psychiatry most directly links experiences of both extreme high and low mood to the diagnostic category BD in the two main diagnosis manuals, the Diagnostic and statistical manual of mental disorders (DSM) (American Psychiatric Association, 2013)) and the International Classification of

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[3] National Institute for Health and Care Excellence in the UK (NICE, 2014), British Association for Psychopharmacology (Goodwin *et al.*, 2016), German societies for BD, and psychiatry and psychotherapy (DGBS e.V. and DGPPN e.V., 2019)

Diseases (ICD) (World Health Organization, 2016). The American Psychiatric Association first published the DSM in 1952. The DSM-III (American Psychiatric Association, 1980) first introduced criteria for mood episodes and separated unipolar and bipolar depression, establishing the diagnosis of BD in place of the previously common term *manic depression* (Mason, Sherwood Brown and Croarkin, 2016, p. 4). The current version is the fifth edition, DSM-5 (American Psychiatric Association, 2013). ICD, conversely, encompasses diagnoses for physical as well as MH issues. It originated from the International List of Causes of Death by the International Statistical Institute in 1893. Since its first version in 1948, the World Health Organisation governs its development. ICD is currently in its 11th iteration (ICD-11). EU countries generally rely on the ICD for MH diagnoses (European Commission, 2020), whereas most English-speaking countries, including the UK and US, use the DSM.

In the DSM-5 'Bipolar and related disorders' form their own chapter (American Psychiatric Association, 2013, p. 123) and consist of the main diagnoses bipolar I disorder, bipolar II disorder, cyclothymic disorder, substance/medication-induced bipolar and related disorder, bipolar and related disorder due to another medical condition, other specified bipolar and related disorder, and unspecified bipolar and related disorder. The only requirement for a diagnosis of bipolar I disorder is at least one lifetime manic episode (American Psychiatric Association, 2013, p. 126), whereas bipolar II disorder requires at least one hypomanic and one major depressive episode (American Psychiatric Association, 2013, p. 132). Cyclothymic disorder applies to numerous periods of hypomanic and depressive symptoms during at least two years that do not meet criteria for hypomanic or major depressive episodes (American Psychiatric Association, 2013, p. 139).

The ICD-11 groups 'Bipolar or related disorders' in the section 'Mood disorders' next to 'Depressive disorders' in the chapter 'Mental, behavioural or neurodevelopmental disorders' (World Health Organisation, 2018). One of the goals for this chapter was to 'minimize random or arbitrary differences between the ICD-11 and DSM-5, although justified conceptual differences were permitted' (Reed *et al.*, 2019, p. 4). Indeed, the ICD-11 contains the same main diagnoses as DSM-5 of bipolar type I disorder, bipolar type II disorder, and cyclothymic disorder, and bases them on criteria for manic, hypomanic, and depressed episodes. As a major conceptual difference, ICD-11 describes essential features of mood episodes, subject to clinical judgment, instead of strict diagnostic criteria such as symptom counts and duration cut-offs in DSM-5 (Angst, Ajdacic-Gross and Rössler, 2020). In a re-analysis of an epidemiological study (Angst, Ajdacic-Gross and Rössler, 2020), the prevalence of mania was equal for DSM-5 and ICD-11 criteria, but hypomania was more frequent according to ICD-11.

Table 1 summarises the diagnostic criteria for a manic, hypomanic, and depressive episode according to the DSM-5 and ICD-11. It is worth noting that almost all symptom definitions rely on subjective reporting and require comparison to the individuals' experiences and behaviour prior to the onset of a suspected episode.

Table 1 Criteria for a manic, hypomanic, and major depressive episode slightly simplified from DSM-5 (American Psychiatric Association, 2013, p. 124-125) and ICD-11 (World Health Organisation, 2018)

Manic episode	Hypomanic episode	Major [ICD-11: Mild, moderate, or severe] depressive episode
Description		
Distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity or energy		Period of almost daily depressed mood or diminished interest in activities with additional symptoms (see below)
Duration		
At least 7 days or requiring hospitalisation	At least 4 days [ICD-11: ‘several’]	At least 14 days
Symptoms		
At least three [ICD-11: ‘several’] symptoms must be present (at least four if only irritable mood) most of the day, nearly every day: 1. Inflated self-esteem or grandiosity 2. Decreased need for sleep (e.g., feels rested after only three hours of sleep) 3. More talkative than usual or pressure to keep talking 4. Flight of ideas or subjective experience that thoughts are racing 5. Distractibility (i.e., attention too easily drawn to unimportant or irrelevant external stimuli), as reported or observed		At least five symptoms [ICD-11: number and intensity of symptoms determines mild/moderate/severe] (one of which must be (1) or (2)) must be present most of the day, nearly every day (except for 9); (1, 2, 8) can be indicated by subjective report or observation of others 1. Depressed mood (e.g., feels sad, empty, hopeless, or appears tearful) 2. Markedly diminished interest or pleasure in all, or almost all, activities 3. Significant weight loss when not dieting or weight gain (e.g., more than 5% of body weight change in a month) or decrease/increase in appetite 4. Insomnia or hypersomnia

<table>
<tr><th>Manic episode</th><th>Hypomanic episode</th><th>Major [ICD-11: Mild, moderate, or severe] depressive episode</th></tr>
<tr><td colspan="2">6. Increase in goal-directed activity (either socially, at work or school, or sexually) or psychomotor agitation (i.e., purposeless non-goal-directed activity)
7. Excessive involvement in activities that have a high potential for painful consequences (e.g., unrestrained buying sprees, sexual indiscretions, foolish business investments)</td><td rowspan="2">5. Psychomotor agitation or retardation (observable by others; not merely subjective feelings of restlessness or being slowed down).
6. Fatigue or loss of energy
7. Feelings of worthlessness or excessive or inappropriate guilt (may be delusional, not merely self-reproach or guilt about being sick)
8. Diminished ability to think or concentrate, or indecisiveness
9. Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, a suicide attempt, or a specific plan for committing suicide</td></tr>
<tr><td>ICD-11: 8. rapid changes among different mood states (i.e., mood lability)</td><td></td></tr>
<tr><th colspan="3">Impairment</th></tr>
<tr><td>Marked impairment in social or occupational functioning [DSM-5: or requires hospitalisation to prevent (self-) harm] or psychotic features</td><td>Unequivocal change in functioning uncharacteristic of asymptomatic individual, [DSM-5: observable by others], not severe enough to cause marked impairment in social or occupational functioning, [DSM-5: or require hospitalisation], no psychotic features</td><td>DSM-5 major depressive episode: Clinically significant distress or impairment in social, occupational, or other important areas of functioning
ICD-11:
Mild: some, but not considerable, difficulty in continuing with ordinary work, social, or domestic activities; no delusions or hallucinations
Moderate: considerable difficulty in continuing with work, social, or domestic activities, but is still able to function in at least some areas
Severe: unable to function in personal, family, social, educational, occupational, or other important domains, except to a very limited degree</td></tr>
<tr><th colspan="3">Cause</th></tr>
<tr><td colspan="3">Episode not attributable to the physiological effects of a substance or a medical condition</td></tr>
</table>

1.2.2 Epidemiology, impacts, and comorbidities

Data in this section mainly stems from a meta-analysis on the prevalence and burden of BD of 14 epidemiological studies from ten EU countries (Pini *et al.*, 2005) and the World Health Organisation World Mental Health Survey of 60K community adults across 11 European, American, and Asian countries with DSM-IV criteria (Merikangas *et al.*, 2011).

1.2.2.1 Epidemiology

Epidemiological studies estimate the lifetime prevalence, the share of respondents that met diagnostic criteria at some point in their life up to the time of assessment (Merikangas and Peters, 2010, p. 52), for BD type I or II to be about 1%-2% (Pini *et al.*, 2005; Merikangas and Peters, 2010; Goodwin *et al.*, 2016), with 0.5%-1% for BD type I according to DSM-IV criteria (Merikangas *et al.*, 2011; Clemente *et al.*, 2015; Goodwin *et al.*, 2016) and 0.5%-1.6% for BD type II (Merikangas *et al.*, 2011; Clemente *et al.*, 2015). For bipolar spectrum disorder, which also includes subthreshold BD, the lifetime prevalence rises to between 2.4% (Merikangas *et al.*, 2011) and 6% (Pini *et al.*, 2005; DGBS e.V. and DGPPN e.V., 2019), depending on the inclusiveness of the criteria. Lifetime prevalence for bipolar spectrum disorders is approximately 2% for the UK (McManus *et al.*, 2016) and ranges from 0.1% (India) to 4.4% (US) across 11 European, American, and Asian countries (Merikangas et al., 2011). The twelve-month incidence, the number of new cases during this time interval, of BD is 1.2%-1.5% in the international average (Merikangas *et al.*, 2011; Clemente *et al.*, 2015).

The age of onset is most frequently in late adolescence and early adulthood (Pini *et al.*, 2005; Merikangas *et al.*, 2011). Children are increasingly diagnosed with BD as well, particularly in the US (Jairam, Prabhuswamy and Dullur, 2012, p. 5), although this is contentious (Goodwin *et al.*, 2016). BD overall is equally frequent in men and women (Pini *et al.*, 2005; American Psychiatric Association, 2013), but type II may be slightly more frequent in women (Merikangas *et al.*, 2011; American Psychiatric Association, 2013). The World Health Organisation Mental Health Survey found no significant differences in BD rates according to marital status, employment status, and family income (Merikangas *et al.*, 2011).

BD is characterised by a risk of recurrences, although trajectories are very variable and predictions about the course and outcome of individuals are difficult according to the current state of knowledge (Treuer and Tohen, 2010). The estimated duration of any type of mood episode is one to three months in population-based epidemiological studies and more than three months in clinical samples (Pini *et al.*, 2005). After a first manic episode, about 40% of people experience a further mood episode within one year, and 60% within four years (Gignac *et al.*, 2015).

1.2.2.2 Impacts and comorbidities

BD is a large cause of burden for the global population and health systems (He *et al.*, 2020). It was the 16th leading cause for years lived with disability in the World Health Organisation Global Burden of Disease study (Ferrari *et al.*, 2016). Among

MH issues, it was the fifth leading cause of disability-adjusted life years following major depressive disorder, anxiety disorders, schizophrenia, and alcohol use disorders (Ferrari *et al.*, 2016). This is mainly due to a decreased quality of life, including the overall sense of wellbeing, and subjective physical, psychological, and social functioning, for people with a BD diagnosis compared to the general population (Ishak *et al.*, 2012). For example, 50%-75% of people who experienced a mood episode in the previous year reported severe role impairment (Merikangas *et al.*, 2011, p. 6). Functioning tends to remain impaired longer after symptom remission and prolonged euthymic (symptom free) periods, partly due to persisting subsyndromal mood symptoms (Gitlin and Miklowitz, 2017). However, a recent review of functioning in BD found that 16% of people exhibit good to excellent social and occupational functioning (Akers et al., 2019).

BD is associated with a high risk of suicide attempts, with more than 30% of people reporting a lifetime suicide attempt retrospectively (Novick, Swartz and Frank, 2010). Also, the risk of completed suicide is 10-30 times higher for people with a BD diagnosis than in the general population (Pompili *et al.*, 2013; Dome, Rihmer and Gonda, 2019; Plans *et al.*, 2019). People with a BD diagnosis often experience other MH problems, most commonly anxiety disorders, obsessive-compulsive disorder, and substance abuse (Merikangas and Peters, 2010, p. 56). BD is also associated with a greater risk of certain physical health issues, especially cardiovascular diseases, migraine, and diabetes (Merikangas and Peters, 2010, p. 56).

Individuals with BD symptoms often get misdiagnosed (Hirschfeld, Lewis and Vornik, 2003) or remain undiagnosed for up to ten years on average (DGBS e.V. and DGPPN e.V., 2019, p. 25; The Bipolar Commission, 2022, p. 9). According to a meta-analysis, on average six years passed between the onset of BD symptoms and their management (Dagani *et al.*, 2017).

1.2.3 Aetiology and models of bipolar disorder

Research so far cannot fully explain the aetiology (causes) of BD (Pfennig et al., 2017; DGBS e.V. and DGPPN e.V., 2019, p. 24). The biggest risk factors for the development of BD symptoms are a family history of BD, childhood anxiety, sleep problems, subthreshold (hypo-)manic symptoms and certain personality traits (Pfennig et al., 2017). First-degree relatives of people with a BD diagnosis have a ten times higher risk to meet BD criteria as well (Smoller and Finn, 2003). Conversely, about 60% of people who meet criteria for BD have a first-order relative with an affective severe MH issue (Baldessarini *et al.*, 2012, p. 43). However, to date, genetic research has not found any genes consistently and exclusively associated with BD, but rather a number of small genetic variations that are also associated with an increased vulnerability for psychotic and major depressive disorder (Craddock and Sklar, 2013; Goodwin *et al.*, 2016). Moreover, not all monozygotic twins always both experience BD symptoms, indicating the importance of environmental factors (Smoller and Finn, 2003, p. 53). There has also been research on other potential biological risk factors, including the hormonal system (e.g., Meinhard, Kessing and Vinberg, 2014; Gogos *et al.*, 2019), structural and functional brain abnormalities (e.g., Hajek, Carrey and Alda, 2005), and chemical imbalances in the brain (e.g., Dogan *et al.*, 2018) but this has not been conclusive.

The current understanding in most research and Western health systems for the development and persistence of BD symptoms underlies a multifactorial bio-psycho-social model (Goodwin and Jamison, 2007). It is based on the diathesis (vulnerability)-stress model, which posits that stressful life events may trigger mood episodes for people with an increased vulnerability, which may be due to genetic factors or previous adverse life events (Nuechterlein and Dawson, 1984; Lam, Jones and Hayward, 2010). There are indications for two biological factors: increased vulnerability to circadian (wake-sleep) rhythm disruptions (Murray and Harvey, 2010) and dysregulation of the behavioural activation system, responsible for reward- and goal-striving behaviour (Depue and Iacono, 1989; Urošević *et al.*, 2008; Alloy *et al.*, 2012; Dempsey, Gooding and Jones, 2017; Kwan *et al.*, 2020). Psychological factors linked to BD are dysfunctional attitudes, such as basing one's self-worth on others' appraisal or being perfect, and negative appraisals of events (Alloy *et al.*, 2006), maladaptive response styles or coping strategies for mood changes such as rumination, risk-taking or distraction (Silveira and Kauer-Sant'Anna, 2015; Dodd *et al.*, 2019), and problematic appraisal of mood changes or sleep disruptions (Jones, 2001; Jones, Mansell and Waller, 2006; Jones and Day, 2008). Social factors are relationship and socioeconomic status (Tsuchiya, Byrne and Mortensen, 2003, p. 235), social support from family and friends (Aldinger and Schulze, 2017, p. 12), (childhood) trauma (Aldinger and Schulze, 2017, p. 12), and stigma (Ellison, Mason and Scior, 2013; Hawke, Parikh and Michalak, 2013). Lam Jones and Hayward (2010) discuss bio-psycho-social models for BD that hypothesise how biological and psychological vulnerabilities might interplay with life stressors in the development of mood episodes.

1.2.4 Treatment

Various guidelines for professional treatment of BD exist internationally[4]. This section mainly draws on three guidelines by the National Institute for Health and Care Excellence (NICE, 2014) and the British Association for Psychopharmacology (Goodwin *et al.*, 2016) in the UK and the societies for BD, and psychiatry and psychotherapy in Germany (DGBS e.V. and DGPPN e.V., 2019). Treatment recommendations differentiate between short-term treatment for acute mood episodes and long-term treatment to prevent further episodes. All three guidelines recommend medication to treat (hypo-)manic episodes and for long term prevention. For long term treatment, they recommend non-pharmacological interventions such as psychoeducation, psychotherapy, and family interventions, in addition to medication. The National Institute for Health and Care Excellence (2014, Section 23) also first recommends psychological interventions for bipolar depression because antidepressants may lead to elated mood. Notably, a survey of 60K households in eleven European, American, and Asian countries found that less than half of the people meeting BD criteria received MH treatment, in low-income

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[4] See https://cpnp.org/guideline/external/bipolar for an overview.

countries even less than a quarter (Merikangas *et al.*, 2011). This highlights that the actual care people receive often differs from clinical guidelines.

1.2.4.1 Pharmacological and other somatic treatments

Three groups of medication are most commonly prescribed to treat BD symptoms (DGBS e.V. and DGPPN e.V., 2019, pp. 82–83). Mood stabilisers, mainly lithium as first line treatment (NICE, 2014, p. 27) and also the anticonvulsants valproate and lamotrigine (DGBS e.V. and DGPPN e.V., 2019), are prescribed for acute (hypo-)manic symptoms and as long-term preventative treatment for mood episodes. Antipsychotics, such as olanzapine, quetiapine, or risperidone (DGBS e.V. and DGPPN e.V., 2019, p. 83), are prescribed in acute (hypo-)manic episodes (NICE, 2014, p. 21) and sometimes also as long term preventative treatment if lithium is not effective (NICE, 2014, p. 28). Antidepressants such as fluoxetine (Goodwin *et al.*, 2016), are sometimes prescribed to treat acute depressed episodes, but may need to be stopped if the individual develops (hypo-)manic symptoms (NICE, 2014; Goodwin *et al.*, 2016).

Electroconvulsive therapy is a non-pharmacological biological treatment that electrically induces seizures in anesthetized patients, typically delivered in 6-12 sessions over the course of a few weeks (DGBS e.V. and DGPPN e.V., 2019, p. 93). Guidelines recommend electroconvulsive therapy for severe cases of mania that do not respond to medication (NICE, 2014; Goodwin *et al.*, 2016; DGBS e.V. and DGPPN e.V., 2019, p. 173) and severe depression (Goodwin *et al.*, 2016, p. 528; DGBS e.V. and DGPPN e.V., 2019, p. 231). However, there is little robust evidence to support these recommendations and they are partly due to a lack of treatment alternatives (DGBS e.V. and DGPPN e.V., 2019, p. 172). Randomised controlled trials[5] that compared real to sham electroconvulsive therapy showed only minimal effectiveness for major depressive or psychotic disorder during treatment and were ineffective in follow ups. There is strong evidence for persistent, sometimes permanent brain dysfunction (amnesia) following electroconvulsive therapy and the small risk of death due to anaesthesia (Read and Bentall, 2010; Read, Kirsch and McGrath, 2020).

1.2.4.2 Psychosocial treatments

All guidelines recommend psychological interventions in addition to pharmacological long-term treatment (Goodwin *et al.*, 2016, p. 506). They stress the complementary roles of both treatments (Goodwin *et al.*, 2016, p. 497), but emphasize that there is currently no evidence base to treat BD without medication (DGBS e.V. and DGPPN e.V., 2019, p. 84). There is currently no effective psychological therapy for acute mania (Goodwin *et al.*, 2016, p. 502).

The guidelines recommend *psychoeducatio*n as well as *family focused, cognitive behavioural*, and *interpersonal social rhythm therapy* as evidence-based psychosocial BD treatments (Goodwin *et al.*, 2016, p. 506; Meyer, 2016; DGBS e.V.

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[5] Randomised controlled trials measure the effectiveness of an intervention or treatment by randomly allocating the participants either to a treatment or control group (e.g., Straus *et al.*, 2018).

and DGPPN e.V., 2019, p. 87). *Psychoeducation* (Colom and Vieta, 2006) provides information about BD and its treatment to manage risk factors, avoid relapses, and increase compliance with pharmacological treatment, typically in a group setting (Division 12 of the American Psychological Association, 2016d). It forms the first part of family focused and cognitive behavioural therapy for BD. *Family focused therapy* (Miklowitz, 2010) addresses overly negative family interactions as trigger for mood episodes. It includes all immediate family members and teaches communication and problem-solving skills to resolve family problems (Division 12 of the American Psychological Association, 2016b). *Cognitive behavioural therapy* (Otto *et al.*, 2009; Lam, Jones and Hayward, 2010; Meyer and Hautzinger, 2013) focuses on identifying and challenging maladaptive negative thoughts about the self in individual or group settings (Division 12 of the American Psychological Association, 2016a). *Interpersonal social rhythm therapy* (Frank, 2005) works with individuals or groups to enhance the regularity of daily routines as sleep and schedule disruptions often trigger mood episodes in BD (Division 12 of the American Psychological Association, 2016c). The interpersonal component aims to resolve current interpersonal problems such as grief, disputes, role transitions, and isolation (Division 12 of the American Psychological Association, 2016c).

A meta-analysis found evidence for group psychoeducation, individual psychological therapies, particularly cognitive behavioural therapy, and family focused therapy, but not interpersonal social rhythm therapy to reduce BD relapse rates (Oud *et al.*, 2016). There was not enough evidence for a general superiority of any one psychosocial intervention (Oud *et al.*, 2016) and this may be more of a question of matching individuals to treatments (e.g., Meyer and Hautzinger, 2012).

1.2.5 Criticism of the concept of bipolar disorder

There are three main lines of criticism that challenge the notion of BD as a distinct entity as defined in the DSM and ICD. Firstly, field trials for BD diagnoses with DSM-5 criteria in the US and Canada showed only moderate agreement between two clinicians (kappa=0.56 for bipolar type I and 0.4 for bipolar type II) (Freedman *et al.*, 2013). While clinic-based field trials in 13 countries with ICD-11 criteria showed high agreement for BD diagnoses (kappa=0.84 (0.62) for bipolar type I (II) (Reed *et al.*, 2018), a large-scale online study with standardised case vignettes showed that the distinction between bipolar type I and II is problematic in ICD-11 (Kogan *et al.*, 2021).

Secondly, there is evidence for large overlaps in symptoms and potentially indicative genes for psychotic, major depressive and bipolar disorder (Peralta and Cuesta, 2008; Van Os and Reininghaus, 2016; Guloksuz and Van Os, 2018). This suggests that these types of severe MH issues may form a continuum rather than distinct categories as in the transdiagnostic psychotic or schizoaffective spectrum (Van Os and Reininghaus, 2016; Guloksuz and Van Os, 2018) illustrated in Figure 2. This also ties in with calls to base research and treatment on individual symptoms, e.g., depressed mood or auditory hallucinations, and not diagnostic labels, which often represent very heterogeneous groups (e.g., Kinderman *et al.*, 2013).

Figure 2 Continuum hypothesis of psychotic and mood symptoms

Thirdly, there is good evidence that most human experiences, including mood, occur on a spectrum or continuum from common (what is considered normal or healthy) to more extreme (often considered abnormal, ill, or pathological) (Jones and Bentall, 2006). Figure 3 illustrates a dimensional view of MH issues, exemplarily assuming a Gaussian distribution of continuous liability in the general population for a MH symptom such as anxiety, depression, (hypo-)mania, or psychotic experiences (Guloksuz and Van Os, 2018). Arguably, duration criteria like 'at least 4 days' to define a hypomanic episode in the DSM-5 (American Psychiatric Association, 2013) are arbitrary cut-off points (Goodwin *et al.*, 2016, p. 508). Conceptualising liability for specific MH symptoms on individual continua as, e.g., a psychosis susceptibility syndrome, may be scientifically more accurate and could help to reduce stigma (Van Os, 2016; Guloksuz and Van Os, 2018).

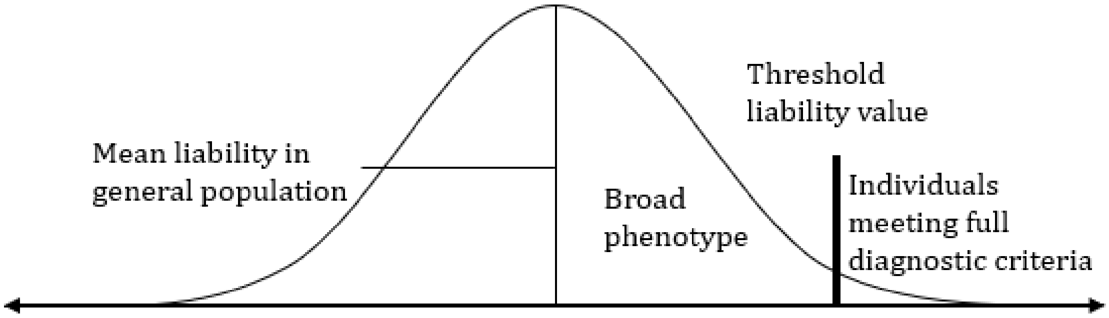

Figure 3 Dimensional view of MH issues (adapted from Guloksuz and van Os, 2018, Figure 2)

Proponents of anti-psychiatry and critical psychiatry (Middleton and Moncrieff, 2019) argue that the expansion of psychiatric diagnoses, including BD, 'medicalises personal and social difficulties' (Moncrieff, 2014, p. 581). However, MH systems may need criteria to determine who deserves what level of support given financial and workforce limitations. For example, the German public health insurance system only compensates psychotherapy for those with a MH diagnosis based on the ICD. Similarly, the UK National Health System largely bases care pathways on DSM diagnoses. Also, distinct categories make it easier in clinical practice to describe common sets of symptoms and group together people that may benefit from the same treatment (Slade, 2009). Qualitative research has found diverging and ambivalent experiences of individuals who received a BD diagnosis. For some this imposed stigma and negative prospects (Warwick *et al.*, 2019), while for others it provided a useful framework to understand difficult experiences and to get help (The Bipolar Commission, 2022).

1.2.6 Summary

BD is a severe MH issue diagnosis, characterised by periods of depressed and (hypo-)manic mood that impair socio-occupational functioning. Importantly, BD is a human-defined concept based on behavioural criteria and there is no brain or gene test to detect it. BD is common around the world, with a lifetime prevalence of around one percent, and constitutes a large burden for the global population and healthcare systems. However, all statistics on the outcome of BD allow for a negative or positive framing, as in either emphasising that 60% of people will relapse after a first manic episode within four years (Gignac *et al.*, 2015) or that 40% will remain without further episodes for at least four years. A substantial group of people meeting BD criteria has positive outcomes and a high level of functioning (Akers *et al.*, 2019). Additionally, there is also evidence for increased or intensified desirable psychological characteristics due to (having lived) with intense mood experiences, notably spirituality, empathy, creativity, realism, and resilience (Galvez, Thommi and Ghaemi, 2011). Furthermore, there is large variability in terms of clinical severity, risk of recurrence, and cognitive and functional impairment among people who meet BD criteria, which the substantive research efforts to date have not been able to fully explain. This suggests the limited utility of population-level prognoses for the treatment of individuals (Martino *et al.*, 2016). Clinical studies that recruit people who are in contact with MH services may have a selection bias and overlook individuals who fare well and therefore do not access formal support (anymore).

There is valid criticism of the current mainstream practice in Western MH systems and research which evaluates peoples' complex experiences into binary healthy vs. pathological categories and classifies pathological experiences into distinct MH diagnoses, including BD. Nevertheless, this thesis uses the label BD as defined in the DSM-5 and ICD-11 to describe the experiences it studies for pragmatic reasons. All studies in this thesis include individuals who self-report having received a BD diagnosis by a health professional. This inclusion criterion tries to maintain some level of conceptual clarity and homogeneity of experiences, while acknowledging that it omits extreme mood experiences of people who never sought a MH diagnosis or that fall outside the boundaries of diagnostic criteria. As a second way to limit heterogeneity, this thesis focuses only on adults. Controversies around BD diagnoses for children prevail and children and adolescents with extreme mood experiences may have specific problems and needs that deserve separate research.

1.3 Personal recovery

This section introduces the concept of PR in severe MH issues and specifically BD. Starting off with the definition of PR in this thesis in Section 1.3.1, Section 1.3.2 then presents a short historical sketch of how PR developed and its status in Western MH systems today. Next, this section discusses conceptualisations of PR and related concepts (Section 1.3.3), ways to implement PR orientation in MH care (Section 1.3.4), and criticism of the concept (Section 1.3.5). Section 1.3.6 concludes with a summary of shortcomings in previous research on PR in BD and how this thesis aims to address them.

1.3.1 Personal recovery definition

Individuals with lived experience of severe MH issues increasingly published first-person accounts of their struggles to recovery in the 1980s and early 90s, trying to bring about a change in the UK and US MH systems (e.g., Spaniol and Koehler, 1994). Most individuals had experienced psychosis (e.g., Houghton, 1982; Deegan, 1988, 1996; Unzicker, 1989), but voices of people with lived experience of extreme mood followed later (e.g., O'Hagan, 1996; Mead and Copeland, 2000).

Importantly, these authors advocated for a different conception of MH recovery than the one predominant in MH systems as well as clinical psychology and psychiatric research at that time. William Anthony summarised this position in his seminal paper 'Recovery from mental illness: the guiding vision of the mental health system in the 1990s', which is the definition of PR in this thesis: 'Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even with the limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness' (Anthony, 1993).

Slade (2009) coined the term *personal recovery* in the UK, which this thesis uses instead of recovery for the sake of conceptual clarity[6]. He summarises PR based on qualitative research by Repper and Perkins (2003) in the UK and Ralph (2005) in the US: 'Recovery involves a journey from disengagement to engagement, from surviving to living and growing. Although awareness of the journey often starts in adversity, such as mental illness, the journey is not about the adversity. Although the journey of recovery has many routes, and each person's journey is unique, it often involves finding the courage to hope for a good future and to relate to yourself and others in beneficial ways. Setbacks are inevitable, but the challenge is universal.' (Slade, 2009, p. 39). Anthony's (1993) and Slade's (2009) definitions share three central points: First, 'even with the limitations caused by the illness' and 'not about the adversity' point to the fact that MH symptoms do not preclude PR. Empirical research has shown that PR and symptom improvements are correlated – but not perfectly (Jones, Mulligan, *et al.*, 2013). Therefore, this thesis refers to PR *in* (rather than *from*[7]) BD to stress that people can experience PR alongside symptoms. Second, PR is 'deeply personal‘ and 'unique' and therefore pre-defined criteria such as clinical symptoms cannot adequately capture it. Finally, PR is a not an outcome or discrete state, but instead an ongoing 'process' or 'journey'.

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[6] Current research literature and policy documents often do not clearly define their understanding of recovery, which must be inferred from the context. This thesis only uses the simple term recovery when discussing literature that does not refer to PR.

[7] Despite the title "Recovery *from* mental illness", the characterisation of recovery alongside "limitations caused by the illness" in Anthony's (1993) seminal paper is very much in line with PR *in* MH issues.

1.3.2 Origins and current status of personal recovery

1.3.2.1 History of personal recovery

The idea of recovery in severe MH issues beyond and independent from symptom reduction had been around for much longer before the 1990s (Allott, Loganathan and Fulford, 2002). Roberts and Wolfson (2004) trace the concept back to the 'moral treatment' approach in MH care based on compassion, respect and hope of recovery established by the Quaker family Tuke in York (UK) in the 19th century (Tuke, 1813). This was in stark contrast to violent medical practices and a view of people with severe MH issues not as humans but wild beasts common at that time as described by, e.g., Glover (1984, pp. 53–55) and Stanley (2010, p. 548). According to Ralph and Corrigan (2005) writings of MH service users have mentioned PR since the 1930s.

Anthony (1993) quotes as a more immediate precursor to his ideas of PR the deinstitutionalization of MH care in the 1960s and 1970s and a move towards care in the community in the US and UK. Broadly, US MH services changed at that time from secluding people with severe MH issues, regarded a threat to themselves or society, and oftentimes subjected to coercive treatment, to treatment at home (Deegan, 1992). However, this newer 'rehabilitation' approach still very much focused on treating symptoms and maintained a strong power imbalance. It regarded professionals as experts and the only holders of knowledge, and expected patients to receive their care compliantly (Deegan, 1988). Therefore, Anthony's (1993) conceptualisation of PR strongly emphasises the empowerment of people with severe MH issues and the recognition of their knowledge from lived experience.

Deegan (1988) and Anthony (1993) both refer to the concept of recovery in long-term physical disabilities, which had already been more established by the 1980s (Wright, 1983). Particularly Deegan (1988) argued to consider recovery in longer-term physical and psychological problems as similar processes and equally deserving of social change towards more acceptance of people with any disability in society. Allott et al. (2002) link the UK recovery developments to anti-discriminatory and disability legislation from the 1990s (e.g., *Americans With Disabilities Act of 1990*, 1990; *Disability Discrimination Act*, 1995).

1.3.2.2 Personal recovery in Western mental health systems today

At least on the level of policy documents, MH systems in the Anglophone world currently endorse a recovery-orientation (Slade *et al.*, 2014). In the US, the President's New Freedom Commission on Mental Health set the following vision in their final report 'Achieving the promise: transforming mental health care in America': 'We envision a future when everyone with a mental illness will recover, a future when mental illnesses can be prevented or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports — essentials for living, working, learning, and participating fully in the community.' (2003, p. 1). The report endorses both a clinical and PR definition: '[recovery constitutes] the process in which people are able to live, work, learn, and participate fully in their communities.

For some individuals, recovery is the ability to live a fulfilling and productive life despite a disability. For others, recovery implies the reduction or complete remission of symptoms' (President's New Freedom Commission on Mental Health (US), 2003, p. 5).

In 'New Horizons: A Shared Vision for Mental Health' the UK Department of Health set down similar ideas for the future of MH care in the UK (2009), followed up by the 'No health without mental health' strategy and call to action (2011). There are similar MH-strategy documents in Northern Ireland (Department of Health Social Services and Public Safety (Northern Ireland), 2010, 2018), Australia (Department of Health and Ageing (Australia), 2009; National Mental Health Commission (Australia), 2017), and Canada (Mental Health Commission of Canada, 2012).

Comparably, the 2005 Mental Health Action Plan For Europe identified as one of five priorities for the upcoming decade to 'design and implement comprehensive, integrated and efficient MH systems that cover promotion, prevention, treatment and rehabilitation, care and recovery' and to 'recognize the experience and knowledge of service users and carers as an important basis for planning and developing mental health services' (World Health Organization Regional Office for Europe, 2005, pp. 2–3). There are official versions of this document in German, French and Russian besides English, demonstrating the spread of PR-oriented MH policy beyond the anglophone world.

It is difficult to assess to what extent current MH practice implements the PR orientation from the policy documents. In the US, a recent study among Californians with experiences of psychological distress a found lower PR levels, particularly for hope and life satisfaction, for those who had used MH services in the past year compared to those who had not, after controlling for symptom severity (McBain *et al.*, 2020). In the UK, Health Education England and the National Health Service have now adopted PR principles as core to training programmes for MH staff including specialist therapy providers (e.g., Health Education England, 2020). The World Health Organisation European Framework For Action On Mental Health 2021–2025 suggests a MH 'service transformation' towards 'more accessible and person-centred care', and stresses that '[MH] service users and their support systems can and should be active participants in care and recovery as opposed to passive recipients of treatment plans developed by health-care professionals and/or care teams' (WHO Regional Office for Europe, 2022). Thus, it follows the PR-orientation of the 2005 action plan but indicates this has not yet been widely implemented. For example, MH systems in most Eastern European countries still consist of 'large mental hospitals and rudimentary psychiatric out-patient clinics only, with very little involvement from primary care or social services' (Muijen and McCulloch, 2019).

1.3.3 Conceptualisations of personal recovery and related concepts

1.3.3.1 Personal recovery conceptualisations

Since the 1990s a substantial amount of primarily qualitative studies based on interpretivist and constructivist (see Section 2.1.3) methodologies have asked people with lived experience of severe MH issues what recovery means to them. The first and arguably most influential systematic review to date of this body of qualitative research resulted in a conceptual framework for PR in severe MH issues, comprising the five main PR processes of Connectedness, Hope and optimism, Identity, Meaning and purpose, and Empowerment (CHIME) (Leamy et al., 2011). An update of this review by Slade et al. (2012) revealed that the evidence largely stemmed from English-speaking countries. Stuart, Tansey, and Quayle (2017) conducted a systematic review of service users' PR experiences using CHIME as a framework. It confirmed the importance of these five components but identified difficulties as an additional key PR component.

Van Weeghel et al. (2019) summarised evidence on conceptualisations, assessments, and implications of PR in a meta-review of systematic reviews. It confirmed wide endorsement of CHIME but argued for extensions of the framework with categories for difficulties and trauma, a greater focus on choice, risk taking and coping with challenges, and adaptations to specific cultural and client populations. None of the 13 included review articles focused on BD or other mood disorders, leading to the conclusion that '[s]triking gaps in our knowledge relate to how personal recovery processes take place in people with mood disorders' (Van Weeghel *et al.*, 2019).

Prior to the systematic review conducted within this thesis (Jagfeld, Lobban, Marshall, *et al.*, 2021), there was one evidence synthesis on the experience of PR in BD (Lapsley *et al.*, 2013) that van Weeghel et al. (2019) did not report. Thematic analysis and narrative synthesis resulted in the four themes summarised in Table 2. The theme *Negative impact of BD* supports the importance of clinical recovery insofar as participants desired treatment and amelioration for BD symptoms that interfered with their wellbeing. However, the clinical recovery model does not provide hope for people who still experience symptoms despite treatment and cannot expect clinical recovery. In this respect, understanding PR as *Personal transformation as a result of lived experience* may offer a more helpful view. *Ambivalence in relation to living with BD* may be stronger compared to other severe MH issues. Besides experiences common to other severe MH issues, such as receiving a diagnosis, medication, and interaction with healthcare professionals, much ambivalence revolved around (hypo-)mania as key BD characteristic (Lapsley *et al.*, 2013). Participants valued elated moods as pleasurable and productive to some extent but also expressed fear of the devastating consequences of manic episodes. Overcautious mood-regulation could lead to a bleak and undesirable life (Lapsley *et al.*, 2013). Precisely finding the balance between some stimulation to live a rich life while not tipping into (hypo-)mania may therefore present one of the key challenges for PR in BD. *Wellness strategies* reflect a mix of conventional MH care approaches, i.e., medication and self-management, approaches with an evidence base but limited offering in MH systems, e.g., family-interventions and workplace support, and individual strategies outside of professional care such as spiritual and creative practice.

Table 2 Summary of themes in the first qualitative systematic review of PR in BD (Lapsley et al. (2013)

Theme	Subthemes and summary
Negative impact of BD	**Negative impact of symptoms:** mania, depression are distressing, cause disruption, loss, instability, negatively affect relationship to self (self-doubt, insecurity, self-contempt) and with others (isolation, rejection) **Stigma:** negative impact on day-to-day life, poor experiences with healthcare systems, difficult to accept chronic condition and long-term medication treatment → feeling uncertain and hopeless about future
Ambivalence in relation to living with BD	Intensity of life with BD as gift and challenge Diagnosis: relief for some, shock for others, some question diagnosis once symptoms recede Medication: helpful to maintain MH vs. side-effects and negative beliefs about medication Mania: pleasurable and productive in early stages- difficult to make changes to prevent further mood elevation, vs. fear of devastating manic episodes Professional treatment: Negative and positive relationships and experiences with treatment providers
Personal transformation as a result of lived experience	Positive impact of BD on subjective perception of self and one's place in the world **Meaning and insight:** Work with own life history, build narratives to construct meaning, value rich own lived experience due to intensity of life with BD **Self and identity:** Personal transformation only possible with healthy relationship to self: self-acceptance, self-esteem, do not define oneself by BD, integrate BD as normal part of personality (not a flaw) **New perspectives:** in relation to view of BD: focus on quality of life rather than pathology, value positive aspects, believe in own capacity to recover
Wellness strategies	Help-seeking and engaging in treatment, self-management and sense of control, healthy relationships and social support, vocation and role in society, educating self and others, physical care, stability and routine, spiritual and creative practice, diagnosis and acceptance, medication

1.3.3.2 Structured measures to assess personal recovery

Although PR is defined as a highly individual process, researchers and MH professionals have attempted to operationalise the concept in quantitative measures to assess individuals' PR status and evaluate interventions and services. Among a plethora of measures, several systematic reviews (Cavelti *et al.*, 2012; Law *et al.*, 2012; Shanks *et al.*, 2013; Sklar *et al.*, 2013, none specific to BD) recommend the Recovery Assessment Scale (Corrigan *et al.*, 1999) to assess dimensions and the Questionnaire about the Process of Recovery (QPR) (Neil *et al.*, 2009, see items in Table S28) to assess stages of PR in severe MH issues.

The Bipolar Recovery Questionnaire (Jones, Mulligan, *et al.*, 2013) is to date the only structured measure to assess PR specifically in BD. It consists of 36 items, phrased in the first person singular, selected by a panel of clinicians, academics, and people with lived experience of BD. Some UK MH services have been using the Bipolar Recovery Questionnaire as routine measure (Jones *et al.*, 2018) and several randomised controlled trials for BD interventions as outcome measure (e.g., Jones *et al.*, 2012, 2015; Jones, McGrath, *et al.*, 2013; Todd *et al.*, 2014; Lobban, Dodd, *et al.*, 2017; Beck *et al.*, 2018; Donoghue *et al.*, 2018; Chan *et al.*, 2019; Wright *et al.*, 2021; Husain *et al.*, 2022).

Strikingly in contrast to the concept of PR as personally defined, most structured measures[8] are not self-reported. Arguments for clinician-assisted measures are low literacy, 'inability to stay focused while completing the instruments' (Jerrell, Cousins and Roberts, 2006, p. 467) or possible influences of mood on self-assessments (Gitlin and Miklowitz, 2017). Yet, clinician-administered measures run the risk of disempowering the assessed individual. Another problem of structured PR instruments are low correlations of staff-only and service user (Hasson-Ohayon, Roe and Kravetz, 2008, p. 234) or even collaborative (Killaspy *et al.*, 2012, p. 67) PR ratings. Finally, van der Krieke, Bartels-Velthuis and Sytema (2019) found that similar proportions among individuals with psychotic disorder, their siblings, and controls without a MH diagnosis were regarded as recovered according to the Recovery Assessment Scale. This renders the question whether PR instruments are sensitive enough to monitor individual progress.

1.3.3.3 Differentiation to related concepts

1.3.3.3.1 Clinical and socio-functional recovery

The narratives of Deegan (1988) and Anthony (1993) constructed PR in opposition to clinical recovery, which has been the dominating recovery definition in Western MH services for most of the 20th century. ICD-11 and DSM-5 both provide specifiers to indicate someone's clinical recovery status: 'currently in partial remission' ('full definitional requirements for the episode are no longer met but some significant mood symptoms remain' (World Health Organisation, 2018)) and 'full remission'

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[8] exceptions: Bipolar Recovery Questionnaire (Jones, Mulligan, *et al.*, 2013), Maryland Assessment of Recovery in People with Serious Mental Illness (Drapalski et al., 2012), Stages of Recovery Instrument (Andresen, Caputi and Oades, 2006)

('full definitional requirements for bipolar [type I/II] disorder have been met in the past but there are no longer any significant mood symptoms' (World Health Organisation, 2018)). DSM-5 requires absence of symptoms for at least two months to qualify for full remission, while ICD-11 does not state specific durations.

Table 3 contrasts the key features of clinical recovery and PR. Clinical recovery consists of discrete outcomes that clinicians can observe objectively to some extent[9], such as current depressive, psychotic, or manic symptoms, vocational and social functioning, and service use and treatment aspects (e.g., time since last hospital admission, taking medication or being in psychotherapy) (Torgalsbøen, 1999; Liberman and Kopelowicz, 2002). Clinical recovery assessments apply the same criteria and rating scales to all individuals in a certain group, e.g., with the same diagnosis, making them suitable target outcomes of group-level evaluations such as randomised controlled trials. Yet, in practice not all criteria may be relevant for an individual to the same extent. For example, occupational functioning is arguably more important for a family-breadwinner than a retired person. PR, on the other hand, is a journey or process with individual meaning that people can only subjectively report. Although PR is much harder to operationalise than clinical recovery, some trials have successfully applied structured PR measures (see Section 1.3.3.2).

Table 3 Comparison of key clinical recovery and PR features based on Slade (2009, p. 35)

Clinical recovery	**PR**
Outcome or state, dichotomous	Journey or process, continuous scale
Observable, objective	Subjective
Clinician-rated	Self-reported
Invariant definition across individuals	Individual, idiosyncratic meaning

Clinical recovery is positively correlated with PR in that improvements in symptoms and fewer episodes often help to support PR. Jones, Mulligan, and colleagues (2013) found significant, medium-size correlations between manic or depressed symptoms and PR in BD. However, wellbeing and personal growth measures explained PR variance in addition to depression scores (Jones, Mulligan, *et al.*, 2013). This provides evidence that clinical recovery does not necessarily entail personal satisfaction in the domains of hope, meaning, identity and personal responsibility (Slade, 2009). On the other hand, the PR definition maintains that good PR can be present despite the experience of symptoms or acute episodes. A randomised-controlled trial of recovery-focused cognitive behavioural therapy for recent-onset BD found a significant improvement of self-assessed PR and time to relapse in the treatment group compared to a group that only received routine medication (Jones *et al.*, 2015). However, there were no significant differences between the treatment groups in terms of professional-assessed manic nor

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[9] As already pointed out for DSM-5 and ICD-11 criteria for BD in Section 1.2.1, the assessment of many MH symptoms relies on subjective reporting of the individual. They are therefore less objective in practice than other clinical recovery criteria such as time since last hospital admission.

professional and self-reported depressive symptoms. A recent group-cognitive behavioural therapy study for BD showed a significant medium-effect PR improvement, significant small-effect improvements for anxiety and depression symptoms and no significant improvement of manic symptoms (Jones *et al.*, 2018). This shows that improvements in PR are to some extent independent of symptom experience.

The clinical recovery view of symptoms as unequivocally negative ignores potential benefits for personal growth and the fact that many people value the experience of some symptoms (Slade, 2009, pp. 31–32, 43). This appears to be particularly prominent in BD, where quantitative (Marshal, 1980; Parker *et al.*, 2012; Forgeard *et al.*, 2016) and qualitative (Rusner *et al.*, 2009; Lobban *et al.*, 2012; Russell and Moss, 2013; Taylor, Fletcher and Lobban, 2015) research has highlighted the many positive aspects people associate with their experiences of intense mood. See also Galvez, Thommi and Ghaemi (2011) for a review and the discussion of ambivalence in Section 1.3.3.1.

Slade (2009, p. 40) argues that a ‘primary focus on clinical recovery is incompatible with a primary focus on [PR]’ due to its negative effects on hope, meaning, and the stance towards symptoms. Enforcing a certain, i.e., biomedical, explanation for MH experiences is desirable to promoting insight in a clinical recovery context, whereas PR takes it as central that individuals make their own sense of their experiences (Slade, 2009). However, clinical recovery can be one approach to support PR, for example in interventions with a more psychosocial model of severe MH issues such as cognitive behavioural therapy. These two diverging views also emerged among the participants in the Lapsley et al. (2013) review: For some, pursuing PR in BD entails no engagement with traditional healthcare systems and they gave their BD experiences a meaning different from symptoms of an illness. For others, a PR approach to BD enriched conventional MH care for clinical recovery with individual work on positive self-transformation and wellness strategies.

1.3.3.3.2 *Quality of life*

To instil more hope and positivity in BD research, researchers, particularly around the Collaborative RESearch Team to study psychosocial issues in BD (CREST.BD), have advocated for the primacy of quality of life instead of symptom measures (Murray and Michalak, 2012). Perich and Meade (2019) found quality of life in the mood domain to be the strongest predictor of PR in BD, followed by self-esteem and identity. A systematic review on what quality of life refers to in the context of BD research (Morton, Michalak and Murray, 2017) found that there is no consensus definition, but the most common one is ‘individuals’ perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns’ (The WHOQOL Group, 1995, p. 1405). The World Health Organisation regards quality of life as ‘subjective evaluation embedded in a cultural, social and environmental context’ (The WHOQOL Group, 1998, pp. 551–552), but other researchers debate whether quality of life measures should also take into account objective factors such as employment or housing (Morton, Michalak and Murray, 2017). This constitutes a difference to the entirely subjectively defined concept of PR.

The Quality of Life in BD scale (Michalak and Murray, 2010) is the only self-reported structured instrument to assess quality of life specific to people with a BD diagnosis. Several randomised controlled trials for psychological interventions applied the Quality of Life in BD scale as outcome measure, often alongside the Bipolar Recovery Questionnaire (e.g., Jones *et al.*, 2012, 2015; Jones, McGrath, *et al.*, 2013; Todd *et al.*, 2014; Lobban, Dodd, *et al.*, 2017; e.g., Beck *et al.*, 2018; Donoghue *et al.*, 2018; Husain *et al.*, 2022). According to reported correlations between the Quality of Life in BD scale and the Bipolar Recovery Questionnaire of 0.5-0.6 both constructs are associated but not mutually redundant (Murray *et al.*, 2017). Like the Bipolar Recovery Questionnaire, the Quality of Life in BD scale also contains questions related to connectedness or identity ('felt accepted by others') and meaning ('been interested in my leisure activities', 'had a clear idea of what I want and don't want'), but overall focuses more on practical aspects ('felt physically well', 'kept my home tidy', 'had enough money for extras').

1.3.3.3.3 Wellbeing

Wellbeing is the basis of the World Health Organisation definitions of both health, 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (WHO, 2001a, p. 1), and MH, 'a state of well-being in which the individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community' (WHO, 2001b, p. 1). By specifying the ability to work productively, the World Health Organisation states a capitalist definition of MH that clearly deviates from the PR concept. PR leaves it up to the individual to determine how to live a satisfying, hopeful, and contributing life – which may or may not include paid work. Despite mentioning a physical, mental, and social domain, the World Health Organisation does not clearly define wellbeing, which remains an area of debate (Dodge *et al.*, 2012). According to Dodge et al. (2012) a common definition is a 'balance point between an individual's resource pool and the challenges faced'.

Positive psychology focuses on research to foster wellbeing and shares some similarities with PR (Slade, 2010). Both fields criticise MH research and practice for being too focussed on deficits, and disorder. Rather, they aim to make life better instead of less bad, encouraging active positive instead of avoidant negative behaviour (Slade, 2010). However, they differ in their target groups and methods. Positive psychology focuses on people with no or mild to moderate MH issues and employs mainly quantitative group-level evaluations, different from the more qualitative and idiographic (individual-centred) PR research (Slade, 2010, p. 6). Moreover, there is critique of positive psychology as 'decontextualised neo-liberalist ideology that causes harm' (Van Zyl *et al.*, 2023, p. 15). For example, positive psychology may shift too much responsibility for wellbeing on the individual rather than societal circumstances and make happiness an imperative, both aspects which go against PR principles.

Structured measures of wellbeing that have been widely used in populations with and without MH issues are the Warwick-Dinburgh Mental Well-being Scale (Tennant *et al.*, 2007) and the Mental Health Continuum-Short Form (Lamers *et al.*, 2011). Kraiss et al. (2019) found large correlations between PR measured via the QPR and the Mental Health Continuum-Short Form among 102 Dutch people with a BD diagnosis. However, PR explained variance in symptoms of depression and anxiety above and beyond wellbeing and seemed to measure a combination of aspects of wellbeing and symptom improvements. Therefore, wellbeing and PR appear as complementary concepts. A recent randomised controlled trial found that an eight week positive psychology group intervention improved both wellbeing and PR for euthymic people with a BD diagnosis and argued that positive psychology might accelerate the PR process (Kraiss *et al.*, 2023).

1.3.4 Personal recovery interventions

An overview over PR-oriented practices in MH services internationally is beyond the scope of this thesis, but see, e.g., Pincus (2016). This section briefly introduces recovery colleges, MH trialogue, and peer support as important facets of PR-oriented MH care internationally and then presents recovery-oriented therapy as an example of a BD-specific PR-focused intervention.

Recovery colleges, pioneered at Boston University (US) in 1984, were one of the first PR-oriented MH services (Slade *et al.*, 2014, p. 16) and now exist in more than 20 countries (Whitley, Shepherd and Slade, 2019, p. 141). The core idea is to provide education on mental and physical health as well as personal development and employment in courses that individuals with severe MH issues partly or completely teach themselves. Related to recovery colleges in the Anglophone world, psychosis seminars started in German-speaking countries in 1990 (Bock and Priebe, 2005). Also known as MH trialogues, they aim to engage three parties dealing with consequences of MH issues in an equitable dialogue: people with experience of MH issues, their friends and family members, and MH professionals (Amering, Mikus and Steffen, 2012). They aim to empower people with severe MH issue diagnoses and to counteract the power imbalances in Western MH services. A first evaluation of a MH trialogue in Ireland highlighted their potential to improve societal communication around MH (MacGabhann *et al.*, 2018).

PR interventions often employ peer support workers with lived experience of MH issues who consider themselves in PR (e.g. Slade *et al.*, 2014). Several reviews demonstrated at least two benefits: it provides positive role-models for the intervention participants and work opportunities for people with MH issues (Repper and Carter, 2011; Davidson *et al.*, 2012; Chinman *et al.*, 2014). A review of 18 randomised controlled trials of peer-support interventions for severe MH issues found evidence for positive impacts on self-rated recovery, hope, and empowerment but no effects on hospitalisation, overall symptoms, or service satisfaction (Lloyd-Evans *et al.*, 2014). Another meta-analysis found that interventions co-delivered by professionals and peer support workers where more effective to foster PR in people with severe MH issue diagnoses than when no people with lived experience were involved in the delivery (Thomas *et al.*, 2018).

Recovery-focused therapy (Jones *et al.*, 2015) is an example for a PR-focused BD intervention. Researchers and clinical psychologists co-developed this adaption of cognitive behavioural therapy with people with lived experience of BD. Instead of presuming relapse prevention as standard target of cognitive behavioural therapy, recovery-focused therapy works towards client-specified goals. It allows to address any issues that the clients find relevant besides mood problems such as comorbidities or functioning. A pilot and a feasibility trial for recent-onset BD and older adults with a BD diagnosis, respectively, showed promising effects of recovery-focused therapy in addition to medication on PR and time to relapse compared to medication only (Jones *et al.*, 2015; Tyler *et al.*, 2022). A recent systematic review of psychological interventions for BD that assessed PR outcomes found that the five retrieved recovery-oriented adaptations of cognitive behavioural therapy (including Jones *et al.*, 2015) indicated effectiveness to improve PR in people living with BD (Hancock *et al.*, 2022).

1.3.5 Criticism of personal recovery

Professionals and MH services as well as individuals with lived experience have also criticised the concept of PR or its implementation in MH systems. The following presents four main criticisms of PR, summarised from Slade (2009). First, PR has been repeatedly criticised as a hard to grasp, vague concept (e.g., Bird *et al.*, 2014; McCabe *et al.*, 2018), posing problems for the development and evaluation of PR-oriented services. Several systematic reviews (Leamy *et al.*, 2011; Van Weeghel *et al.*, 2019) led to some clarification of PR conceptualisations, but also highlighted that PR might entail different aspects for people with different MH issues and cultural backgrounds.

Second, PR originates largely from ideas of white, Western researchers (Deegan, 1988) based on research conducted in wealthy, anglophone Western countries, lacking a wider cultural basis (Slade *et al.*, 2014, p. 17). Slade (2009, p. 219) admits that the PR literature is 'permeated by implicit notions of how people should be'. PR focuses on the independent individual, whereas communities with non-Western values such as Chinese or indigenous people of New Zealand, might rather value interdependence within the community (Tse, 2004; Slade *et al.*, 2014).

Third, PR originated mostly from people with experiences of psychosis and most PR research has focused on this group (Slade *et al.*, 2014, p. 13). An example is the UK National Institute for Health Research-funded research programme 'Psychological approaches to understanding and promoting recovery in psychosis and bipolar disorder: a mixed-methods approach' (Morrison *et al.*, 2016b) in which only one out of six projects targeted BD. Van Weeghel et al. (2019) contend that there is a lack of knowledge about PR experiences of people with anxiety and extreme mood experiences.

Fourth, PR entails encouragement for positive risk-taking. This seems contradictory to a focus on risk-management previously prevalent in Western MH systems (Slade, 2009; Holley, Chambers and Gillard, 2016) which have a legal responsibility to prevent individuals from harming themselves or others. MH professionals held the top PR concern '[i]f recovery is the persons' responsibility, then how come I get the blame when things go wrong?' (Davidson *et al.*, 2006), to which, Slade (2009) argues that services should hold the responsibility and never individual workers. Additionally, the level of responsibility services can realistically take on is limited in practice anyway. Unless all clients are inpatients in secure settings, services have little control over individuals' choices regardless of a PR or clinical recovery approach. Moreover, despite a decline in the general UK population, suicide rates for people with a BD diagnosis did not decrease from 1996 to 2013 (Clements *et al.*, 2013) and services seem to often underestimate the suicide risk of this population (Clements *et al.*, 2013, 2019).

There has also been criticism of how some Western MH services have implemented PR orientation in ways that differ from original PR principles (Perkins and Repper, 2017; Recovery in the Bin, 2017). In response to new MH policy requirements, some existing services might have been relabelled as PR-oriented without changing their care model (Slade *et al.*, 2014, p. 12), possibly due to lack of funding for more individualised care (Crowe, 2017). Some people have been concerned that MH systems might have hijacked the PR concept (Slade, 2009, p. 218) and used it as justification for service cuts (Slade, 2009; Slade *et al.*, 2014; Stuart, Tansey and Quayle, 2017) or to blame individuals who fail to meet institutionalised PR criteria (Slade, 2009, p. 220).

1.3.6 Summary

This section set down the definition and conceptualisation of PR for this thesis, followed by a critical discussion of the concept. The current body of research on personal recovery (in BD), suffers from several shortcomings. First, it is primarily based on qualitative studies involving a small number of participants (Stuart, Tansey and Quayle, 2017) and expert opinions, lacking complementary quantitative evidence from larger samples (Slade *et al.*, 2012). A recent systematic review of psychological interventions for BD that assessed PR outcomes retrieved only five quantitative studies with a total of 485 participants (Hancock *et al.*, 2022). The two completed pilot randomised controlled trials of recovery-oriented therapy for BD to date (Jones *et al.*, 2015; Tyler *et al.*, 2022) comprised 67 and 39 participants, respectively. Second, research on PR in BD has taken place only in structured settings, i.e., semi-structured interviews, focus groups, structured measures, where researchers have an important influence on data production, potentially leading to interviewer bias (Briggs, 1986). Moreover, data collected in structured settings often constitute retrospective accounts from participants (Seale *et al.*, 2010), which may suffer from recall bias (Thomas and Diener, 1990). Third, recruitment may have been biased towards people who are managing to stay comparably well and are in contact with services or research groups, missing experiences of those who disagree with the concept of PR or have a low quality of life (see Section 4.4.6). Overall, participant diversity in previous qualitative studies on PR in BD has been limited, with a preponderance of middle-aged women from Western countries (see Section 4.4.6).

This thesis directly addresses two points of conceptual criticism of previous PR research. It ensures conceptual clarity by explicitly stating the underlying PR definition in Section 1.3.1and consolidates and contributes to the previously small body of research on PR experiences of people with extreme mood experiences. Criticism of recovery implementations mainly arises due to deviations from the PR concept. Indeed, Recovery in the Bin (2019), an activist collective of individuals with lived experience of severe MH issues, recently argued that current MH services are following a 'Neorecovery' approach, distinct from 'Grassroots recovery' founded in ideas by Anthony (1993), Deegan (1988) and a social disability model (Repper and Perkins, 2003). This demonstrates that PR is relevant and attractive for individuals with severe MH issues despite implementation problems. This thesis adopts the ‘grassroots’ PR definition and aims to generate knowledge that may support PR in people with lived experience of BD, also by involving them in the research process.

1.4 Language analysis

This section reviews previous research that analysed online posts by people with lived experience of BD (Section 1.4.2). Given the expected interdisciplinary readership of this thesis, the first subsection (Section 1.4.1) briefly introduces the main concepts and language analysis methods from health research, linguistics, corpus linguistics, and NLP that the studies summarised below have used.

1.4.1 Language analysis methods

The health research, linguistics, corpus linguistics, and NLP research communities have each developed their own language analysis approaches, some of which overlap. Health research and linguistic language studies are mainly manual, qualitative, and small-scale, whereas NLP approaches are automatic, quantitative, and large-scale, and corpus linguistics combines automatic quantitative and manual qualitative approaches in small- or large-scale studies. Health research and linguistics employ some of the same methods such as thematic or conversation analysis. They mainly differ with respect to the implications of their research: While health research usually aims to inform health treatment and policies, linguistic research may rather aim to better understand how people use language. The two computer-assisted approaches corpus linguistics and NLP also differ with respect to their research aims: Corpus linguistics results in a better understanding of language use and structure through integrating qualitative and quantitative methods (McEnery and Hardie, 2011). Conversely, NLP usually aims to solve practical tasks such as information retrieval, translation, summarisation, or question answering by creating computer programs that process or generate natural language. Additionally, corpus linguistics only analyses language data in the form of corpora. A *corpus* usually refers to a collection of texts that are sampled to be representative of a particular language variety (McEnery et al., 2006, p. 5). In contrast, NLP works with various forms of language data including corpora, but also unbalanced text collections (*datasets*) and thesauri.

1.4.1.1 Health research

This section first briefly introduces the main methodologies in which health researchers collect language data and then describes the main methods for analysing it.

1.4.1.1.1 Qualitative health research methodologies

Methodologies provide frameworks for how to gain knowledge (Mackenzie & Knipe, 2006), including the choice of data collection and analysis methods (Crotty, 1998, p. 3). Health research that analyses language data often operates within one of these four main qualitative research methodologies: *narrative research, phenomenological research, grounded theory,* and *ethnography*. *Narrative research* (e.g., Clandinin and Connelly, 2004) studies the lived experience of research participants by asking them to tell stories about their lives. Researchers then often retell the narrative interview in a narrative chronology (Creswell and Creswell, 2018, p. 13). *Phenomenological research* (e.g., Moustakas, 1994) studies the experience of some phenomenon through interviews with people with lived experience. The analysis describes the essence of the experience as extracted from the interviews (Creswell and Creswell, 2018, p. 13). *Grounded theory* (e.g., Glaser and Strauss, 1967; Charmaz, 2006; Corbin and Strauss, 2015) is a methodology to develop theory from qualitative data in an iterative process, involving multiple passes back and forth between the data and emerging theories (Creswell and Creswell, 2018, p. 13). In an *ethnography* (e.g., Wolcott, 2008; Fetterman, 2010) (in online contexts virtual ethnography (Hine, 2008) or *netnography* (Kozinets, 2019)) researchers observe the participants in their naturally occurring environments over a prolonged time and take field notes to document their behaviour (Creswell and Creswell, 2018, p. 13).

1.4.1.1.2 Health research methods for language analysis

A basic process in many manual language analysis approaches is to index sections in the data with codes based on their meaning (Pope, Ziebland and Mays, 2000). Qualitative analysis computer programs like NViVo[10] or ATLAS.ti[11] support this process. A main distinction of language analysis approaches in health research is whether they are deductive (theory-driven, top-down) or inductive (data-driven, bottom-up) (Pope, Ziebland and Mays, 2000, p. 114). In a *framework analysis*, an a priori theoretical framework provides the codes to mark up the data, thus constituting a deductive approach (Pope, Ziebland and Mays, 2000). Conversely, in an inductive *content analysis*, the researchers create the codes based on their understanding of the data and develop the analytical framework during the analysis (Pope, Ziebland and Mays, 2000). Higher-level framework categories constitute 'summaries of (often divergent) responses on a particular issue or topic' (Clarke and Braun, 2018, p. 109). (Reflexive) *thematic analysis* (Braun and Clarke, 2006, 2019) is another inductive analysis method in which researchers iteratively combine the initial codes to create higher order 'themes'. Different to the categories in a content analysis, themes tie together observations around a 'core concept that underpins and unites' them (Clarke and Braun, 2018, p. 108).

Conversation analysis (e.g., Sacks, 1992; Hutchby and Wooffitt, 2008) studies naturally occurring talk-in-interaction. It often works with very detailed conversation transcripts that also include non-verbal information such as gestures, facial expressions, prosody, and paralinguistic cues, e.g., laughter, sighs, or throat

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[10] https://lumivero.com/products/nvivo/

[11] https://atlasti.com

clearing. *Narrative analysis* (e.g., De Fina and Georgakopoulou, 2015) may analyse why stories are considered worthy to be told (tellability), their structure (Labov, 1972), and the practice of storytelling, how participants construct possibly different narratives depending on the context and audience.

Some methodologies link directly to a preferred analysis method, i.e., narrative research mostly involves narrative analysis, while other methodologies work with different and often multiple methods. Most health research language analysis methods are primarily qualitative, although content analyses can yield quantitative data.

1.4.1.2 Linguistics

Linguistic researchers often utilise the qualitative methodologies and analysis methods described in the previous section (Section 1.4.1.1.2), such as linguistic ethnography (Copland and Creese, 2015), and conversation and narrative analysis. However, there are also language analysis approaches that mainly originated from linguistics. This section presents three of these approaches utilised in previous research of physical and MH issues: *metaphor analysis, systemic functional linguistics,* and *critical discourse analysis*.

Metaphor analysis studies how people conceptualise and verbalise often complex subjective experiences through metaphor (Demjén, Semino and Koller, 2016, p. 2). For example, people often use conventional metaphors (Lakoff and Johnson, 1980) to describe the abstract target concept of PR metaphorically via the more concrete source concepts of a ‘journey’ or ‘struggle’ (Leamy *et al.*, 2011). Therefore, some linguistic researchers have applied metaphor analysis to study the lived experience of physical health (cancer and end of life: Semino *et al.*, 2017) and MH issues (depression: Levitt, Korman and Angus, 2000; Charteris-Black, 2012; extreme mood: Schoeneman *et al.*, 2012).

Systemic functional linguistics (Halliday and Matthiessen, 2014) is a theory of language, which postulates that language production means to make meaningful choices among alternatives. This theory distinguishes three kinds of meaning: experiential (topic and focus of activities), interpersonal (power and solidarity relationships between producer(s) and audience of the text), and textual (organisation of language into coherent, meaningful sequences). Thus, systemic functional linguistic analyses scrutinise lexicogrammatical choices in texts via (mainly manual) categorisations to considerable detail such as identifying social actors (Van Leeuwen, 1996; Koller, 2009; Fairclough, 2013) and their representations, or speech acts (i.e., questions, statements, commands) (Searle, 1985). In a systemic functional linguistics analysis, Sercu (2022) found that brochures of Flemish psychiatric hospitals failed to reflect the tenets of recovery-oriented and empowering care.

Critical discourse analysis (Fairclough, 1989, 2013) constitutes a methodology that integrates linguistic research and socio-cultural theory within a transformative research paradigm (see Section 2.1.6) to show how discourses (re)produce power abuse and social domination. It employs methods such as conversation analysis, systemic functional linguistics, and corpus linguistics (corpus-assisted discourse analysis; e.g., Baker, 2006; Partington and Marchi, 2015; Taylor and Marchi, 2018). There are a few corpus-assisted discourse analyses of online messages concerning the lived experience of MH issues, but not BD (adolescent health emails regarding depression: Harvey, 2012; online support forum posts of heterosexual men experiencing sexual-orientation obsessive-compulsive disorder: Coimbra-Gomes and Motschenbacher, 2019; online support forums for anorexia, depression, and diabulimia: Hunt and Brookes, 2020).

1.4.1.3 Corpus linguistics

This section first introduces some core linguistic terminology that features in the ensuing description of corpus linguistic and NLP methods.

1.4.1.3.1 Basic linguistic concepts

Table 4 illustrates some core linguistic terminology for the example sentence ‘My great aunt helped my recovery.’ *Tokens* constitute the atomic elements of a sentence. *Tokenisation* refers to the (manual or automatic) process of segmenting a string of characters into individual *tokens* (Jurafsky and Martin, 2023, p. 4), which involves, for example, separating punctuation marks from their adjacent words such as the full stop from ‘recovery’. While the example sentence contains seven tokens, it only comprises six *types* (tokens with distinct *wordforms*) (Jurafsky and Martin, 2023, p. 4) since ‘my’ appears twice. Moreover, tokens can be part of a multiword phrase such as ‘great aunt’ in the example. *Terms* can constitute single words or multiword phrases. *Lemma* refers to the dictionary form of a word (Jurafsky and Martin, 2023, p. 14), e.g., ‘helped’ and ‘helps’ are wordforms of the verb lemma ‘help’. The *part of speech* denotes the class of a word such as ‘noun’ for ‘aunt’ and ‘verb’ for ‘helped’. Part of speech taggers automatically assign a tag to each token in a sentence from a fixed tagset (Jurafsky and Martin, 2023, p. 163). Finally, syntactic parsers automatically analyse the syntactic structure of a sentence, either in the form of bracketed constituents (syntactic phrases) or a dependency tree (Jurafsky and Martin, 2023, p. 355). The final row in Table 4 presents the dependency relations in the form of relation (head) tuples. In the example sentence, ‘helped’ is the root of the syntactic tree with the nominal subject ‘aunt’ and the direct object ‘recovery’.

Table 4 Tokens, lemmas, and part of speech tags for the example sentence 'My great aunt helped my recovery.'

Level/ token id	0	1	2	3	4	5	6
Token	My	great	aunt	helped	my	recovery	.
Lemma	my	great	aunt	help	my	recovery	.
Part of speech[12]	PRON	ADJ	NOUN	VERB	PRON	NOUN	PUNCT
Syntax[13]	poss (aunt)	amod (aunt)	nsubj (helped)	ROOT	poss (recovery)	dobj (helped)	punct (helped)

1.4.1.3.2 Corpus linguistic methods

Table 5 shows an overview of the five main corpus linguistic methods[14] (e.g., Baker, 2010, pp. 19–28; McEnery and Hardie, 2011) to analyse the frequency, saliency, and consistency of linguistic patterns in corpora (Baker, 2010, p. 27). To provide relevant examples, the table presents data from the BD Subreddit Corpus constructed for this thesis (see Appendix G.1). *Frequency lists* count all instances of some linguistic level of analysis in a corpus. Dispersion measures (e.g., Egbert, Burch and Biber, 2020) can quantify and visualise the distribution of these instances over the corpus. In its most basic form, corpus linguistic methods work with tokenised corpora. However, all methods can work on top of additional preprocessing steps (usually using NLP methods) such as lemmatisation, part of speech tagging, or semantic tagging. Comparison of the frequency lists for two corpora with a statistical measure such as log likelihood (Rayson and Garside, 2000), yields *key items,* which appear significantly more frequently in one corpus over the other. *Collocations* constitute words that a target word co-occurs with more frequently than by chance as calculated via an association measure such as mutual information (Evert, 2005). Like collocations, *n-grams* or *lexical bundles* (e.g., Biber, Conrad and Cortes, 2004) are item sequences that frequently occur together, but they are usually identified by their raw frequency rather than a collocation measure. *Concordance analysis* constitutes the main qualitative corpus linguistic method. It involves close reading and possibly manual categorisation of the contexts of some linguistic patterns such as key items, collocations, or n-grams, often through iterative sorting according to different left and right context positions (Baker, 2010).

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[12] Universal part of speech tagset (https://universaldependencies.org/u/pos/), PRON: pronoun, ADJ: adjective, NOUN: noun, VERB: verb, PUNCT: punctuation

[13] Universal dependency relations (https://universaldependencies.org/u/dep/), poss: possessive determiner, amod: adjectival modifier, nsubj: nominal subject, dobj: direct object, punct: punctuation

[14] This thesis only refers to corpus linguistics as a collection of methods instead of as a theory (see Hardie and Mcenery, 2010).

Table 5 Overview of corpus linguistic methods

Corpus linguistic method	Example from the BD Subreddit Corpus (see Appendix G.1)
Frequency lists show the frequency of words, lemmas, part of speech tags, semantic domains.	*I, and, to, the, it* are the five most frequent words in the BD Subreddit Corpus.
Key items appear statistically significantly more frequently in the corpus compared to a reference corpus.	According to the log likelihood statistic, the BD Subreddit Corpus contains significantly more mentions of the semantic domain *B3: Medicines and medical treatment* compared to a reference corpus of posts by Reddit users who never mentioned MH issues (see Appendix G.1.3.1).
Collocations co-occur with target words (or tags) significantly more frequently than chance	*road, smart, addiction* have the highest mutual information values (Stubbs, 1995; Anthony, 2005, 2019) with *recovery*.
n-grams/lexical bundles are sequences of words (or tags) of length n that frequently occur together.	*my recovery* is the second most frequent bigram (two-word sequence) with *recovery* appearing 122 times, whereas *your recovery* is only ranked ninth, appearing 61 times.
Concordances are all results for a query presented in their contexts.	Below are three concordance lines for *recovery* in a symmetrical context of up to seven words: *... therapist was a huge help in my recovery.* *I have hope for recovery today. For the first time I ...* *... she cannot be a part of my recovery this time because she just ...*

The currently most widely used corpus linguistic software programs AntConc (Anthony, 2005, 2019), #LancsBox (Brezina, Platt and McEnery, 2021), Sketch Engine (Kilgarriff *et al.*, 2004, 2014), Wmatrix (Rayson, 2008), and WordSmith Tools (Scott, 1996, 2022) implement some or all corpus linguistic methods. They vary with respect to the statistical measures they implement, their customisability, and the visualisations they offer. Atanasova et al. (2019) and Prize (2022) are two recent corpus-linguistic studies of how UK newspapers talk about MH recovery and MH issues, respectively.

1.4.1.4 Natural language processing

This section presents the two lines of NLP[15] research that are most relevant in the context of previous BD research, *automatic content analysis* and *classification*.

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[15] For the sake of consistency, this thesis only uses NLP rather than the largely synonymous term *computational linguistics*. Some people distinguish NLP as engineering discipline from computational linguistics as more concerned with the theoretical implications of computational language descriptions (e.g., Tsujii, 2021).

1.4.1.4.1 Automatic content analysis

Eichstaedt and colleagues differentiate two main approaches to automatic content analysis, 'theory-based, closed-vocabulary methods from the social sciences as well as data-driven, open-vocabulary methods from computer science' (2021, p. 398). Closed-vocabulary methods deductively assign words or phrases to semantic categories via manually created lexicons based on psychological or social theories. They may include rules for context-sensitive word sense disambiguation. Some studies developed bespoke lexicons (e.g., Kramer, Fussell and Setlock, 2004). However, this is very labour intensive, and such lexicons may still only cover a small part of the lexical variety of larger datasets. Therefore, most closed-vocabulary content analyses rely on existing systems built for more general purposes.

The main tool in psychological research for closed-vocabulary automatic content analysis has been Linguistic Inquiry and Word Count (LIWC) (Pennebaker *et al.*, 2015), while corpus linguistic research has also frequently applied the UCREL Semantic Analysis System (USAS) (Rayson *et al.*, 2004). LIWC captures sensory, emotional, and cognitive perceptions, comprising eight categories for psychological constructs with 34 subcategories and six personal concern categories (e.g., leisure, home, work) (Pennebaker *et al.*, 2015). Researchers around James Pennebaker have psychometrically validated and developed LIWC for English over the course of 25 years (Kahn *et al.*, 2007; Tausczik and Pennebaker, 2010; Golder and Macy, 2011; Dzogang, Lansdall-Welfare and Cristianini, 2016; Boyd and Pennebaker, 2017; Dzogang, Lightman and Cristianini, 2018; Newell *et al.*, 2018; Entwistle, Marceau and Boyd, 2022; Kennedy *et al.*, 2022; Pennebaker, 2022). However, some linguists critique LIWC for ignoring local context (e.g., Hunt and Brookes, 2020). In contrast, the USAS lexicon intends to capture a general interpretation of the world and contains 21 top-level and 232 second- and third-level domains (see Table S14). It also implements some context-dependent word sense disambiguation rules.

Open-vocabulary methods inductively construct dataset-specific term groupings based on their co-occurrences with other terms under the assumption that meaning is relational (de Saussure, 2011). There exist three main approaches, *semantic maps* (Carley, 1997), *topic modelling* (Blei, Ng and Jordan, 2003), and *word embeddings* (e.g., Mikolov *et al.*, 2013). *Semantic maps*, sometimes also called semantic network analysis, construct a co-occurrence matrix with frequency counts for all words and then reduce the dimensionality of this space via factor analysis (Carley, 1997; Bernard, Wutich and Ryan, 2016). *Topic modelling* analyses the co-occurrences of words (irrespective of their order) within the documents (e.g., articles, posts) in a dataset and calculates the statistically optimal assignment of words to a pre-defined number of topics (Blei, Ng and Jordan, 2003). Non-NLP researchers often apply topic modelling for automatic content analysis because there exist easy to use out-of-the box implementations such as genism[16] and Mallet[17]. Previous research applied topic modelling to explore cultural differences in online posts of people with MH issues (De Choudhury *et al.*, 2017; Loveys *et al.*, 2018). However, linguists have critiqued that word groups resulting from topic

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[16] https://radimrehurek.com/gensim/

[17] https://mimno.github.io/Mallet/topics.html

modelling do not always capture coherent and theoretically meaningful categories (Brookes and McEnery, 2019; Gillings and Hardie, 2022). *Word embeddings*, e.g., word2vec (Mikolov *et al.*, 2013), GloVe (Pennington, Socher and Manning, 2014), or more recent variants such as BERT (Devlin *et al.*, 2019) and RoBERTa (Liu *et al.*, 2021) train a continuous vector representation for each word by predicting the vectors for the surrounding words via neural networks.

1.4.1.4.2 Automatic classification

Classification aims to automatically assign language samples to pre-defined categories (classes) (Jurafsky and Martin, 2023, p. 58). Predicting whether a social media user likely meets BD criteria (yes or no) from their post text constitutes a binary classification task. Conversely, predicting which (if any) MH issue a social media user might experience requires multi-class classification. To perform classification, *features* extracted from the language input are fed into a decision algorithm. Popular features are simply raw word frequencies, irrespective of their order (bag of words), character or word sequences (n-grams), word frequencies weighted by the number of documents in which they appear (term frequency-inverse document frequency (tf-idf), see Appendix G.5), outputs of automatic content analysis methods such as LIWC, and word embeddings (see Section 1.4.1.4.1). The main features in previous classification approaches for BD have been LIWC and tf-idf (Harvey *et al.*, 2022). Classification algorithms can also be rule-based or probabilistic such as logistic regression, decision trees, random forests, gradient boosting, support vector machines, or naïve Bayes (e.g., Friedman, Hastie and Tibshirani, 2001). Currently, most state-of-the art NLP research applies neural network models such as convolutional neural networks, recurrent neural networks with long short-term memory (Hochreiter and Schmidhuber, 1997) and/or attention mechanisms (e.g., Luong, Pham and Manning, 2015), or transformer architectures (Vaswani *et al.*, 2017).

Probabilistic models require fitting their parameters via training inputs with known correct classes (*gold standard*). The main evaluation measures for (binary) classification systems are accuracy, precision, recall, and the F-score as harmonic mean of precision and recall (see Table 6).

Table 6 Main evaluation measures for classification systems based on the confusion matrix in Table 7

Evaluation measure	Equation
Accuracy	TP / (TP + FP + FN + TN)
Precision (P)	TP/ (TP+FP)
Recall (R)	TP/ (TP+FN)
F-score	2 * P * R / (P + R)

Table 7 Confusion matrix for binary classification

Predicted (below) / actual (right)	Yes	No
Yes	true positive (TP)	false positive (FP)

No	false negative (FN)	true negative (TN)

1.4.2 Bipolar disorder research via language analysis of online posts

This section reviews previous research to answer, 'What are the characteristics, methods, and findings of previous studies that analysed online posts by people with lived experience of BD'?

1.4.2.1 Method

Time constraints did not permit to conduct a second systematic literature review in addition to the POETIC review (Chapter 4). Therefore, this section presents previous research on BD online posts via a non-systematic literature review. The main differences to a systematic review are (cf., Aromataris and Munn, 2020, Section 11.1.2): No adoption of a formal systematic review methodology, no pre-publication of a review protocol, a potentially non-exhaustive search strategy, no double-checking of screening decisions, no quality appraisal of included studies. Nevertheless, the review transparently states the search strategy and eligibility criteria. Like in a scoping review, a charting table with inductively developed categories served to extract data from the included studies. Summary statistics, tables and a narrative review summarise focal aspects of the retrieved literature.

1.4.2.1.1 Search strategy

Table 8 provides the search strategy of this non-systematic literature review. Citation tracking of retrieved articles yielded a few further relevant studies. All searches were updated in March 2023.

Table 8 Search strategy to identify BD research using language analysis of online posts

Source	Search terms	Search dates
Google scholar[18]	bipolar reddit; bipolar Twitter; bipolar social media; bipolar online forum recovery; bipolar online forum	March – June 2020, March 2023
ACL Anthology[19]	bipolar disorder	May 2020, March 2023

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[18] https://scholar.google.com/

[19] https://www.aclweb.org/anthology

Relevant journals, series, conference proceedings[20]	bipolar	November 2021, March 2023

1.4.2.1.2 Eligibility criteria

Articles included in this review needed to fulfil the following criteria:

- Peer-reviewed study published in a journal or conference proceedings
- Primary research (no literature reviews, commentaries etc.)
- English, German, Dutch, or French full text (language skills of the PhD student)
- Use of online posts by people with lived experience of BD as research data
- If the study includes data from people with other or no MH issues, it reports at least some BD-specific results

1.4.2.2 Results and discussion

Overall, this review includes 43 articles published between 2004 and 2022. Table S1 provides the extracted information of the included articles. The original searches in 2020 and 2021 retrieved 22 articles that informed the research design for the studies in this thesis. The 2023 search update retrieved 21 additional articles.

1.4.2.2.1 Study characteristics

As Figure 4 illustrates, the number of yearly publications increased until 2016 and has since stabilised around five publications per year, except for a peak in 2019. Figure 4 also shows that most studies were published in computational journals or conference proceedings (n=24), followed by clinical journals (n=9), interdisciplinary outlets for computational-clinical (n=7) and clinical-social (n=2) work, and one publication in a social science journal[21]. Similarly, most of the first authors had a computational (n=34), only eight a clinical, and four a social science background (including three interdisciplinary researchers with two backgrounds each). Accordingly, more than three quarters of the articles used only NLP methods (n=33). Seven articles used only health research methods, two combined corpus linguistics and linguistic methods (McDonald and Woodward-Kron, 2016; Abdo, Ali and Sarhan, 2019) and one NLP and health research methods (Budenz *et al.*, 2020).

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[20] all John Benjamins journals (https://benjamins.com/catalog), the Brill "Language and Computers" series (https://brill.com/view/serial/LCON), eVarieng online publications (https://varieng.helsinki.fi/series), ICAME Journal issues from 1979 to 2021 (http://icame.uib.no/journal.html), proceedings of the 2001 and 2003 Corpus Linguistics conference at Lancaster University (http://ucrel.lancs.ac.uk/cl2001, http://ucrel.lancs.ac.uk/cl2003), and Lancaster University UCREL research centre publications (http://ucrel.lancs.ac.uk/reference.html).

[21] Mapping of scientific fields: computational (NLP, computer science, information science, data science, information management), clinical (medicine, (mental) health research), social (sociology, discourse studies)

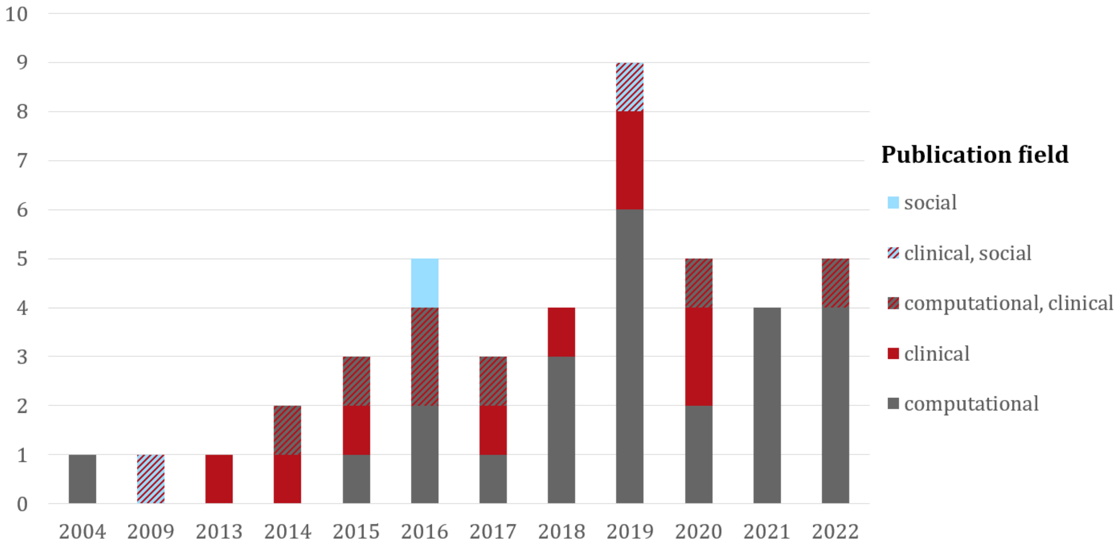

Figure 4 Articles by publication year and field

Most studies analysed data from Reddit (n=22), followed by Twitter (n=10), dedicated peer support forums (n=8), personal blogs (n=2), and a peer support chatroom (n=1). All but three articles that studied Czech, German, or Spanish online support forums, focused only on English data. Less than a third of the articles (n=12) reported any user characteristics such as gender (n=7), MH comorbidities (n=4), country of residence (n=3), age (n=1), or BD subtype (n=1). Less than half of the articles reported at least some ethical considerations (n=20). No article stated that people with lived experience of BD were actively involved in the research.

Inductive grouping of the study aims similar to Harvey et al. (2022) revealed the following topics: Predict BD diagnosis or classify content according to MH issues (n=29), Study BD online peer support (n=15), and Characterise language of BD (n=11). Eleven studies combined two or more aims, six of them to predict a BD diagnosis or classify content according to MH issues and to characterise the language of BD. The remainder of the results sections reviews the methods and findings of the articles according to these study goals.

1.4.2.2.2 Bipolar disorder diagnosis prediction or content classification according to mental health issues

Two thirds of all articles (n=29) solely or partly focused on building classifiers to predict whether a social media user meets BD criteria or what MH issue a post or forum pertains to. All of them used NLP methods for automatic classification. All but two studies used data from the general social media platforms Reddit or Twitter. Posts either stem from BD-specific Reddit subforums (subreddits) or from sometimes manually but predominantly automatically identified users with a self-reported BD diagnosis (e.g., 'I was recently diagnosed with bipolar'). The dataset sizes range from 1K (Tariq *et al.*, 2019) to 5.8M (Jiang *et al.*, 2020) posts and 188 (Coppersmith *et al.*, 2015) to 14.3K (Kim *et al.*, 2020) users.

Earlier approaches between 2014 and 2016 employed logistic regression classifiers with discrete features such as tf-idf, LIWC, or manually defined features based on the posts texts and user posting behaviour (Coppersmith, Dredze and Harman, 2014; Coppersmith *et al.*, 2015; Wang *et al.*, 2015; Chang, Saravia and Chen, 2016; Gkotsis, Oellrich, *et al.*, 2016; Saha *et al.*, 2016; Saravia *et al.*, 2016). In 2017, the first two approaches that compared logistic regression to neural network classifiers were published (Benton, Mitchell and Hovy, 2017; Gkotsis *et al.*, 2017) and following this, most articles included neural network-based classification models and or continuous features (word or character embeddings) derived via neural networks.

Classification performance has increased over the years. For binary classification whether a user meets BD criteria compared to users with other or no MH issues, Jiang et al. (2020) report a near-perfect F-score of 98.2% for Reddit users and Huang et al. (2019, 2021) achieve 91% F-score for Twitter users. Multi-class classification to distinguish users with different or no MH issues appears more difficult, with the best F-scores for the BD class reaching 86%-87% (Guo, Sun and Vosoughi, 2021; Murarka and Raleigh, 2021; Lokala *et al.*, 2022). For the multi-class classification task to distinguish posts from BD support forums from posts concerned with other or no MH issues, Low et al. (2020) report the highest F-score of 81.1%.

However, it is difficult to compare the performance across articles since most of them use different datasets and differ in the identification of users with a BD diagnosis and the comparison group(s). For example, Sekulić and Strube (2019) show that the performance of the baseline model by Cohan et al. (2018) increases from an F-score of 35% to 62% on the same dataset when changing the assignment of control users to MH issues. Most studies allocate randomly selected control users. Some notable exceptions are Coppersmith et al. (2015) who match control users based on age and gender estimates and Sekulić *et al.* (2018) who sample control users that frequently posted in the same non-MH related subreddits as users with a self-reported BD diagnosis. Huang *et al.* (2019) report that their classification models work less well for masculine compared to feminine users. Studies that did not control for differences between the diagnosed and control user set, cannot conclude that their classifiers indeed learned MH condition-specific differences or rather other characteristics due to sampling differences of the user groups (Preoţiuc-Pietro *et al.*, 2015).

Putting the technical feasibility aside, there are numerous problems in the practical deployment of MH issue or diagnosis prediction systems, which only four articles discuss (Huang *et al.*, 2019, 2021; Thorstad and Wolff, 2019; Lokala *et al.*, 2022). The main motivation authors provide for this kind of research is to identify people at risk of or suffering from MH issues who are not aware of this themselves already in order to support them with preventative measures or treatment (Benton, Coppersmith and Dredze, 2017; Guntuku *et al.*, 2017; Cohan *et al.*, 2018). First, this assumes that intervention is likely to be beneficial, which is debatable. For example, for psychotic disorder, where early interventions have been increasingly introduced in the last decades, systematic reviews showed no improvements of clinical and social recovery rates over the last hundred years (Jääskeläinen *et al.*, 2013). Second, MH systems are already under strain, requiring increased capacities and more efficient treatments to deliver care to additionally identified individuals (Kohn *et al.*, 2004). Third, false alarms may have especially adverse consequences for individuals (Inkster *et al.*, 2016). Finally, detection systems for MH issues strongly suffer from the dual-use problem, meaning they could be used in both morally desirable as well as undesirable ways (Jonas, 1984). Someone's likelihood to meet criteria for MH diagnoses are of interest to insurance companies and future employers (Šuster, Tulkens and Daelemans, 2017). Given the prevailing stigma of MH issues, unwanted exposure of such issues can have damaging consequences for individuals in their professional and social life (e.g., Naslund and Aschbrenner, 2019). See also the review of studies on anxiety and depression using Reddit data by Boettcher (2021) on a discussion of these final two issues. As Guntuku *et al.* (2017) conclude, considerations of how to integrate automatic detection systems into health care systems need urgent addressing before deploying them.

1.4.2.2.3 Bipolar disorder language characterisations

Eleven articles solely or partly focused on characterising the language of people with lived experience of BD. All but one study with a corpus linguistic approach (Abdo, Ali and Sarhan, 2019) used NLP methods. Like for research on other MH issues (Guntuku *et al.*, 2017; Wongkoblap, Vadillo and Curcin, 2017), most studies compared the frequencies of LIWC categories in posts by users with lived experience of BD to randomly sampled users. No LIWC category emerged as statistically significantly different for the BD group across all studies. There is most consistent evidence for an overuse of the first-person singular pronoun 'I' in posts by people with a BD diagnosis (Coppersmith, Dredze and Harman, 2014; Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018; Huang *et al.*, 2019). However, a review by Tackman *et al.* (2019b) identified self-referential language using first person singular pronouns as common to mental distress and not BD-specific. Additionally, two studies both found significant increases in function words (e.g., it, to, no, very), auxiliary verbs (e.g., am, will have), cognitive processes (a summary variable for insight, discrepancy, tentative, certainty, differentiation (Pennebaker *et al.*, 2015)) and the content category health (Coppersmith *et al.*, 2015; Cohan *et al.*, 2018). There is mixed evidence regarding negative sentiment. Several studies found significantly increased negative sentiment in posts by people with lived experience of BD (Coppersmith, Dredze and Harman, 2014; Wang *et al.*, 2015; Gkotsis, Velupillai, *et al.*, 2016; Huang *et al.*, 2021), while other studies found no significant differences for the LIWC anger and negative emotion category (Coppersmith, Dredze and Harman, 2014; Coppersmith *et al.*, 2015; Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018).

There are three important points of criticism of the methodologies of this line of research. First, given the large sample sizes in these studies, it is important to consider effect sizes, which only Cohan et al. (2018) report. With a sample size of almost 6.5K the largest Cohen's d of 0.28 for the overuse of the first person singular pronoun indicates only a small effect (Cohen, 1988). Second, several studies do not report between-MH issue comparisons (Coppersmith, Dredze and Harman, 2014; Coppersmith *et al.*, 2015; Cohan *et al.*, 2018) (but see Wang *et al.*, 2015; Yoo, Lee and Ha, 2019; Low *et al.*, 2020). Therefore, it remains unclear if any language differences are BD-specific or rather common to multiple MH issues. Third, none of the studies except for Coppersmith et al. (2015) match demographic characteristics of the BD and control user groups. Preoţiuc-Pietro *et al.* (2015) found that language features including LIWC discriminating between depression and post-traumatic stress disorder were also largely predictive of demographics and personality. Therefore, without controlling for these variables, it is unclear whether any observed differences are due to MH experiences or any other user characteristics.

Considering these methodological limitations, the lack of consistently significant language differences, and small effect sizes, the current body of research rather points to large commonalities in the language of online posts by people with and without lived experience of BD. Persisting research efforts to find such differences may rather lead to topic overexposure. Topic overexposure, ‘where certain groups are perceived as abnormal when research repeatedly finds that their language is different or more difficult to process’ (Jagfeld, 2019, p. 21), may lead to biases and discrimination (Hovy and Spruit, 2016), feeding into existing stigma against BD.

1.4.2.2.4 Study bipolar disorder online peer support

There were two main aims among the 15 studies that studied BD online peer support. Ten studies analysed the objective post content, eight focused on the interactions between forum participants. Compared to research on BD diagnosis prediction or content classification or BD language characterisations, this body of research is more diverse in terms of the analysed data and employed methods. Eight articles used social media data from Reddit or Twitter, but five studies analysed dedicated BD or MH peer support forums including three non-English language ones, and one article each studied a peer support chatroom and personal blogs. Again, only a minority (n=6) of the articles discussed ethical considerations, all but one that did so used health research methods.

1.4.2.2.4.1 Content of bipolar disorder peer online support posts

The six articles that studied the content of BD peer support posts via health research methods, analysed 9-2,400 posts each, while the four articles with NLP methods analysed 2,433-1.5M posts. Most studies identified topics pertaining to a medicalised view of BD as most frequent topics or main themes, such as medication (Bauer *et al.*, 2013; Poole, Smith and Simpson, 2015; Mandla, Billings and Moncrieff, 2017; Yoo, Lee and Ha, 2019; Low *et al.*, 2020; Song and Kim, 2022), medication side effects (Yoo, Lee and Ha, 2019; Song and Xie, 2020; Song and Kim, 2022), BD symptoms (Bauer *et al.*, 2013; Latalova *et al.*, 2014; Mandla, Billings and Moncrieff, 2017; Yoo, Lee and Ha, 2019; Low *et al.*, 2020), and professional treatment (Latalova *et al.*, 2014; Poole, Smith and Simpson, 2015; Low *et al.*, 2020). These topics align with an international survey by Conell and colleagues (2016) that found that people with a BD diagnosis mainly searched online for information regarding symptoms, medication, the general course of BD, and coping strategies.

Several studies also found evidence for discussions of psychosocial aspects of living with BD such as romantic and other social relationships (Bauer *et al.*, 2013; Latalova *et al.*, 2014; Poole, Smith and Simpson, 2015; Song and Kim, 2022), financial and legal issues (Bauer *et al.*, 2013; Low *et al.*, 2020), employment (Poole, Smith and Simpson, 2015), and reproductive decision making (Sahota and Sankar, 2019), although such issues were usually less frequent or salient than the medicalised topics. Two studies performed data mining of online posts to find evidence for the effectiveness of specific diets on mood stabilisation (Campbell and Campbell, 2019) or not previously known medication side effects (Song and Xie, 2020).

1.4.2.2.4.2 Interactions in bipolar disorder peer online support

Articles that studied interactions in BD online peer support used the largest variety of methods among all aims: Four studies used NLP, two health research, and one each a combination of corpus linguistics and linguistic or health research and NLP methods. The main mechanisms or desired benefits of BD online peer support were to provide or receive emotional support in the form of encouragement or comfort (Vayreda and Antaki, 2009; Bauer *et al.*, 2013; Latalova *et al.*, 2014; Poole, Smith and Simpson, 2015; Budenz *et al.*, 2020), and to give or receive advice (Vayreda and Antaki, 2009; Bauer *et al.*, 2013; Latalova *et al.*, 2014; Poole, Smith and Simpson, 2015). Silveira et al. (2021) provide quantitative evidence that online peer support may improve users' emotional state. Their automatic emotion analysis shows that the emotional tone of a user's comments (including their final one) is more positive than their initial post that started the thread.

Two studies that looked at language changes associated with forum membership length found contradictory trends: Kramer et al. (2004) observed that forum users mentioned BD-specific terms less frequently over time, whereas veteran support forum members in McDonald and Woodward-Kron's (McDonald and Woodward-Kron, 2016) study were more likely to use BD-specific forum jargon than new members. Finally, Vayreda and Antaki (2009) observed in their Spanish forum that new users first needed to legitimise themselves via a formal diagnosis and seeking professional support, before established forum members provided advice and support. In contrast, Latalova et al. (2014) found the Czech peer support forum in their study to be open unequivocally to newcomers and did not report such gatekeeping behaviour.

In sum, a comparably small body of research has used a variety of language analysis methods to analyse different forms of BD online peer support. Given the large heterogeneity of the online communities and sometimes conflicting findings, it seems difficult to draw generalised conclusions. Rather, it appears that the mechanisms and forms of BD peer online support may be platform specific, thus motivating further research into this area such as the ongoing Improving Peer Online Forums study (Lobban, Rayson and Coole, 2022).

1.4.2.3 Summary

This literature review summarised the characteristics, methods, and findings of 43 previous studies that analysed online posts by people with lived experience of BD. The findings align well with those of a recent scoping review of 35 studies of BD using NLP methods published between 2004-2021 (Harvey *et al.*, 2022). Harvey and colleagues also identified Reddit, followed by Twitter as main data sources and a large focus on diagnosis prediction and classification in previous research. Given the interdisciplinary nature of the research topic, it appears surprising that only three studies used an interdisciplinary approach. Noteworthy gaps in the literature are a lack of reporting of user characteristics in two thirds of the articles, no mention of ethical considerations in more than half of the articles, and no references to active involvement of people with lived experience of BD into the research in any article.

1.5 Aim and research questions in the context of previous work

This section succinctly summarises the previous research considered above to situate the aim and RQs of this thesis presented subsequently. The chapter concludes with an overview of the remainder of this thesis.

1.5.1 Situating this thesis in previous work

The following key observations summarise the review of previous research on PR and BD in this chapter:

- BD is a fairly common long-term MH issue characterised by periods of intense and changing mood.
- People living with BD have a wide range of socio-occupational outcomes and quality of life.
- PR, living a hopeful and satisfying life despite symptoms, has become an important goal of Western MH care agendas, but it is not well understood yet what it means for people living with BD and how to best support their PR.
- Online posts as a naturalistic data source available in large quantities can complement clinical studies. To date, there have only been a few small-scale health research studies that analysed online posts by people with lived experience of BD.
- NLP methods allow researchers to collect and analyse large amounts of data. However, previous NLP research on BD has mainly focused on trying to predict diagnoses and identify language differences.
- Corpus linguistics combines qualitative and quantitative methods to analyse language data and can offer a trade-off between sample size and analytical depth. However, previous corpus linguistic studies in BD focused more on language descriptions rather than health RQs.
- Overall, previous language analysis research of online posts by people with lived experience of BD has been lacking in several aspects, including availability or reporting of the characteristics of the online users, ethical considerations, and involvement of people with lived experience of BD.

1.5.2 Aim and research questions

Based on the above considerations, the **overarching aim of this thesis is to study PR experiences that people living with BD have shared in online support forums through integrating health research, NLP, and corpus linguistics in a mixed-methods approach within a pragmatic research paradigm, while considering ethical issues and involving people with lived experience.** NLP and corpus linguistic methods can consider much more data than the manual collection, selection, and analysis in traditional qualitative health research approaches. Corpus linguistic methods afford a more systematic analysis of the language around PR in BD than qualitative health research. Finally, the health research lens provides the theoretical and ethical foundation of the research and ensures that the findings have practical implications for MH professionals, informal carers, and people living with BD. The pragmatic paradigm (see Section 2.1.7) provides the theoretical framework to integrate these methods in a mixed-methods approach. Concretely, this thesis aims to answer the following RQs:

- RQ 1: What do we know about the experience of PR of individuals diagnosed with BD from qualitative evidence?
- RQ 2a: What characteristics of Reddit users who disclose a BD diagnosis can be automatically inferred from their public Reddit information and how do they compare to general Reddit users and clinical populations?
- RQ 2b: What are the ethical considerations around determining users' characteristics and ways to minimise potential negative impacts?
- RQ 3a: What proportion of Reddit users with a BD diagnosis posts in MH and non-MH subreddits?
- RQ 3b: What differences exist in the emotions that Reddit users with a BD diagnosis express in MH and non-MH subreddit posts?
- RQ 3c: How does mood differ between Reddit users with a BD diagnosis who post in MH subreddits and those who only post in non-MH subreddits?
- RQ 4a: What are the main topics that people with a self-reported BD diagnosis talk about in BD online support forums?
- RQ 4b: With what meanings do Reddit users with a self-reported BD diagnosis use *recover* terms (i.e., recovery, (to) recover, recoverable)?
- RQ 4c: What can online support forum posts reveal about the processes and experience of PR in BD in relation to the POETIC framework?

1.5.3 Thesis structure

The ensuing methodology chapter (Chapter 2) justifies the pragmatic paradigm underlying this thesis, presents the research design and considers validity and reflexivity. Next, the methods chapter (Chapter 3) introduces the online discussion platform Reddit that served as source of online posts by people with lived experience of BD in this thesis and provides details on some data analysis methods. This chapter also presents how this research involved people with lived experience of BD and concludes with discussing ethical considerations.

Chapter 4-7 each present a self-contained article. The POETIC review in Chapter 4 answers RQ 1 via a systematic literature review of qualitative studies on PR in BD. The Reddit user characteristics study in Chapter 5 addresses RQ 2a by applying existing NLP methods to infer social media user characteristics from their usernames and posts after discussing the ethical considerations of doing so in response to RQ 2b. This chapter also details the data collection from Reddit to create the Self-reported BD diagnosis (S-BiDD) dataset, which the following two studies analyse as well. The Reddit mood and posting behaviour study in Chapter 6 deals with RQs 3a – 3c using automatic emotion analysis. Lastly, the POETIC on Reddit study in Chapter 7 answers RQ 4a – 4c by integrating qualitative framework analysis and corpus linguistic methods.

Finally, the discussion chapter (Chapter 7) ties together all findings in response to the RQs and presents the contributions and implications of this thesis. Then, it critically reviews the strengths and limitations of this research with suggestions for future work and offers some personal reflections on dealing with challenges in this PhD project.

2 Methodology

This chapter details the fundamental methodological considerations in this thesis. First, Section 2.1 introduces the five main research paradigms and justifies the pragmatic paradigm underlying the project. Second, Section 2.2 lays out the research design. The chapter concludes with considerations of validity in Section 2.3 and reflexivity in Section 2.4.

2.1 Research Paradigm

Research paradigms provide a theoretical framework to ground decisions in a research project and a theoretical lens to interpret the results (Crotty, 1998; Mackenzie and Knipe, 2006; Creswell and Plano Clark, 2018). The research paradigm entails four aspects (Mackenzie and Knipe, 2006; Weaver, 2018):

- Epistemology: what constitutes credible knowledge (Blackburn, 2008)
- Ontology: what is the nature of entities in the world (Crotty, 1998, p. 10)
- Axiology: what are values and how do the researchers' values influence the research (Creswell and Plano Clark, 2018, p. 69)
- Methodology: how to gain knowledge (Mackenzie and Knipe, 2006), conduct research (Somekh and Lewin, 2005, p. 346), and choose methods (Crotty, 1998, p. 3)

2.1.1 Overview of the main health research paradigms

Table 9 presents an overview of the main health research paradigms, (post-)positivism, interpretivism/constructivism, pragmatism, critical realism, and transformatism, and their epistemological, ontological, axiological, and methodological assumptions. It is difficult to provide clear-cut distinctions between these research paradigms, as they are not 'watertight compartments' (Crotty, 1998, p. 9). They often developed over long periods of time, shaped by philosophical thinkers with different positions (e.g., in the case of constructivism (Alvesson and Sköldberg, 2018, p. 37)) and their practical applications differ from theoretical texts (e.g., in the case of pragmatism (Crotty, 1998, pp. 75–76)). Current MH research employs all of these paradigms (Peters, 2010), and each has both merits and shortcomings (Doucet, Letourneau and Stoppard, 2010).

Table 9 Overview of main research paradigms

Paradigm and origin	Epistemology	Ontology	Axiology	Methodology
Positivism, originates from empiricism started by Aristotle, Bacon, Locke, Comte, Kant, replaced by post-positivism in the 1960s (Mertens, 2014, p. 58)	Discoverable natural laws drive reality (realist) (Bhaskar, 1975, p. 15)	Researcher-independent reality exists (objectivist) (Bhaskar, 1975, p. 15)	Observations (measurements) are independent of the values and beliefs of the researcher (Collier, 2005, p. 328)	Experiments, quantitative (Phillips and Burbules, 2000)
Post-positivism, largely replaced positivism starting from the 1960s (Mertens, 2014, p. 59)	Scientific theories can never be proven true, statements 'remain tentative forever' (Popper, 1959, p. 280) (critical realist)	Researcher-independent reality exists (objectivist), but can be known only imperfectly and probabilistically (Phillips and Burbules, 2000)	Bias is inevitable but researchers need to detect and try to correct it (Phillips and Burbules, 2000)	Predominantly quantitative, but sometimes also qualitative (Mertens, 2014, p. 63)
Interpretivism/ Constructivism, mainly introduced by Berger & Luckmann (1966), taken up by Gergen (1985) and Lincoln & Guba (1985), among others	Knowledge is relative, meaningless to search for general knowledge or truth, cannot compare and evaluate knowledge except in very limited contexts (Rorty, 1979; Alvesson and Sköldberg, 2018, p. 37) (relativist or interpretivist)	Reality is socially constructed and completely subjective, need not be shared with others (constructivist) (Alvesson and Sköldberg, 2018, p. 35)	Observations are heavily influenced by and cannot be separated from the values and beliefs of the researcher (Creswell and Plano Clark, 2018, p. 69)	Predominantly qualitative, sometimes with additional numerical data, but usually no statistical analyses (Mackenzie and Knipe, 2006, p. 3)

Paradigm and origin	Epistemology	Ontology	Axiology	Methodology
Pragmatism, originated in US in 1870s by Charles Sanders Peirce, revival in 1970s with Rorty (1979) and others (Legg and Hookway, 2019)	Do not doubt everything, only what makes a practical difference (anti-scepticist) (Creswell and Creswell, 2018, p. 10-11; Legg and Hookway, 2019), focus on inquiry that allows for continuous correction (instead of certain knowledge) (Legg and Hookway, 2019), between objective and subjective (intersubjective) (Morgan, 2007, p. 71)	Humans actively create an ever-changing reality, 'truth is what works at the time' (neither objectivist nor constructivist) (Weaver, 2018, p. 3)	No strong emphasis on values, compatible with critical or transformative approaches (Creswell and Creswell, 2018, p. 10-11; Legg and Hookway, 2019), puts democracy over philosophy (Rorty, 1991)	Mixed-methods, action research, practical considerations and empirical conditions guide choice (Danermark et al., 2002, p. 204; Morgan, 2007, p. 67)
Critical realism, developed since 1970s, started by Bhaskar (1975) some regard it as form of post-positivism (Ryan and Rutty, 2019)	Theory influences but does not determine knowledge (Danermark et al., 2002, p. 17), can uncover mechanisms but impossible to predict active mechanisms in a situation → cannot make predictions in social science (Danermark et al., 2002, p. 70) (constructivist)	Division of reality in three domains: Real (1) core of reality exists as mechanisms that cause the Actual (2) (what actually happens), which manifests as the measurable or observable Empirical (3) (Danermark et al., 2002, p. 20) (realist)	While the Real core (underlying mechanisms) is researcher-independent, Empirical observations depend on the values and beliefs of the researcher (Danermark et al., 2002, p. 20)	Mixed-methods, ontology guides choice: studied object and purpose of investigation (Danermark et al., 2002, p. 204)

Paradigm and origin	Epistemology	Ontology	Axiology	Methodology
Transformatism, arose during 1980s and 1990s (Creswell and Creswell, 2018, p. 9), draws on Marx, Adorno, Habermas, among others (Neuman, 2009, p. 110)	Theory must go deeper than the surface level to uncover mechanisms (critical realist), good knowledge empowers people to take action and change the world (Neuman, 2009, p. 121)	Critical realist (Neuman, 2009, p. 111)	Research must begin with value position (Neuman, 2009, p. 121), intertwined with politics, needs to transform participants' lives, institutions, researchers (Mackenzie and Knipe, 2006) (transformative)	Mixed-methods, participatory and action research (Neuman, 2009, p. 111)

2.1.2 (Post-)positivism

Positivism originated from studying the material world. Social science has applied it under the assumption that 'the social world can be studied in the same way as the natural world' (Mertens, 2005, p. 8). (Post-)positivist research generally follows a deductive methodology, where researchers test an a priori theory with experiments (Creswell and Plano Clark, 2018, p. 69). After the Second World War, post-positivism replaced positivism (Mackenzie and Knipe, 2006, p. 2) when the realist epistemology and objectivist ontology were slightly softened. Post-positivism still holds that reality is driven by natural laws. But it takes a scepticist position that proposed laws can never be proven to be true, only not to be false (Popper, 1959, p. 280). While still upholding the objectivist view that an absolute reality exists, post-positivism acknowledges that it can only ever be known imperfectly (Phillips and Burbules, 2000).

Post-positivism was long the dominant (Alvesson and Sköldberg, 2018, p. 15), but implicit research paradigm in social (and health) research (Morgan, 2007, p. 56). Only in the 1970s, the upcoming constructivists/interpretivists explicitly formalised it in their critiques (Morgan, 2007, p. 56). One of the main points of criticism from this perspective, which is also especially relevant to MH research, concerns the objectivist ontology, which places little importance on the inner subjective world of human experience (Slade, 2012, p. 80). Furthermore, proponents of the transformative worldview criticised that post-positivist research generated laws and theories that do not fit marginalised groups in society (Creswell and Creswell, 2018, p. 9). This may be due to a strive for generalisability that tends to overlook minorities.

Post-positivism is still very influential in Western modern health research as it underlies evidence-based health care (Slade, 2012; Van Os *et al.*, 2019). Aggregating information over study participants and drawing inferences on a wider population are important cornerstones to inform health care policies and develop consistent practices. However, policy institutes now also start to consider other research paradigms to inform evidence-based practices. For example, the UK Medical Research Council recently endorsed critical realism to evaluate complex interventions (Skivington *et al.*, 2021).

2.1.3 Interpretivism or constructivism

Interpretivism or constructivism[22] is a research paradigm that can be seen as backlash against the post-positivist paradigm in many aspects (Alvesson and Sköldberg, 2018, p. 18). For example, constructivism rejects the idea that researchers can study the social world in the same way as the natural/inanimate world (Neuman, 2009, p. 103). As Slade (2012, p. 83) put it: 'Humans differ in important ways from the objects of study of the natural sciences - we have attitudes, we are active agents in our world, we have consciousness, and we can make

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[22] The literature uses both terms mostly synonymously; this section always uses constructivism.

decisions and change our minds.' Husserl's (1859-1938) phenomenology formed the basis of constructivism (Mackenzie and Knipe, 2006, p. 3). Key texts were 'The Social Construction of Reality' (Berger and Luckmann, 1966) and 'Naturalistic Inquiry' (Lincoln and Guba, 1985). Some modern summarisations of this position are Crotty (1998), Mertens (2014), and Lincoln, Lynham and Guba (2017).

The German philosopher Wilhelm Dilthey (1883) argued for two fundamentally different types of science: *Naturwissenschaft* (natural science) and *Geisteswissenschaft* (social science or humanities). Whereas the former seeks *Erklärung* (explanation), the latter is about *Verstehen* (understanding) (Neuman, 2009, p. 103). Constructivism refutes the objectivist ontology (Alvesson and Sköldberg, 2018, p. 35) and the idea that research can or should be free from researchers' values and interpretations (Creswell and Creswell, 2018, p. 8). Instead of theory-driven deduction, interpretivist methodology is inductive and generates patterns, theories and interpretations bottom up from participants' views (Creswell and Plano Clark, 2018, p. 70).

The interpretivist epistemological stance holds that knowledge can only be compared in very limited contexts and it is meaningless to search for a general truth (Rorty, 1979; Alvesson and Sköldberg, 2018, p. 37). Because of this, this paradigm does not accept aggregation of information and generalisations to populations beyond the study. This also constitutes one of the main criticisms of constructivism: a tendency to purely descriptive research and analyses that stay at the individual level rather than formulating more informative theories (Alvesson and Sköldberg, 2018, p. 37). Moreover, in merely describing social constructions, this paradigm tends to eschew questions that are important in other research paradigms: 'Why do people construct society in the way they do?' and 'How do these constructions function, as patterns of social reality, once they have been constructed'?' (Alvesson and Sköldberg, 2018, p. 37).

Nevertheless, research founded on this paradigm has been influential in providing alternative views on MH and recovery besides the medical model largely founded on post-positivist tenets (Slade, 2012). Interpretivist qualitative research on PR in severe MH issues contributed to the concept of PR (Slade, 2009), which claims that the recovery of such experiences is a very individual, idiosyncratic process.

2.1.4 Pragmatism

Pragmatism in philosophy, originated in the US in 1870s, with philosophers such as John Dewey, William James and Charles Sanders Peirce (Creswell and Plano Clark, 2018, p. 71) and had its revival in the 1970s with Richard Rorty (1979) among others (Legg and Hookway, 2019). More recent propositions of pragmatism such as Morgan (2007) can be seen as backlash after the US 'science wars' in the 1990s where discussions about philosophical foundations dominated the scientific discourse (Labinger and Collins, 2001). Morgan (2007, p. 64) criticises the view that the epistemological and ontological positions of post-positivism and constructivism are incommensurable as unhelpful and instead tries to reconcile them. Pragmatism values both objective and subjective knowledge (Creswell and Plano Clark, 2018, p. 71). In fact, Morgan (2007, p. 72) argues that a completely objective position is too idealistic, but a completely subjective position is not conceivable either since researchers need mutual understanding with their participants and academic colleagues for peer review. This epistemological middle way is called intersubjective (Morgan, 2007, p. 71). Likewise, instead of deduction (as in positivism) or induction (as in constructivism), which Morgan (2007, p. 70) sees as idealised descriptions of research processes, pragmatic research explicitly acknowledges to move back and forth between theory and data in a process called abduction (Morgan, 2007, p. 71).

Pragmatism also encourages the use of multiple methods and triangulation (Creswell and Plano Clark, 2018, p. 69). As such, it is often seen as prime theoretical underpinning of mixed-method research (Johnson and Onwuegbuzie, 2004; Morgan, 2007; Johnson and Gray, 2010)), even though other paradigms endorse mixed methods as well, predominantly transformatism (Mertens, 2003) and critical realism (Maxwell and Mittapalli, 2010). One of the main points of critique of pragmatism comes from researchers who believe that philosophical assumptions are more important in research than the secondary role pragmatism assigns them to (Maxwell and Mittapalli, 2010, p. 147).

2.1.5 Critical realism

Critical realism criticises both positivism and social constructionism as too superficial in concentrating just on data but not on the mechanisms and structures underlying manifest phenomena (Alvesson and Sköldberg, 2018, p. 39). Going beyond describing 'what happened', critical realism tries to explain 'why it happened, for whom, and under what circumstances' (Jagosh *et al.*, 2011, p. 7). The British philosopher Roy Bhaskar (1975) developed its main theoretical foundation in social science research and so far it has been mainly attracted attention in the UK (Alvesson and Sköldberg, 2018, p. 39). Other recent writers include House (1991), Pawson and Tilley (1997b) and Porter (2007). Its positions are very close to post-positivism and some consider it to be a form of it rather than a separate research paradigm (Ryan and Rutty, 2019).

Like positivism, critical realism upholds the realist ontological belief of an observer-independent reality, but couples this with the constructivist epistemological belief that our understanding of the world depends on our individual standpoint and it is impossible to gain an objective view of things (Maxwell and Mittapalli, 2010, p. 147). According to realist ontology, reality consists of three domains (Bhaskar, 1975, p. 56; Danermark *et al.*, 2002, p. 20). The Real constitutes structures of physical and social objects behaving according to underlying *mechanisms*. Mechanisms cause the Actual, which is what actually happens independent of the observer or researcher. The Empirical is what researchers can measure or observe (Bhaskar, 1975, p. 56; Danermark *et al.*, 2002, p. 20).

Mechanisms are a central concept in critical realism. They are 'that which is capable of making things happen in the world' (Alvesson and Sköldberg, 2018, p. 42). They can trigger events and constitute the sort of deeper-lying phenomena that the paradigm claims to try to uncover. For example, in a realist interview (Pawson and Tilley, 1997a), the interviewer would explain her theory about the mechanisms that triggered a certain behaviour and directly ask the participant if that fits with her experience (Smith and Elger, 2014). Another central concept is *structures*. They are internally related objects, connected by configurations of causal mechanisms, such as the teacher-student relationship (Alvesson and Sköldberg, 2018, p. 42).

Critiques of critical realism challenge its strong conviction in realism as too naïve (Alvesson and Sköldberg, 2018, p. 45) and the main concepts of mechanisms and structures as too broad and diffuse (Putnam, 1990, p. 2; Cherryholmes, 1992, p. 15; Alvesson and Sköldberg, 2018, p. 44). Critical realism also has some overlap with pragmatism. Some key pragmatists endorse critical realist ontology (Maxwell and Mittapalli, 2010, p. 154) and the contemporary philosophers Putnam (1990) and Haack (2006) integrate pragmatism and realism. Notable in the context of MH research is that critical realism regards mental phenomena as real and endorses an interpretive perspective to study them (Maxwell and Mittapalli, 2010, p. 147).

2.1.6 Transformatism

The transformative paradigm, as mentioned above, came up as another critique of post-positivism and constructivism in the 1980-90s (Mackenzie and Knipe, 2006, p. 3). Drawing on ideas of Marx, Adorno, Marcuse, Habermas, and Freire (Creswell and Creswell, 2018, p. 9), key texts include Fay (1987), Heron and Reason (1997), Kemmis and McTaggart (2005), Mertens (2008), and Kemmis, McTaggart and Nixon (2014). It mainly targets issues of diversity and inclusiveness in research by pillorying previous social science research as 'developed from the white, able-bodied male perspective' (Mertens, 2005, p. 17). Like critical realism (and post-positivism) it adopts a critical realist epistemological and ontological stance, but differs from these paradigms in the axiological dimension. The post-positivist paradigm values knowledge for its own sake and does not require the researcher to know future use of this information (Brown and Hedges, 2009). Instead, transformatism makes 'the researcher's responsibility with regard to uses made of their work' (Mertens, 2010, p. 12) a key question and 'gives social justice a priority as the value that underlies research' (Mertens, 2010, p. 12). Consequently, transformative research pushes for more inclusive research concerning all aspects – the researchers, topics, and participants involved (Creswell and Creswell, 2018, p. 9). Thus, transformative research places central importance on the study of lives and experiences of traditionally marginalised diverse groups (Mertens, 2014) and 'focuses on inequities based on gender, race, ethnicity, disability, sexual orientation, and socioeconomic class that result in asymmetric power relationships' (Creswell and Creswell, 2018, p. 10).

Furthermore, transformatism champions stronger forms of public and participatory involvement (Neuman, 2009, p. 111) such as collaboration and lay-controlled research (Oliver *et al.*, 2008; INVOLVE, 2012). It strives to empower people to improve their lives with the generated knowledge and the research process itself. As Mertens (2003, p. 159) put it: 'Transformative […] scholars recommend the adoption of an explicit goal for research to serve the ends of creating a more just and democratic society that permeates the entire research process, from the problem formulation to the drawing of conclusions and the use of results.' This also highlights the important formative role of researchers' values and political views in this paradigm. Research by community action groups, political organisations, and social movements often adopts the transformative paradigm, but less so research in more traditional academic institutions (Neuman, 2009, p. 117). By aiming for empowerment and endorsing participatory action research, transformative research is very much in line with the service user movement and service user-led research (Rose *et al.*, 1998; Wallcraft, Read and Sweeney, 2003; Callard and Rose, 2010). While research design textbooks do not offer specific critiques of the transformative paradigm, Biddle and Schafft (2015) contest whether it constitutes a research paradigm in its own right or rather an infusion of critical realist or pragmatist epistemological, ontological, and methodological views with a strong axiological focus.

2.1.7 Research paradigm underlying this project: pragmatism

Choosing a research paradigm is often a very personal process. For example, Darlaston-Jones (2007) wrote: 'in embarking on this journey I discovered as much about me'. Hence, this section justifies the choice of pragmatism as research paradigm underlying this thesis in the context of the research topic, envisioned approach, and personal positioning of the PhD student reported in first person language.

Delving into the philosophical literature was an exciting and eye-opening experience for me since I had had little exposure to it in my previous NLP and corpus linguistic research. These fields tend to not discuss their foundational philosophical assumptions explicitly and mostly operate within an implicit (post-)positivist stance (Ignatow and Mihalcea, 2018, p. 9). Through engaging with the philosophical positions presented in this section so far, I formulated my own positioning:

- Realist ontology: I believe that there is a reality in our world, although it might be only imperfectly measurable or observable. I believe that extreme mood experiences are real because many people describe them similarly.
- Intersubjective epistemology: While I do not subscribe to an objectivist view that there is absolute truth, I am not subjectivist either because I believe that groups of people can share views. Pragmatism calls this position intersubjective. Particularly, I hold the view that social construction rather than natural laws govern human social life such as culture, values, and the organisation of societies. Thus, different groups of people can interpret our real reality differently and ascribe different meanings to the same observations or events. I regard MH diagnoses as social constructions as explained in Section 1.2.6. Different cultures have interpreted extreme mood and psychotic experiences differently: while mainstream modern Western culture mostly sees them as symptoms of an illness that hinder a productive life and need to be removed or cured, there are also contemporary non-pathological interpretations of MH issues (e.g., Grof and Grof, 1986; Sass, 1992; Bentall, 2003). Moreover, some ancient or indigenous cultures regard(ed) such experiences and behaviour as sacred and constituting valuable contributions to their societies (e.g., Marsella and White, 1982; Ustinova, 2018).
- Critical realist axiology: In line with critical realist axiology, I am convinced that my previous experiences, beliefs, and values shape how I approach this project

and interpret participants' experiences. Additionally, I align with post-positivist axiology in so far that researcher subjectivity is inevitable and needs to be detected but I do not believe it can be removed, only made transparent.

My ontological, epistemological, and axiological views are broadly compatible with the pragmatic, critical realist, and transformative research paradigm. The following considerations led to adopting the pragmatic paradigm in this project. I sympathise with the transformative paradigm in that I strongly agree that knowledge should be 'given to people to help them take charge of and improve their lives‘ instead of 'hidden in ivory towers for intellectuals to play games with' (Neuman, 2009, p. 117). Michalak et al. (2016) suggested community-based participatory research as promising but at that time not yet widely used approach for BD research. However, the funding scheme and timeframe of this PhD project only allowed for consultation of people with lived experience rather than collaboration (see Section 3.3). Since this is a less strong form of participatory and public involvement (PPI)[23] with little researcher commitment (Arnstein, 1969; Oliver *et al.*, 2008), a transformative stance was not appropriate for this project.

Critical realism and pragmatism are similar in many aspects related to mixed-method research but differ in their regard of philosophical discussions as fruitful or counterproductive. In advocating for a critical realist stance in mixed-method research Maxwell and Mittapalli (2010, p. 147) argue that 'the pragmatist position underestimates the actual influence of philosophical assumptions on research methods' and that these are 'lenses for viewing the world, revealing phenomena and generating insights that would be difficult to obtain with other lenses‘ (Maxwell and Mittapalli, 2010, p. 148). Pragmatism, in turn, focuses on the practical consequences of the questions we ask (Cherryholmes, 1992, p. 16). This aligns well with the goal of the project to generate knowledge on PR in BD with the intention to inform positive changes for people living with BD. Two aspects of the pragmatic research paradigm were particularly beneficial for this time-limited interdisciplinary project. First, it allows to justify methodological decisions based on pragmatic considerations and empirical conditions (Danermark *et al.*, 2002, p. 204), Second, instead of focussing on differences and incommensurability of research disciplines, it emphasises their shared meanings and joint action, that manifest their success in being able to productively work together on joint projects (Morgan, 2007, p. 67).

In sum, these considerations justify the approach of this project to study PR experiences of people living with BD via language analysis of their online posts, without directly interacting with them. The project assumes that the written participant statements are real in so far as they reflect their experiences, emotions, and beliefs at the time of writing, although our means to observe or measure them may be imperfect. Furthermore, it assumes that shared beliefs exist between people who describe similar experiences. The underlying theory of language allows for intersubjective meaning construction (Ignatow, 2016).

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[23] PPI more frequently refers to *patient* and public involvement. However, not everyone with lived experience of MH issues is or would like to be referred to as a patient.

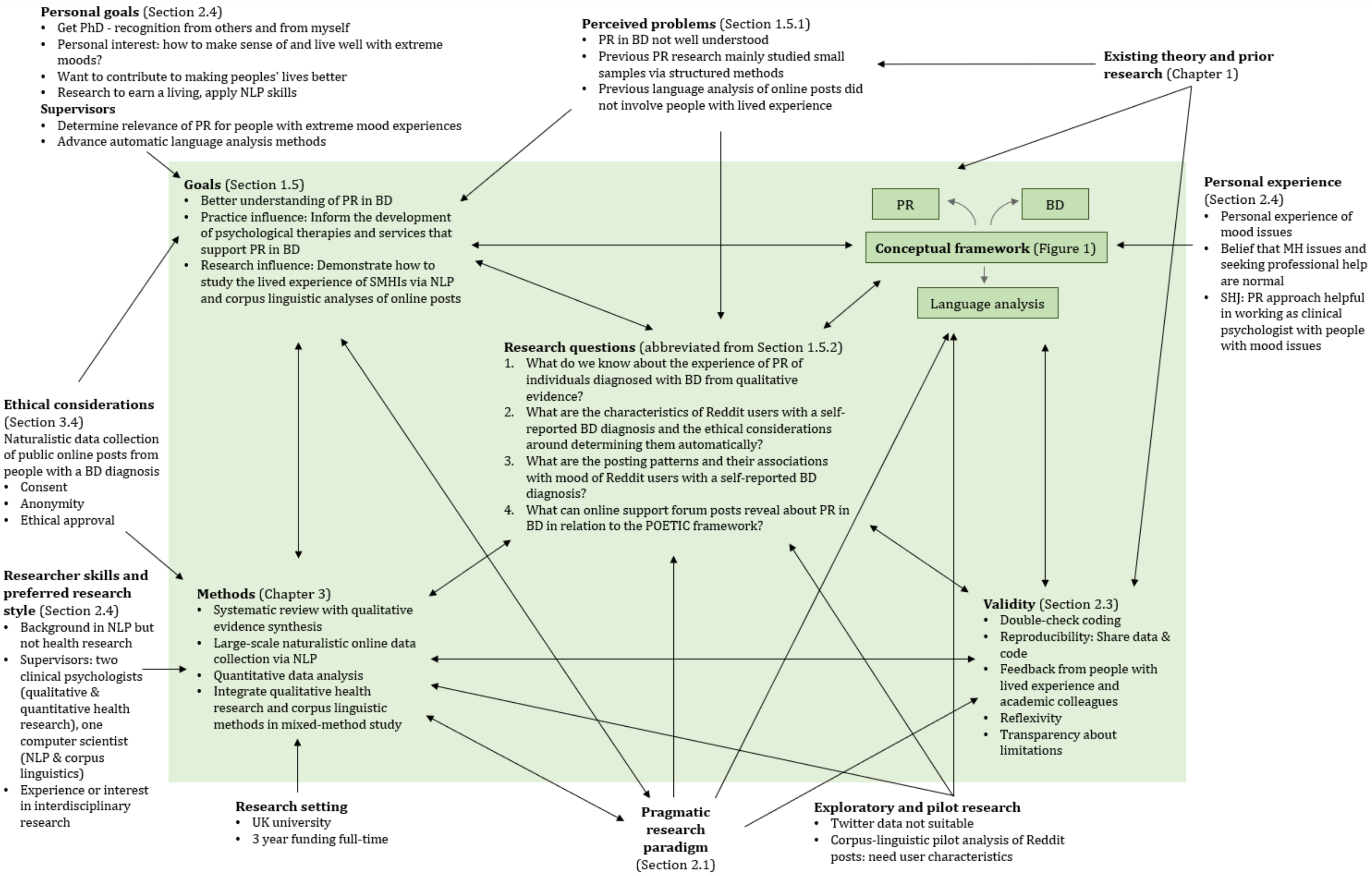
2.2 Research design

This PhD project uses mixed methods to combine the advantages of qualitative and quantitative methods (Tashakkori and Teddlie, 1998; Johnson and Onwuegbuzie, 2004; Greene, 2007; Creswell and Plano Clark, 2018). Specifically, it integrates qualitative evidence from previous health research with quantitative analyses of social media users' characteristics and their mood and posting behaviour, and a mixed-methods analysis of online posts. Mixed-method approaches are established in MH research (Steckler *et al.*, 1992; Baum, 1995; Sale, Lohfeld and Brazil, 2002; Lund, 2012) and specifically recommended for PR research (Leonhardt *et al.*, 2017). Quantitative methods are suitable to study observable behaviour such as how frequently someone posts and manifest language and can yield more generalisable results based on larger samples. However, they fall short of capturing the subjective, idiosyncratic meaning of socially constructed reality, which is important to understand individuals' PR experience (Russell and Browne, 2005; Mansell *et al.*, 2010; Morrison *et al.*, 2016b; Crowe and Inder, 2018).

2.2.1 Interactive model of research design

Maxwell (2009, 2012) proposes an interactive research design model. The core elements study goals, conceptual framework, RQs, methods, and validity concerns shape the design, alongside contextual factors such as personal goals, perceived problems, existing theory and prior research, personal experience, researcher skills, research setting, and ethical considerations. The research design evolves during the project. For example, exploratory and pilot research can influence the methods, RQs, and conceptual framework (Creswell and Plano Clark, 2018, Chapter 3).

Figure 5 illustrates how the core elements and contextual factors of the interactive model interplayed to design the present project. The chapter references for each component in Figure 5 highlight how Chapter 1-3 of this thesis cover all elements of this model. The project started with the *goal* to better understand PR in BD based on the *perceived problem* of a lack of naturalistic evidence from larger samples in *existing theory and prior research* on this topic. The supervisory team had the initial idea to study PR in BD by analysing online posts via NLP and corpus linguistic *methods*, which formed the basis for *RQ 4*. This aligned with the *personal goals* and *researcher skills and preferred research style* of the PhD student and supervisory team. *Existing theory and prior research* along with *personal experience* informed the *conceptual framework* that encapsulates the core concepts in this project. Early on, it became apparent that a synthesis of previous qualitative evidence on PR in BD would serve as basis against which to compare the new findings of this project, leading to *RQ 1*. *Ethical considerations* and *exploratory and pilot research* guided the data collection and analysis *methods*. Initial Twitter data collection revealed that short tweets contained few mentions of recovery and little depth of experiences, compared to often longer and richer Reddit posts. A corpus linguistic pilot analysis of Reddit posts showed that more information about the characteristics and posting behaviour of the users could help to contextualise the experiences in the posts. Thus, *RQ* 2 and *RQ* 3 completed the research design. The *research setting, pragmatic research paradigm,* and *validity* considerations further impacted on the *methods.*



Personal goals (Section 2.4)
- Get PhD - recognition from others and from myself
- Personal interest: how to make sense of and live well with extreme moods?
- Want to contribute to making peoples' lives better
- Research to earn a living, apply NLP skills

Supervisors
- Determine relevance of PR for people with extreme mood experiences
- Advance automatic language analysis methods

Perceived problems (Section 1.5.1)
- PR in BD not well understood
- Previous PR research mainly studied small samples via structured methods
- Previous language analysis of online posts did not involve people with lived experience

Existing theory and prior research (Chapter 1)

Goals (Section 1.5)
- Better understanding of PR in BD
- Practice influence: Inform the development of psychological therapies and services that support PR in BD
- Research influence: Demonstrate how to study the lived experience of SMHIs via NLP and corpus linguistic analyses of online posts

Personal experience (Section 2.4)
- Personal experience of mood issues
- Belief that MH issues and seeking professional help are normal
- SHJ: PR approach helpful in working as clinical psychologist with people with mood issues

Research questions (abbreviated from Section 1.5.2)
1. What do we know about the experience of PR of individuals diagnosed with BD from qualitative evidence?
2. What are the characteristics of Reddit users with a self-reported BD diagnosis and the ethical considerations around determining them automatically?
3. What are the posting patterns and their associations with mood of Reddit users with a self-reported BD diagnosis?
4. What can online support forum posts reveal about PR in BD in relation to the POETIC framework?

Ethical considerations (Section 3.4)
Naturalistic data collection of public online posts from people with a BD diagnosis
- Consent
- Anonymity
- Ethical approval

Researcher skills and preferred research style (Section 2.4)
- Background in NLP but not health research
- Supervisors: two clinical psychologists (qualitative & quantitative health research), one computer scientist (NLP & corpus linguistics)
- Experience or interest in interdisciplinary research

Methods (Chapter 3)
- Systematic review with qualitative evidence synthesis
- Large-scale naturalistic online data collection via NLP
- Quantitative data analysis
- Integrate qualitative health research and corpus linguistic methods in mixed-method study

Validity (Section 2.3)
- Double-check coding
- Reproducibility: Share data & code
- Feedback from people with lived experience and academic colleagues
- Reflexivity
- Transparency about limitations

Research setting
- UK university
- 3 year funding full-time

Pragmatic research paradigm (Section 2.1)

Exploratory and pilot research
- Twitter data not suitable
- Corpus-linguistic pilot analysis of Reddit posts: need user characteristics

Figure 5 Interactive research design model of this project, adapted from Maxwell (2012, Figure 1.2)

2.2.2 Convergent mixed-method research design

The typology-based model of mixed-method research designs (Creswell and Plano Clark, 2018) offers a complementary perspective to the interactive model. Creswell & Plano Clark (2018, Chapter 3) distinguish three major types of mixed-method designs based on the order and weight of qualitative and quantitative elements: explanatory sequential, exploratory sequential, and convergent. In the explanatory sequential design qualitative data collection and analysis explain initial quantitative results. Conversely, in the exploratory sequential design, initial qualitative data informs quantitative measures, instruments, or interventions, which a subsequent quantitative phase then tests. The convergent design adopted for this thesis merges and compares the results of parallel qualitative and quantitative data collection and analysis after completion of both streams.

As Figure 6 shows, this project follows a three-step convergent design (Creswell and Plano Clark, 2018, Chapter 3). The rationale for the convergent design is that the strengths of qualitative and quantitative data collection and analysis can complement each other to shed light on different facets of the same underlying question. Thus, it fits ideally with the pragmatic research paradigm (Creswell and Plano Clark, 2018, p. 100). Moreover, compared to the sequential designs, the convergent design is more time efficient because the qualitative and quantitative strand can happen concurrently (Creswell and Plano Clark, 2018, p. 102).

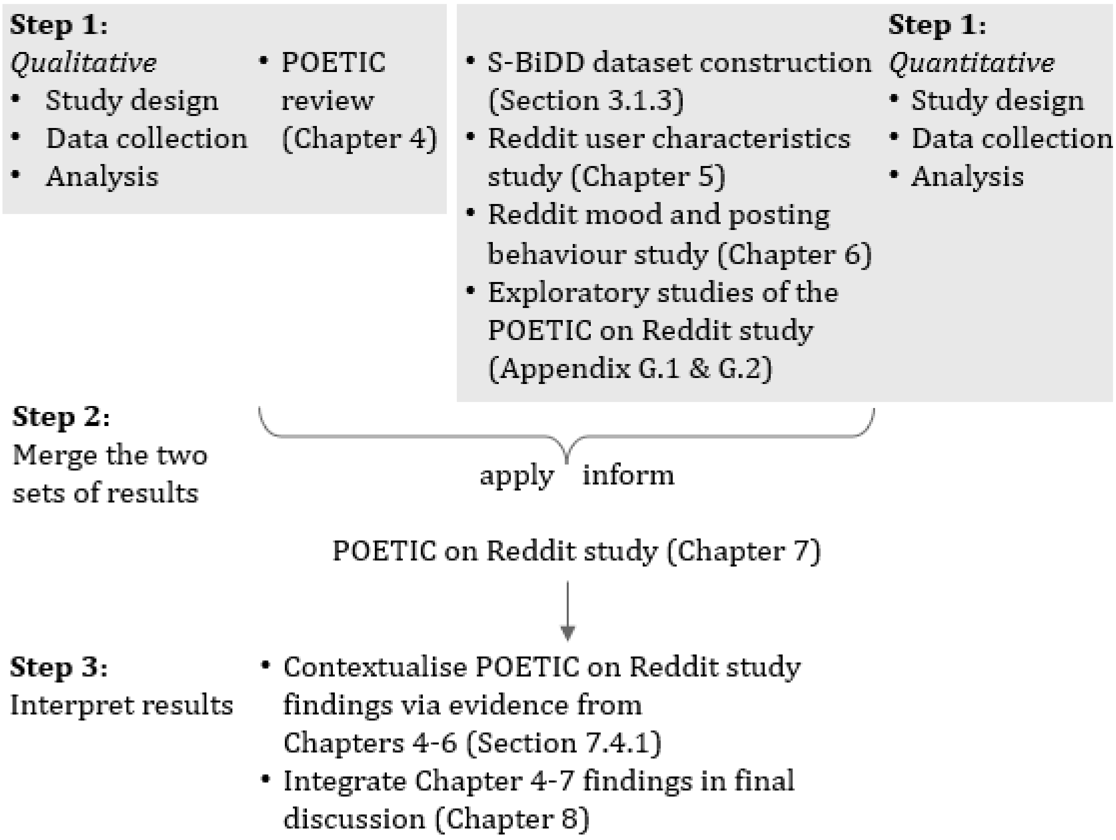


Figure 6 Outline for this project in the convergent mixed-method design, adapted from Creswell & Plano Clark (2018)

The first step consists of qualitative and quantitative data collection and analysis in parallel. The POETIC review (Chapter 4) will synthesise qualitative evidence on PR in BD from previous interviews and focus groups. Concurrently, the Reddit user characteristics study (Chapter 5), the Reddit mood and posting behaviour study (Chapter 6), and the two exploratory studies in the POETIC on Reddit study (Appendices G.1 and G.2) will provide quantitative evidence on the S-BiDD dataset. The second step will merge these qualitative and quantitative results to inform the final study: The main study in the POETIC on Reddit study (Chapter 7) will identify PR experiences in the S-BiDD dataset based on quantitative evidence from the two exploratory studies and analyse them within the POETIC framework using mixed methods. In the third step, the results of the first three studies will help to contextualise the findings of the POETIC on Reddit study. Ultimately, the discussion in Chapter 8 will integrate the evidence of all four studies in final implications and conclusions.

The challenges in the convergent design lie in the merging and final interpretation step that need to integrate different sample sizes, text and numerical data, and potentially disagreeing qualitative and quantitative results. This project applies an innovative approach to this challenge by merging the results of the first step in a further mixed-method study.

2.3 Validity

Quantitative research often equates validity with the correct choice and application of methods, whereas qualitative and mixed-methods research has a broader notion of it (Maxwell, 2012, Chapter 6). Maxwell defines validity as 'correctness or credibility of a description, conclusion, explanation, interpretation, or other sort of account' (2012, p. 122). Validity threats provide alternative explanations for the conclusions of a study, which only evidence that makes them less plausible can refute (Maxwell, 2012, Chapter 6). Following this, the project team identified specific validity threats for each empirical study, along with pre-planned strategies to yield evidence to address them (see Table 10).

Maxwell (2009, 2012, Chapter 6) also notes that it is generally inefficient or impossible to rule out all validity threats in a single study. Therefore, a first strategy to increase validity is transparency about validity threats that could not be refuted. Each study individually and Section 8.3 for the whole thesis discuss strengths, limitations, and future work. Section 8.3.1.2 also reviews which of the strategies from Table 10 the project could implement.

Table 10 Strategies for dealing with validity threats in this project

Validity threats, alternative explanations they leave open	Strategies for dealing with validity threats
POETIC review (Chapter 4)	
Synthesis method bias: coding against an a priori framework renders the analysis process more	• Protocol leaves open to also do full thematic analysis if framework turns

Validity threats, alternative explanations they leave open	**Strategies for dealing with validity threats**
mechanistic and could constrain or bias the synthesis towards the chosen framework (Carroll *et al.*, 2013)	out to not fit well or to be too constraining • Pay attention to diverging evidence that does not fit a priori or emerging framework
Researcher subjectivity: decisions of a single person may be unreliable and generate results that do not generalise well	• At least one other person from the review team checks the decisions at every stage (abstract and full-text screening, quality appraisal, CHIME codebook development, qualitative coding, framework development)
Researcher subjectivity: Belief of the project team that BD merits specialised research and care could lead to more pessimistic assessment of the fit of the a priori framework for general severe MH issues	• Make prior assumptions and how could have influenced results explicit via reflexive researcher positioning
Lead author (PhD student) has little experience in interacting with people with a BD diagnosis and therefore the results may be too theoretical	• PhD student engages with people with lived experience through various PPI activities • Draw on expertise of the two project team members who are clinical psychologists experienced in working with people with a BD diagnosis
Reddit user characteristics study (Chapter 5)	
Imperfect automatic user selection, cannot externally validate if they meet diagnostic criteria (Valdez and Keim-Malpass, 2018, p. 265) – results may not translate to ‘real world’ samples of people with a BD diagnosis	• Manual annotation (with double checking) to check accuracy of the user identification
Automatic methods to infer user characteristics may lack validity and produce misleading findings	• Manual evaluation of the automatic methods with users’ public Reddit content • Ask Reddit users to fill in questionnaires for their user characteristics and evaluate automatic methods against this • Triangulate different methods to infer user characteristics

Validity threats, alternative explanations they leave open	**Strategies for dealing with validity threats**
Reddit mood and posting behaviour study (Chapter 6)	
Findings may not be specific to Reddit users with a self-reported *BD* diagnosis	• Repeat the analyses for Reddit users with other self-reported diagnoses (e.g., depression, borderline personality disorder, a chronic physical health issue)
Findings may be specific to Reddit users with a *self-reported* BD diagnosis	• Repeat the analyses for a more general sample of users who posted in BD subreddits but did not match the self-reported diagnosis patterns – however, expect them to be different because could contain undiagnosed people, carers, etc.
Researcher subjectivity: Study may miss important associations (e.g., socioeconomic status) because of the choice of predictor variables based on what the review team thinks is important and what measures are readily available ('searching where the light is, not where the keys were lost')	• Justify choice of selected variables • Repeat the analysis with a different sample of Reddit users who also fill in questionnaires that allow measurement of more variables
Automatic emotion analysis method may lack validity and produce misleading findings	• Select widely used emotion analysis method with a strong body of psychometric research that backs up its validity • Discuss method limitations • Triangulate results with other automatic emotion analysis methods
POETIC on Reddit study (Chapter 7)	
Thin data: Little reliable data about Reddit users (age, gender, country of residence, comorbidities, time since diagnosis, medication use, religious beliefs, etc.) - PR is a very subjective topic, and it may be difficult to make sense of some of peoples' experiences without much context of their lives; unclear to which population of people with BD the findings may generalise	• Automatically determine as many user characteristics as possible and compare to the samples in clinical studies • Try to find more user information by close reading of their other Reddit posts if needed • Complementary interview study of Reddit users with a BD diagnosis
Researcher subjectivity: whole researcher team finds PR relevant, so	• Transparently discuss researcher positions in reflexivity section

Validity threats, alternative explanations they leave open	Strategies for dealing with validity threats
could over-estimate importance for Reddit users with a BD diagnosis	
Comparing the frequency of terms associated with PR vs clinical recovery (symptoms and their treatment) may not allow conclusions about the relative importance of these concepts for online forum users due to two reasons: Frequency may not be directly associated with importance and PR may be more difficult to capture via isolated terms than clinical recovery.	• Base conclusions on mix of qualitative and quantitative evidence • Psycholinguistic research found robust evidence for relationship between how frequently people mention something and how important it is for them (Boyd and Schwartz, 2020) • Complement naturalistic online post analysis with qualitative interviews to ask people living with BD if PR is a relevant concept for them

A common validity threat of all studies is the impact of researcher subjectivity[24] on their design and the interpretation of results. Researcher subjectivity not only impacts the qualitative but also quantitative aspects of research. For example, in the Reddit mood and posting behaviour study (Chapter 6), the researchers will need to decide which variables to include to model users' posting behaviour, based on previous research, affordances of the data and what they think is relevant, which determines the associations that the study will be able to uncover. In line with the pragmatic research paradigm, this project combines the critical realist axiological view that previous experiences, beliefs, and values of the researchers inevitably shape the research with the more post-positivist view that there are ways to reduce subjective biases (see Section 2.1.7). Nevertheless, the pragmatic position taken here is that no methodology or method can completely remove subjectivity from research. In line with this, the PhD student and supervisors engaged in reflexive thinking about their personal goals, previous experiences, and skills and how they might influence the project (Finlay and Gough, 2008). Section 2.4 below makes these aspects transparent, so readers can account for them in their reception of this research.

Additionally, two strategies aim to reduce subjectivity in this project. First, wherever possible, clear coding guidelines will operationalise decisions such as which articles to include in the POETIC review (Section 4.2.2.2) and what constitutes a self-reported BD diagnosis, or a PR-related post. The agreement of at least two independent coders will indicate the plausibility of the categorisation and clarity of the guidelines. The project team will resolve disagreements in discussion, providing opportunities to reconsider the tasks. All data, guidelines, and programming code will be available for other researchers to verify and extend the research.

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[24] Many qualitative researchers prefer this term over researcher bias (Maxwell, 2009, p. 124).

Second, a range of PPI activities will seek feedback from people with lived experience of BD on the research proposal and the results of each study (see Section 3.3). Additionally, academics from different scientific backgrounds external to the review team will provide feedback in response to posters and presentations on the project at scientific meetings (see Appendix I for a list of all presentations and publications related to this project). As Maxwell states ‘asking others for feedback on your conclusions is a valuable way to identify your biases and assumptions and to check for flaws in your logic or methods’ (2009, pp. 126–127).

2.4 Reflexivity

Reflexivity originated in qualitative research traditions (Finlay and Gough, 2008; Braun and Clarke, 2019) and some corpus linguists, particularly in the field of corpus-assisted discourse analysis, are also engaging with it (see Taylor and Marchi (2018) and particularly Baker (2018)). Practical strategies to implement reflexivity in a project are reflexivity statements where authors declare their position in relation to the research topic (e.g., Finlay and Gough, 2008) and research or reflexivity diaries that researchers maintain for personal reflections (e.g., Nadin and Cassell, 2003; Lobban, Appleton, *et al.*, 2017). In the second year of the project, the PhD student and supervisors wrote reflexivity statements reflecting on how their personal experiences may impact on the conduct or supervision of the thesis and the interpretation of the results (see Appendix A). While the PhD student did not systematically maintain a research diary, she used reflexive journalling (Ortlipp, 2018; Meyer and Willis, 2019) whenever she became aware that the research resonated with her on a more personal level, or she was experiencing strong emotions. The remainder of this section briefly summarises the reflexivity statements of the supervisors and PhD student and offers some first reflections (see Section 8.4.2.3 for final reflections on reflexivity in this thesis).

Supervisors: Two supervisors, FL and SHJ, are professors of clinical psychology and clinical psychologists with experience of developing and delivering (recovery-oriented) psychological therapies for people with BD and psychosis. They embraced a PR approach in BD but were aware of criticism by other researchers and service users regarding this approach. The third supervisor, PER, is a professor of NLP with limited prior experience of MH research.

PhD student[25]: I had a strong intrinsic motivation to conduct research on PR in BD because I have experienced (less extreme) mood swings myself and within my family, raising my interest in how people manage to live well alongside extreme mood experiences. My upbringing in a family of psychotherapists has shaped my preconception of psychotherapy as go to approach for dealing with MH issues. However, my academic education prior to this PhD was in NLP, so I was not familiar with qualitative methods and health research. At the start of the project in 2019, I had a positivist approach to research, of which I was not aware. I thought that a large enough amount of social media data would almost automatically make my results

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[25] Different from elsewhere in this thesis, I write in the first person here.

credible and I could ‘mitigate [my subjective] biases‘ as I wrote in my reflexivity statement in May 2020 (see Appendix A.1).

Through engaging with research philosophy, qualitative and mixed-methods research design, previous qualitative research, and reflexivity, I developed the position I summarise in Section 2.1.7 at the end of 2020. As stated in Section 2.3, I no longer believe that it is possible to remove subjectivity from research. Rather, I think that it is important and valuable for researchers to transparently position themselves in relationship to their work.

I very much appreciated that my supervisors also wrote personal reflexive statements. Reading them gave me a clearer sense of their expectations and demonstrated their motivation and commitment to supervise me to undertake this research.

3 Methods

This chapter explains and describes the research methods in this project. Firstly, it provides justifications for the data collection (Section 3.1), and secondly for the chosen analysis methods in the individual studies (Section 3.2). Thirdly, it explains how this project involved people with lived experience and members of the public (Section 3.3). Finally, it discusses ethical considerations (Section 3.4).

3.1 Data collection

This section justifies and details the important aspects around the data collection in this project: the necessity of bespoke data collection (Section 3.1.1), choice and characterisation of the online forum (Section 3.1.2), and the data collection method (Section 3.1.3).

3.1.1 Necessity of bespoke data collection for this project

This project required online support forum posts representing the PR experiences from a range of people living with BD of sufficient quantity and richness to allow for the mixed-methods analysis via health research, NLP, and corpus linguistic methods. Additionally, analysing these posts for research and sharing them with other researchers to verify the results and for future research needed to be legally permitted and ethically acceptable.

NLP research prior to 2019 had collected datasets of social media posts of users with self-reported MH diagnoses, including BD (Coppersmith *et al.*, 2015; Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018). Unfortunately, the BD portion of the Twitter dataset (Coppersmith *et al.*, 2015) was unavailable for further research[26]. In both Reddit datasets (Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018), MH-related posts were removed to train classifiers that try to predict MH diagnoses even if users do not explicitly discuss MH issues. Therefore, these datasets were unlikely to contain PR-relevant content. The lack of available appropriate data required this project to create such a resource.

3.1.2 Data collection site: Reddit

3.1.2.1 Justifications for the choice of Reddit

The project proposal (Jagfeld, 2019) planned to collect and analyse online posts by people with lived experience of BD from various sources. Table 11 lists the potential

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[26] Personal e-mail communication with Glen Coppersmith in February 2019.

sources that the project initially considered in its first six months but did not use, and the reasons why. Due to the limited timeframe of three years of funding, the project needed to obtain access to the data within the first few months. All online data in this project stems from the discussion platform Reddit[27]. There were two main reasons for this choice: First, all Reddit posts are in the public domain and could therefore be collected, analysed, and redistributed for research purposes at no cost and without having to negotiate individual access with the site providers. Second, Reddit users are more diverse in terms of age and country of origin compared to some dedicated MH platforms in Table 11 such as Talklife, which only focuses on adolescents, or the UK MH charity forum with mainly UK users. Twitter was the only other identified online data source with similarly permissive terms and conditions. However, initial exploratory analyses of tweets showed that due to the restriction to 140/280 characters, they did not offer rich enough data for the purposes of this project. While it would have been possible to include additional data, e.g., blog posts, into the project at a later stage, the Reddit dataset offered such ample and rich data, that the project team decided to focus only on this dataset.

Table 11 Alternative sources of online posts by people living with BD and reasons for not using them

Site	Description	Reasons for not using data
Twitter	Microblogging platform for posts (tweets) with at most 140/280 characters with hashtags and mentions, everyone can read public tweets without registration	Initial analyses showed that tweets did not provide rich enough data to analyse PR. Between 2018-2021 Twitter restricted free access to its application programming interface that precluded collection of more data within the project timeframe (Bruns, 2019, p. 1550; Twitter Inc., 2020; Tornes, 2021). Paid access costs exceeded the project budget.
Blogs	Publicly accessible online articles written by people with MH issues, often hosted on their own websites	Would have had to ask each blog author for individual consent to analyse their data and the texts would have had to be copied manually. This was a backup option if the project did not obtain sufficient data from other sources.
Facebook support groups	Posts in BD or MH support groups on Facebook that usually only group members can read	Would have had to negotiate consent to use forum posts for each support group individually. Facebook restricted their application programming interface in 2018 (Bruns, 2019, p. 1549), such that the posts would have had to be

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[27] https://www.reddit.com/

Site	Description	Reasons for not using data
		copied manually. This was deemed impractical for the amount of data that the project required.
OurData Helps[28] by Qntfy	Public posts from various social media platforms donated by people with and without MH issues for research, wearable sensor data, questionnaires	OurDataHelps did not reply to email request and follow up in March and April 2019. The project ended in 2021.
7 Cups[29]	Commercial platform that connects people with MH issues to volunteers who provide support via (a)synchronous online messages as well as paid therapists who provide counselling via the platform. Also hosts peer support forums.	An online meeting with two 7 Cups team members in August 2019 revealed that they would need up to one more year to be able to share data, which was too late for the project. Also, the project team would not have been able to share the data with other researchers who had no formal agreement with 7 Cups.
Health Unlocked[30]	Commercial platform that hosts peer support forum for physical and MH issues, free for users, companies and researchers can pay to recruit or run studies on the platform.	A Lancaster University researcher who had previously analysed HealthUnlocked data told the project team privately in April 2019 that they had paid multiple thousands of pounds for two online forums. This exceeded the research budget for this project by far.
Patients LikeMe[31]	Commercial platform that hosts peer support forums for physical and MH issues, free for users, companies can pay for data, researchers can partner with them.	The platform providers state that they seldomly participate in student projects.[32] They only participate in research projects where they are actively involved in the research protocol. Given the set topic of the project and the limited timeframe, this was not deemed practicable.
Talklife[33]	Commercial platform that hosts peer support forums for youth MH, companies can advertise on the platform, users can pay to	The platform targets only teenagers, which is a too narrow demographic for the purpose of this project interested in adult PR experiences.

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[28] The project ended in 2021 (https://ourdatahelps.org/).

[29] https://www.7cups.com/

[30] https://healthunlocked.com/

[31] https://www.patientslikeme.com/

[32] https://www.patientslikeme.com/research/faq#qr4

[33] https://www.talklife.co/

Site	Description	Reasons for not using data
	remove advertisement, researchers can partner with them.	
Online forum of a large UK MH charity	Online support forum run by a large UK MH charity, only registered users can read and write posts.	SHJ reached out to the charity, but it was not possible to arrange a meeting in 2019 with someone who could have provided data access.

Additional reasons made Reddit an attractive data collection site for this project: Since Reddit hosts many subforums for various topics, it facilitated the comparison of users who posted in MH support forums to those who did not in the Mood and posting behaviour study. This would not have been possible with data from dedicated MH platforms. From a practical point of view, Reddit offers an application programming interface[34] that allowed the downloading of all posts with meta data in a structured format, ready for further computational processing. Also, Reddit has been the main data source for research on online posts by people with lived experience of BD (see Section 1.4.2.2.1) and for BD research using NLP methods (Harvey *et al.*, 2022).

3.1.2.2 Brief overview of the online discussion platform Reddit

The commercial online discussion forum Reddit was established in the US in 2005 (Ohanian, 2006). Condé Nast/Advance Publications acquired the site in 2006 and is still the majority shareholder in 2023 (Advance, 2023). In January 2023, it was the 20th most visited web site worldwide (Routley, 2023). Reddit users are international, but predominantly from the US and other English-speaking countries (Bianchi, 2023). The platform hosts various subforums called *subreddits* for general topics such as politics or MH as well as for specific interests, including several subreddits concerned with BD. Table 12 provides an overview of the four largest BD-related subreddits for illustration[35].

Table 12 Overview of four largest BD-related subreddits as of November 2019 (description and rules: verbatim quotes from subreddits)

r/bipolar[36]
Statistics: 88.3K members; funded on 26 October 2008; seven moderators (plus two automatic ones), appointed 4-8 years ago; 441,689 S-BiDD dataset posts by 8,745 users
Description: A safe haven for bipolar related issues. We are a community here not just a help page. Be a part of something that cares about who you are.
Rules: 1. do not share personal information 2. no self-promotion 3. no participant-seeking for medical studies 4. no offering treatment as medical

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[34] https://docs.google.com/forms/d/e/1FAIpQLSezNdDNK1-P8mspSbmtC2r86Ee9ZRbC66u929cG2GX0T9UMyw/viewform

[35] The data collection and analysis were not limited to these four BD subreddits (see Section 3.1.3).

[36] https://www.reddit.com/r/bipolar

professionals 5. no personal insults 6. only post memes on Fridays 7. do not take or provide medical advice 8. do not mention other subreddits in negative way (avoid Reddit fights) 9. flair all posts 10. search before posting about medication issues 11. do not ask for diagnosis (referred to professionals)
r/BipolarReddit[37]
Statistics: 40.2K members; funded on 4 June 2009; five moderators, appointed 1-11 year(s) ago; 153,689 S-BiDD dataset posts by 4,582 users **Description:** A Reddit to share information about who you are, how you think, and what helps you cope in life. **Rules:** 1. Do not recommend alternative medicine, only share personal experience 2. no self-promotion 3. Be nice (This forum is open to those who are unsure of their diagnosis, those who are confident in their diagnosis, those who are symptomatic, those who are in remission, those who take medication, and those who do not.) 4. no medical advice 5. no participant-seeking for studies/survey 6. ok to share information about other chatrooms 7. flair suicide/self-harm posts, may be removed if deemed too upsetting
r/bipolar2[38]
Statistics: 14.3K members; funded on 30 April 2014; nine moderators (plus one automatic one), appointed 1-6 year(s) ago; 36,291 S-BiDD dataset posts by 1,636 users **Description:** This is a community for people living with bipolar disorder type 2 (the whole bipolar spectrum is also welcome), their loved ones, and anyone wanting to understand the bipolar spectrum. **Rules:** none stated
r/bipolarSOs[39]
Statistics: 9.1K members; funded on 24 January 2014; three moderators, appointed 5-6 years ago; 3,647S-BiDD dataset posts by 511 users **Description:** Being in a relationship where one or both partners have bipolar disorder is not easy. This sub is a place that people can come for advice or just to vent so that we do not affect our significant others with our emotions. There are a couple of already popular bipolar subs but having a specific sub just for relationships is important in order to facilitate a community of support. **Rules:** 1. no self-promotion 2. be kind (encourage positivity in relationships) 3. do not post personal identifying information

Anyone can view public posts without registration. Posting requires a user account, which minimally consists of a self-chosen username. Discussions (*threads*) consist of an initial post (*submission*) with subsequent *comments*. In this thesis, *post* refers to both submissions and comments. Registered users can upvote or downvote a post and the share of upvotes out of all votes are displayed below a post.

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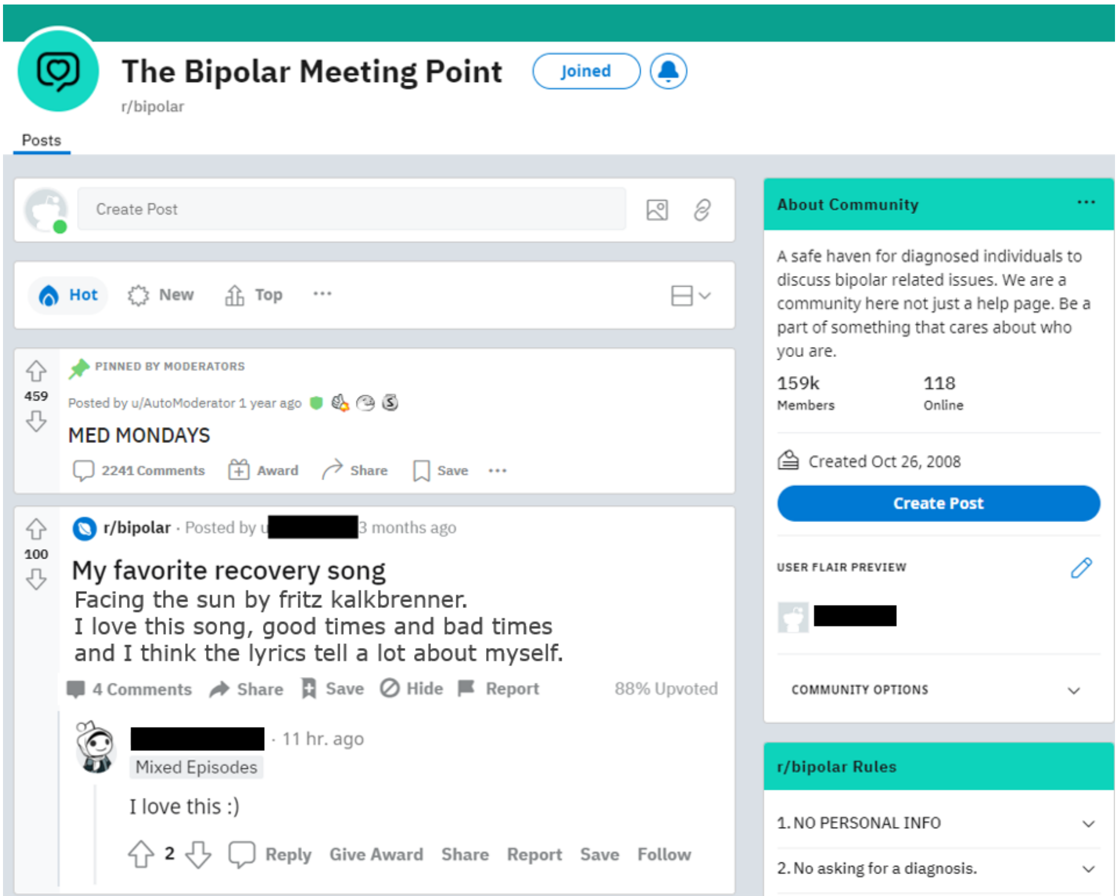
[37] https://www.reddit.com/r/BipolarReddit/

[38] https://www.reddit.com/r/bipolar2

[39] https://www.reddit.com/r/bipolarSOs

Figure 7 shows a subreddit page as displayed by web browsers. The right panel lists various general information about the subreddit, namely a short description, the number of members and when it was funded, subreddit rules, the usernames of the moderators, a subreddit chat (if available), and *flairs* available in the subreddit for tagging posts. Post authors or subreddit moderators can assign flairs to posts based on their content (e.g. ‘art’, ‘med question’, ‘suicidal thoughts trigger’), which other (registered) users can user for filtering the content they see.



Posted by u/AutoModerator 1 year ago

MED MONDAYS

r/bipolar · Posted by u[redacted] 3 months ago

My favorite recovery song

Facing the sun by fritz kalkbrenner.
I love this song, good times and bad times
and I think the lyrics tell a lot about myself.

[redacted] · 11 hr. ago

Mixed Episodes

I love this :)

A safe haven for diagnosed individuals to discuss bipolar related issues. We are a community here not just a help page. Be a part of something that cares about who you are.

159k Members

118 Online

Created Oct 26, 2008

[redacted]

r/bipolar Rules

1. NO PERSONAL INFO

2. No asking for a diagnosis.

Figure 7 Browser layout of a BD subreddit with anonymised and paraphrased example submission and comment

Reddit users can start a new subreddit, of which they automatically become a moderator. They can also appoint any number of additional moderators. Moderators can specify rules for the subreddits and enforce them by editing or deleting posts and banning users from posting in the subreddit. These rules give an indication of the overall stance of a subreddit towards its topic and its member group, for example ‘This forum is open to those who are unsure of their diagnosis, those who are confident in their diagnosis, those who are symptomatic, those who are in remission, those who take medication, and those who do not’ (r/BipolarReddit moderators, 2023). Additionally, some subreddits have a *pinned post* always displayed at the top of the list of posts, which can provide information for people interested in the subreddit and general community rules.

3.1.3 Pattern-based data collection

The choice of Reddit as data collection site required the identification of posts of users with a BD diagnosis. Unlike in some dedicated MH support forums, Reddit users do not provide their MH diagnoses in a structured format. Not all users who post in BD subreddits may live with BD. For example, people might post in a BD subreddit because they wonder if they meet BD criteria or because they seek advice for dealing with someone they know who experiences mood issues.

Reddit users were automatically identified via self-reported BD diagnosis statements, e.g. 'I was diagnosed with bipolar disorder.' Previous work had successfully used this approach to collect large datasets of online posts by people with MH diagnoses (Coppersmith *et al.*, 2015), including BD (Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018). This approach had three advantages in the context of this project compared to the alternative of applying a classification system that automatically predicts the likelihood of a Reddit user to meet BD criteria. First, the rule-based approach required much fewer calculations and therefore computing time and resources compared to a more complex machine learning model. This facilitated matching every post ever made between Reddit's inception and the time of data collection in 2019 against the diagnosis patterns. Second, the rule-based approach provides transparent decisions and is straightforward to explain to MH researchers without NLP knowledge. Third, this project could adapt proven self-reported diagnosis patterns from previous work, which provided a time-efficient solution in line with the pragmatic paradigm. See Section 5.2.1 for details on the patterns used to create the S-BiDD dataset.

3.2 Data analysis

This section provides additional details and justifications for some of the methods in the POETIC review (Chapter 4) in Section 3.2.1 and the POETIC on Reddit study (Chapter 7) in Section 3.2.2. It complements the method sections of these chapters, which had to be brief due to journal wordcount restrictions. The Reddit user characteristics study (see Section 5.2) and Reddit mood and posting behaviour study (see Section 6.2) contain all necessary detail and justifications for the method choices in these studies.

3.2.1 POETIC review synthesis method

Seven criteria guided the systematic review method selection: review question, epistemology, time, resources, expertise, audience and purpose, and type of data (Booth *et al.*, 2016). The four steps detailed in the following four subsections applied these criteria. Finally, Section 3.2.1.5 explains 'best fit' framework synthesis as chosen method.

3.2.1.1 Research question, inclusion and exclusion criteria and initial body of primary literature

A crucial first step formulated the concise RQ for the review: What do we know about the experience of PR of individuals diagnosed with BD from qualitative evidence? The Population, Intervention, Condition, Outcome, Study type tool (Centre for Reviews and Dissemination, 2009) served to translate the review question into a set of search terms for literature databases, following the recommendation of Methley at al. (2014).

- Population: individuals clinically diagnosed with BD
- Intervention: not applicable
- Comparison: not applicable
- Outcome: experience of PR of individuals diagnosed with BD, factors that facilitate and hinder PR
- Study type: qualitative and mixed methods, all methods that report lived experience of BD as primary data, including interviews, focus groups, case studies, opinion pieces if based on the author's own experience of BD

Pilot searches via Google scholar based on the initial inclusion and exclusion criteria served to gauge the size of the body of literature and identify an initial list of potentially relevant studies. These searches identified nine qualitative studies published between 1999 and 2018 (Young and Ensing, 1999; Chapman, 2002; Russell and Browne, 2005; Mansell *et al.*, 2010; Murray *et al.*, 2011; Michalak *et al.*, 2012; Veseth *et al.*, 2012; Morrison *et al.*, 2016b; Crowe and Inder, 2018).

3.2.1.2 Available resources: time, funding, and expertise of the project team

Planning for this review took place in March-April 2019. Since it was part of a three year PhD project and should inform subsequent studies in the project, the synthesis results were devised to be ready by the end of October 2019. This left six months for conducting the review.

All articles that the initial search had retrieved were publicly available or accessible through Lancaster University library's electronic access services. Therefore, interlibrary loan costs were considered less relevant for the choice of the review methodology.

The team for this review consisted of the following members:

- Glorianna Jagfeld (GJ): lead reviewer and author, Health Research PhD student, background in NLP, inexperienced in systematic reviews and qualitative research
- Paul Marshall (PM): secondary reviewer, Health Research PhD student, inexperienced in qualitative evidence synthesis

- Steven Jones (SHJ): supervisor and potentially reviewer, professor in clinical psychology, expert in developing psychological interventions for BD, experienced in systematic reviews
- Fiona Lobban (FL): supervisor and potentially reviewer, professor in clinical psychology, expert in developing psychological interventions for BD, experienced in qualitative evidence syntheses and qualitative methods

3.2.1.3 Purpose and intended audience of the review

The aim of the review was to consolidate previous qualitative and mixed-method research on PR in BD. Within the PhD project this should provide the basis for the subsequent studies, particularly to compare the findings from online posts to previous PR research. It primarily targeted an audience of researchers and MH professionals working with people with a BD diagnosis, and secondarily people living with BD and their informal carers, aiming to yield implications for MH research, care, and how to live well with BD. The pragmatic paradigm required a methodology that would help answer the review question and achieve these purposes in an efficient manner without constraining the epistemological stance.

3.2.1.4 Selection of the appropriate method

Booth et al. (2016, Table 5) characterise and compare 14 synthesis methods for systematic reviews of qualitative evidence. Having the RQ already clearly defined ruled out four approaches that iteratively refine and shape the question (grounded formal theory, meta-ethnography, meta-interpretation, meta-study). Considering the available resources and the pragmatic paradigm, led to four methods with low requirements for time and qualitative research expertise, 'best fit' framework synthesis, framework synthesis, textual narrative synthesis, thematic synthesis.

After consulting the descriptions of these four methods, 'best fit' framework synthesis (Carroll, Booth and Cooper, 2011; Carroll *et al.*, 2013) was identified as best fitting the goal to synthesise the body of qualitative research on PR in BD in a time-efficient manner by using the existing CHIME framework. Framework synthesis (Brunton *et al.*, 2006) requires the framework to be specific to the review question and not for a comparable population. CHIME was developed based on experiences of people living with various severe MH issues and not specifically BD. Neither textual narrative synthesis (Lucas *et al.*, 2007) nor thematic synthesis (Thomas and Harden, 2008) incorporate a priori frameworks.

3.2.1.5 'Best-fit' framework synthesis

'Best fit' framework synthesis (Carroll, Booth and Cooper, 2011; Carroll *et al.*, 2013) as method for the systematic review of qualitative evidence evolved from framework synthesis (Brunton *et al.*, 2006; Nilsen *et al.*, 2006). Framework synthesis is based on framework analysis (Pope, Ziebland and Mays, 2000) and offers a highly structured way of organising and analysing the results of qualitative studies. As a primarily deductive approach (Carroll, Booth and Cooper, 2011), framework syntheses can be conducted more time efficiently than reviews with inductive methodologies (Booth *et al.*, 2016) and take a positivist-realist epistemological stance, in line with this thesis (c.f. Section 2.1.7). In framework syntheses, the review team usually constructs a bespoke data analysis framework for the information needs of the review after retrieving and reading the literature (Oliver *et al.*, 2008). In contrast, 'best fit' framework syntheses use an already available a priori framework developed for a comparable situation or population, which constitute a 'best fit' (Carroll *et al.*, 2013). Only data which the framework cannot accommodate is subjected to the more laborious thematic analysis (Boyatzis, 1998; Silverman, 2004; Braun and Clarke, 2006), which can lead to additional framework components.

Compared to a fully inductive thematic synthesis, 'best fit' framework synthesis has the advantage that the results will be largely organised according to the a priori framework already. This means that the analysis did not need to translate the results to the CHIME framework first, as would have been necessary in a thematic analysis that may have yielded comparable but differently named or organised themes. The main disadvantage of framework synthesis is that coding against an a priori framework renders the analysis process more mechanistic, could constrain or bias the synthesis towards the chosen framework, and might lead to less creative solutions than more inductive synthesis methods (Carroll *et al.*, 2013). Validity considerations recognised this as potential threat prior to starting the review and identified suitable countermeasures (see Table 10).

3.2.2 POETIC on Reddit method

3.2.2.1 Exploratory study 1: automatic content analysis via USAS

Exploratory study 1 in the POETIC on Reddit study (Appendix G.1) applied automatic content analysis to determine the main topics in BD subreddit posts to consider more data than possible via manual analysis. As Section 1.4.1.4.1 explained there are closed- as well as open vocabulary approaches for automatic content analysis. An advantage of deductive closed-vocabulary approaches is that the categories are the same across datasets (Eichstaedt *et al.*, 2021, p. 418), whereas they are dataset-dependent for inductive open-vocabulary approaches. Therefore, this exploratory study chose a closed-vocabulary approach to be able to compare the topics in BD subreddit posts to non-MH related posts.

Although the most prevalent closed-vocabulary content analysis approach in psychological research has been LIWC (Pennebaker *et al.*, 2015), the exploratory study 1 in the POETIC on Reddit study (Appendix G.1) used USAS (Rayson *et al.*, 2004), which is more common in corpus linguistic research. LIWC focuses more on sensory, emotional, and cognitive perceptions and only comprises six personal concern categories such as leisure, home, work (Pennebaker *et al.*, 2015). In contrast, the USAS lexicon intends to capture a general interpretation of the world via 21 top-level and 232 second- and third-level domains (see Table S14). Since this exploratory study was interested in the post content rather than just the psychological states or processes of their authors, USAS offered finer-grained distinctions for this task.

3.2.2.2 Corpus framework analysis

The main study in the POETIC on Reddit study (Chapter 7) introduces a novel method to analyse what support forum posts can reveal about the processes and experience of PR in BD using the POETIC framework. Corpus framework analysis integrates qualitative and quantitative corpus linguistic methods and qualitative framework analysis. This section explains the development of this novel method.

The study design entails the analysis of several thousands of online posts, which rules out purely manual health research and linguistic text analysis approaches, leaving (semi-automatic) NLP and corpus linguistic methods. A closed-vocabulary NLP analysis via USAS as in exploratory study 1 was not suitable because the lexicon is not specific enough for the MH, let alone PR domain. An open-vocabulary approach could lead to insights that are more relevant to the specific RQ. However, there are several disadvantages to these approaches, particularly with respect to topic modelling. Linguists have critiqued that word groups resulting from topic modelling do not always capture coherent and theoretically meaningful categories (Brookes and McEnery, 2019; Gillings and Hardie, 2022). Additionally, two aspects of these approaches bear the danger of cherry picking (Brookes and McEnery, 2019): First, topic modelling requires pre-defining the number of topics and words per topic, but only the results can reveal the appropriateness of these choices (Eichstaedt *et al.*, 2021, p. 422). Second, the process is non-deterministic such that each run of a topic modelling algorithm on the same data may yield different topics. Considering this, the study adopted a corpus linguistic approach,

From the choice of the five main corpus linguistic methods (see Section 1.4.1.3.2), the project team considered analysing keywords in PR-relevant vs. not PR-relevant posts as most useful to capture PR-related discussions. Pure frequency lists of S-BiDD dataset posts would not allow teasing apart of what issues are particularly relevant for people living with BD in their PR. Concordance analysis then allows the researcher to get immersed in the data via close reading and determine the contextual meaning of the keywords. Collocations can offer additional insights and are particularly helpful to summarise the contexts of high frequency terms. While n-grams could offer an additional perspective on the data, project time and journal space constraints may preclude their analysis. Previous corpus linguistic research of MH online support forum posts also mainly employed a combination of keyword, concordance, and collocation analysis (e.g., Harvey, 2012; Hunt and Brookes, 2020).

Usually, concordance analyses of keywords result in inductive meaning categories (Baker, 2010; Hunt and Brookes, 2020). Instead, corpus framework analysis codes concordance lines according to an a priori framework via qualitative framework analysis (Pope, Ziebland and Mays, 2000). This is an obvious pragmatic choice in this study since the POETIC review (Chapter 4) provides a framework for PR in BD. Deductive analysis with the POETIC framework will make it time-efficient and straightforward to relate the findings from online evidence to previous results from interviews and focus groups. This also has the additional benefit of providing a first validation of the framework.

To our knowledge, the language analysis literature so far has not yet formally described such an integration of framework and keyword-concordance analysis, justifying the coining of corpus framework analysis for this novel approach. Corpus framework analysis specifies one method to undertake corpus-assisted discourse analysis. Compared to critical discourse analysis (Fairclough, 2013), which approaches textual data with a socio-critical lens, e.g., working with social actor frameworks (Van Leeuwen, 1996) and often within a transformative paradigm, corpus framework analysis is theory agnostic in accepting any framework. Since the POETIC on Reddit study (Chapter 7) adopts a PR focus that criticises the dominant clinical recovery paradigm, one could see it as example of critical discourse analysis. Qualitative health researchers, in turn, may find it useful to relate corpus framework analysis to the computer-assisted qualitative data analysis functionalities of some recent qualitative analysis software packages such as NVivo or ATLAS.ti (Rayson, 2015). Compared to these, corpus framework analysis provides a more solid grounding in linguistic theory and a higher degree of formality and replicability of the analysis method via keywords with specified parameter settings.

3.2.2.3 Corpus linguistic software

The POETIC on Reddit study (Chapter 7) used four different corpus linguistic software packages (see Table 13). This was necessary because not all software packages supported all corpus linguistic methods applied in the study and they differed in terms of scalability to larger corpora and customisability (e.g., for collocation measures). A disadvantage was that each corpus linguistic software uses different tokenisation methods (e.g., either treating hyphenated words as one or two tokens), resulting in slightly different word counts for the same corpus depending on the tool.

Table 13 Corpus linguistic software in the POETIC on Reddit study (Chapter 7)

Software	Supported methods[40]	Unique features	Reasons for use
Wmatrix 4 (Rayson, 2008)	Frequency lists Key items (words, part of speech, semantic domains) Concordances (no sorting)	Semantic tagging via USAS	Calculate key semantic domains and keywords in the BD Subreddit Corpus in exploratory study 1 (see Appendix G.1.3.2), calculate keywords for the PR terms list (Appendix G.4)

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[40] The supported methods and unique features refer to the stated software versions, which were the most recent ones at the respective project stages. Later software versions may have changed.

Software	Supported methods[40]	Unique features	Reasons for use
Sketch Engine (Kilgarriff et al., 2004, 2014)	Frequency lists Keywords Concordances Collocations n-grams	Cloud-based, therefore can process corpora that are too large to process on a single machine; requires paid subscription	Analyse concordances in the 20M word BD Subreddit Corpus in exploratory study 1 (Appendix G.1.3.3)
AntConc 3.5.8 (Anthony, 2005, 2019)	Frequency lists Keywords (does not report reference corpus frequency) Concordances Collocations n-grams	Similar functions as Wmatrix (without semantic tagging) but can sort concordances	Analyse concordances to create the PR terms list (Appendix G.4)
#LancsBox 6.0 (Brezina, Platt and McEnery, 2021)	Frequency lists Keywords Concordances Collocations n-grams	Graphical display of collocations, MI^3 collocation measure (not available in Wmatrix or AntConc)	Concordance and collocation analysis in the PR-BD Reddit corpus (Section 7.2.3)

3.3 Participatory and public involvement

The INVOLVE initiative by the UK National Institute for Health and Care Research 'defines public involvement in research as research being carried out *with* or *by* members of the public rather than *to*, *about* or *for* them' (INVOLVE, 2012, p. 6). Some people have been arguing for more involvement of people with lived experience in health research for a long time (e.g., Arnstein, 1969) and funders such as the UK National Institute for Health and Care Research now require PPI activities for publicly funded projects (NIHR, 2021). Arnstein's (1969) Ladder of Citizen Participation describes a range of how researchers can involve the public from non-participation (manipulation, therapy), via tokenistic involvement (informing, consultation), to true citizen power (partnership, power delegation, public control). Recent PPI conceptualisations (e.g., Oliver *et al.*, 2008) more broadly distinguish *consultation* (asking lay people for their one-off non-binding advice to inform decision-making) and *collaboration* (active, on-going partnerships with lay people).

The remainder of this section reports the aims and methods of the PPI activities in this project according to items 1 and 2 of the Guidance for Reporting Involvement of Patients and the Public short form (GRIPP2) checklist (Staniszewska *et al.*, 2017). See Section 8.3.4 for PPI results and influences (GRIPP2 item 3-4) and critical reflections (GRIPP2 item 5).

3.3.1 Aims of participatory and public involvement

Table 14 lists the aims of PPI in the overall project. The project needed to meet these aims within the time and financial resources of the project funding, consisting of a three-year maintenance grant for the PhD student with an annual budget of £750 for all research expenses including hardware, training, conference travels, and volunteer reimbursements.

Table 14 PPI aims in this project

Aim (GRIPP2 item 1)	Short form
Acquaint the PhD student coming from a non-clinical background with the reality of living with BD	Acquaint researcher
Ensure that the outcomes of the project will be relevant to people living with BD	Relevant outcomes
Ensure that the research design is acceptable to people with lived experience of BD and using social media in relation to their MH issues	Acceptable research design
Gain additional perspectives on initial interpretations of findings	Additional perspectives
Ensure that the results of the individual studies make sense to people with lived experience of BD and that the implications are in alignment with the kind of support or system changes they would like	Relevant implications
Ensure that people with lived experience of BD find the language of the research outputs understandable and acceptable	Understandable language

3.3.2 Methods of participatory and public involvement

The PhD student conducted all PPI activities in this project (see Table 15), the supervisory team supported the planning. In general, the PPI methods in this thesis consisted primarily of consulting with people with lived experience of BD who were preferably also social media users. All volunteers (except the Spectrum Centre service user researcher, who was university-paid, and the Bipolar UK support group and dragon's den participants) received £10 for meetings lasting up to one hour in the form of online vouchers or direct bank transfers. Due to limited funding, the project could not reimburse the cost of replacement carers for volunteers with a caring role, which might have precluded them from volunteering. While the 2019 PPI activities happened in-person in the Lancaster (UK) area, all activities starting from 2020 were online due to the global Covid-19 pandemic.

Table 15 PPI methods in this project

Month/ year	PPI methods (GRIPP2 item 2)	Aims (see Table 14)
03/19	Meet with Spectrum's service user researcher who has lived experience of BD	Acquaint researcher
05/19	Consult with members of the Spectrum advisory panel (three participants with lived experience of BD in addition to the service user researcher) to get initial feedback on the project plan and aims	Relevant outcomes
10/19	Visit a local Bipolar UK support group (eight attendants) with the service user researcher and presenting the project	Acquaint researcher, relevant outcomes
09/20	Consult with the Spectrum advisory panel (one participant, in addition to the service user researcher) to get feedback on the POETIC review (Chapter 4) findings	Additional finding perspectives
05/21	Message the moderators of two large BD subreddits to get feedback on the project overall	Relevant outcomes
05/21	Pitch the project at a Young People's Involvement in Digital Mental Health[41] Dragon's Den	Acceptable research design
05/21	Talk to a lawyer with a bipolar I disorder diagnosis who lives in a US MH state facility about the project overall and plans for the Reddit mood and posting behaviour study (Chapter 6) and POETIC on Reddit study (Chapter 7)	Acquaint researcher, Additional perspectives
06 - 07/21	Consult with four volunteers with lived experience of BD and using social media in relation to their MH issues recruited via PeopleInResearch[42] to get feedback on the initial results of the Reddit mood and posting behaviour study (Chapter 6) and plans for the POETIC on Reddit study (Chapter 7)	Additional perspectives, Relevant implications
06/22	Consult with two of the volunteers recruited via PeopleInResearch on the final results of the Reddit mood and posting behaviour study (Chapter 6)	Relevant implications, Understandable language
08/22	Consult with the same two volunteers as in 06/22 on the findings of the POETIC on Reddit study (Chapter 7)	Additional perspectives, Relevant implications, Understandable language

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[41] https://emergingminds.org.uk/special-interest-research-group-young-people-involvement-in-digital-mental-health/

[42] https://www.peopleinresearch.org/

Month/ year	PPI methods (GRIPP2 item 2)	Aims (see Table 14)
11/22	Consult with Spectrum Centre's service user researcher on the dataset name	Understandable language

3.4 Ethical considerations

The Lancaster University Faculty of Health and Medicine research ethics committee approved this research in May 2019 (reference: FHMREC18066) (see Appendix C). Ethical considerations are an essential part in planning MH research and most research projects undergo approval by an ethics committee. On the contrary, the NLP community has only recently started to consider ethical issues (Hovy and Spruit, 2016; Hovy *et al.*, 2017). NLP research traditionally used publicly available, impersonal texts such as newspapers or texts published with some temporal distance, e.g., novels, which left a distance between the text and author. Conversely, recent social media research often deals with highly personal information of living individuals, who can be directly affected by the research (Hovy and Spruit, 2016).

Hovy and Spruit (2016) discuss issues that can arise when constructing datasets from social media and conducting analyses or developing predictive models based on these data. Firstly, demographic bias in sampling the data can lead to exclusion of minority groups, resulting in overgeneralisation of models or analyses based on these data. Secondly, topic overexposure arises when research disproportionally scrutinises the language of certain groups and repeatedly finds it to be different or more difficult to process. This could lead to the perception of these groups as abnormal. Unlike most previous NLP research (see Section 1.4.2.2) the goal of the present project was not to reveal particularities in the language of individuals who experience MH issues. Instead, the aim was to learn about their lived experience from what they share in public online support forum posts. Lastly, most research, even when conducted with the best intentions, suffers from the dual-use problem (Jonas, 1984), in that it can be misused or have consequences that affect people's life negatively. For this reason, this project did not build MH classifiers, which, as just one example, insurance companies could use in the risk assessment of applicants based on their social media profiles.

3.4.1 Participant consent and anonymity

Whether and how research on social media data needs to obtain informed consent is still a debate (Eysenbach and Till, 2001; Beninger *et al.*, 2014; Paul and Dredze, 2017), mainly because it is not straightforward to determine if social media users post in a public or private context. From a legal point of view, the Reddit privacy policy explicitly allows analysis of the user contents by third party: 'Much of the information on the Services is public and accessible to everyone, even without an account. By using the Services, you are directing us to share this information publicly and freely.' 'When you submit content (including a post, comment, chat message, or broadcast) to a public part of the Services, any visitors to and users of our Services will be able to see that content, the username associated with the content, and the date and time you originally submitted the content. Reddit allows other sites to embed public Reddit content via our embed tools. Reddit also allows third parties to access public Reddit content via the Reddit application programming interface and other similar technologies. Although some parts of the Services may be private or quarantined, they may become public (e.g., at the moderator's option in the case of private communities) and you should take that into consideration before posting to the Services.' (Reddit Inc., 2022).

However, it is unclear to what extends users are aware of this when posting to these platforms (Ahmed, Bath and Demartini, 2017). In practice it is often infeasible to seek retrospective consent from hundreds or thousands of social media users. According to current ethical guidelines for social media research (Benton, Coppersmith and Dredze, 2017; Williams, Burnap and Sloan, 2017; The British Psychological Society, 2021) and practice in comparable research projects (O'Dea *et al.*, 2015; Ahmed, Bath and Demartini, 2017), it is regarded as acceptable to waive explicit consent if the research outputs preserve the anonymity of the users. Therefore, this project did not seek informed consent of the social media users who wrote the posts in the S-BiDD dataset.

Benton, Coppersmith and Dredze (2017) formulate guidelines for ethical social media health research that pertain especially to data collection and sharing. In line with these and following other qualitative research on public social media posts (Berry *et al.*, 2017; Coppersmith *et al.*, 2018; Stubbs-Richardson, Rader and Cosby, 2018; Brownlie and Shaw, 2019), the research outputs only share anonymised and paraphrased posts and excerpts, as it is often possible to recover a user name via a web search for the verbatim text of a public post. Other researchers can request the dataset after signing a data usage agreement that specifies ethical terms for its use (Jagfeld, Jones, *et al.*, 2022).

3.4.2 Risk assessment: dealing with alarming content

An important issue to consider is how the project team should handle alarming content indicating a risk of self-harm or harm to others and in what situations it would be appropriate or even required by duty of care to pass on information to clinical experts or the police. This concern was of particular importance in this project since individuals with a BD diagnosis are at a higher risk of suicide attempts than the general population (Novick, Swartz and Frank, 2010). Even though any social media dataset bears the potential to contain alarming content, surprisingly, only two discussions of this issue surfaced in the literature so far.

A research project trying to classify the risk level of suicide-related tweets both manually and automatically (O'Dea *et al.*, 2015), that did not seek informed consent of the users, decided not to offer psychological support to participants who appeared to be at risk. The researchers argued that an intervention via Twitter 'may not be appropriate' due to the fact that suicidal ideation fluctuates, the conducted risk assessment may not be reliable, and uninvited contact would constitute an invasion of the privacy of the participants that 'could lead to unsolicited attention' (O'Dea *et al.*, 2015). In this project, the ethical review board required researchers to not analyse tweets earlier than three months after their posting date.

On the other hand, Young and Garett (2018) reported on a case in which a study on general health and wellbeing by chance discovered alarming tweets indicating depression and suicidal ideation of a participant. In contrast to O'Dea *et al.* (2015), the participants (university students) had provided their explicit consent. The study team decided to pass on the student's information to the university's psychological service after a clinically trained team member confirmed that the tweets indicated a high self-harm risk. This was complicated because the team had not foreseen this case and the consent form did not include a clause to pass on information of the participants if they themselves or others seemed at risk.

The project team agreed with Young and Garett (2018) that a plan for dealing with alarming content was necessary, yet, the lack of explicit consent complicated this. In line with O'Dea *et al.'s* (2015) argument the project team acknowledged that Reddit users might perceive researchers contacting them with concerns about their MH as intrusive and that this might cause more distress and harm than help. Therefore, this project also adopted the practice to only analyse at least three months old posts. In that way, the project team avoided encountering posts that indicated an acute risk. Since suicidal ideation fluctuates (Matsuishi *et al.*, 2005; Williams *et al.*, 2006; Prinstein *et al.*, 2008), it appeared ethically appropriate to not contact the authors of older posts that indicated risk. However, the project team committed to use Reddit's reporting service for abusive or harassing behaviour[43] to report posts they judged as indicating a risk of significant harm to others.

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[43] https://www.reddit.com/report

4 Personal recovery in bipolar disorder: Systematic review and "best fit" framework synthesis of qualitative evidence – a POETIC adaptation of CHIME

Glorianna Jagfeld, Fiona Lobban, Paul Marshall, Steven H. Jones[44]

Abstract

Background: PR, living a satisfying, hopeful life alongside symptoms, has become an increasingly valued aim across MH care agendas internationally. However, there is little understanding of how people experience PR alongside the mood challenges characteristic of a BD diagnosis. PR frameworks have been developed for populations with mixed psychiatric diagnoses, predominantly psychotic disorders.

Methods: This systematic review of qualitative data used the widely adopted CHIME PR processes in a 'best fit' framework synthesis to understand PR experiences in BD. Included studies were coded with deductive framework analysis based on the CHIME processes and inductive thematic analysis for aspects beyond the a priori framework.

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[44] The authors would like to thank Chris Lodge, Service User Researcher at the Spectrum Centre, for discussions of the results and facilitating an advisory panel of people with lived experience of BD, who helped to reflect on the results and implications of this review. The authors would also like to thank Lancaster University faculty librarians Caroline Gibson and Tanya Williamson for help in designing the literature searches for this review. We very much appreciated Jasper Palmier-Claus' helpful comments on an earlier draft of this manuscript.

Results: A comprehensive search of six literature databases led to inclusion of twelve articles published 2010-2020. Deductive coding supported the fit with the CHIME framework but revealed difficulties, losses, and tensions within and across recovery processes. The proposed framework for PR in BD, Purpose and meaning, Optimism and hope, Empowerment, Tensions, Identity, Connectedness (POETIC), organises all CHIME processes around these tensions.

Limitations: Diversity among study participants was limited with majority middle-aged, female, Western participants.

Conclusions: The compact POETIC PR framework tailored for BD is directly applicable to clinical practice with PR objectives. It highlights the need for professionals to introduce PR in a realistic and balanced way to address recent criticism by service user organisations of PR as overly optimistic.

Keywords: BD, PR, recovery, qualitative research, meta-synthesis, framework synthesis

Highlights

- The CHIME framework is useful for understanding PR in BD
- POETIC: Purpose, Optimism and hope, Empowerment, Tensions, Identity, Connectedness
- POETIC extends the transdiagnostic CHIME recovery framework with a Tensions domain
- All POETIC PR processes capture negative and positive experiences
- Ambivalence about mania, self-management and work are important in BD

4.1 Introduction

People who experience marked mood fluctuations – episodes of depressed or elated (hypomanic or manic) mood – such that they cause distress and impair social or occupational functioning meet the criteria for BD according to current diagnostic manuals (American Psychiatric Association, 2013; World Health Organization, 2016). Rates for meeting bipolar spectrum disorders criteria range from 0.1% (India) to 4.4% (US) across several European, American and Asian countries (Merikangas *et al.*, 2011). BD is associated with a high risk of suicide (Novick, Swartz and Frank, 2010), making its prevention and treatment important tasks for society. However, there is also evidence that many individuals with this diagnosis achieve good socio-occupational functioning outcomes (Coryell *et al.*, 1998; Tohen *et al.*, 2003; Goldberg and Harrow, 2004; Akers *et al.*, 2019) and satisfaction within these domains (Goldberg and Harrow, 2005).

4.1.1 Personal recovery in severe mental health issues and bipolar disorder

Clinical recovery in severe MH issues is usually clinician-assessed in terms of symptom severity and socio-occupational functioning (Torgalsbøen, 1999; Liberman and Kopelowicz, 2002). Alternatively, from the 1980s on, initiatives by people with lived experience of severe MH issues started advocating for the importance of outcomes that each individual defines as relevant to them and their self-reported life satisfaction (Deegan, 1988; Anthony, 1993). Anthony (1993) defined the concept of PR as 'a way of living a satisfying, hopeful and contributing life even with the limitations caused by the illness'. Given this broad definition, PR has been repeatedly criticised as a hard to grasp, vague concept (Bird *et al.*, 2014; McCabe *et al.*, 2018). This makes it difficult to consistently develop and evaluate recovery-oriented services that have been mandated by MH policies internationally since the beginning of this century (e.g., President's New Freedom Commission on Mental Health (US), 2003; World Health Organization Regional Office for Europe, 2005; Department of Health (UK), 2009; Department of Health and Ageing (Australia), 2009; Mental Health Commission of Canada, 2012).

A large-scale systematic literature review led to a conceptual framework for PR in severe MH issues, comprising the five CHIME recovery processes (Leamy et al., 2011). The evidence considered in the review predominantly concerned psychotic disorder and to a much smaller extent major depressive disorder and BD[45]. A recent scoping review of PR conceptualisations (Van Weeghel *et al.*, 2019) supports CHIME as a widely endorsed framework but recommends several additions: a greater focus on trauma, choice, risk taking and coping with challenges, and adaptation to the specifics of the cultural and client populations to which it is applied. Moreover, van Weeghel et al. (2019) conclude '[s]triking gaps in our knowledge relate to how PR processes take place in people with mood disorders'. Indeed, ongoing mood instability and dealing with the upsurge of elated moods often constitute special challenges for people diagnosed with BD compared to other severe MH issues (Jones, Lobban and Cook, 2010; Lapsley *et al.*, 2013).

Therefore, this review seeks to develop a conceptual framework for PR specific to BD based on CHIME in a 'best fit' framework synthesis (Carroll, Booth and Cooper, 2011; Carroll *et al.*, 2013). 'Best fit' framework synthesis extends framework synthesis (Brunton *et al.*, 2006; Nilsen *et al.*, 2006) by adopting an already available framework for a comparable situation (a "best fit") compared to the bespoke framework developed after literature retrieval in traditional framework synthesis. In doing so 'best fit' framework synthesis takes a realist epistemological stance (Booth *et al.*, 2016) and combines deductive framework analysis with

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[45] The CHIME review does not report participant numbers for different diagnostic groups. At least 29 articles contain participants with a diagnosis of psychosis or schizophrenia, compared to only 16 with BD (based on 44 retrievable full texts from 51 articles based on lived experience out of 99 included articles (the other evidence is reviews and policy documents)). In at least 16 articles people with a diagnosis of psychotic disorder are the largest participant group, while this is not the case for BD in any article.

inductive thematic analysis for data that cannot be accommodated in the 'best fit' framework. The main advantage of this approach is that adopting an a priori transdiagnostic analysis framework can form a basis to identify BD-specific experiences.

The concept of subjective quality of life in BD (Murray *et al.*, 2017; Morton *et al.*, 2018b), defined most frequently as 'individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns' (The WHOQOL Group, 1995, p. 1405), has parallels to PR. Structured measures of quality of life (Murray and Michalak, 2012) and PR (Jones, Mulligan, *et al.*, 2013) in BD are associated but not mutually redundant (Murray *et al.*, 2017). Further, a systematic review found that the studies on quality of life in BD so far lack a coherent definition of the term (Morton, Michalak and Murray, 2017). Thus, to ensure conceptual clarity, inclusion criteria in this review required articles to explicitly focus on PR experiences as part of the RQ or provide a definition of PR (see Section 4.2.2.2). This specificity also sets the present review apart from a previous qualitative evidence synthesis on PR in BD (Lapsley *et al.*, 2013), which included any qualitative study of people with a BD diagnosis with a psychosocial focus. Moreover, growing clinical use of the PR concept warrants an updated review.

4.1.2 Aim

This review aims to answer: 'What do we know about the experience of PR of individuals diagnosed with BD from qualitative evidence?'

4.2 Method

The review protocol was pre-registered on PROSPERO[46]. Reporting of this review follows guidelines for systematic reviews (PRISMA-P (Moher *et al.*, 2015)) and qualitative evidence syntheses (ENTREQ (Tong *et al.*, 2012)).

4.2.1 Framework selection

This review concentrates on the original CHIME recovery processes as a 'best fit' framework despite recommendations for extensions summarised by van Weeghel et al. (2019) due to two considerations. First, none of these recommendations are based on populations with BD diagnoses. Second, CHIME is well established with more than 1000 citations[47] and applications in a randomised controlled trial of a pro-recovery intervention (Slade et al., 2011, 2015), qualitative studies of service user experiences (Ådnøy Eriksen et al., 2014; Brijnath, 2015) and the validation (Shanks et al., 2013) and development (Williams et al., 2015) of PR

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[46] https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=136978

[47] 1059 citations according to Google Scholar on 10.4.2019

measures. In contrast, extensions such as ‘difficulties’ proposed by Stuart, Tansey and Quayle (2017) have had limited impact to date.

4.2.2 Searches and screening

4.2.2.1 Search strategy

In line with guidance for framework syntheses, this review adopted a comprehensive search strategy. The Population, Intervention, Condition, Outcome, Study type tool (Centre for Reviews and Dissemination, 2009) helped to concretise the review question and form the query. Seven marker articles served as query sensitivity test. Six literature databases EMBASE (via Ovid SP), MEDLINE, PsycINFO, CINAHL, SocINDEX, and Scopus (via EBSCOhost) were searched from January 1980 until present in the initial search on 21 June 2019 and the update on 14 October 2020. The lower time limit was set to the publication year of DSM-III (American Psychiatric Association, 1980), which more precisely operationalised the definition of BD compared to previous versions. The final query consisted of the four concepts BD, PR, experiences, and qualitative research that were connected with AND. Each concept was expressed via multiple free-text terms and database-specific taxonomy terms connected with OR. Since PR was difficult to operationalise, additionally all articles citing the most widely cited PR definition (Anthony, 1993) were retrieved via Scopus. References and citations of all included articles were screened as well. The full search strategy was published alongside the PROSPERO review protocol[48].

4.2.2.2 Eligibility criteria

Articles included in this review state personal or subjective recovery experiences in their RQs or aim or otherwise provide a PR definition and discuss their qualitative results within a PR framework. Table 16 shows the full eligibility criteria.

Table 16 Screening criteria to select abstracts and full texts

Rank	Criteria	Include	Exclude
1	Language	Full text language is English, German, Dutch, and French	Any other language
2	Publication type	Peer reviewed articles describing primary research	Dissertations, theses, conference abstracts without associated full article, reviews, discussion articles, summaries, theoretical and policy papers, not peer-reviewed (e.g., newspaper articles, books, book chapters)

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[48] https://www.crd.york.ac.uk/PROSPEROFILES/136978_STRATEGY_20191111.pdf

Rank	Criteria	Include	Exclude
3	Qualitative data	Contains direct quotes of participants	
4	Participants	At least three[49] participants	Single-author opinion pieces, case studies with less than four participants
5	Participant age	Average age of participants at least 16 years	
6	Diagnosis	6.A) All participants have BD as primary diagnosis OR 6.B) Results for participants with BD diagnosis reported separately for all RQs and/or themes (if some participants have different diagnoses or no diagnosis such as caregivers, professionals)	6.1) If participants have dual or multiple diagnoses, exclude if remission criteria or recovery are defined for these instead of BD (e.g. from other MH problems, substance abuse, addiction, eating disorders) 6.2) Diagnosis of quoted participants is not provided.
7	PR	Title and abstract screening	
		Experiences of PR, including facilitators and barriers The recovery definition clearly goes beyond clinical recovery (symptom reduction, relapse prevention) by including, e.g., self-defined goals, social or vocational functioning, empowerment, wellbeing, and quality of life	Studies that only focus on symptoms as outcomes or evaluate specific interventions not directly targeting PR (i.e., have only symptom-focused outcomes)
		Full text screening	
		At least two out of the following must hold: 7.A) Research question or aims refer to personal or	7.1) Only focuses on clinical or functional recovery (e.g., symptoms remission, relapse prevention, resuming employment etc.) OR

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[49] Minimum participant number chosen for consistency with the CHIME review (Leamy *et al.*, 2011, p. 445). Systematic reviews synthesise aggregated results. Small case studies mainly represent primary data and generally represent outliers, so they are more likely to bias the review findings.

Rank	Criteria	Include	Exclude
		subjective recovery experiences 7.B) PR definition is provided 7.C) Stated relevance to PR elsewhere in the article	7.2) Reported qualitative data only focuses on experience of specific intervention OR 7.3) Only refers to related concepts such as quality of life, or wellbeing but not any PR definition or literature

4.2.2.3 Screening process

Retrieved abstracts were deduplicated with Mendeley Desktop[50] and imported into Rayyan (Ouzzani *et al.*, 2016) for screening. The lead reviewer (GJ) and a second reviewer (PM) independently screened all abstracts. Agreement was checked after 15%, 30%, 60% and 100% of abstract screening to resolve disagreements via discussion, involving the wider review team if needed. GJ checked eligibility of all full texts. Additionally, PM independently assessed 25% of the full texts using Covidence systematic review software (Veritas Health Innovation, 2019). Finally, GJ discussed all inclusion decisions with the review team.

4.2.2.4 Quality appraisal

Following current consensus recommendations for qualitative evidence syntheses, quality of the included studies was assessed to review methodological rigour but not to exclude studies (Dixon-Woods *et al.*, 2006, 2007; Thomas and Harden, 2008). GJ appraised all articles with the 10-item CASP (Critical Appraisal Skills Programme, 2018) questionnaire. PM independently appraised four randomly selected articles. The review team discussed diverging assessments to reach consensus.

4.2.2.5 Data synthesis

'Best fit' framework synthesis guidelines (Carroll, Booth and Cooper, 2011; Carroll *et al.*, 2013) informed data analysis and synthesis. Initially, GJ read all included articles and made notes on paper to familiarise herself with the data. Second, she marked up participant quotes and author interpretations in the results, discussion and conclusion sections in the article PDF files for subsequent line-by-line coding with the qualitative analysis software NVivo 12. The a priori framework CHIME (Leamy *et al.*, 2011) shown in Table 17 comprises five recovery domains, further differentiated in 74 subdomains organised in hierarchies which are up to five levels deep, which served as codes in the deductive analysis. Since there was no codebook available, the code descriptions in Table S3 were added from publications on the framework (Bird *et al.*, 2014; Bird, 2015) in discussion with Mike Slade, leader of the research group that developed CHIME.

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[50] https://www.mendeley.com/download-desktop

Table 17 CHIME PR domains (dark blue) with subdomains (light blue) ordered according to number of studies identifying the subdomain (adapted from Leamy et. al (2011)); see Table S3 for lower-level subdomains

C	Connectedness	Peer support and support groups	Relationships	Support from others	Being part of the community		
H	Hope & optimism	Belief in possibility of recovery	Motivation to change	Hope-inspiring relationships	Positive thinking, valuing success	Having dreams and aspirations	
I	Identity	Dimensions of identity	Rebuilding positive sense of self	Overcoming stigma			
M	Meaning & purpose	Meaning of mental illness experiences	Spirituality	Quality of life	Meaningful life and social roles	Meaningful life and social goals	Rebuilding life
E	Empowerment	Personal responsibility	Control over life	Focusing upon strengths			

Article excerpts were coded at the most specific suitable subdomain in line-by-line coding via deductive framework analysis. For data that could not be accommodated in CHIME, the first reviewer derived new codes via inductive reflexive thematic analysis (Braun and Clarke, 2006, 2019). Two other reviewers (SHJ & FL) audited coding of the first three articles and of one additional article after coding of all articles had been completed. The CHIME conceptual framework elements are referred to here as (sub-)*domains* as they constitute 'summaries of (often divergent) responses on a particular issue or topic' (Clarke and Braun, 2018, p. 109). In addition, reflexive thematic analysis allowed creation of fully realised *themes* from inductive and deductive codes, tying together observations around a 'core concept that underpins and unites' them (Clarke and Braun, 2018, p. 108).

GJ, FL, and SHJ collaboratively performed the synthesis, starting from the list of pre-existing (sub-)domains and new themes proposed by GJ (Carroll *et al.*, 2013). First, a new conceptual framework was produced by dropping or promoting a priori subdomains depending on the richness and thickness of coded data. Second, relationships between the conceptual framework domains were explored via the new themes, which were refined during this process. Third, the synthesis was tested by exploring differences between the a priori and resultant framework and paying special attention to contradictory views (Carroll *et al.*, 2013). To complement the researcher and clinician perspectives of the review team, GJ presented the results to a service user researcher and a volunteer with lived experience of BD (see Section 4.3.4).

4.2.2.6 Reflexive positioning of the review team

Reflexivity is important to highlight how subjectivity may have impacted on qualitative research findings (Finlay and Gough, 2008). GJ and PM are Health

Research PhD students. FL and SHJ are both professors of clinical psychology and clinical psychologists with experience of developing and delivering (recovery-oriented) psychological therapies for people with BD and psychosis. The review team embraces a PR approach in BD. We anticipated that the CHIME domains would usefully capture many aspects of PR in BD but were aware of its criticism as overly positive by service user researchers, which might have led us to focus more on difficulties.

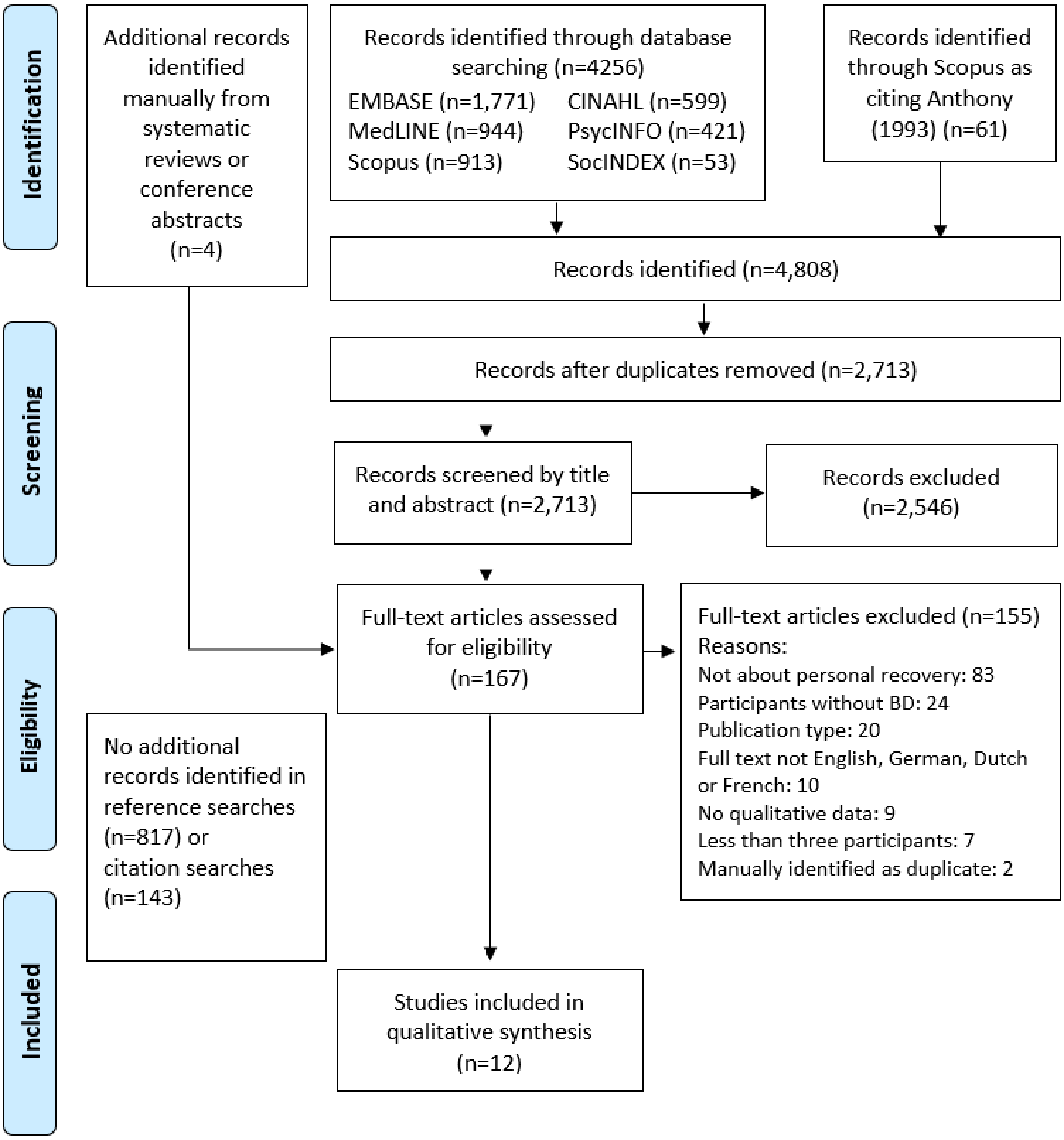

Figure 8 PRISMA diagram for study identification

4.3 Results

Database searches returned 2,713 unique abstracts, which were all screened (Figure 8). Agreement for abstract exclusions was above 94% at all four checkpoints. Of the 167 assessed full texts, 155 were excluded, most frequently due to lacking a PR focus. Although abstracts in any language were eligible, only twelve non-English full texts were assessed, which were all excluded[51]. Agreement in double-screening of 25% of full texts was 86%. Reference and citation searches for the included articles yielded no new inclusions. The search update identified three additional eligible articles (Echezarraga *et al.*, 2019; Tse *et al.*, 2019; Durgu and Dulgerler, 2020). Line-by-line coding with the framework resulting from the analysis of the nine initially retrieved articles revealed no contradictions, nor new framework elements or substantive changes in their importance.

4.3.1 Study and participant characteristics

Twelve articles published between 2010 and 2020 met eligibility criteria. Table S2 provides all extracted data. The articles reported results from eleven studies involving 163 participants, two thirds of whom were female. The participant ages ranged from 19-68 years (mean 45 years). Out of 118 participants for which employment information was available, 51% were employed full or part-time, while 36% were unemployed or on long term disability grants. Only five studies reported the ethnicity or nationality of their participants. Seven studies mentioned involvement of people with lived experience of BD beyond participation in interviews or focus groups.

Six studies took place in English-speaking countries (four in the United Kingdom (UK), one in Canada, one in Australia), two in Norway and one each in Spain, Turkey, and China. Seven studies aimed to explore personal or subjective recovery experiences in BD in general, while five had a more specific focus on the role of work (Borg *et al.*, 2013), parenting (Tjoflåt and Ramvi, 2013), loss (Fernandez, Breen and Simpson, 2014), resilience (Echezarraga *et al.*, 2019), and knowledge provided by peer support workers (Tse *et al.*, 2019). The interview schedules of all studies but the one by Tjoflåt and Ramvi (2013) asked participants for their experience or meaning of recovery and for their own strategies for recovery, staying well, or coping with BD.

4.3.2 Study quality

Table 18 presents the CASP (Critical Appraisal Skills Programme, 2018) ratings for the included articles. A second rater independently appraised four articles, yielding disagreements on a total of four questions, which were resolved through team discussion. Overall, quality ratings were high, all included articles adequately used qualitative research methods to provide valuable contributions. The only major

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[51] Ten full texts were not in an eligible full-text language (English, German, Dutch, or French) and one German and French article did not meet other inclusion criteria.

concern was whether the articles adequately discussed the relationship between researchers and participants. Also, there was doubt for three articles (Todd, Jones and Lobban, 2012; Borg *et al.*, 2013; Durgu and Dulgerler, 2020) whether the participant recruitment and/or data collection was appropriate to address the research aims. In sum, there was no indication to perform a sensitivity analysis excluding lower-quality articles.

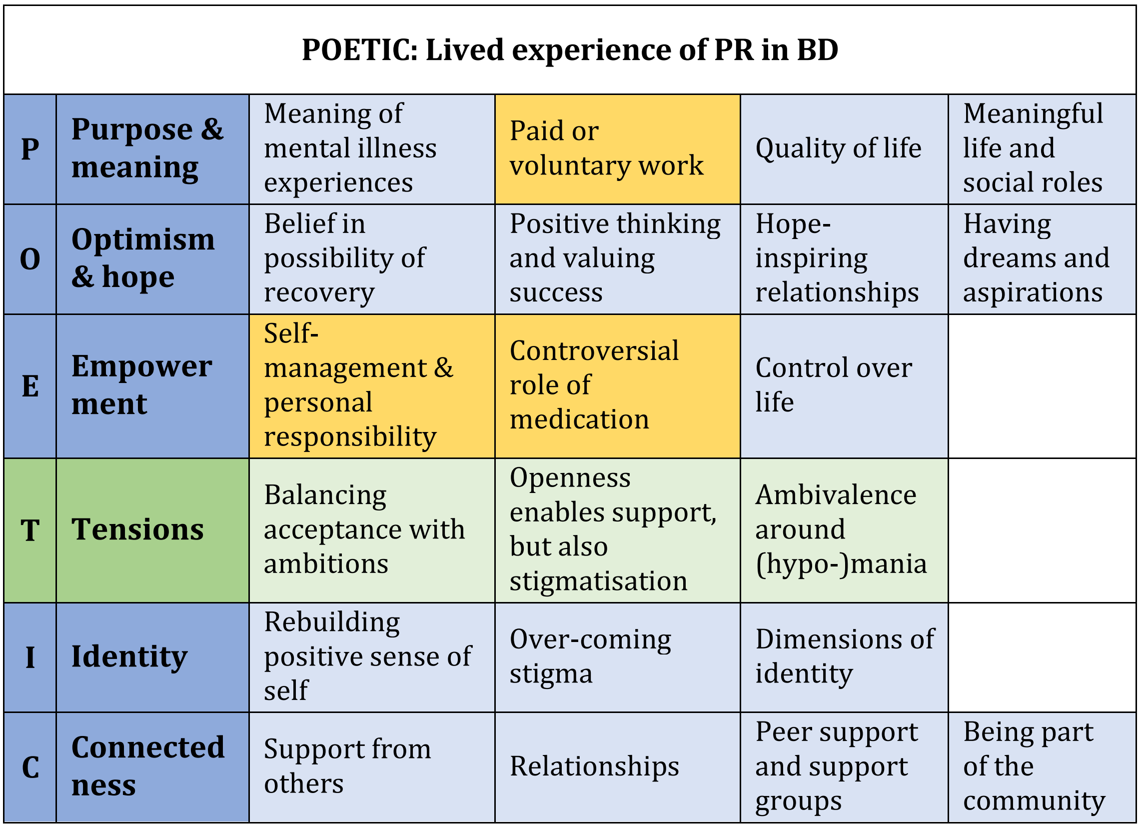
Table 18 Study quality appraisal using CASP criteria

Article	1	2	3	4	5	6	7	8	9	10
Mansell et al. (2010)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Michalak et al. (2012)	✓	✓	✓	✓	✓	u	✓	✓	✓	✓
Todd et al. (2012)	✓	✓	✓	✓	u	u	✓	✓	✓	✓
Veseth et al. (2012)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Borg et al. (2013)	✓	✓	✓	u	u	✓	✓	✓	u	✓
Tjoflåt & Ramvi (2013)	✓	✓	✓	✓	✓	u	✓	✓	✓	✓
Fernandez et al. (2014)	✓	✓	u	✓	✓	u	✓	✓	✓	✓
Morrison et al. (2016a)	✓	✓	✓	✓	✓	u	✓	✓	✓	✓
Warwick et al. (2019)	✓	✓	✓	✓	✓	u	✓	✓	✓	✓
Echezarraga et. al (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Tse et. al (2019)	✓	✓	u	✓	✓	u	✓	✓	✓	✓
Durgu & Dulgerler (2020)	✓	✓	u	u	u	u	✓	✓	✓	✓

Table 18 note: 1. Was there a clear statement of the aims of the research? 2. Is a qualitative methodology appropriate? 3. Was the research design appropriate to address the aims of the research? 4. Was the recruitment strategy appropriate to the aims of the research? 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. Is the research valuable? u: unclear

4.3.3 Synthesis

Figure 9 summarises the synthesis. The left part shows the domains of the proposed conceptual framework for PR in BD, Purpose and meaning, Optimism and hope, Empowerment, Tensions, Identity, Connectedness (POETIC). The right part shows the main retained domains (blue), promoted subdomains (work, self-management, medication) (yellow) from the deductive CHIME framework (see Table 17 for comparison), and themes in the new inductive Tensions domain (green), ordered from left to right according to their relative importance. Table S3 and Table S4 contain the codebook and number of articles coded in each (sub-)domain or theme. Table S5 provides additional quotes, also for less rich and lower-level subdomains.



POETIC: Lived experience of PR in BD					
P	**Purpose & meaning**	Meaning of mental illness experiences	Paid or voluntary work	Quality of life	Meaningful life and social roles
O	**Optimism & hope**	Belief in possibility of recovery	Positive thinking and valuing success	Hope-inspiring relationships	Having dreams and aspirations
E	**Empower ment**	Self-management & personal responsibility	Controversial role of medication	Control over life	
T	**Tensions**	Balancing acceptance with ambitions	Openness enables support, but also stigmatisation	Ambivalence around (hypo-)mania	
I	**Identity**	Rebuilding positive sense of self	Over-coming stigma	Dimensions of identity	
C	**Connected ness**	Support from others	Relationships	Peer support and support groups	Being part of the community

Figure 9 Proposed conceptual framework for PR in BD: POETIC; deductive CHIME domains (dark blue) with retained second-level (light blue) and promoted (yellow) subdomains; inductive new domain and themes in green

The findings can be summarised as follows: First, deductive coding revealed that the CHIME domains covered most of the PR processes in BD, confirming its suitability as 'best fit' framework. All domains apart from Optimism and hope appeared in all included articles and the framework encompassed most of the data. Importantly, however, the data unveiled ample evidence of difficulties and losses within all CHIME domains despite their positive original framing. Second, looking at the subdomains within each deductive domain in more detail indicated that self-management and medication in the Empowerment domain, and work in the Purpose and meaning domain have higher significance in BD than in transdiagnostic CHIME. Third, inductive analysis revealed tensions between PR processes and ambivalence about elated mood. The new Tensions domain reflects this with the three themes 'Balancing acceptance with ambitions,' 'Openness enables support, but also stigmatisation', and 'Ambivalence around (hypo-)mania'. The remainder of this section briefly reviews the POETIC domains and the feedback from two people with lived experience of BD (Section 4.3.4).

4.3.3.1 Purpose and meaning

Purpose and meaning unified two important PR processes, having or finding meaningful activities in the present and making sense of extreme mood experiences from the past. All but one article discussed work, which was promoted from third-level subdomain within 'Quality of life' in CHIME to the second level in POETIC. Many participants valued part or fulltime employment because it provided structure, social interaction, a socially valued role, and opportunities for recognition: '… it lets me know that they they do not judge me based on a diagnosis, they judge me based on what I am able to deliver in [work], and that feels that feels good …' (Warwick, Tai and Mansell, 2019). On the other hand, work entailed many challenges 'such as finding work, problems associated with symptoms or simply coping with the psychosocial stress in working life' (Borg *et al.*, 2013), which could trigger mood episodes.

Parenting was another meaningful life and social role discussed in depth, which, like work, provided both opportunities and challenges for PR. 'Parental responsibility was seen as an incentive to fight for their health, to live regularly and to be a good role model' (Tjoflåt and Ramvi, 2013): 'I get better for my daughter, she's my everything' (Durgu and Dulgerler, 2020). At the same time, parents 'felt shame and guilt' and questioned whether they were 'good enough' (Tjoflåt and Ramvi, 2013) as parents.

4.3.3.2 Optimism and hope

Optimism and hope was the a priori domain least strongly explicitly reflected in the articles. 'Hope-inspiring relationships' often helped to foster a 'Belief in the possibility of recovery': 'We have a cooking class and I met a few peers there. After sharing their stories with us, I realized that mental illness is not terminal; we can recover. The peer workers experienced a lot of ups and downs, but they were able to bounce back, teach us how to cook, and share their experience. I feel good that we, who have mental illnesses, are not hopeless' (Tse et al., 2019).

4.3.3.3 Empowerment

Empowerment meant that participants felt they had 'Control over life' by understanding and being able to manage their moods and accessing professional support if needed. 'Self-management and personal responsibility' featured richly in all included articles, and inductive new themes were 'knowing oneself', 'always vigilant' (of mood), and 'lifestyle changes towards routine, balance, calmness'. Generally, participants self-managed by noticing early signs of mood changes and acting upon them accordingly. However, they described finding their individual warning signs and coping strategies as 'time-consuming and challenging task' involving 'trial and error' (Veseth *et al.*, 2012) and 'substantial effort' (Warwick, Tai and Mansell, 2019).

All but two articles discussed the benefits and downsides of medication to control mood, which was therefore promoted to the second level in POETIC from its fifth level in CHIME. Opinions on medication encompassed the whole spectrum from an essential factor to stay well, to not particularly helpful, or even a hindrance to PR: 'at least when it comes to the mental health stuff, I do not find … that medication's a useful part of that toolbox […] I also do not think that my toolbox has to be the same as everybody else's' (Warwick, Tai and Mansell, 2019). In their considerations around coming off medication, participants traded negative side effects off against their fear of relapse.

4.3.3.4 Tensions

New inductive themes revealed tensions between PR processes and in the stance on elated mood that participants needed to negotiate.

4.3.3.4.1 Balancing acceptance with ambitions

Acceptance of vulnerability and personal limitations in the Meaning and purpose and Identity domains motivated self-management: 'the realization that, for example, participants may not 'react as well to stress as everyone else' encouraged them to take personal measures towards reducing their stress levels' (Mansell *et al.*, 2010). This often meant reducing work hours or responsibility: 'I gave myself permission and and really under doctors' orders, not to ... try to do everything I was doing prior to being hospitalized' (Warwick, Tai and Mansell, 2019). Yet, this needed balancing with 'Having dreams and aspirations' in the Optimism and hope domain: 'there was discussion among participants about the way accepting limitations can both help and hinder recovery. For some, hoping for change and not accepting too many limitations was an important part of recovery' (Michalak *et al.*, 2012).

4.3.3.4.2 Openness enables support, but also stigmatisation

The Connectedness subdomain 'Support from others' could conflict with the Identity subdomain 'Over-coming stigma'. To access support, individuals needed to disclose MH issues, risking negative judgement or over-protective behaviour. This played out both on the level of formal and informal support. Being open with family or friends enabled 'increasing feelings of closeness and trust in others' (Mansell *et al.*, 2010) and informal support, for example, '[p]eople also subsequently took more active roles in alerting participants to behaviour that could escalate symptoms of mania' (Mansell *et al.*, 2010). Still, some participants experienced a 'loss of credibility' or 'control' (Fernandez, Breen and Simpson, 2014) when they felt their behaviour was monitored disproportionately as a result of their disclosure.

Ambiguity also arose in response to receiving a BD diagnosis. On the one hand, the diagnosis enabled access to treatments and support such as medication, psychological therapy, and disability allowance. However, it also could lead to experiencing self- or societal stigma, posing a significant PR challenge: 'having an awareness of it, actually knowing you are ill at times can be difficult … people give you these "oh it's a lifelong condition, you can't recover from it, you are never going to get rid of it", that can have quite detrimental effects' (Todd, Jones and Lobban, 2012).

4.3.3.4.3 Ambivalence around (hypo-)mania

Few individuals had an unequivocally negative view of elated mood states, while the majority felt inherently ambivalent and had 'mixed feelings' (Veseth *et al.*, 2012) about curtailing them. They recognised both positive aspects of 'productive', 'creative' (Morrison *et al.*, 2016a), and 'adventurous' (Fernandez, Breen and Simpson, 2014) elated mood as well as the 'dangerous' (Veseth *et al.*, 2012) downside of becoming 'uncontrollable' (Tse *et al.*, 2019), 'destructive', and 'scary' (Fernandez, Breen and Simpson, 2014). Especially at the beginning of their PR journey, some participants felt a 'need' for elated states to counterbalance depression because 'endless energy' allowed 'to clean up the mess I have made when I have been depressed' and 'manage everyday life' (Veseth *et al.*, 2012). Many viewed manic states as special treat, like a 'big bag of sweets' (Veseth *et al.*, 2012), that allowed them to 'create nice and exciting situations' (Tjoflåt and Ramvi, 2013). Some participants wondered whether they erred on the side of caution in supressing 'seductive' (Morrison *et al.*, 2016a) rises in energy to stabilise mood and 'whether there could ever be a place' for manic experiences in their lives (Mansell *et al.*, 2010).

4.3.3.5 Identity

Rebuilding a positive sense of self was an important PR process because societal and self-stigma associated with a BD diagnosis posed external and internal threats to identity. Moreover, episodic mood swings, particularly when viewed as separate from the self, could cause identity crises: '… it made me feel quite insecure because I wasn't sure […] whether … reactions I was having to people, things that I was feeling were genuine feelings or part of the illness or it was me, so it left me having this real sense of kind of loss of identity […] I think that was the hardest thing to cope with it all, how it made me think about myself and question myself' (Warwick, Tai and Mansell, 2019). Importantly, challenges to the sense of self could also arise later in the PR process due to increased self-awareness if self-surveillance created self-doubt: 'I have felt less trust in myself. I felt I did not have as much confidence in different things that I did.' (Fernandez, Breen and Simpson, 2014).

4.3.3.6 Connectedness

The Connectedness domain highlighted the importance of feeling connected with different groups of people, including family, friends, peers with lived experience of BD, and professionals, particularly psychotherapists. These groups could be important sources for practical or emotional support, e.g., 'my kids tell me that I am the best mother in the world' (Echezarraga *et al.*, 2019). However, MH difficulties often put especially intimate relationships under strain: 'I always say that I do not suffer from bipolar; it is my family and friends that suffer from it.' (Fernandez, Breen and Simpson, 2014).

4.3.4 Feedback from people with lived experience of bipolar disorder

A service user researcher and a volunteer with lived experience of BD confirmed that the review results and implications resonated with their experiences and priorities. For example, the service user researcher explained how he first needed to accept the loss of his job before he could explore new careers. Conversely, accepting personal limitations, part of the new theme 'Balancing acceptance with ambitions' in the Tensions domain, was less important to them because they perceived MH services as over-cautious and over-pessimistic. Their feedback did not lead to changes in the framework but introduced nuances to the manuscript, for example a more fine-grained discussion of ways to foster helpful acceptance and dealing with losses.

4.4 Discussion

This systematic review synthesised qualitative evidence on PR in BD by adopting the transdiagnostic CHIME PR processes in a 'best fit' framework synthesis. Overall, the deductive analysis demonstrated that PR in BD entails the same main processes as in other severe MH issues, but with a greater emphasis on self-management, medication, and socially meaningful roles such as work and parenting. All PR domains involved difficulties and losses. Inductive analysis revealed tensions within and across PR processes, demonstrating their interconnectedness and the ambivalence of living with BD. Since these tensions were so pervasive in the PR experience in BD, merely adding on to the harmony-emphasising CHIME acronym was not considered appropriate and POETIC is suggested as more fitting descriptor.

4.4.1 Specific aspects and challenges of personal recovery in bipolar disorder

Finding 'something in your life you really love doing' (Warwick, Tai and Mansell, 2019) surfaced as a core driver for PR in BD. All but one article in this review discussed the benefits and challenges of work as meaningful life role. More than half of the participants were working full-or part-time, an additional 10% were retired, students, or volunteered. People with a BD diagnosis are more likely to be employed than people with a psychotic disorder diagnosis mainly considered in the original CHIME review, where only 22% of the articles discussed working (Marwaha, Durrani and Singh, 2013; Carmona *et al.*, 2017).

The new theme 'Balancing acceptance with ambitions' foregrounds accepting limitations and even reducing ambitions compared to pursuing ambitions to increase hope more unequivocally emphasised by CHIME. In relation to work, this meant to achieve 'adequate work pressure' (Veseth *et al.*, 2012). There is some evidence that people with a high behavioural activation system sensitivity, resulting in increased goal directed behaviour, may be more vulnerable to develop BD symptoms (Depue and Iacono, 1989; Alloy *et al.*, 2012; Dempsey, Gooding and Jones, 2017). This could explain why identifying and overcoming unrealistic expectations appeared as a PR challenge for some individuals with a BD diagnosis.

Self-management in the Empowerment domain was particularly important, also evident in the 'Wellness strategies'-theme in the metasynthesis by Lapsley et al. (2013). Participants needed to develop individualised strategies over time. Critically, a recent survey found that two thirds of people diagnosed with BD in the UK did not receive any self-management advice (Bipolar UK, 2020). Due to this lack of information, many participants reported experiencing relapse, longer mood episodes, and relationship and work problems.

Some people in later PR stages claimed to manage well without medication. In general, this review supports a higher importance of balancing the pros and cons of medication, in line with a CHIME framework analysis of interviews with a mixed diagnostic sample (Bird *et al.*, 2014).

Curtailing symptoms experienced as positive emerged as particular PR challenge in BD, particularly in the new theme 'Ambivalence around (hypo-)mania'. 'Handling ambivalence about letting go of manic states' (Veseth *et al.*, 2012) and 'Avoidance of mania' (Mansell *et al.*, 2010) were themes in two included articles and this is also reflected in the wider 'Ambivalence' theme in the Lapsley et al. (2013) metasynthesis. CHIME does not discuss ambivalence towards positively experienced MH symptoms, although there is also evidence for positive aspects of psychosis (Romme and Escher, 1993; Chadwick, 1997; Richards, 2008; National Hearing Voices Network, 2020). The presence of symptoms experienced as positive may be particularly strong in BD compared to other severe MH issues. Rusner et al. (2009) characterise the intensity of living with BD as 'both a gift and a challenge' (see also Taylor, Fletcher and Lobban, 2015).

4.4.2 Difficulties and losses within personal recovery processes

Participants described difficulties and losses due to extreme mood experiences in all CHIME domains, spanning all areas of life: loss of their jobs, careers, or ability to fulfil their parenting role (Purpose and meaning), loss of aspirations or hope (Optimism and hope), loss of control over their behaviour in acute mood episodes, loss of autonomy undergoing paternalizing or coercive treatment of services or continuous symptom surveillance by family, friends, and work colleagues (Empowerment), loss of their sense of self due to mood changes or obtaining a BD diagnosis (Identity), and loss of relationships and credibility by their friends or colleagues (Connectedness). Not adopting a separate Difficulties domain (Stuart, Tansey and Quayle, 2017) a priori allowed this review to extend previous findings by uncovering the challenges within each recovery domain.

Repeatedly experiencing losses due to 'sporadic and cyclical mood episodes' (Fernandez, Breen and Simpson, 2014) intermitting with stable periods appears as particular challenge in BD. A recent metasynthesis (Warwick *et al.*, 2019) also identified this as one of the main causes of distress in BD. To move from 'shameful and bitter feelings […] towards a more accepting and realistic view of themselves' (Tjoflåt and Ramvi, 2013) participants needed to cope with and accept these losses. A UK service user organisation recently criticised CHIME for being overly positive and focussing on individualised, future-oriented goals in an unbalanced way, whereas 'grassroots recovery' (Deegan, 1988; Anthony, 1993) maintains negative thoughts, emotions, and experiences as key features of PR (Recovery in the Bin *et al.*, 2019). Thus, the POETIC framework could help to rectify the impression of PR as mainly positive endeavour with a more nuanced account of the experiences of people who live with BD.

4.4.3 Facing tensions, difficulties, and mood swings with mindful acceptance

Beyond the established CHIME domains, Tensions characterises PR in BD as a complex process. The two new themes ‘Balancing acceptance with ambitions’ and ‘Openness enables support, but also stigmatisation’ highlight conflicts between PR domains. They underline that PR cannot be attained by targeting PR processes in isolation.

‘Balancing acceptance with ambitions’ connects two instances of acceptance in the CHIME framework, ‘Accepting or normalising the illness’ within Purpose and meaning and ‘Acceptance’ of self within Identity, pointing out their potential tension with maintaining ambitions in the Optimism and hope domain. Non-judgmental, mindful (instead of dismissive or fatalistic) acceptance seems to be important here as for example contained in psychological therapies based on Buddhist philosophy (e.g., Kabat-Zinn, 1982). Mindful acceptance of limitations allows to explore ways forward from seeing the current reality as it is: ‘you have to acknowledge that it [the illness] is there and you have to turn it to your advantage’ (Todd, Jones and Lobban, 2012). Other tensions and difficulties in PR in BD may benefit from mindful acceptance as well. For example, ‘a gradual shift between confidentiality and openness’ (Mansell *et al.*, 2010) may constitute a mindful approach to navigate the conflict between support and stigmatisation in disclosing MH difficulties.

Mindfulness also appeared as a promising strategy in the long-term self-management of mood. Awareness of ‘present thoughts and feelings’ (Veseth *et al.*, 2012) can ‘pick up on minor changes’ (Warwick *et al.*, 2019) of behaviour, thinking, and mood, and mindful acceptance helps to respond to them: ‘One of the things I found most difficult at the time but since have since found quite useful is just accepting a feeling and not judging the feeling and kind of getting to understand that that feeling would pass’ (Warwick, Tai and Mansell, 2019).

4.4.4 Implications for research

Finding a balance between acceptance and ambitions and dealing with recurrent experiences of loss seem to pose particular challenges in BD. Mindful acceptance appears as promising approach to cope with the difficulties and tensions involved in PR on a macro-level and mood swings on a micro-level. A range of third-wave psychological therapies aim to support individuals in accepting themselves and difficult thoughts or feelings, such as dialectical behaviour therapy (Linehan, 1993), acceptance and commitment therapy (Hayes, Strosahl and Wilson, 2009), mindfulness-based cognitive therapy (Segal, Williams and Teasdale, 2002), compassion-focused therapy (Gilbert, 2009), and recovery-focused cognitive behavioural therapy (Jones *et al.*, 2015). While pilot trials for some of these therapies for BD are promising (e.g., Goldstein *et al.*, 2015), the evidence base is still thin. For example, systematic reviews of mindfulness-based cognitive therapy and other mindfulness-based interventions as adjunct therapy for BD found evidence for significant reductions in depression and anxiety symptoms in pre-post trials (Bojic and Becerra, 2017; Chu *et al.*, 2018; Lovas and Schuman-Olivier, 2018), but not in the only three randomised controlled trials (Chu *et al.*, 2018).

Moreover, research on mindfulness-based interventions for BD so far has focused on symptom and functioning outcomes (Murray *et al.*, 2017). This review encourages development of interventions to foster mindful acceptance and evaluation with more holistic outcome measures, such as quality of life (Michalak and Murray, 2010) and PR (Jones, Mulligan, *et al.*, 2013). Finally, research still needs to evaluate whether structured therapeutic approaches more reliably or faster improve quality of life or PR in BD, as some individuals also benefit from other experiences such as spirituality.

4.4.5 Implications for practice

This review also has implications for recovery-oriented psychotherapy and general care for people with BD. Foremost, it highlights that professionals should take caution not to introduce PR processes in an overly optimistic and simplistic way but to acknowledge clients' challenges as natural part of the process.

Self-management appeared very important to live well with BD in the Empowerment domain. Information and support for self-management should be provided early on along with general psychoeducation about the condition, which currently does not seem to be the case for a large proportion of people who receive a BD diagnosis in the UK (Bipolar UK, 2020).

In the Connectedness domain, family members were an important resource for support but also frequent cause of distress for people living with BD (cf., Warwick *et al.*, 2019). This draws further attention to the potential benefits of family interventions. They have an evidence base for BD in addition to pharmacotherapy (Justo, Soares and Calil, 2007; Mansfield, Dealy and Keitner, 2012; Reinares *et al.*, 2016; Chatterton *et al.*, 2017) but are often difficult to access (Miklowitz and Chung, 2016; Reinares *et al.*, 2016).

Although many aspects of PR in BD appear individual, continued efforts for social change to increase awareness and decrease stigma of severe MH issues are likely to benefit everyone (Warwick *et al.*, 2019). This review found that disclosure of MH issues often entails the risk of stigmatisation as evidenced in an inductive theme in the Tensions domain. Therefore, social change could improve the chances that people with extreme mood experiences request the support that can help them to perform well in their valued social roles, for example workplace adjustments or help with childcare (cf., Purpose and meaning domain), and that they have a positive experience in doing so.

4.4.6 Strengths and limitations

To our knowledge this is the first systematic review of PR experiences in BD with a transdiagnostic framework. Double-checking at all stages (abstract and full-text screening, quality appraisal, qualitative coding, framework development) ensured rigour and dependability of the results. The three articles identified in the search update concurred with the POETIC framework and therefore provide additional confirmation of its completeness and validity. As a theoretical contribution, this review provides a codebook for the CHIME framework, which was not previously available.

Additionally, the strengths and limitations of three aspects of this review need to be highlighted. First, 'best fit' framework synthesis enabled efficient data analysis and comparison of PR experiences in BD to other severe MH issues but introduced a different bias to the analysis compared to a fully inductive approach (Carroll *et al.*, 2013). Second, the strict inclusion criteria led to a small number of included studies with explicit PR focus, representing a more coherent set of literature compared to a previous review (Lapsley *et al.*, 2013). However, this excluded related evidence on quality of life (Michalak *et al.*, 2012), staying well (Russell and Brown, 2005; Crowe and Inder, 2018), and self-management (Murray *et al.*, 2011; Morton *et al.*, 2018a). Third, diversity among study participants was limited. Onset of BD symptoms is most frequently in late adolescence and early adulthood (Pini *et al.*, 2005; Merikangas *et al.*, 2011) with equal prevalence in men and women (Pini *et al.*, 2005; American Psychiatric Association, 2013). This contrasts with the study participants who were on average 45 years old and in majority female. Moreover, only one study from Hong Kong focused on non-Western views. Five studies only included participants that self-defined to be in recovery or were clinically recovered. While the remaining studies did not report such criteria, it seems likely that their framing would have attracted participants who are managing to stay fairly well, missing out on experiences of those who disagree with the concept of PR. Thus, despite consolidating experiences from 163 participants from seven countries, generalisation of the findings requires caution.

4.5 Conclusions

This systematic review synthesised qualitative research to answer the question 'What do we know about the experience of PR of individuals diagnosed with BD?.' The transdiagnostic CHIME PR processes (Leamy *et al.*, 2011) capture a large part of PR experiences in BD, importantly comprising both positive *and* negative experiences. The amended framework, Purpose and meaning, Optimism and hope, Empowerment, Tensions, Identity, Connectedness (POETIC), retains all original CHIME processes but organises them around the new Tensions domain. Despite the harmony emphasised by the CHIME acronym, this review revealed many tensions and difficulties across and within PR processes in BD. Self-management, medication, taking on socially valued roles, and ambivalence around elated mood states emerged as areas deserving particular attention for people living with BD. Mindful acceptance may be a promising way to cope with mood changes and some of the tensions in PR in BD. Extending on CHIME, this review argues that PR in BD is POETIC.

5 Understanding who uses Reddit: Profiling individuals with a self-reported bipolar disorder diagnosis

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Abstract

Recently, research on MH conditions using public online data, including Reddit, has surged in NLP and health research but has not reported user characteristics, which are important to judge generalisability of findings. This paper shows how existing NLP methods can yield information on clinical, demographic, and identity characteristics of almost 20K Reddit users who self-report a BD diagnosis. This population consists of slightly more feminine- than masculine-gendered mainly young or middle-aged US-based adults who often report additional MH diagnoses, which is compared with general Reddit statistics and epidemiological studies. Additionally, this paper carefully evaluates all methods and discusses ethical issues.

5.1 Introduction and related work

People who experience extreme mood states that interfere with their functioning, meet the criteria for BD according to the diagnostic manuals DSM (American Psychiatric Association, 2013) and ICD (World Health Organisation, 2018). DSM and ICD operationalise extreme mood states in terms of major depressive episodes, 'almost daily depressed mood or diminished interest in activities with additional

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[52] We would like to thank Anna Tigunova and Keith Harrigian for their assistance in applying their Reddit user profiling NLP tools. We would also like to express our heartfelt thanks to Daisy Harvey, Stephen Mander, and the anonymous reviewers for helpful comments on a draft version of this article, to Andrew Moore for testing the code release, and to Alistair Baron for the initial idea for this work.

symptoms for at least 14 days' (World Health Organisation, 2018) and (hypo-)manic episodes, 'a distinct period of abnormally and persistently elevated, expansive, or irritable mood and abnormally and persistently increased goal-directed activity or energy' that lasts at least seven (four) days (American Psychiatric Association, 2013, p. 124).

DSM and ICD distinguish several BD subtypes based on the lifetime frequency and intensity of (hypo-)manic and depressed episodes. The only requirement for a diagnosis of bipolar I disorder is at least one lifetime manic episode, whereas bipolar II disorder requires at least one hypomanic and one major depressive episode (American Psychiatric Association, 2013, pp. 126, 132). Cyclothymic disorder applies to numerous periods of hypomanic and depressive symptoms during at least two years that do not meet criteria for hypomanic or major depressive episodes (American Psychiatric Association, 2013, p. 139).

Bipolar mood episodes are often recurring (Treuer and Tohen, 2010; Gignac *et al.*, 2015), so many individuals living with BD require life-long treatment (Goodwin et al., 2016) and have a heightened suicide risk (Novick, Swartz and Frank, 2010). However, characteristics and outcomes of people meeting BD criteria are diverse, with some living well, (e.g., Warwick, Tai and Mansell, 2019) and even functioning on a high level (Akers *et al.*, 2019).

5.1.1 Online forums as research data source

Online forums have become an increasingly attractive source for research data, enabling naturalistic data collection, where researchers do not influence data creation, at large scale (Fielding *et al.*, 2016). NLP research in this area has focused on predicting people at risk of BD (Coppersmith, Dredze and Harman, 2014; Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018). Health researchers have explored the lived experience of BD with qualitative analyses of online posts (Mandla, Billings and Moncrieff, 2017; Sahota and Sankar, 2019). Unlike in clinical studies, usually little or no demographic information is available for online forum users, so it is unclear to what populations these results generalize (Ruths and Pfeffer, 2014). For example, language differences between Twitter users with self-reported major depressive disorder or post-traumatic stress disorder correlated highly with their personality and demographic characteristics (Preoţiuc-Pietro *et al.*, 2015). Thus, it is unclear whether these findings really indicate MH diagnoses or other user characteristics.

5.1.2 The online discussion forum Reddit

Besides MH-specific platforms (Kramer, Fussell and Setlock, 2004; Vayreda and Antaki, 2009; Bauer *et al.*, 2013; Latalova *et al.*, 2014; Poole, Smith and Simpson, 2015; McDonald and Woodward-Kron, 2016; Campbell and Campbell, 2019), blogs (Mandla, Billings and Moncrieff, 2017), and Twitter (Coppersmith, Dredze and Harman, 2014; Ji *et al.*, 2015; Saravia *et al.*, 2016; Huang *et al.*, 2019; Budenz *et al.*, 2020), much recent research of user-generated online content in BD has focused on the international online discussion forum Reddit[53] (Gkotsis, Oellrich, *et al.*, 2016; Gkotsis *et al.*, 2017; Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018; Sahota and Sankar, 2019; Yoo, Lee and Ha, 2019).

The platform Reddit is among the most visited internet sites worldwide (Alexa Internet, 2020), hosting a number of subforums ('subreddits') for general topics as well as interest groups. There is a vast and growing amount of BD-related content on Reddit, with more than 50K new posts per month in the four largest BD-related subreddits[54]. Anyone can view posts without registration and the Reddit application programming interface offers free access to all historic posts. Reddit profiles do not provide any user characteristics besides the username and sign-up date in a structured format or comparable to a Twitter bio. While some surveys provide general information on Reddit users, none of the BD-specific studies looked at particular user characteristics of their sample, which is important (Amaya *et al.*, 2019).

5.1.3 Research questions and contributions

The above considerations motivate our RQs: What characteristics of Reddit users who disclose a BD diagnosis can be automatically inferred from their public Reddit information and how do they compare to general Reddit users and clinical populations? What are the ethical considerations around determining users' characteristics and ways to minimise potential negative impacts?

This work has two main contributions, both of which may be relevant to different parts of the Workshop on Computational Linguistics and Clinical Psychology community. Crucially, the authors are an interdisciplinary team of NLP and clinical psychology researchers, as well as practising clinical psychologists, who regularly consult with people with lived experience of BD in an advisory panel.

First, this paper estimates and discusses clinical, demographic and identity characteristics of Reddit users who self-report a BD diagnosis (see Figure S1 for a visual results summary). This has implications for future BD-focused research on Reddit and helps to contextualise previous work. Moreover, this information is relevant for clinicians who may want to recommend certain online forums to clients and to clinical researchers interested in recruiting via Reddit. Second, this work shows how simple rule-based and off-the-shelf state-of-the-art NLP methods can estimate Reddit user characteristics, and carefully discusses ethical considerations and harm-mitigating ways of doing so. These findings and discussions apply to other, also non-clinical, subgroups of Reddit users. The evaluation with manual annotations evaluates published NLP methods in an applied setting.

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[53] https://www.reddit.com/

[54] r/bipolar, r/BipolarReddit, r/bipolar2, r/bipolarSOs

5.2 Methods

5.2.1 User identification

In this work, the identification of Reddit users with lived experience of BD adapts previous approaches based on self-reported diagnosis statements, e.g., 'I was diagnosed with BD today' (Coppersmith *et al.*, 2015; Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018). Importantly, this captures self-*reported* diagnoses by a professional and not *self-diagnoses*, which were excluded. Contrary to existing datasets of Reddit posts by people with a self-reported BD diagnosis, all posts of identified people were retained and not only those unrelated to MH concerns. This enables subsequent research on the lived experience of people with BD. All available Reddit posts (January 05 - March 19) that mentioned 'diagnosis' and a BD term (see below) were downloaded from Google BigQuery. User account meta-data (id, username, UTC timestamp of sign-up) for all matching posts was retrieved via the Reddit python application programming interface *praw*[55] to remove posts by users who had deleted their profile after creation of the BigQuery tables. Each of the 170K posts was classified as self-reported diagnosis post after automatically removing quoted content if it met the following criteria adapted from Cohan et al. (2018) (see Table 19 for examples):

- Contains at least one condition term for BD.
- Matches at least one inclusion pattern, i.e., BD diagnosis of any type by a professional.
- Does not match any exclusion pattern, e.g., self-diagnosis.
- The distance between at least one condition term and the beginning or end of an inclusion phrase is less than the experimentally determined threshold of 56 characters.

Table 19 Components of patterns-to identify English self-reported diagnosis statements

Component	Number	Examples (*: wildcard)
Inclusion patterns	145	as someone with a diagnos*, my recent CONDITION diagnos*, I went to a DOCTOR and got diagnos*
CONDITION terms	92	bipolar, manic depression, BD-I, BD-II, cyclothymia
DOCTOR terms	18	doctor, pdoc, shrink
Exclusion patterns	74	not formally diagnos*, self diagnos*, she's diagnos*

Subsequently, all posts (id, submissions title, text, subreddit, user id, UTC timestamp of time posted) of the 21K user accounts with at least one self-reported diagnosis

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[55] https://github.com/praw-dev/praw

post were downloaded via *praw*. The first author checked the self-reported diagnosis statements of all accounts with more than 1.5K submissions or 200K comments or whose name included 'bot' or 'auto', removing 30 automated user accounts (bots). Finally, 960 user accounts with a self-reported psychotic disorder diagnosis were removed because this constitutes an exclusion criterion for BD (American Psychiatric Association, 2013, pp. 126, 134).

5.2.2 User characteristics extraction and inference

Several NLP methods were applied and compared to extract or infer clinical (MH comorbidities = diagnoses additional to BD), demographic (age, country of residence), and identity (gender) characteristics of Reddit users with a self-reported BD diagnosis. See Appendix E.1 for more details on the age, country, and gender methods and their previously published performance. The first and third author manually annotated self-reported BD diagnoses, age, country, and gender for random included users for evaluation.

5.2.2.1 Mental health comorbidities

Frequencies for other self-reported MH diagnoses were obtained by matching all dataset posts against inclusion patterns for other diagnoses, in the same way as for identifying self-reported BD diagnoses. Condition terms for nine major DSM-5 and ICD-11 diagnoses were extended from Cohan et al. (2018): anxiety disorder (generalised or social anxiety disorder, panic disorder), attention deficit hyperactivity disorder, borderline personality disorder, major depressive disorder, post-traumatic stress disorder, psychotic disorder (schizophrenia or schizoaffective disorder), obsessive-compulsive disorder, autism spectrum disorder, and eating disorder.

5.2.2.2 Age

Two methods to recognise a user's age relative to one of their posts were compared. An approximate date of birth was calculated from the post timestamp to then calculate the user's age when posting for the first time and their mean age over all posts.

- **Self-reported**: Reddit users sometimes self-report their age and gender in a bracketed format, e.g. 'I [17f] just broke up with bf [18m]'. Regular expressions extracted age and gender from such self-reports in submission titles.
- **Language use**: Tigunova's (2019) neural network model predicts the age group of users with at least ten posts from their contents and language style. Training data for this model came from Tigunova et al. (2020) who automatically labelled Reddit users with their self-reported age (see Appendix E.1.2).
- **Hybrid**: The Hybrid method assigns the extracted age from the Self-reported method if available, and otherwise the predicted age from the Language use method because evaluation revealed that the Self-reported method had higher accuracy but lower coverage than the Language use method (see Section 5.4.2).

5.2.2.3 Country of residence

The only published method for Reddit user localisation to date (Harrigian, 2018) infers a user's country of residence via a Dirichlet process mixture model[56]. It uses the distribution of words, posts per subreddit, and posts per hour of the day (time zone proxy) of a user's up to 250 most recent comments.

5.2.2.4 Binary gender

Three methods to recognise binary gender (feminine or masculine) leveraging different types of information were compared. All three methods pertain to a performative gender view, which posits that people understand their and others' gender identity by certain behaviours (including language) and appearances that society stipulates for bodies of a particular sex (Larson, 2017). Non-binary gender identities were not included due to a lack of NLP methods to detect them.

- **Username**: The character-based neural network model of Wang and Jurgens (2018) predicts whether a username strongly performs feminine or masculine gender, otherwise it assigns no label.
- **Self-reported**: See Section 5.2.2.2.
- **Language use**: The neural network model by Tigunova et al. (2019) predicts gender for Reddit users with at least ten posts from the post texts. It was trained on data automatically labelled with self-reported gender provided by Tigunova et al. (2020) (see Appendix E.1.1).
- **Hybrid**: Evaluation revealed an accuracy ranking of Username > Self-reported > Language use and the inverse for coverage (Section 5.4.2). The Hybrid method assigns a binary gender identity in a sequential approach, disregarding possible disagreements between methods: If the Username method found the username to perform feminine or masculine gender, it takes this prediction, otherwise assumes the self-reported gender if available, and else resorts to the predictions of the Language use method.

5.3 Ethical considerations

At least four main ethical considerations arise for the work presented here: Concerns around (1) consent and (2) anonymity of Reddit users, around the (3) selection, category labels, and assignment of user characteristics (MH diagnoses, age, country, gender), and (4) potentially harmful uses of the presented dataset and methods. The Lancaster University Faculty of Health and Medicine research ethics committee reviewed and approved this study in May 2019 (reference number FHMREC18066).

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[56] https://github.com/kharrigian/smgeo

5.3.1 Consent

If and how research on social media data needs to obtain informed consent is debated (Eysenbach and Till, 2001; Beninger *et al.*, 2014; Paul and Dredze, 2017), mainly because it is not straightforward to determine if posts pertain to a public or private context. Legally, the Reddit privacy policy[57] explicitly allows copying of user contents by third parties via the Reddit application programming interface, but it is unclear to what extends users are aware of this (Ahmed, Bath and Demartini, 2017). In practice it is often infeasible to seek retrospective consent from hundreds or thousands of social media users. Current ethical guidelines for social media research (Benton, Coppersmith and Dredze, 2017; Williams, Burnap and Sloan, 2017) and practice in comparable research projects (O'Dea *et al.*, 2015; Ahmed, Bath and Demartini, 2017), regard it as acceptable to waive explicit consent if users' anonymity is protected. Therefore, Reddit users in this work were not asked for consent.

5.3.2 Anonymity

In line with guidelines for ethical social media health research (Benton, Coppersmith and Dredze, 2017), this research only shares anonymised and paraphrased excerpts from posts in publications. Otherwise, it is often possible to recover usernames via a web search with the verbatim post text (see also Section 5.3.5).

5.3.3 Rationales for user characteristics

As stated in the introduction, user characteristics are important to determine about which populations research on this dataset may generalise. The NLP community increasingly expects data statements for datasets (Bender and Friedman, 2018), which include speaker age and gender specifications. As Section 5.4.3 shows, characteristics of Reddit users with a self-reported BD diagnosis deviate from both general Reddit user statistics and epidemiological studies, which therefore do not constitute useful proxies. Relying entirely on self-reported information introduces selection biases because not all user groups may be equally inclined to explicitly share certain characteristics. This motivates using statistical methods to infer Reddit users' age, country, and gender here.

The user characteristics comorbid MH issues, age, country, and gender were chosen because they impact peoples' lived experience in BD as discussed in the following. This work identifies users with a self-reported BD diagnosis because collecting posts from BD-specific subreddits does not suffice as carers and people who are unsure if they meet diagnostic criteria also post there. Other self-reported MH diagnoses were extracted because people with BD diagnoses frequently experience additional MH issues (Merikangas *et al.*, 2011). Self-reported diagnoses capture only users who

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[57] https://www.redditinc.com/policies/privacy-policy

explicitly and publicly share their diagnosis. This research does not infer any users' MH state.

Depp and Jeste (2004), among others, provide evidence for age-related differences in BD symptoms and experiences, also through increasing importance of physical health comorbidities with ageing. Age estimates were grouped in the same way as in a US survey of Reddit users for comparison.

Healthcare systems, including provision of MH care, vastly differ between countries, even within Western countries such as the US, UK, and Germany. The MH services people can access may influence their experience of BD, motivating estimation of their country of residence. While Harrigian (2018) predicts longitude/latitude coordinates in 0.5 steps, these are mapped to countries because more fine-grained user localisations are not needed.

Using a gender variable in NLP deserves special consideration because it concerns people's identity (Larson, 2017). Biological sex can impact on the experience of BD, primarily through issues around childbirth and menopause, also related to mood-impacting hormonal changes (Diflorio and Jones, 2010); Sajatovic et al. (2011) found effects of gender identity on treatment adherence in BD. This work only uses binary feminine or masculine gender labels since no NLP method with more diverse categories was available. The gender recognition methods could cause harm to individual users if they were misgendered and then incorrectly addressed or referred to. This project minimises such harm because the labels only serve to estimate the gender distribution and not to target individual users.

5.3.4 Dual use

This research aims to learn more about Reddit users who share their experiences with BD to yield findings that will ultimately lead to new or improved interventions that support living well with BD. However, most research, even when conducted with the best intentions, suffers from the dual-use problem (Jonas, 1984), in that it can be misused or have consequences that affect people's life negatively. Adverse consequences of this study could arise for the Reddit users included in the dataset if they are sought out based on their self-reported BD diagnosis to be targeted with, e.g., medication advertisements. The large number of Reddit posts in this dataset can serve as training data for machine learning systems that assign a likelihood to other Reddit/social media users for meeting BD criteria (e.g., Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018). For example, health insurance companies could misuse this, using applicants' social media profiles in risk assessments.

5.3.5 Transparency: Dataset and code release

Based on all above considerations, the dataset will only be shared with other researchers upon request and under a data usage agreement that specifies ethical usage of the dataset as detailed in this section. The dataset release necessarily contains the original post texts but with replaced post and user ids. This requires verbatim web searches with the post texts to seek out individual Reddit users and thus complicates automatisation and scaling. User characteristics, including the manually annotated subsets, will only be shared separately with researchers who justify a specific need for them. To aid transparency, the code and patterns to identify self-reported MH diagnoses, age, and gender are released[58].

5.4 Results and discussion

The self-reported BD diagnosis matching method identified 19,685 Reddit users who together had 21,407,595 public Reddit posts between March 2006 and March 2019. Compared to 9K unique user accounts who posted in the four largest BD-related subreddits in May 2020, this likely only constitutes a small fraction of Reddit users with a BD diagnosis that could be reliably automatically identified (see following subsection).

5.4.1 Manual annotation

Two authors manually annotated random subsets of users to evaluate all automatically extracted or inferred information according to the annotation guidelines[59]. As shown in Table 20 agreement for all annotations was above 90%, demonstrating feasibility and high reliability.

Table 20 Number of users in manual annotation, raw annotator agreement, and label distributions after resolving disagreements in discussion

Variable	Users	Agree ment	Labels (%)[60]
Self-reported BD diagnosis	100	97.0%	Yes: 97.0, no: 3.0
Date of birth	116	99.1%	Date: 90.5, ?: 19.5
Country	100	90.0%	US: 46.0, Canada: 90.0, UK: 8.0, other: 25.0, ?: 12.0
Gender	116	95.7%	Feminine: 51.7, masculine: 34.5, transgender: 0.9, ?: 13.8

The annotators checked all extracted self-reported BD diagnosis statements of 100 random included users, disagreeing only for three users (see first line of Table 20)[61]. The pattern matching approach for self-reported diagnosis statements mistakenly identified only three users (subsequently removed from the dataset) based on

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[58] https://github.com/glorisonne/reddit_bd_user_characteristics

[59] https://github.com/glorisonne/reddit_bd_user_characteristics/blob/master/ManualAnnotationGuidelines.pdf

[60] ?: no label assigned due to lack of user-provided information on Reddit

[61] No attempt was made to evaluate recall of user identification. Given an international prevalence of meeting BD criteria of about 2% (Merikangas *et al.*, 2011) and expecting numbers of posts per account close to the average of 1,224 in the collected dataset, it was deemed infeasible to manually check all posts of randomly selected user accounts for self-reported BD diagnosis statements.

reports of other MH diagnoses where the word bipolar occurred close to the diagnosis term as well[62].

To facilitate manual age and gender annotation, 116 users where randomly selected from the 2854 (14%) of users where the Self-reported age or gender extraction method matched. This explains the discrepancy between the coverage of the Self-reported method in Table 21 for the test set and full dataset. The annotators only checked whether date of birth or gender could be unambiguously extracted from all of a users' posts that matched a self-reported age and gender pattern. The test set for the gender evaluation results in Table 21 comprises only users labelled as feminine or masculine and excludes one manually identified transgender person.

5.4.2 Evaluation of natural language processing methods

Table 21 shows accuracy and coverage for the user characteristics extraction and inference methods described in Section 5.2.2 against the manually labelled users for which the annotators could determine a label. For age, the Self-reported method outperforms the Language use method for accuracy but not coverage[63]. The Hybrid method, subsequently used in Section 5.4.3.2, achieves 99% test set accuracy and 68% coverage on the full dataset. Harrigian's (2018) method assigns a country estimate to every user with 78% test set accuracy. For gender, accuracy decreases from the Username, Self-reported, and Language use method, while coverage increases[64]. The Hybrid gender identification method, used in Section 5.4.3.4, achieves 97% test set accuracy, gender-labelling 72% of users.

Table 21 Accuracy ($\frac{\text{correct}}{\text{total}}$) for user metadata extraction and inference methods (see Section 5.2.2) for manually annotated users (test), coverage ($\frac{\text{predicted}}{\text{total}}$) for manually annotated (test) and all (all, n=19,685) users

Variable	Users^{test}	Method	Accuracy^{test}	Coverage^{test}	Coverage^{all}
Age group	105	Self-reported	100%	98.1%	11.5%
		Language use	60.6%	94.3%	66.0%
		Hybrid	99.0%	100%	68.3%
Country	88	Words, subreddits, timing	78.4%	100%	100%

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[62] Paraphrased excerpts of incorrectly identified self-reported BD diagnoses: 'clinical depression with bipolar tendencies', 'diagnosed with BPD today, thought it was BD for years', 'diagnosed with depression, but sure I've got bipolar'.

[63] The Language use method for age or gender does not have full coverage because it requires at least ten posts per user. The methods agree for 62.6% of the 1,788 users where both assign an age group.

[64] For 195 users where all three methods assign a gender identity, they agree on 73.8% (90.8% agreement between the Username and Self-reported method, 80% between the Language use and Username or Self-reported method).

Variable	Users^{test}	Method	Accuracy^{test}	Coverage^{test}	Coverage^{all}
Gender	100	Username	100%	12.0%	10.9%
		Self-reported	97.9%	94.0%	11.9%
		Language use	84.2%	95.0%	66.0%
		Hybrid	97.0%	100%	71.5%

5.4.3 Reddit users' characteristics

The following subsections compare characteristics of Reddit users with a self-reported BD diagnosis to general Reddit users and epidemiological statistics.

5.4.3.1 Mental health comorbidities

Table 22 shows how many users disclosed other concurrent or lifetime MH diagnoses besides BD. Rates for self-reported MH diagnoses in addition to BD are slightly higher in our dataset compared to the Self-reported MH diagnoses (SMHD) dataset (Cohan *et al.*, 2018), potentially because our dataset covers 27 more months of posts.

Table 22 Self-reported comorbid diagnoses with BD in this work, the SMHD dataset, and epidemiological studies

Diagnosis	Dataset n=19,685	SMHD n=6,434	Epidemiological studies[65]
Major depressive disorder	30.2%	27.4%	N/A
Anxiety disorder	15.8%	12.8%	13.3%-16.8%*, n=921-1,537
Attention deficit hyperactivity disorder	12.9%	9.6%	17.6%†, n=399
Borderline personality disorder	8.4%	N/A	16.0%$ n=1,255
Post-traumatic stress disorder	6.5%	5.1%	10.8%*, n=1,185
Obsessive-compulsive disorder	3.9%	3.4%	10.7%*, n=808
Autism spectrum disorder	2.2%	2.0%	Unknown
Eating disorder	1.0%	0.8%	5.3%-31.0%§, n=51-1,710

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[65] *Nabavi et al. (2015), †McIntyre et al. (2010), $Zimmermann and Morgan (2013), §Álvarez Ruiz and Gutiérrez-Rojas (2015)

Like psychotic disorder (5.2% of users prior to exclusion), a major depressive disorder diagnosis is mutually exclusive with BD according to the DSM (American Psychiatric Association, 2013, pp. 126, 134)[66]. A large part of identified self-reported major depressive disorder diagnoses were false positives where 'depression' occurred near to a BD diagnosis statement. More conservatively only considering self-reported major depressive disorder diagnosis posts that do not also match BD patterns, results in 8.7% users reporting both diagnoses. major depressive disorder and psychotic disorder diagnoses jointly with BD might indicate subsequently changed (mis-)diagnoses or disagreement of professionals. Surveys in Germany (Pfennig *et al.*, 2011) and the US (Hirschfeld, Lewis and Vornik, 2003) have shown that often more than ten years pass between onset of BD symptoms and receiving the diagnosis, with two thirds of people being misdiagnosed, most frequently with major depressive disorder. Moreover, field trials for BD diagnoses with DSM-5 criteria only showed moderate clinician agreement (Freedman *et al.*, 2013).

Comorbidity rates for anxiety disorders, borderline personality disorder and post-traumatic stress disorder align with results from epidemiological studies. Rates for comorbid attention deficit hyperactivity disorder, obsessive-compulsive disorder, and eating disorder are lower in the Reddit dataset population, which might in part be due to incomplete coverage of the patterns to capture diagnosis self-reports. Additionally, epidemiological studies can be expected to yield higher comorbidity rates because they determine if participants meet criteria for various diagnoses with clinical interviews, whereas Reddit users may not have (or report) diagnoses for every condition they meet the criteria of. Overall, 50.7% of users reported at least one additional MH diagnosis, slightly less than three quarters of surveyed people in the World Mental Health Survey Initiative who met criteria for at least one other MH diagnosis besides BD (Merikangas *et al.*, 2011).

More than 2% of users reported an autism spectrum disorder diagnosis in addition to BD, with no epidemiological studies on autism spectrum disorder prevalence with BD yet. Dell'Osso et al. (2019) found significant levels of autistic traits among 43% of people with a BD diagnosis.

5.4.3.2 Age

As shown in Figure 10, less Reddit users with a self-reported BD diagnosis are 18-29 but more 30-49 years old compared to average US Reddit users (Barthel *et al.*, 2016, p. 7)[67]. The age of onset of BD symptoms is most frequently in late adolescence and early adulthood (Pini *et al.*, 2005; Merikangas *et al.*, 2011). In line with this, the majority of Reddit users who disclose a BD diagnosis are between 13-29 years old at their first post. In the Global Burden of Disease study 2013, BD 12-months prevalence rates were significantly elated for 20-54-year olds (Ferrari *et al.*, 2016,

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[66] The dataset includes users with self-reported major depressive disorder but not psychotic disorder because depression but not psychosis is a core aspect of extreme mood, our focus of future research.

[67] The Barthel et al. (2016) survey only targeted adults, therefore there are no 13-17-year-old users.

p. 447). In our dataset, almost 80% of the Reddit users are 18-49 years old at their first post.

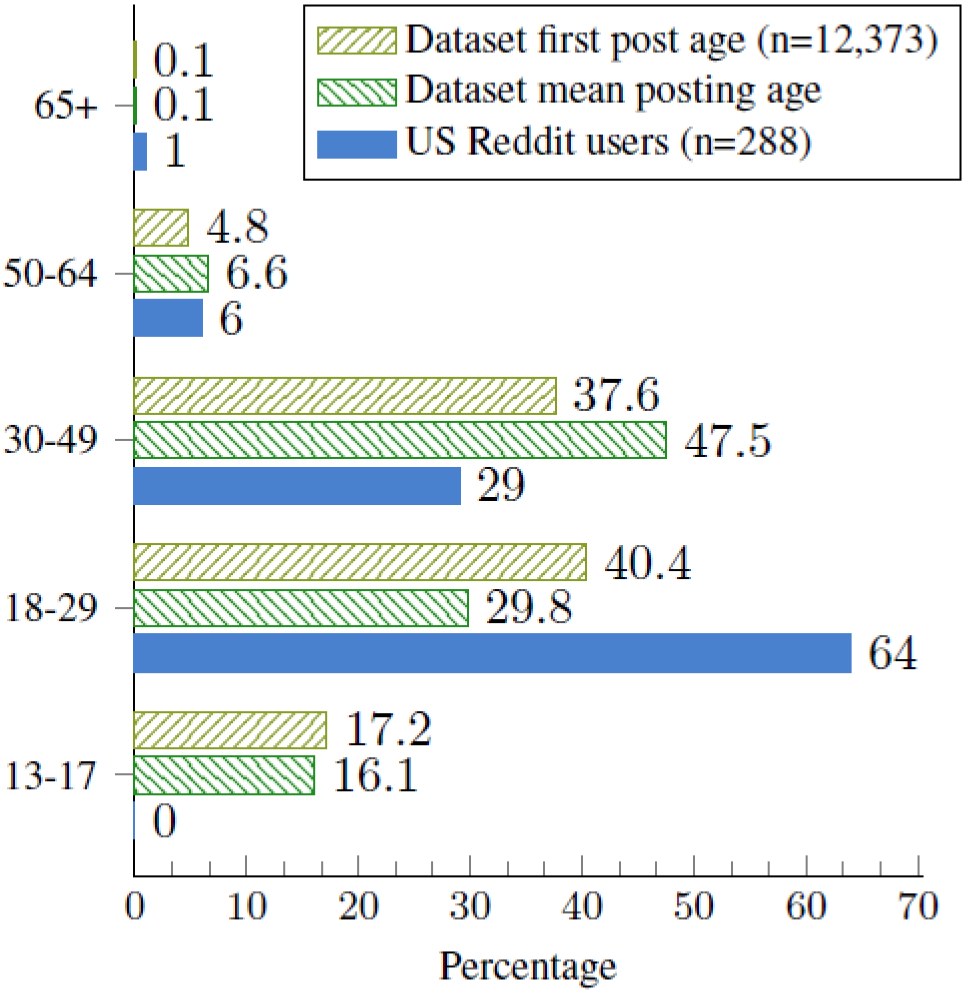

Figure 10 Age of Reddit users

5.4.3.3 Country of residence

As shown in Table 23, more than 80% of the Reddit users with a self-reported BD diagnosis are estimated to live in the US, and 95% in one of the English-speaking countries US, UK, Canada, Australia. This ranking aligns with site visitors of the Reddit desktop version (Statista.com, 2020), although US users are even more prevalent in the BD dataset. All of the top-5 countries in the dataset have a 12-months prevalence of BD diagnoses above the global average of 0.62% according to the 2017 Global Burden of Disease Study (Global Burden of Disease Collaborative Network, 2018).

Table 23 Top five estimated countries of residence of Reddit users with a self-reported BD diagnosis, location of reddit.com site visitors (Statista.com, 2020) and 12-months prevalence of BD (Global Burden of Disease Collaborative Network, 2018)

Country	Dataset	reddit.com traffic	12-months prevalence
US	81.9%	49.7%	0.7%
UK	5.6%	7.9%	1.1%
Canada	4.9%	7.9%	0.8%
Australia	1.7%	4.3%	1.2%
Germany	1.4%	3.2%	0.8%

5.4.3.4 Binary gender

Figure 11 shows that the Hybrid method assigned feminine gender to slightly more than half of the Reddit users for which it ascribed a gender identity. This sharply contrasts with only 9% feminine vs. 41% masculine gender-performing usernames among Reddit users who posted in the top 10K subreddits with most posts (Wang and Jurgens, 2018). A survey of adult US Reddit users (Barthel *et al.*, 2016) found that two thirds were men.

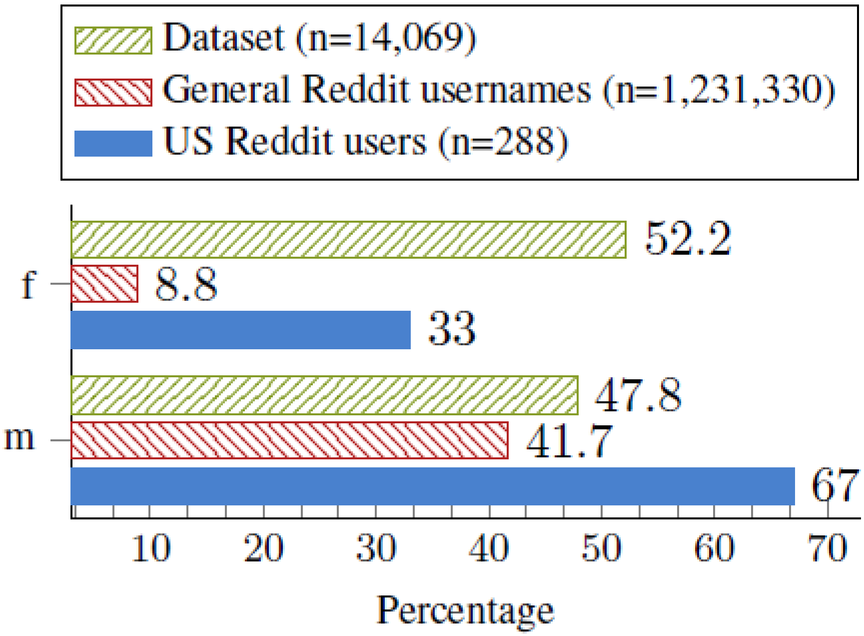

Figure 11 Binary gender of Reddit users (f: feminine, m: masculine)

In epidemiological studies, biological men and women are equally likely to meet criteria for BD overall (Pini *et al.*, 2005; American Psychiatric Association, 2013) although there is evidence that bipolar II disorder is more frequently diagnosed among women (Diflorio and Jones, 2010). Sajatovic et al. (2011) found that biological men with a BD diagnosis scored significantly lower on masculine gender identity than the general male population, while there were no gender identity differences for biological women. Considering a majority of male Reddit users and sex-equal prevalence of the diagnosis, feminine-gender-identifying people with a BD diagnosis seem to be more likely to use Reddit and/or to disclose their diagnosis. The increased rates of female-gender identifying Reddit users with a self-reported BD diagnosis might also point towards a higher relative frequency of bipolar II disorder diagnoses (compared to bipolar I disorder) in this population.

5.5 Limitations and implications

5.5.1 Limitations

First, unlike in clinical studies with face-to-face interactions, we cannot assume that every Reddit user in the dataset corresponds to one person. Additionally, self-reported diagnoses cannot be confirmed with diagnostic interviews as in clinical research.

Furthermore, there are several limitations to the NLP methods to infer user characteristics. The method to extract self-reported MH diagnoses does not distinguish between actual comorbidities and misdiagnoses or previous diagnoses, for which symptoms may have resolved. Manual evaluation of ten users with borderline personality disorder comorbidity showed that seven reported concurrent diagnoses, one a BD to borderline personality disorder change, one a borderline personality disorder misdiagnosis, and one referred to BD by 'BPD'. Harrigian's (2018) method indicates the predominantly reflected country in a user's most recent posts, disregarding relocations. The Self-reported age and gender extraction method is fallible to users providing incorrect information, for example disguising themselves as younger than they really are on dating subreddits.

Finally, none of the gender inference methods allow us to estimate how many users identify as transgender or non-binary. Such indications were also too diverse to be captured in the regular expressions for self-reported age and gender. Still, four of the subreddits with more than 10K posts by users with a self-reported BD diagnosis target transgender people, indicating that a proportion of the users in this research may not identify with their born sex.

5.5.2 Health research implications

Most importantly this work provides the first large-scale characterisation of Reddit users with a self-reported BD diagnosis, who are on average 27.7 years old at their first post, seem to overwhelmingly live in the US, and are more likely to identify with the feminine gender. Insofar they deviate from general Reddit as well as epidemiological statistics and also from participants in clinical studies.

A large meta-analysis of psychological interventions for BD (Oud *et al.*, 2016) showed that in 55 trials conducted across twelve countries (35% in the US) comprising 6,060 adults with BD, 89% had recruited participants with a mean age higher than the 30 year-average of adult Reddit users with a self-reported BD diagnosis. 67% of the trials recruited a higher percentage of females than the 52%

figure in the Reddit dataset (Oud *et al.*, 2016, Table DS2). This cautions against generalising findings from Reddit data to all people with a BD diagnosis but stresses its complementary role to clinical studies with different selection biases.

Another important implication is that NLP analysis of Reddit social media users largely confirmed high prevalence rates for comorbid MH conditions with BD from epidemiological studies. Besides clinically established comorbidities with, e.g., anxiety disorder and attention deficit hyperactivity disorder, the present analysis also revealed substantial prevalence of autism spectrum disorder, for which there is little clinical research to date. Reddit may constitute a useful platform to learn about the experiences of people with BD with such currently under-researched comorbidities and may be a way to target them for recruitment to clinical studies.

5.5.3 Natural language processing research implications

This work evaluated state-of-the-art methods to infer Reddit user characteristics (Harrigian, 2018; Wang and Jurgens, 2018; Tigunova *et al.*, 2019) and demonstrated their utility in applied research. A hybrid method achieved the best accuracy and coverage for age and gender identity by using high-accuracy information from self-reports (or a gender-performing username) when available, filling in information for more users with less accurate predictions from a neural network language use-based method (Tigunova *et al.*, 2019).

Importantly, gender-inference methods so far are limited to detecting binary gender, although, e.g., 0.4% of the US population identify as transgender (Meerwijk and Sevelius, 2017). Off-the-shelf NLP tools supporting a wider range of gender identities may be more inclusive and give more visibility to these groups of people in research. However, important ethical considerations arise around identifying people with transgender and non-binary gender identities, which are often stigmatised.

5.6 Conclusion

This paper set out to automatically profile Reddit users under consideration of ethical aspects. A combination of pattern-based and previously published NLP methods served to estimate clinical, demographic, and identity characteristics of nearly 20K Reddit users with a self-reported BD diagnosis. Half of the Reddit users disclosed MH diagnoses besides BD and 80% were located in the US. From the users for which age or gender could be estimated, 80% were between 18-49 years old and 52% performed or identified with feminine gender. These findings indicate about which populations BD-focused research on Reddit may generalise. Additionally, this work may serve as a model for how to provide more information on other specific Reddit populations as requested by recent transparency and accountability movements in NLP.

6 Posting patterns in peer online support forums and their associations with emotions and mood in bipolar disorder: exploratory analysis

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Abstract

Background: MH peer online forums offer robust support where internet access is common, but healthcare is not, e.g., in countries with under-resourced MH support, rural areas, and during pandemics. Despite their widespread use, little is known about who posts in such forums, and in what mood states. The discussion platform Reddit is ideally suited to study this as it hosts forums (subreddits) for MH and non-MH topics. In BD, where extreme mood states are core defining features, mood influences are particularly relevant.

Objectives: This exploratory study investigated posting patterns of Reddit users with a self-reported BD diagnosis and the associations between posting and

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[68] The authors would like to thank the people with lived experience of BD, who provided input to the design of this study and the results and their implications. We would also like to thank Enrica Troiano for insightful discussions on emotion text analysis. We are grateful to the UCREL research group at Lancaster University for multiple opportunities to discuss and present this work, with particular thanks to Andrew Moore and Daisy Harvey for helpful comments and Matthew Coole for testing the code release.

emotions, specifically: 1) What proportion of the identified users posts in MH versus non-MH subreddits? 2) What differences exist in the emotions that they express in MH or non-MH subreddit posts? 3) How does mood differ between those users who post in MH subreddits compared to those who only post in non-MH subreddits?

Methods: Reddit users were automatically identified via self-reported BD diagnosis statements and all their 2005-2019 posts were downloaded. First, the percentages of users who posted only in MH (non-MH) subreddits were calculated. Second, affective vocabulary use was compared in MH versus non-MH subreddits by measuring the frequency of words associated with positive emotions, anxiety, sadness, anger, and first-person singular pronouns via the LIWC text analysis tool. Third, a logistic regression distinguished users who did versus did not post in MH subreddits, using the same LIWC variables (measured from users' non-MH subreddit posts) as predictors, controlling for age, gender, active days, and mean posts/day.

Results: 1) Two thirds of the identified 19,685 users with a self-reported BD diagnosis posted in both MH and non-MH subreddits. 2) Users who posted in both MH and non-MH subreddits exhibited less positive emotion but more anxiety and sadness and used more first-person singular pronouns in their MH subreddit posts. 3) Feminine gender, higher positive emotion, anxiety, and sadness were significantly associated with posting in MH subreddits.

Conclusions: Many Reddit users who disclose a BD diagnosis use a single account to discuss MH and other concerns. Future work should determine whether users exhibit more anxiety and sadness in their MH subreddit posts because they more readily post in MH subreddits when experiencing lower mood or because they feel more able to express negative emotions in these spaces. MH forums may reflect the views of people who experience more extreme mood (outside of MH subreddits) compared to people who do not post in MH subreddits. These findings can be useful for MH professionals to discuss online forums with their clients. For example, they may caution them that forums may underrepresent people living well with BD.

Keywords: BD; peer online support forums; peer support; online forums; MH; emotions; mood

6.1 Introduction

Experiences of extreme high and low mood states that interfere with functioning, constitute core criteria for a BD diagnosis (American Psychiatric Association, 2013; World Health Organization, 2018). Prevalence rate estimates for bipolar spectrum disorders range from 0.1% (India), 2% (England), to 4.4% (US) across several European, American, and Asian countries (Pini et al., 2005; Merikangas et al., 2011; McManus et al., 2016). The characteristics and outcomes of people meeting BD criteria are diverse, with some functioning on a high level (Coryell *et al.*, 1998; Tohen *et al.*, 2003; Goldberg and Harrow, 2004; Akers *et al.*, 2019), achieving long-term remission (Goldberg, Garno and Harrow, 2005), and living well (Russell and Browne, 2005; Crowe and Inder, 2018; Warwick, Tai and Mansell, 2019). However, many individuals with a BD diagnosis experience recurring mood episodes (Treuer and Tohen, 2010; Gignac et al., 2015) and require life-long treatment (Goodwin et al., 2016). Moreover, BD has the highest rate of suicide across all MH diagnoses (Novick, Swartz and Frank, 2010; Goodwin *et al.*, 2016). Therefore, it is important to understand how people living with BD can best be supported to live well.

The internet, including social media and online support forums, plays an increasingly important role in sharing information and support for health and MH concerns (Sundar *et al.*, 2011; Bujnowska-Fedak, Waligóra and Mastalerz-Migas, 2019). Like the general population, most people with a (BD) diagnosis are internet users (Martini *et al.*, 2013; Bauer *et al.*, 2016) and seek information about BD online (Conell *et al.*, 2016). In 2014-15, 13%-17% of people with a BD, major depressive disorder, or psychotic disorder diagnosis reported posting and seeking information on their condition in online support forums or social media (Naslund, Aschbrenner and Bartels, 2016; Bauer *et al.*, 2017). Since then, the importance of online MH forums has likely increased. In 2019 the number of members in support forums for BD on the online discussion platform Reddit (bipolar, BipolarReddit, bipolar2, BipolarSOs) increased by more than 50%. In light of the global Covid-19 pandemic, where in-person care has become more difficult to access for many people, international BD experts have highlighted the importance of online MH support and the 'great need' to 'train and support clinicians to go where people are already online' (Stefana *et al.*, 2020).

There are a number of content analyses of BD online forums (Kramer, Fussell and Setlock, 2004; Vayreda and Antaki, 2009; Bauer *et al.*, 2013; Latalova *et al.*, 2014; Poole, Smith and Simpson, 2015; McDonald and Woodward-Kron, 2016; Campbell and Campbell, 2019), including Reddit forums (Sahota and Sankar, 2019). Jagfeld, Lobban, Rayson, et al. (2021) characterised the demographics (age, gender identity, country of origin, comorbidities) of Reddit users with a self-reported BD diagnosis. However, little is known about the users of online MH support forums and why some users chose to engage in them and others not. This knowledge is both relevant to improve online MH support forum design and to contextualise the increasing body of research relating to such forums.

The online discussion platform Reddit (reddit.com) is one of the most visited internet sites worldwide and hosts subforums (subreddits) for a variety of topics, ranging from general interests to specific topics, including MH (Alexa Internet, 2020). Researchers increasingly analyse Reddit data (Amaya *et al.*, 2019; Proferes *et al.*, 2021) and it is one of the main sources of data for research on BD with NLP methods (Harvey *et al.*, 2022). Because users may post in MH-focused as well as other subreddits, Reddit is uniquely useful to study who chooses to engage in online MH support forums (Ireland and Iserman, 2018). However, only Reddit users who post both in MH and non-MH subreddits can be considered for such within-person comparisons. Ireland and Iserman (2018) noted that only one-third of Reddit users who had posted at least 50 words in anxiety subreddits had also posted at least 50 words in other subreddits; no similar studies exist for other MH concerns. Therefore, the first RQ investigates what proportion of Reddit users with a self-reported BD diagnosis post in MH and non-MH focused subreddits using the same account. Research using NLP methods with online posts of people with a BD diagnosis has mainly focused on language differences between users with a BD and other or no MH diagnosis and used these to build machine-learning classifiers to identify social media users likely experiencing BD symptoms (Harvey *et al.*, 2022). While earlier studies compared all of users' content (Coppersmith, Dredze and Harman, 2014; Coppersmith *et al.*, 2015), more recent work excluded MH-related posts (Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018; Sekulić and Strube, 2019) aiming to build classification systems that could also detect users with MH issues who do not discuss MH concerns online. Yet, to date, only one study has investigated differences between posts in MH and non-MH contexts of the *same* users. Ireland and Iserman (2018) found that people used more anxious language in anxiety-focused subreddits compared to their posts in other subreddits. Such a comparison could provide insights into the extent to which findings from earlier studies that compared all of users' posts were due to language differences between people with MH and without MH issues or rather due to the different contexts of the posts in MH vs. non-MH subreddits that may impact on their emotional content. However, no comparable analyses exist for mood disorders or BD. Hence, the second RQ examines what differences exist in the emotions that Reddit users with a BD diagnosis express in MH and non-MH subreddit posts.

Extreme and changing mood states are the core defining features of BD (American Psychiatric Association, 2013; World Health Organization, 2018). Yet, very little research has been conducted so far on the relationship between mood and engaging with online MH forums for people with a BD diagnosis. Garnering data on peoples' emotions and mood is difficult. Surveys require people to fit their complex emotional experiences into rigid scales or describe them with a fixed set of preselected terms. Asking about past emotions and mood might suffer from recall bias (Thomas and Diener, 1990; Colombo *et al.*, 2020). In general, any kind of self-report method may be biased by social desirability (Tanaka-Matsumi and Kameoka, 1986; Barrett, 1996; Van de Mortel, 2008). Moreover, in online forums, users may not be active anymore and therefore cannot be invited to active study participation.

Computational text analysis approaches such as LIWC (Pennebaker *et al.*, 2015) can provide naturalistic behavioural indicators of emotions and mood that sidestep a lot of the problems with self-reported mood measures. LIWC provides indicators of peoples' affective and cognitive processes based on what percentage of the words in their language falls into categories such as positive emotion, sadness, and anxiety. A number of studies have applied LIWC to online posts of people with MH issues, including BD (Coppersmith, Dredze and Harman, 2014; Coppersmith *et al.*, 2015; Fineberg *et al.*, 2016; Park and Conway, 2017; Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018). Park and Conway (2017) provide evidence using LIWC that Reddit users' negative emotions decrease, and positive emotions increase with every post they make in a depression support subreddit. Text emotion analysis with machine learning methods (Silveira *et al.*, 2021) has shown that users' emotional tone improves during exchanges in four large MH subreddits for depression, suicidality, BD, and anxiety. As these are the only two studies looking at the relationship of emotions and mood and posting in online MH communities, the third

RQ addresses a critical gap in answering how mood differs between Reddit users with a BD diagnosis who post in MH subreddits and those who only post in non-MH subreddits.

6.1.1 Aim, research questions, and contributions

To summarise, this study aims to shed more light on the posting patterns in online support forums and their associations with the emotions and mood of people with a BD diagnosis. By applying psychological text analysis methods to the public online posts of a large sample of Reddit users with a self-reported BD diagnosis this exploratory study investigates the following RQs:

RQ 1: What proportion of Reddit users with a BD diagnosis posts in MH and non-MH subreddits?

RQ 2: What differences exist in the emotions that Reddit users with a BD diagnosis express in MH and non-MH subreddit posts?

RQ 3: How does mood differ between Reddit users with a BD diagnosis who post in MH subreddits and those who only post in non-MH subreddits?

This study makes the following contributions to MH research:

- Provides the first quantitative evidence on the posting behaviour of people with a BD diagnosis and how demographic and emotional factors may impact posting in MH forums specifically (see Figure 13 for a visual summary of the results)
- Demonstrates differences in the emotional content of MH vs non-MH subreddit posts
- Shows how to use established NLP methods to provide quantitative data and generate findings relevant for MH researchers and professionals
- Provides a large dataset of 21M Reddit posts by 20K Reddit users with a self-reported BD diagnosis that is available for future research

6.2 Methods

Reporting of this study follows the STROBE guidelines for cross-sectional studies (Von Elm *et al.*, 2007).

6.2.1 Reddit user identification and dataset construction

Reddit users who stated on the platform that they had received a BD diagnosis from a professional were automatically identified via self-reported diagnosis statements like ‘I was diagnosed with BD’ (see Jagfeld, Lobban, Rayson, *et al.*, 2021). All posts of candidate users (id, text, timestamp created at, subreddit) between 01/2005 (site inception) and 03/2019 (data available at time of data collection in 05/2019) were downloaded via the Reddit application programming interface *praw* (Boe, 2023). Candidate users were filtered by matching all of their posts against 74 exclusion patterns like 'not officially diagnosed' or 'self-diagnosed'. Also, users who reported a psychotic disorder diagnosis were removed, as this constitutes an exclusion criterion for BD according to DSM-5 (American Psychiatric Association, 2013). Users with other MH comorbidities, including depression, were retained. The final S-BiDD dataset comprises 21,407,595 posts (both submissions (thread starts) and comments) of 19,685 users with a self-reported BD diagnosis.

6.2.2 Mental health subreddit identification

To determine whether posts were posted in subreddits with a MH focus, subreddit-to-topic assignments were amended and extended from existing resources as there is no official subreddit topic taxonomy from Reddit (see Appendix F.1 for details). The final four-level taxonomy (Jagfeld, 2022c) comprises 30,867 topic-categorised subreddits, including 158 MH-related subreddits, of which 37 are BD-specific. Only 3.6% of the posts by people with a self-reported BD diagnosis are in a subreddit not assigned to a topic. See Table S12 for an overview of the top ten BD, MH (not BD-specific), and non-MH subreddits with most posts in the S-BiDD dataset.

6.2.3 Language analysis

LIWC (Pennebaker *et al.*, 2015) was used to obtain text-analytic measures of peoples' emotions and mood. In this study, users' emotions – usually short-lived (seconds (Ekman, 1992)), high in intensity and in response to the evaluation of a stimulus (Ekkekakis, 2013, p. 41) – are operationalised via the LIWC scores of single posts. Averaged LIWC scores of multiple posts over a longer timespan are assumed to represent users' mood, which is of longer duration, lower intensity and not in direct temporal relationship to a stimulus (Ekkekakis, 2013, pp. 44–45).

Recent NLP research focuses on emotion text analysis systems based on machine learning or deep learning methods (e.g., Köper, Kim and Klinger, 2017; Demszky *et al.*, 2020; Pérez, Giudici and Luque, 2021). Yet, LIWC was considered the most suitable emotion analysis tool for this study for four main reasons. First, this type of language analysis via expert-created dictionaries is rooted in over 100 years of empirical research in the behavioural sciences and there is a large evidence base for the psychometric validity of this approach (e.g., Tausczik and Pennebaker, 2010; Boyd and Pennebaker, 2017; Entwistle, Marceau and Boyd, 2022; Kennedy *et al.*, 2022; Pennebaker, 2022). Particularly for the LIWC emotion categories, Kahn et al. (2007) demonstrated that the scores for positive emotion, negative emotion and sadness significantly differ in the expected ways in peoples' responses to discrete stimuli. The participants had higher positive emotion and lower negative emotion and sadness scores when writing about an amusing versus sad life experience and describing their feelings after exposure to a funny versus sad video clip. Newell et al. (2018) showed that more negative emotion, less positive emotion, and a higher use of first-person singular pronouns correlates with peoples' subjectively reported stress level and their blood pressure. Moreover, LIWC emotion variables also correlate with established daily and seasonal mood fluctuations within individuals and for entire populations (Golder and Macy, 2011; Dzogang, Lansdall-Welfare and Cristianini, 2016; Dzogang, Lightman and Cristianini, 2018). In contrast to this, machine learning-based NLP methods require labelled training data and usually only perform well on data that is similar to the training data. While Google recently released an emotion-labelled dataset of Reddit posts (Demszky *et al.*, 2020), it is not specific to people with MH issues and therefore not suitable to train or fine-tune an emotion classifier for the aims of this study. Second, LIWC emerged from Pennebaker's work on narrative therapy (e.g., Pennebaker and Beall, 1986), which is widely recognised amongst clinicians, while most of them are not familiar with machine learning and deep learning approaches. Applied psycholinguistic research using LIWC is very active as evidenced by many studies published just in the past two years (O'Dea *et al.*, 2021; Andy, Sherman and Guntuku, 2022; Stone and Ryerson, 2022; e.g., Tay and Qiu, 2022). Third, LIWC yields results that are easy to interpret because they directly relate to the frequencies of words in the dictionaries. This is not the case for machine learning or deep learning systems whose predictions are often opaque and hard to trace back to the input (Canales and Martínez-Barco, 2014). Fourth, several previous studies have applied LIWC to online posts of people with MH issues, including BD (Coppersmith, Dredze and Harman, 2014; Coppersmith *et al.*, 2015; Fineberg *et al.*, 2016; De Choudhury *et al.*, 2017; Park and Conway, 2017; Cohan *et al.*, 2018; Ireland and Iserman, 2018; Sekulić, Gjurković and Šnajder, 2018), to the extent that most research on BD using NLP methods has used LIWC (Harvey *et al.*, 2022). This allows for a straightforward comparison of the present results with previous work in the discussion of RQ 2 and RQ 3.

Five LIWC categories were preselected for the analyses (see Table 24), including all affective processes subcategories (*positive emotion, anxiety, anger, sadness*). A number of previous studies used these categories to predict perceived emotions from text (see Park and Conway, 2017, p. 3). Additionally, the linguistic variable *1st pers. sg.*, measuring the frequency of first person singular pronouns, was included because previous research pervasively links it to mental distress (Tackman *et al.*, 2019a). Only posts with at least 25 words were included in the analyses because LIWC estimates for shorter texts are less reliable (Boyd, 2017, p. 71; Seraj, Blackburn and Pennebaker, 2021).

Table 24 LIWC variables related to emotions and mental distress selected for this study

LIWC variable	Example vocabulary (Pennebaker *et al.*, 2015, Table 1)
Affective processes	
Positive emotion (posemo)	love, nice, sweet
Negative emotion	
Anxiety	worried, fearful
Anger	hate, kill, annoyed
Sadness	crying, grief, sad

LIWC variable	**Example vocabulary (Pennebaker *et al.*, 2015, Table 1)**
Linguistic variables	
First person singular (1st pers. sg.)	I, me, mine

6.2.4 RQ 1: What proportion of Reddit users with a bipolar disorder diagnosis posts in mental health and non-mental health subreddits?

To address RQ 1, the percentages of users who posted only in MH subreddits, only in non-MH subreddits or in both were calculated. Previous work considered only Reddit users with at least four posts in MH subreddits as active contributors and those with fewer posts as *lurkers* (Park and Conway, 2017, p. 3). Therefore, the number of users with at least four posts in both MH and non-MH subreddits was also calculated, and, for comparison, the number of users with at least eight posts who posted only in MH or non-MH subreddits.

6.2.5 RQ 2: What differences exist in the emotions that Reddit users with a bipolar disorder diagnosis express in mental health and non-mental health subreddit posts?

To address RQ 2, the mean LIWC variable scores of the posts of users in MH subreddits were compared to the mean scores in non-MH subreddits via dependent t-tests. Only users with at least four posts with at least 25 words each in both MH and non-MH subreddits were included. Comparable studies of Reddit language using LIWC required at least four posts in depression subreddits (Park and Conway, 2017) or five posts overall (Seraj, Blackburn and Pennebaker, 2021).

6.2.6 RQ 3: How does mood differ between users who post in mental health subreddits and those who only post in non-mental health subreddits?

To address RQ 3, a logistic regression model was fitted via the R (R Core Team, 2022, Windows version 4.1.0) glm function to predict whether a user had posted in MH subreddits based on the mean LIWC variable scores of their non-MH subreddit posts and some control variables (see Appendix F.2 for method details). The outcome variable *posted in MH* was coded as 1 for users who had at least four posts in MH subreddits and at least four posts in non-MH subreddits with at least 25 words each (same users as in RQ 2), and 0 for users who had no posts in MH subreddits and at least eight posts with at least 25 words each in non-MH subreddits. Importantly, only non-MH subreddit posts were used to measure mood to provide a more comparable source of measures for users from both groups. LIWC emotion variables might be affected by the communicative context (Hunt and Brookes, 2020, pp. 20–25). By only including posts made in non-MH subreddit we avoid the problem of conflating mood and context.

The model also included the four control variables, age, gender, active days, and activity. *Age* was users' average age, considering all their posts in the S-BiDD dataset, as automatically inferred from their post texts via NLP models (see Jagfeld, Lobban, Rayson, *et al.*, 2021). There is some evidence for a decrease in perceived stigma, perceived discrimination, and stigmatising newspaper articles for MH issues in recent years (Goulden *et al.*, 2011; Corker *et al.*, 2013; Angermeyer *et al.*, 2014). Moreover, younger cohorts use social media differently than older adults. For example, 68% of 18-35 year old young adults with MH issues but only 54% of 36-65 year olds reported sharing personal experiences about MH issues as the main reason for their social media use (Naslund *et al.*, 2019). Therefore, it appeared relevant to check whether younger users would be more likely to post in MH subreddits. *Gender* corresponded to users' binary gender as automatically inferred from their gender identity via self-reported statements like '*I'm 34M*' or their performed gender from the username or post texts via NLP models (see Jagfeld, Lobban, Rayson, *et al.*, 2021) (0 = feminine, 1 = masculine). Gender was included as a control variable because previous research found men were less likely to disclose and seek support for MH issues than women (Addis and Mahalik, 2003; Wang *et al.*, 2007; Rosenfield and Mouzon, 2013; Brown, Sagar-Ouriaghli and Sullivan, 2019), although it is unknown how this plays out online. Finally, *active days* corresponded to the number of days between user's first and last post in the S-BiDD dataset and *activity* to the number of posts divided by *active days.* These two variables were included to check if users' overall activity on Reddit had an impact on their likelihood to post in MH support forums. For example, someone who is more active on Reddit generally and has been for a longer time may be more likely to have come across and post in a wider range of subreddits, including MH related ones.

6.2.7 Ethical considerations and transparency

The study is consistent with the Helsinki Declaration (World Medical Association, 2013), the ethics guidelines for internet-mediated research of the British Psychological Society (The British Psychological Society, 2021) and received approval from the Lancaster University Faculty of Health and Medicine research ethics committee. Current ethical guidelines permit the waiving of explicit consent of internet users if only public content is analysed without a threat to anonymity or confidentiality (e.g., The British Psychological Society, 2021, p. 9). In line with this, the present paper only shares aggregated results of anonymous Reddit users. See Jagfeld, Lobban, Rayson et al. (2021) for further ethical considerations in collecting the S-BiDD dataset. The purpose of this work is to better understand online users with a self-reported BD diagnosis and only comparisons within this group are conducted. Therefore, the methods and results presented here do not serve to identify online users with MH issues. People with lived experience of BD and using social media that were consulted did not raise any ethical concerns of this research (see Section 6.3.5).

The S-BiDD dataset is available for non-commercial research (Jagfeld, Lobban, Davies, *et al.*, 2022) upon request via rdm@lancaster.ac.uk and under a data usage agreement that specifies ethical usage as detailed in (Jagfeld, Lobban, Rayson, *et al.*, 2021). The code is publicly available (Jagfeld, 2022b).

6.2.8 Involvement of people with lived experience

In preparation for this study, four volunteers with lived experience of BD and using online support forums recruited via PeopleInResearch were invited to share their relevant experiences and comment on the research plan in individual online meetings which lasted 30-60 minutes. The volunteers had a positive attitude towards the study as they were generally not aware of other work analysing online forum posts of people with a BD diagnosis. They agreed that analysis of public online posts was justifiable if users' anonymity was safeguarded. Most of the volunteers reported that they were posting in MH support forums when in low (but not very low) mood. Moreover, they all gradually reduced their engagement with online forums once they were better able to manage their BD and found a job or other projects they engaged with which may have been accompanied with more positive mood. Since sadness and anxiety were found to constitute core symptoms of low mood (Fried *et al.*, 2016), this led to the following expectations: RQ 2: MH subreddit posts express more anxiety and sadness; RQ 3: Users who post in MH subreddits have higher long-term measurements of anxiety and sadness. After completion of the analyses, the volunteers were contacted again to provide feedback on our interpretations of the results in individual online meetings.

6.3 Results

6.3.1 RQ 1: What proportion of Reddit users with a bipolar disorder diagnosis posts in mental health and non-mental health subreddits?

Figure 12 shows that two thirds of the 19,685 identified Reddit users who disclosed a BD diagnosis posted in both MH and non-MH subreddits. One quarter never posted in MH subreddits and only 6.8% posted exclusively in MH subreddits. The majority (54.7%) of users in the S-BiDD dataset were active contributors in both MH and non-MH subreddits. Most users with less than eight posts posted in both MH and non-MH subreddits (14.6%) and equally likely posted only in MH/non-MH subreddits (5.1%/5.2%).

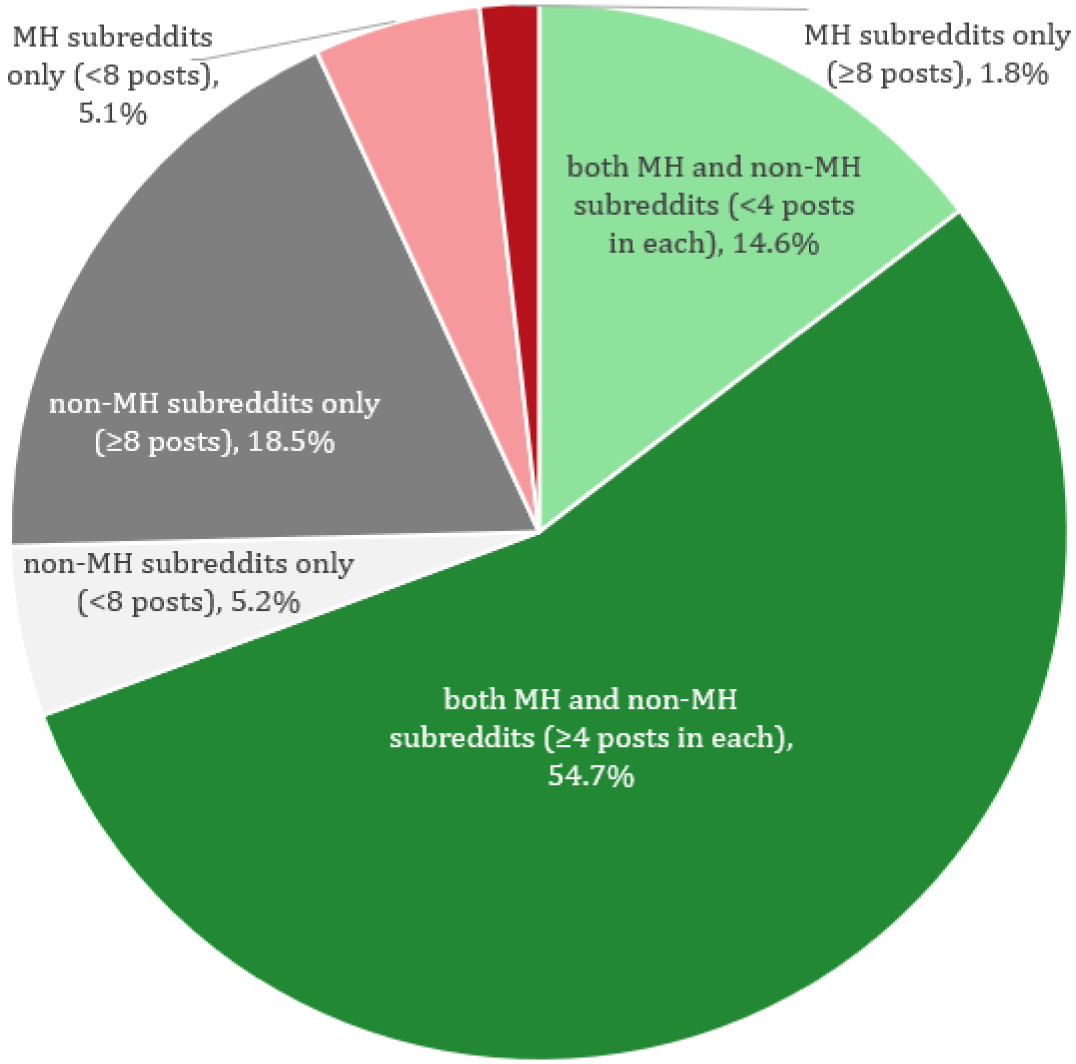

Figure 12 Reddit users with a self-reported BD diagnosis (n=19,685) according to the subreddit types in which they post

6.3.2 RQ 2: What differences exist in the emotions that Reddit users with a bipolar disorder diagnosis express in mental health and non-mental health subreddit posts?

N=9,821 users (49.9% of total) with 6,493,626 posts of at least 25 words (11.4% in MH subreddits) met the eligibility criteria set out in Section 6.2.5 as active contributors in both MH and non-MH subreddits with at least four posts in each. As Table 25 shows, there is a significant difference between users' posts in MH and non-MH subreddits for each preselected LIWC variable except anger. Users exhibited slightly less positive emotion in their MH subreddit posts but more anxiety and sadness, and they used much more first-person singular pronouns.

Table 25 Within user differences between MH and non-MH subreddit posts

	MH posts		Non-MH posts		Dependent t-test, *P* after Bonferroni correction for five comparisons		
	mean	std	mean	std	*P*	effect size (Cohen's d)	effect size interpretat.
positive emotion	3.48	1.08	3.64	0.93	<.001	-0.20	Small
anxiety	0.67	0.42	0.37	0.22	<.001	0.97	Large
anger	0.75	0.49	0.78	0.44	<.001	-0.07	Very small
sadness	0.81	0.44	0.45	0.24	<.001	1.11	Large
1st pers. sg.	8.82	2.28	6.39	1.96	<.001	1.63	Very large

6.3.3 RQ 3: How does mood differ between users who post in mental health subreddits and those who only post in non-mental health subreddits?

A total of n=13,190 users met the eligibility criteria set out in Section 6.2.6. However, the NLP methods could not assign age or gender for all users. Therefore, 10,158 users (51.6% of total) for whom all control variables were available were included in the regression model, of which 2,312 (22.8%) had only posted in non-MH subreddits. Table S13 provides descriptive statistics of the dependent variables. Logistic regression assumptions were checked according to Field, Miles and Field (2012) (see Appendix F.3 for details). As Table 26 shows, the regression model including the LIWC variables as predictors fit the data better than the model with the control variables only.

Table 26 Model fit comparison for controls only and controls with LIWC variables (N subjects = 10,309)

Model name	Nested / simpler Model	Predictors added	Model fit				LRT against nested	
			AIC	BIC	LL	df	df	X2
Controls	-	age, gender, active days, activity	10464	10500	-5227	10153		
Controls + LIWC	Controls	posemo, anxiety, anger, sadness, 1st pers. sg.	10403	10476	-5192	10148	5	70.12, *P* <.001

According to the regression results for the full model in Table 27, Reddit users with feminine gender are 33% more likely to post in MH subreddits compared to users with masculine gender (see Appendix F.4 for the calculation via the odds ratios of the coefficients). Moreover, higher levels of mean positive emotions, anxiety, and sadness were associated with increased odds to post in MH subreddits. Although the timespan for how long users were active on Reddit was a significant predictor, the coefficient was very small, thus practically negligible. Users' age, their average posts per day, anger, and 1st person singular pronoun use were not significantly related to whether someone posted in MH subreddits.

Table 27 Results for the glm regression model including controls and LIWC variables

Model Controls + LIWC	**Est/ Beta**	**SE**	**95% CI**	**z**	**P**	**Odds ratio (exp(coeff))**	
						Est/ Beta	**95% CI**
(Intercept)	0.56	0.17	0.22 – 0.90	3.21	0.001	1.75	1.24 – 2.47
age	<.001	<.001	-0.01 – <.001	-0.24	0.81	1.00	0.99 – 1.00
gender	-0.79	0.06	-0.90 – -0.68	-14.33	<.001	0.45	0.41 – 0.51
active days	<.001	<.001	<.001– <.001	11.18	<.001	1.00	1.00 – 1.00
activity	-0.01	0.01	-0.02 – 0.01	-1.17	0.24	0.99	0.98 – 1.01
posemo	0.05	0.01	0.03 – 0.08	4.94	<.001	1.06	1.03 – 1.08
anxiety	0.62	0.15	0.32 – 0.91	4.08	<.001	1.85	1.39 – 2.51
anger	-0.09	0.04	-0.17 – -0.01	-2.10	0.04	0.92	0.85 – 0.99
sadness	0.41	0.12	0.18 – 0.63	3.49	<.001	1.50	1.20 – 1.89
1st pers. sg.	0.02	0.02	-0.02 – 0.05	0.97	0.33	1.02	0.98 – 1.05
Model fit							
Pseudo R^2	Hosmer and Lemeshow			Cox and Snell			Nagelkerke
	0.047			0.049			0.075
Key: p-values for fixed effects calculated using Satterthwaite's approximations. Confidence Intervals have been calculated using the Wald method. Model equation: glm(*posted in MH* ~ age + gender + active days + activity + posemo + anxiety + anger + sadness + 1st pers. sg., family = binomial(link="logit"))							

6.3.4 Results summary

Figure 13 provides a visual summary of all results. Two thirds of the identified 19,685 users with a self-reported BD diagnosis posted in both MH and non-MH subreddits, while 24% never posted in MH subreddits. Users who posted in both MH and non-MH subreddits used more first-person singular pronouns and exhibited more sadness and anxiety, but less positive emotion in their MH subreddit posts. Feminine gender and expressing more anxiety, sadness, and positive emotion in non-MH subreddit posts were significant predictors for posting in MH subreddits.

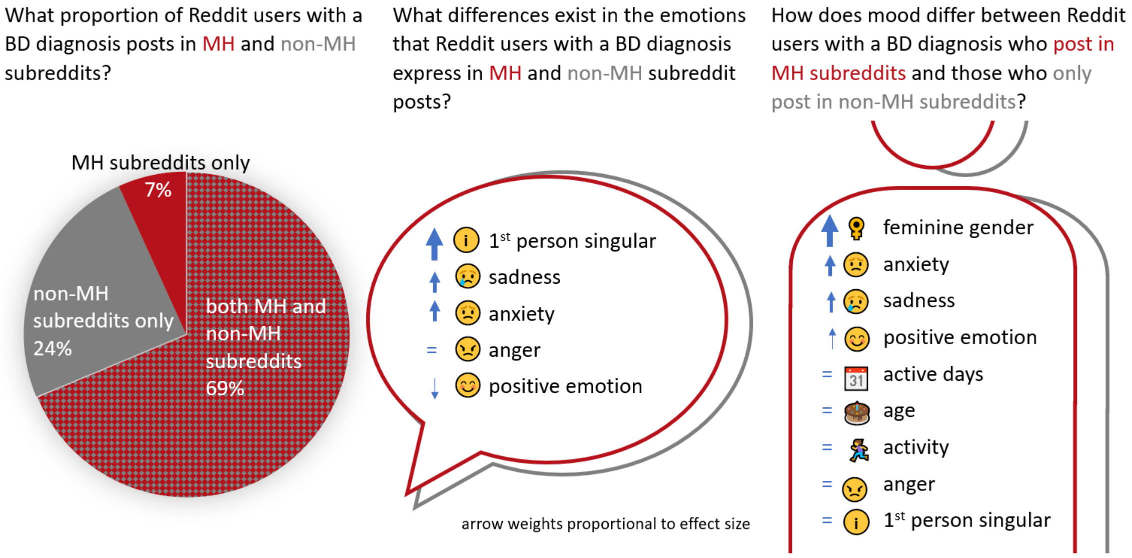

Figure 13 Visual summary of the results

6.3.5 Feedback from people with lived experience

Two of the four people with lived experience who commented on the study design agreed to provide feedback on the results. Overall, the results resonated with their experience of using online support forums, particularly the finding that people who experienced more anxiety and sadness were more likely to post in these forums. One of them shared that initially she had the expectation that online support forums would portray a holistic picture of living with BD. However, over time she noticed a strong focus on difficult experiences in the posts while users who posted that they were doing well got almost no reactions. Both volunteers agreed that it might be beneficial to encourage more discussions around living well with BD and aspects that can make life meaningful to balance out the strong focus on symptoms and diagnosis that they perceived in the forums. Neither of them reported concerns about potential for misuse of the research methods or misinterpretation of the results in a manner that could be harmful for people living with BD.

6.4 Discussion

6.4.1 Principal Results

By applying psychological text analysis to a large sample of Reddit users with a self-reported BD diagnosis, this exploratory study shed more light on the posting behaviour of these users and the associations between posting, emotions, and mood.

6.4.1.1 RQ1: What proportion of Reddit users with a BD diagnosis posts in mental health and non-mental health subreddits?

RQ 1 results showed that most (> 50%) Reddit users with a BD diagnosis frequently post both in MH and non-MH subreddits. This exceeds the one third of Reddit users who had posted at least 50 words in both anxiety and non-anxiety-related subreddits identified by Ireland and Iserman (2018).

A specific feature of Reddit are throwaway accounts. Since Reddit accounts only require a username for registration, users may create single-use online identities to discuss sensitive topics such as MH issues even more anonymously than via the main account through which they usually engage on the platform (De Choudhury and De, 2014). Separating an online identity from one's offline identity or a more holistic online identity (the main Reddit account) may be a main factor of online disinhibition (Lapidot-Lefler and Barak, 2012, 2015), causing people to act differently than in identifiable online settings (Chester and O'Hara, 2007). De Choudhury and De (2014) found that 4.5% of the 1,209 Reddit users who had posted in one of eight MH subreddits in their dataset used a throwaway account as identified by usernames matching *throw*; 61% of these user accounts had made exactly one post. Similarly, in the present study, 3.9% of users had made exactly one post. Moreover, user accounts with less than eight posts equally likely posted only in MH or non-MH subreddits. This suggests that single-use accounts are not necessarily favoured for posting about MH issues.

The fact that so few Reddit users with a self-reported BD diagnosis seem to make use of throwaway accounts and (by inference) to compartmentalise their Reddit identity into only MH vs. non-MH-related concerns is encouraging for further research on the S-BiDD dataset. While (Ireland and Iserman, 2018) considered users with anxiety concerns who post in both MH and non-MH subreddits to be atypical, this does not seem to be the case for users who disclose a BD diagnosis. The present findings imply that most user profiles with a self-disclosed BD diagnosis can be identified as users' main profiles: these profiles are associated with posts covering several aspects of their interests and concerns, which may more closely reflect them compared to throwaway accounts.

The RQ 1 findings also demonstrate that the eligibility criteria for the subsequent RQs that require users to have at least four posts in MH and non-MH subreddits are not too restrictive but capture more than half of the Reddit users who disclose a BD diagnosis.

6.4.1.2 RQ 2: What differences exist in the emotions that Reddit users with a BD diagnosis express in MH and non-MH subreddit posts?

The comparison between users' posts in MH and non-MH subreddit posts showed that, in MH subreddits, users expressed somewhat fewer positive emotions, more anxiety and sadness, and used much more first-person singular pronouns. These findings aligned with the expectations of people with lived experience that people may mainly post in MH support forums about MH struggles and when experiencing mental distress. They also aligned with the finding from Ireland and Iserman (2018) that people used more anxious language in anxiety-focused subreddits compared to their posts in other subreddits. Increased use of first person singular pronouns has been mainly linked to mental distress (Tackman *et al.*, 2019a), although positive I-talk may also occur (Tackman *et al.*, 2019a).

Overall, the findings demonstrate substantial differences in LIWC scores between posts in MH and non-MH contexts. Although this could be expected, this had not been empirically tested so far. This provides strong support for comparative language analyses and detection systems of people with and without MH issues to only consider posts in a comparable context as done in more recent research (Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018; Sekulić and Strube, 2019), compared to earlier work (Coppersmith, Dredze and Harman, 2014; Coppersmith *et al.*, 2015).

The results demonstrate a higher presence of negative emotions and self-focus in MH subreddit posts, which previous research links to rumination and low mood (Mor and Winquist, 2002; Brockmeyer *et al.*, 2015). However, this analysis cannot determine why these differences occur. Possible explanations that future research needs to test are that Reddit users in a lower mood state may be more likely to post in MH subreddits or that they may feel more comfortable expressing negative emotions there.

6.4.1.3 RQ 3: How does mood differ between users who post in mental health subreddits and those who only post in non-mental health subreddits?

Users who exhibited more anxiety and sadness in their non-MH subreddit posts, behaviours that constitute core symptoms of low mood (Fried *et al.*, 2016), were more likely to post in MH subreddits. This was expected by people with lived experience who reported that they mainly used online support forums when experiencing low mood. Interestingly, exhibiting more positive emotions also increased the odds of posting in MH subreddits, although the effect was an order of magnitude smaller than for anxiety and sadness. Taken together, these findings could indicate that users who experienced more extreme mood, hence stronger BD symptoms, are more likely to post in MH subreddits.

Another finding was that users with a feminine gender identity were 33% more likely to post in MH subreddits compared to users with a masculine gender identity. While biological men and women are equally likely to meet BD criteria (Pini *et al.*, 2005; American Psychiatric Association, 2013), Jagfeld et al. (2021) already established that slightly more than half of the Reddit users who self-report a BD diagnosis had a feminine gender, although two thirds of Reddit users in general are male (Barthel *et al.*, 2016). Of the users who never posted in MH subreddits, 60.5% had a masculine gender, while 59.2% of the users who posted in MH subreddits had a feminine gender. This proportion is in line with an average of 58% of women enrolled in 55 trials included in a large meta-analysis of psychological interventions for BD (Oud *et al.*, 2016, p. 215). Overall, the finding that users with a feminine gender identity are more likely to post in MH forums is in line with previous research that found men were less likely to disclose and seek support for MH issues (Addis and Mahalik, 2003; Wang *et al.*, 2007; Rosenfield and Mouzon, 2013).

Also using LIWC, De Choudhury et al. (2017) found that feminine-identified users who disclosed MH issues on Twitter exhibit more anxiety and sadness in their posts and less positive emotions compared to masculine-identified users who disclosed MH issues. This mirrors our findings on the differences between Reddit users who post or do not post in MH subreddits. To check whether our findings of mood differences between Reddit users who post versus do not post in MH subreddits could be attributed to the gender imbalance in the outcome groups, an additional regression model was evaluated with gender-balanced samples for both outcome groups. However, the results for the gender-balanced sample of 8,092 users did not change substantially compared to the original sample (see Appendix F.5).

6.4.2 Implications

The findings of this study have important implications for research and practice.

6.4.2.1 Implications for research

In general, a better understanding of people with a BD diagnosis who post on Reddit is important to contextualise other research on this kind of data, with Reddit being one of the most frequently used data sources for research on BD using NLP methods (Harvey *et al.*, 2022). More specifically, the findings for RQ 2 demonstrated substantial differences in LIWC scores between posts in MH and non-MH subreddits. Although expected, this had not been empirically tested so far. Providing quantitative evidence for this is important because what seems ‘common sense’ is actually only so when it has been empirically demonstrated (Furnham, 1983). The RQ 2 findings provide strong support for all studies relying on emotion text analysis, specifically comparative language analyses and detection systems of people with and without MH issues, to only consider posts in a comparable context as done in more recent research (Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018; Sekulić and Strube, 2019), compared to earlier work (Coppersmith, Dredze and Harman, 2014; Coppersmith *et al.*, 2015). For studies that consider recruiting participants from online support forums, it is relevant to know that mainly users who may experience stronger mood symptoms tend to be active there. There is also a higher proportion of feminine-identified users who post in these forums, which is similar to the proportion of women recruited into clinical trials. Relying only on online support forums for recruitment may thus introduce sampling biases.

6.4.2.2 Implications for practice

In general, this study provides information to MH professionals about online support forums for BD – something for which international BD experts highlighted a currently critical need (Stefana *et al.*, 2020). Since the analyses aggregated several thousands of Reddit users and found mostly small to medium effect sizes, the findings are relevant on the group level and do not permit conclusions for individual people. It may be helpful to inform people living with BD who (want to) use online support forums that people living well with MH issues might be underrepresented there and recommend additional information sources to obtain a more balanced picture of living with BD. Forum providers and moderators might consider encouraging more discussions around living well with BD to potentially balance some of the content exhibiting higher levels of anxiety and sadness. On the other hand, online support forums may be a useful outlet where people living with BD feel safe and welcome to express their more intense emotions, particularly anxiety and sadness. Spaces where people can express intense negative emotions are important because they counteract suppression and avoidance of such emotions. These are considered maladaptive emotion-regulation strategies and have been linked to depression and anxiety (Aldao, Nolen-Hoeksema and Schweizer, 2010).

6.4.3 Strengths, limitations, and future work

Three aspects of this study merit discussion because they present both strengths as well as limitations that could be addressed in future research. First, the automatic user identification via self-reported diagnosis statements resulted in a large sample of participants. Since the data collection did not require direct interaction with the social media users, there was no researcher influence on the behaviour of the participants. However, it was not possible to check the veracity of self-reported diagnoses, although it appears unlikely that people would deliberately unfaithfully identify with a stigmatised MH condition. Cluss et al. (1999) verified that 93% of 804 individuals who self-reported BD diagnosis met criteria for a lifetime BD diagnosis according to an in-person structured diagnostic interview. Nevertheless, future complementary research could conduct diagnostic interviews to determine the eligibility of participants, which would also allow inclusion of people who meet criteria for BD but have not received a diagnosis yet.

Second, the text analysis tool LIWC provided easily interpretable measures for in-the-moment emotion assessments, unbiased by self-report. Its wide use facilitated comparison with related work and its psychometric validity to measure emotions has been well established (Tausczik and Pennebaker, 2010). Still, future work could triangulate LIWC results with emotion text analysis systems trained via machine learning that may be more accurate in context but less interpretable than the dictionary-based LIWC tool (Canales and Martínez-Barco, 2014), as well as with self-reported mood and qualitative interviews.

Third, this study is the first to provide quantitative evidence of the relationship between mood and engaging with MH support forums for BD. Due to a lack of previous research, the study needed to be exploratory and future research should be carried out to confirm the findings and explore possible causal relationships between posting behaviour and mood. Future research should also explore whether the present findings are specific to BD or mood or MH issues more general.

This study considered data until March 2019. While online MH forum usage has likely increased since then, fuelled by the global Covid-19 pandemic (Sorkin *et al.*, 2021), there are no apparent reasons why the usage patterns found here would have changed. However, future research could replicate these analyses with more recent data and consider changes over time.

Future research could extend the present findings by looking at what effects engaging with online MH support forums has on users' mood as well as on person-centred holistic wellbeing in longitudinal studies. Recommendations for people living with BD for how to use social media and online support forums to achieve good long-term quality of life (Morton, Michalak and Murray, 2017) or PR (Jagfeld, Lobban, Marshall, *et al.*, 2021) was something that people with lived experience of BD considered as particularly helpful to develop. The ongoing Improving Peer Online Forums study, which aims to find out how online MH forums work, why some work better than others, and why some people find them helpful and others do not, may yield promising evidence for this (Lobban, Rayson and Coole, 2022).

6.5 Conclusions

This exploratory study was the first quantitative investigation to provide information on forum posting behaviour and its relationship with emotions and mood in Reddit users with a self-reported BD diagnosis. The study had three main findings: First, Reddit users with a self-reported BD diagnosis frequently post in both MH and non-MH subreddits. Second, for the same users, there are large differences in the expressed emotions in MH versus non-MH subreddit posts. Third, feminine gender, higher anxiety, sadness and positive emotions were associated with significantly increased odds that a Reddit user posted in MH subreddits. These findings have important implications for research on Reddit and online MH forums in general, as well as for the design of online MH forums, and for recommendations concerning their use to people living with BD.

7 How people with a bipolar disorder diagnosis talk about personal recovery in peer online support forums: corpus framework analysis using POETIC

Glorianna Jagfeld, Fiona Lobban, Chloe Humphreys, Paul Rayson, Steven H. Jones[69]

Abstract

Background: PR is of particular value in BD where symptoms often persist despite treatment. The authors previously defined a POETIC framework for PR in BD. So far, PR has only been studied in researcher-constructed environments (interviews, focus groups). Support forum posts can serve as a complementary naturalistic data resource to understand the lived experience of PR.

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[69] The authors wish to thank the volunteers with lived experience who provided helpful insights for conducting and writing up this research. GJ is grateful to Enrica Troiano for insightful discussions on designing and evaluating the coding for PR relevance. She would also like to thank Gavin Brookes and the participants of the 6th Corpora & Discourse International Conference for helpful comments on the corpus construction and analysis. Thank you also to Matthew Coole for testing the code release.

Objective: This study aimed to answer the question ‘What can online support forum posts reveal about the processes and experience of PR in BD in relation to the POETIC framework?’.

Methods: By integrating health research, NLP, and corpus linguistic methods, this study analysed public BD support forum posts relevant to the lived experience of PR. Comparing 4.5K PR-relevant posts by 2K users to 25K non-PR-relevant posts identified 130 significantly overused key lemmas. Key lemmas were manually coded according to the POETIC framework.

Results: PR-related discussions primarily focussed on three domains: Purpose and meaning (particularly reproductive decisions, work), Connectedness (romantic relationships, social support), Empowerment (self-management, personal responsibility). The study confirmed the validity of the POETIC framework to capture PR experiences shared online and highlighted new aspects beyond previous studies using interviews and focus groups.

Conclusions: This study is the first to analyse naturalistic data on PR in BD. Indicating the key areas that people focus on in PR when posting freely and the language they use, provides helpful starting points for formal and informal carers to understand the concerns of people diagnosed with BD and to consider how best to offer support.

Keywords: BD; PR; peer online support forums; NLP; corpus linguistics; social media

Highlights

- First study of peer online support forum posts on PR experiences
- Online posts reveal novel insights about PR in BD
- Key concerns: relationships, self-management, reproductive decisions, (hypo-)mania
- Data analysis validates the POETIC framework for PR in BD
- Insights highlight key issues in formal and informal support for BD

7.1 Introduction

BD is a severe MH problem characterised by recurring episodes of depressed and elevated mood (Jones, Lobban and Cook, 2010). Its lifetime prevalence ranges from 0.1% to 2.6% internationally (Rowland and Marwaha, 2018, p. 258). BD is associated with lower quality of life (Michalak, Yatham and Lam, 2005) and high suicide risk (Novick, Swartz and Frank, 2010). Therefore, fostering recovery and living well with BD are important societal tasks.

MH care agendas increasingly focus on enhancing PR, defined as ‘a way of living a satisfying, hopeful and contributing life even with the limitations caused by the illness' (Anthony, 1993). This contrasts with a previously narrower focus on reducing symptoms (clinical recovery). PR might be of particular value in BD (Murray *et al.*, 2017) where symptoms often persist despite treatment but has been under-researched to date (Van Weeghel *et al.*, 2019). Jagfeld, Lobban, Marshall, *et al.* (2021) (hereafter POETIC review (Chapter 4)) recently synthesised twelve qualitative studies to develop the first conceptual framework for PR in BD. POETIC, based on the CHIME framework (Leamy *et al.*, 2011), comprises the processes Purpose and meaning, Optimism and hope, Empowerment, Tensions, Identity, and Connectedness (see Table 28).

Table 28 First-level domains (boldfaced) and second-level categories in the POETIC framework (Jagfeld, Lobban, Marshall, et al., 2021)

POETIC: Lived experience of PR in BD					
P	**Purpose & meaning**	Meaning of mental illness experiences	Paid or voluntary work	Quality of life	Meaningful life and social roles
O	**Optimism & hope**	Belief in possibility of recovery	Positive thinking and valuing success	Hope-inspiring relationships	Having dreams & aspirations
E	**Empower-ment**	Self-management & personal responsibility	Controversial role of medication	Control over life	
T	**Tensions**	Balancing acceptance with ambitions	Openness enables support, but also stigmatisation	Ambivalence around (hypo-)mania	
I	**Identity**	Rebuilding positive sense of self	Over-coming stigma	Dimensions of identity	
C	**Connected-ness**	Support from others	Relationships	Peer support and support groups	Being part of the community

Current research on PR in BD has several limitations. First, it is mainly based on qualitative studies with few participants (Stuart, Tansey and Quayle, 2017) and expert opinions, lacking quantitative evidence from larger samples (Slade *et al.*, 2012). Second, data collection is limited to structured settings (semi-structured interviews, focus groups, structured measures), which are not naturalistic and subject to either interviewer bias (Briggs, 1986) or constrained responses in structured measures. Third, recruitment is biased towards people who want to talk about PR and are in contact with services or researchers (Jagfeld, Lobban, Marshall, *et al.*, 2021).

Naturalistic data collection , where 'participants are not aware that they are being studied' (Fielding *et al.*, 2016), overcomes many of these limitations. Online forum posts are a source of naturalistic data, which can offer potential insights into 'an experience as it is lived rather than as it is enacted in the researcher constructed environment' (Seale *et al.*, 2010, p. 600). Some NLP studies have analysed large numbers of BD online forum posts via automatic quantitative methods like content analysis (Kramer, Fussell and Setlock, 2004) or emotion analysis (Coppersmith *et al.*, 2015; Gkotsis, Oellrich, *et al.*, 2016) to identify forum topics or language differences between people with different or no MH diagnoses. Qualitative studies have applied conversation analysis (Vayreda and Antaki, 2009), thematic analysis (Mandla, Billings and Moncrieff, 2017), grounded theory (Sahota and Sankar, 2019), and content analysis (Bauer *et al.*, 2013) to BD online forum posts. Such studies offer rich nuanced accounts of online discussions on BD but include only few, often hand-picked posts.

Corpus linguistics (McEnery and Hardie, 2011) provides a mix of qualitative and quantitative methods informed by linguistic theory for analysing large amounts of text data with depth and richness that can overcome some of the shortcomings of previous NLP and qualitative studies. Semino and colleagues (2017) analysed interviews and online forum posts of cancer patients and their carers to learn about their lived experience and the metaphors they use for dealing with cancer. Hunt and Brookes (2020) applied a combination of corpus linguistics and discourse analysis (Baker, 2006) to MH forum posts. Two corpus-linguistic studies have focused on BD specifically: Abdo, Ali and Sarhan (2019) studied linguistic types of judgments, and McDonald and Woodward-Kron (2016) forum users' roles and identities.

A systematic review strongly recommended considering online content from individuals with lived experience in PR research (Stuart, Tansey and Quayle, 2017), which has not yet been done. Therefore, the main aim of this paper is to gain further insights into the experience of PR in BD from online forum posts via a combination of NLP, corpus linguistics, and qualitative health research methods. Furthermore, the POETIC framework, synthesised from data collected via interviews or focus groups, has not been applied to new data yet. Hence, the secondary aim of this paper is to validate the framework by exploring to what extent it captures experiences shared online. The RQ covering both aims is 'What can online support forum posts reveal about the processes and experience of PR in BD in relation to the POETIC framework?'.

7.2 Methods

7.2.1 Data

This study analysed posts from the international online discussion platform Reddit (reddit.com), which hosts subforums (subreddits) for various topics, including BD. Several reasons motivated the choice of this site: Reddit is one of the most visited internet sites worldwide with an international user base (Alexa

Internet, 2020); in contrast to other online support communities, everyone can read all public posts without a user account; and Reddit allows data analysis by third parties.

Reddit users with a self-reported BD diagnosis were automatically identified by matching phrases like 'I was diagnosed with bipolar' in all posts between January 2005 (Reddit inception) and March 2019 (see Jagfeld, Lobban, Rayson et al. (2021)). All posts of identified users form the S-BiDD dataset. Naturalistic data collection required subsequent filtering for content relevant for PR in BD as an exploratory study revealed S-BiDD dataset posts covered many other topics (see Appendix G.1). Figure 14 displays a flow chart for construction of the PR-BD Corpus. In linguistics, a corpus is a sampled collection of texts representing a particular language variety (McEnery, Xiao and Tono, 2006, p. 5). The basis for the corpus was only posts in BD subreddits (Jagfeld, 2022c, fourth level = 'bipolar') because a second exploratory study found references to 'recovery' and associated word forms in relation to BD occurred almost exclusively in BD subreddits (see Appendix G.2). Furthermore, only posts mentioning BD (Jagfeld, 2021b) were selected because only two thirds of MH-related 'recovery' mentions in BD subreddits referred to BD.

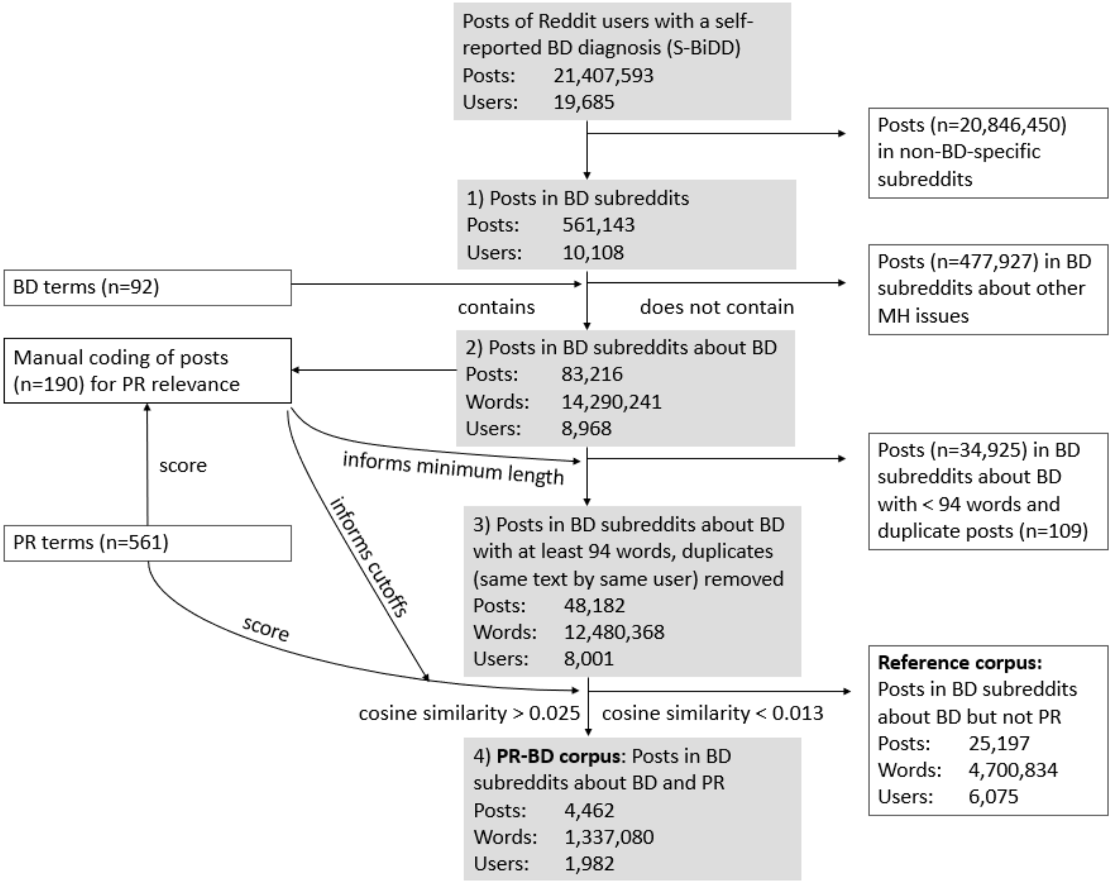

Figure 14 Flowchart of the four steps to create the PR-BD corpus and Reference corpus

To select PR-relevant posts a list of PR terms (comprising both single words and multiword phrases) (n=562) (Jagfeld, Lobban, Humphreys, *et al.*, 2022) was compiled using corpus linguistic methods (see Appendix G.4). BD subreddit posts that mentioned BD were ranked according to their similarity with the PR terms list via tf-idf weighted cosine similarity, a standard information retrieval approach (Spärck Jones, 1972; Robertson, 2004) (see Appendix G.5). To determine the cosine similarity cutoff, GJ manually coded whether 90 posts[70] pertained to PR in BD using a preliminary codebook based on the second exploratory study and the POETIC codebook. SHJ audited the coding. Following this, a minimum length of 94 words was set as five posts shorter than this lacked context to decide on their PR relevance (Figure S7). The codebook was refined to its final version in Appendix G.6. GJ and CH blindly coded 120 additional posts, again randomly sampled from each quantile of the cosine scores.

7.2.2 Ethical considerations, involvement of people with lived experience, and reflexivity

The Lancaster University Faculty of Health and Medicine research ethics committee approved this research in May 2019 (reference: FHMREC18066), which follows ethics guidelines for internet-mediated research (The British Psychological Society, 2021, p. 9). It was infeasible to seek individual informed consent from the large number of included forum users, but quotes were paraphrased to protect users' anonymity (see Appendix G.7). We recognise that some people may object to the use of online posts as research data without individual consent (e.g., Morant *et al.*, 2021). Users generally post to share information or seek support, and do not directly provide their content for research. However, we believe that on balance the benefits of this research to better understand PR makes it worthwhile, whilst acknowledging these potential objections.

Five volunteers with lived experience of BD and using online forums recruited via PeopleInResearch provided input on the study design, results, and subsequent plans in individual online meetings. Importantly, all volunteers were very supportive of the project, and none raised ethical concerns. After study completion, the volunteers were reinvited to provide feedback on our interpretations of the results.

Reflexivity is important to highlight how subjectivity may have impacted on research findings (Finlay and Gough, 2008). The research team embraces a PR approach in BD. GJ, FL, and SHJ previously developed the POETIC framework for PR in BD. They anticipated that it would capture many aspects shared online, but that data analysis would reveal new aspects and deeper insights into the experience of PR in everyday life.

7.2.3 Corpus framework analysis

Data was analysed via corpus framework analysis, a novel approach based on methods from corpus linguistics (McEnery and Hardie, 2011), and qualitative

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[70] ten randomly sampled posts from every 10% quantile of the cosine similarity scores, taking only ten posts from the first two quantiles which all scored zero

framework analysis (Pope, Ziebland and Mays, 2000). Quantitative corpus linguistics methods derive frequency lists of the words in the corpus, identify key words that occur statistically significantly more frequently in the corpus compared to other language samples, and find collocations, i.e., words a target word co-occurs with more frequently than by chance. The main qualitative method is to analyse the context of specific words or phrases in so called concordances. Key lemmas[71] in the PR-BD Corpus were identified by comparing it to a Reference corpus of posts with low similarity to the PR terms list via #LancsBox 6.0 (Brezina, Platt and McEnery, 2021). To focus on the most salient topics of the PR-BD Corpus, key lemmas overused at least twice at a significance level of $P<.0001$ (Rayson, Berridge and Francis, 2004) and used by at least 5% of users were analysed. See Appendix G.8 for methodological details.

The key lemmas were coded into the POETIC framework via concordance analysis. First, overall impressions of all concordances were noted after sorting them according to the lemma, left, and right context (20 words each) in #LancsBox. Subsequently, 30 randomly sampled concordances for each key lemma were manually coded into the second level POETIC categories (Jagfeld, Lobban, Marshall, *et al.*, 2021, codebook in Tables S3 and Table S4). The coders read the full post if the 40 words were not enough context and noted impressions for every key lemma again. Finally, concordances that did not fit into existing POETIC categories were coded inductively. GJ coded all key lemmas, SHJ and FL audited six key lemmas each.

Finally, new key lemmas (not in the PR terms list) and absent PR terms (Duguid and Partington, 2018) were analysed. Absence was defined as zero frequency in the PR-BD Corpus or a lower relative frequency than in the Reference Corpus. Also, collocations[72] of some key lemmas were analysed via the #LancsBox GraphColl tool.

7.3 Results

The S-BiDD Dataset (Jagfeld, Jones, *et al.*, 2022) contains 21,407,595 posts by 19,685 users (available for non-commercial research after signing a data usage agreement). The programming code is publicly available (Jagfeld, 2022a).

7.3.1 Coding the personal recovery relevance of posts and constructing the PR-BD Corpus

Following a blind trial of coding the PR relevance of 20 posts and a subsequent discussion, GJ and CH achieved moderate agreement (Cohen's kappa (k) = 0.51, 77% observed agreement) in coding the remaining 100 posts (see Table S36). The team resolved all disagreements. In total, 31.4% of the posts were coded as PR-relevant (see Table S37). Based on this, the PR-BD Corpus comprises posts with a PR score above 0.025 to balance precision in selecting PR-relevant posts and corpus

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[71] the dictionary form of a word, e.g., recovering and recovered are wordforms of the lemma recover

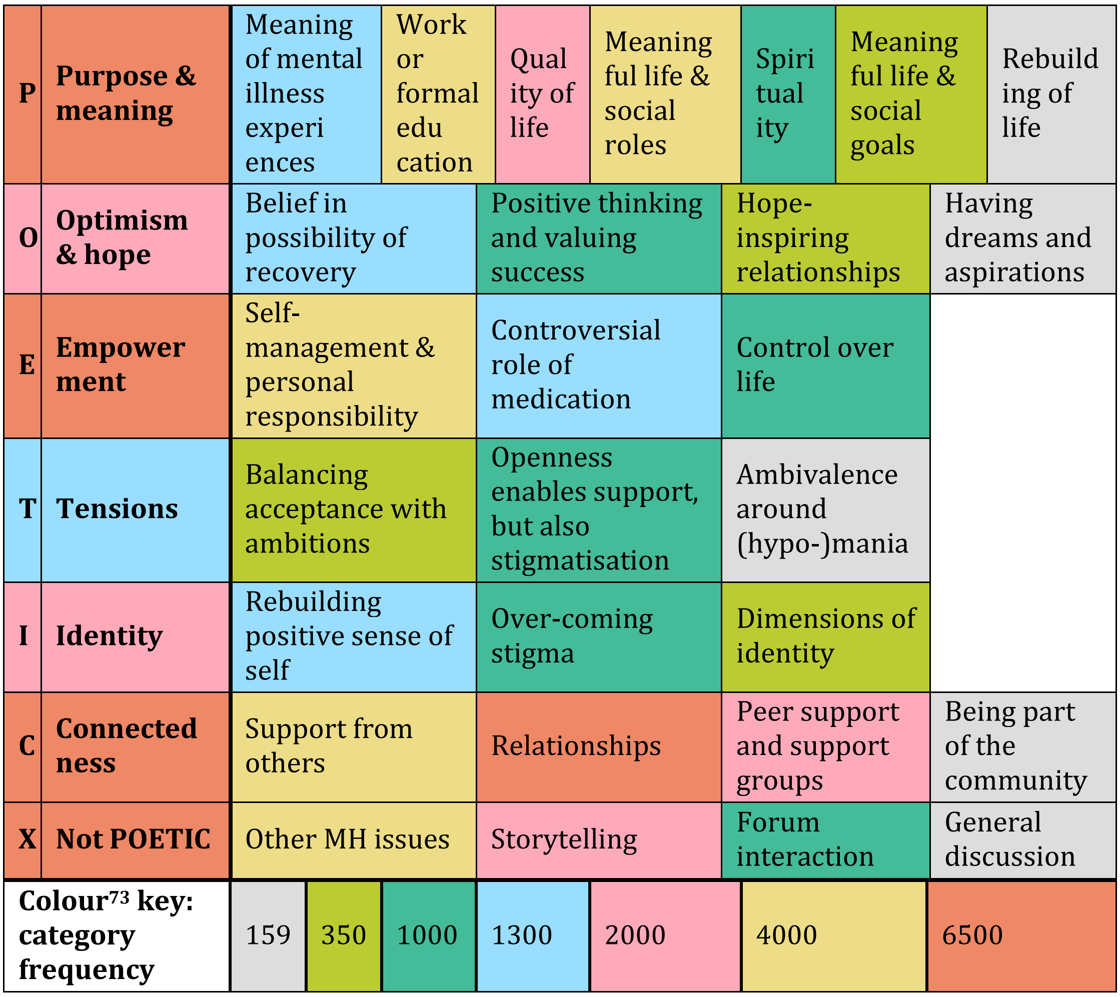
[72] Content words (noun, verb, adjective, adverb) within a context of five words left and right of the target term, minimum collocation frequency of five, ranked by MI^3 (Hunt and Brookes, 2020)

size (see Table S38). The PR-BD Corpus has 4,462 posts with 1,337,080 words by 1,982 users. The Reference Corpus of posts with a PR score below 0.013 (see Table S39), comprises 25,197 posts with 4,700,834 words by 6,075 users.

7.3.2 Concordance analysis with the POETIC framework

In total, 130 lemmas met the pre-specified keyness criteria. Table 29 shows the domain and category frequencies, extrapolated from the 30 coded concordance lines for each key lemma. Table S40 lists the key lemmas coded into each category and Table S41 the categories each key lemma was coded into. Overall, POETIC captured the experiences in the PR-BD Corpus very well: There was evidence for all categories. Only 8% of instances were coded into the new Not POETIC domain rather than the existing framework. The text below reviews each domain with key lemmas in italics, highlighting differences between the original framework and the online data. Table S42 and Table S43 provide illustrative quotes for all categories.

Table 29 Frequency of POETIC domains and categories and new categories



P	**Purpose & meaning**	Meaning of mental illness experiences	Work or formal education	Quality of life	Meaningful life & social roles	Spirituality	Meaningful life & social goals	Rebuilding of life
O	**Optimism & hope**	Belief in possibility of recovery	Positive thinking and valuing success	Hope-inspiring relationships	Having dreams and aspirations			
E	**Empowerment**	Self-management & personal responsibility	Controversial role of medication	Control over life				
T	**Tensions**	Balancing acceptance with ambitions	Openness enables support, but also stigmatisation	Ambivalence around (hypo-)mania				
I	**Identity**	Rebuilding positive sense of self	Over-coming stigma	Dimensions of identity				
C	**Connectedness**	Support from others	Relationships	Peer support and support groups	Being part of the community			
X	**Not POETIC**	Other MH issues	Storytelling	Forum interaction	General discussion			
Colour[73] key: category frequency		159	350	1000	1300	2000	4000	6500

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[73] The colours from Tol's (2021) *Light* qualitative scheme are accessible for colour-blind readers.

7.3.2.1 Purpose and meaning

Purpose and meaning was the most frequent domain and contained the most salient topic differences between the POETIC review and online data. While participants in the POETIC review mainly discussed the meaningful life and social role of being a *parent*, online discussions focused on reproductive decisions. Participants discussed perceived *risks* they might be *responsible* for, e.g., the *possibility* for their *child* to *develop* MH issues, that affected their *decision* or *choice* to *bear* and *raise kids*. In the Work category, extended to include formal education, many discussions focused on *struggles* around *studying* and *graduating college.* No participant in the POETIC review reported financial or housing issues, whereas several online users complained about a low *quality* of *life* due to *money* problems, causing homelessness or inability to afford treatment. Spirituality was discussed more frequently and richer than in the POETIC review. Users often wondered whether to regard their experiences as truly spiritual or rather as (hypo-)manic symptoms.

7.3.2.2 Optimism and hope

Reddit users differed in their Belief in the possibility of *recovery*. The mainstream opinion on Reddit was that BD is a ‘chronic condition that cannot be *cured*, only *managed*’. Users questioned whether feeling fully *recovered* was not just a temporary experience caused by (hypo-)mania. In the *Positive* thinking and valuing *success* category many users were *grateful* for aspects of their BD experiences, e.g., *challenges* providing *opportunities* for *growth* and demonstrating *strength.*

7.3.2.3 Empowerment

As in the POETIC review, Self-management and personal *responsibility* was the most frequent and richest category. Forum users generally considered (taking *steps* towards) *maintaining* a *healthy lifestyle* (including *routines* or *schedules, diet, exercise, coping skills*) as individual *responsibility* to reach *recovery*. In contrast, experiencing MH symptoms or feeling stuck in their recovery was regarded outside of someone’s responsibility if they followed professional or mainstream forum advice. The Controversial role of medication category included concerns about drug effects on the *baby* during pregnancy or nursing and alternative not evidence-based treatments such as the keto *diet* or cannabis, which lacked in the POETIC review.

7.3.2.4 Tensions

Experiences coded in the Tensions domain were similar to the POETIC review. Several participants shared feeling more comfortable to discuss Ambivalence around (hypo-)mania online. Some asked if there was a *possibility* to *enjoy* increased *motivation* and *confidence* to make *progress* in their goals without the hypomania getting out of control.

7.3.2.5 Identity

Some participants shared rich *success* stories in the Rebuilding positive sense of self category, in which they moved away from *shame* and *guilt* by *forgiving* themselves for past behaviours and towards *accepting* themselves, while others were struggling with this process. *Shame* associated with *stigma* in the *society* was another focus of discussions and some participants shared creative ways for Overcoming stigma.

7.3.2.6 Connectedness

Regarding Connectedness, users mainly discussed Relationships and *Support* from others. While there were positive accounts, participants often discussed *struggles* with romantic *relationships* or *marriage*, and *friendships* and complained about issues with *professional* and *family support,* similar to the POETIC review. However, the online accounts, particularly of relationship and family problems, appeared more candid, e.g., also discussing *sexual* issues, *trauma,* and *shame*.

7.3.2.7 Not POETIC

Inductive coding of the 8% of quotes that did not fit into POETIC revealed they were unrelated to individuals' PR and/or lived experience. Most quotes discussed other MH issues without PR relevance (symptoms, genetics and heredity, treatment, diagnosis, societal issues, scientific research), followed by storytelling of their own or others' situation without PR relevance, direct interactions between forum users, e.g., giving advice or congratulating, and discussions of non-MH issues.

7.3.2.8 New PR terms

While 99 of 130 key lemmas were PR terms, 31 key lemmas were new. Of these, 15 conveyed similar meanings to PR terms, e.g., *brother* likened other family members in the PR terms list such as son, nephew. Seven new key lemmas introduced aspects not covered by PR terms, e.g., *baby, raise, bear* related to reproductive decision making, *childhood* to making sense of MH issues via early traumatic experiences, and *environment* to a focus on structural and societal circumstances rather than the individual (see Table S44).

7.3.2.9 Absent PR terms

Only 13% of 416 unique PR terms (after removing spelling and phraseological variants) were absent: 46 did not appear in the PR-BD Corpus; eight were underused compared to the Reference Corpus. The underused PR terms referred to symptoms (*high mood, mania, manic, sleep*) or medical MH professionals (*doctor, pdoc, psychiatrist*) (see Table S45). These terms are relevant for some PR domains but also strongly associated with clinical recovery. All PR terms missing in the PR-BD Corpus were also missing in the Reference Corpus. They were mostly complex phrases, e.g., *brush yourself off*, and none indicated aspects that were not covered by other key lemmas (see Table S46).

7.3.3 Feedback from people with lived experience

Two volunteers who had commented on the first exploratory study provided feedback on the main study results. Overall, they valued the results and agreed with our findings, but indicated limitations of the data, reflected in the discussion (Section 7.4). One volunteer argued that categorisations of experiences can be problematic for masking individual differences. Conversely, the other volunteer had found it particularly helpful to align some of her behaviours with CHIME categories because this gave her a sense of being on the right track.

7.4 Discussion

This study analysed Reddit posts of people with a BD diagnosis via corpus framework analysis to learn about the lived experience of PR in BD and validate the POETIC framework.

7.4.1 Key findings in relationship to previous work

The primary study aim was to provide new insights on PR in BD. Indeed, the online data contained candid in-the-moment experiences that traditional qualitative data collection is unlikely to retrieve. For example, one user posted about their experiences in a current manic episode on two subsequent days: 'Yesterday I posted here about the realization that I've entered a manic episode'. Other users shared things online that they had not shared elsewhere: 'Talking about this part of my inner world to a psychiatrist would require a lot of trust for me*'.* The users had different interpretations of elated mood as signs of recovery, spiritual experiences, helpful motivational boosts, or dangerous MH symptoms to avoid. Quantitative (De Choudhury and De, 2014; Pavalanathan and De Choudhury, 2015) and qualitative (Wright, 2016, p. 69; Smith-Merry *et al.*, 2019) evidence shows that online anonymity affords personal self-disclosures and discussions of sensitive and stigmatised issues.

The results show that three POETIC domains featured most in Reddit discussions: Purpose and meaning (particularly reproductive decision making, work and formal education), Connectedness (romantic relationships and social support), and Empowerment (self-management and personal responsibility). In line with a recent quantitative review (Akers *et al.*, 2019), the concerns raised on Reddit pointed to a wide range of social and occupational functioning among people with a BD diagnosis: some were not working or not leaving their house and therefore seeking support online while others asked for specific advice to further improve their already functional lifestyle. The popularity of the Self-management and personal responsibility category agrees with recent quantitative findings. A review by Mezes et al. (2022) found positive associations between PR and psychological characteristics focusing on control and personal agency and a longitudinal study identified positive impacts of adaptive coping and balanced risk-taking on PR (Mezes *et al.*, 2021).

Importantly, the analysis highlighted PR issues that exclusively or more frequently came up online. This might be due to differences in sample demographics and data collection methods between the present study and those included in the POETIC review. Users in the S-BiDD dataset were younger than in the studies included in the

POETIC review[74]. This might explain why transitioning into adulthood with BD, challenges of college education, and reproductive decision making exclusively surfaced in the online data. Sahota & Sankar (2019) summarise their qualitative analysis of discussions of genetic risk and reproductive decision making in two BD subreddits as centring around the manageability of parenting a child for people with a BD diagnosis, which aligns well with the experiences found in the present study.

Moreover, users in the S-BiDD dataset were overwhelmingly from the US (Jagfeld, Lobban, Rayson, *et al.*, 2021, p. 8), while all POETIC review studies stemmed from countries that provide at least a basic level of free public mental healthcare and social security (UK, Norway, Australia, Canada, China, Spain, Turkey). This may explain why existential financial issues such as (threat of) homelessness and the inability to afford treatment surfaced only in the online data. Since health insurance in the US (except for Medicare for 65+ years old) is either employer-provided or privately paid, individuals who cannot work due to their MH issues lose their insurance and in turn access to professional support, often causing MH issues to exacerbate, e.g., by abruptly stopping medication. One Reddit user described this as a ‘vicious cycle’. It also appears plausible that Reddit users stem from a different socioeconomic group than the participants recruited into the POETIC review studies.

The secondary aim of the study was to validate the POETIC framework. Results confirmed that the framework usefully captured PR experiences shared online. Online users discussed all second level POETIC categories and only 8% of the analysed data could not be accommodated in the framework, demonstrating its comprehensiveness.

7.4.2 Strengths and limitations

Three aspects of this study constitute both strengths and limitations. First, online forums as data source provided rich and candid in-the moment experiences. However, there is limited background and demographic information on the online forum users (but see Jagfeld, Lobban, Rayson, *et al.*, 2021) and they are not representative of the general population with a BD diagnosis. One user in the PR-BD Corpus posted ‘My hunch is that r/bipolarreddit overrepresents those who are struggling, who, understandably, may be more pessimistic about everything’. One volunteer shared his experience that discussions on Reddit MH forums mainly followed a mainstream opinion and deviant opinions were ignored or suppressed. McDonald and Woodward-Kron (2016) support this with corpus linguistic evidence that BD forum users over time shifted from advice-seeking to -giving and used more medicalised language. Similarly, Vayreda and Antaki (2009) showed that established BD forum users urged new members to seek a formal diagnosis and reinforced a biomedical view of BD. Our Reddit study provides one lens on the lived

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[74] Mean age 32 vs. 45 years, 30% vs. 17% of participants between 18-29 years, 7% vs. 34% 50-64 years (Jagfeld, Lobban, Marshall, *et al.*, 2021, p. 377; Jagfeld, Lobban, Rayson, *et al.*, 2021, Figure 1).

experience of some people that can complement studies of other MH forums and other sources, such as one-on-one interviews.

Second, the list of PR terms facilitated focusing on the concept of interest among the wealth of data, yet it arguably biased the data selection. Nevertheless, half of the key lemmas that were not PR terms contributed new PR aspects. Moreover, explicitly stating our expectations of PR aspects via the terms list enabled identification of absent aspects in the data.

Third, corpus linguistic methods, particularly the coding of key lemmas, allowed analysis of more data than traditional qualitative methods. However, single words probably more readily capture topic-like (e.g., Relationships) rather than theme-like (e.g., Balancing acceptance with ambitions) categories. Therefore, the relative category frequencies should be interpreted with some caution.

7.4.3 Research implications

This study has at least four research implications. Firstly, it demonstrates the usefulness of analysing online forum posts to tap into authentic and candid accounts of lived experiences of MH issues. Secondly, this study served as first validation of the POETIC framework. Ideally, this encourages other researchers to apply it in their research. Thirdly, the combination of corpus linguistics and qualitative framework analysis allowed analysis of large amounts of data. Hence, corpus framework analysis may also be useful for future studies of text data, such as therapy transcripts (e.g., Tay and Qiu, 2022). Lastly, the S-BiDD dataset and derived corpora are available for future research, e.g., on other aspects of the lived experience of BD.

7.4.4 Clinical implications

This study identifies the key issues relevant to PR in BD shared by people with lived experience online and extends previous knowledge from interviews and focus groups. These findings, including the quotes in Table S42 and Table S43, are a rich resource for understanding more about the experience of PR in BD for individuals living with BD, their loved ones and informal carers, and MH professionals. This is also relevant for recent initiatives to educate MH professionals on the lived experience of severe MH issues such as the current Understanding psychosis and BD training for the UK National Health Service (Health Education England, 2020). Subsequently, issues identified in this study may provide helpful starting points for therapists to collaboratively consider them with their clients, e.g., in recovery-focused therapy (Jones *et al.*, 2015; Tyler *et al.*, 2022).

Individuals discussed issues online that they considered contentious and personal and were not comfortable sharing offline, such as sexuality, spirituality, and (hypo-)mania. Recovery-focused therapies that are free to work with whatever model the clients bring for their BD experiences (Jones *et al.*, 2015) may be particularly suitable to create a therapeutic environment where clients feel comfortable to discuss such sensitive issues. Moreover, Jones et al. (2021) showed that recovery-focused therapy reduces the positive self-appraisal of hypomanic experiences.

Reproductive decision making surfaced as a major issue for young adults living with BD and dedicated counselling on this topic may be advisable. While understanding genetic vulnerability and risk data in MH is challenging, there is evidence that genetic counselling can offer effective support (Hippman *et al.*, 2016).

7.4.5 Conclusions

This study analysed 4.5K Reddit posts by 2K people with a self-reported BD diagnosis within the POETIC framework (Jagfeld, Lobban, Marshall, *et al.*, 2021) for PR in BD. It is the first to analyse online forum data on PR. The study confirmed the validity of the POETIC framework to also capture PR experiences shared online and highlighted new aspects in PR that did not come up in previous studies using interviews and focus groups. It also demonstrated the utility of integrating corpus linguistics and qualitative framework analysis to identify key themes within large text datasets. Indicating the key areas that people focus on when posting freely, provides rich insights into the lived experience of PR in BD for formal and informal carers of people with a BD diagnosis.

8 Discussion

The final chapter first summarises the contributions of this thesis in Section 8.1 and then draws meta conclusions by synthesising the findings of the four studies in Section 8.2. Following this, it critically reflects on the strengths and limitations of the research and identifies opportunities for future work in Section 8.3. Subsequently, Section 8.4 offers personal reflections on the project as a whole and the research process. The thesis closes with a brief conclusion in Section 8.5.

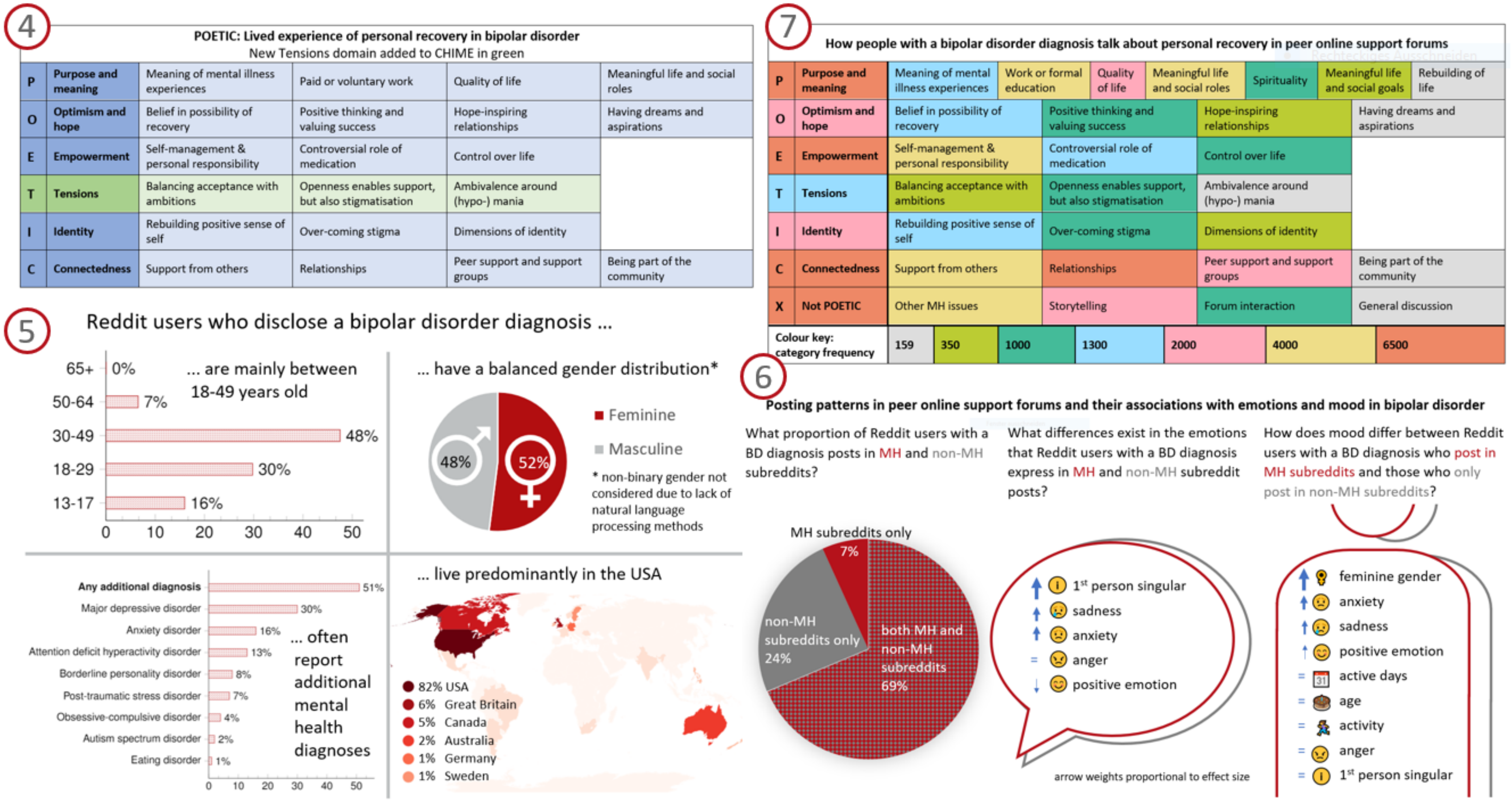
8.1 Review of the thesis rationale and key findings

The aim of this thesis was to **study PR experiences that people living with BD have shared in online support forums through integrating health research, NLP, and corpus linguistics in a mixed-methods approach within a pragmatic research paradigm, while considering ethical issues and involving people with lived experience.**

The research design ensured consideration of ethical issues and involvement of people with lived experience of BD throughout the project. The four empirical studies generated new knowledge on PR in BD and demographic and mood characteristics of Reddit users with a self-reported BD diagnosis. Table 30 recalls the RQs of the four empirical studies and introduces short forms by which the remainder of this chapter refers to them. Figure 15 shows the graphical summaries of the findings of the four studies.

Table 30 Overview of the empirical studies and RQs in this thesis

Chapter, short form	Study title	RQs
4, POETIC review	Personal recovery in bipolar disorder: Systematic review and “best fit" framework synthesis of qualitative evidence – a POETIC adaptation of CHIME	1) What do we know about the experience of PR of individuals diagnosed with BD from qualitative evidence?
5, Reddit user characteristics study	Understanding who uses Reddit: Profiling individuals with a self-reported bipolar disorder diagnosis	2a) What characteristics of Reddit users who disclose a BD diagnosis can be automatically inferred from their public Reddit information and how do they compare to general Reddit users and clinical populations? 2b) What are the ethical considerations around determining users’ characteristics and ways to minimise potential negative impacts?
6, Reddit mood and posting behaviour study	Posting patterns in peer online support forums and their associations with emotions and mood in bipolar disorder: exploratory analysis	3a) What proportion of Reddit users with a BD diagnosis posts in MH and non-MH subreddits? 3b) What differences exist in the emotions that Reddit users with a BD diagnosis express in MH and non-MH subreddit posts? 3c) How does mood differ between Reddit users with a BD diagnosis who post in MH subreddits and those who only post in non-MH subreddits?
7, POETIC on Reddit study	How people with a bipolar disorder diagnosis talk about personal recovery in peer online support forums: corpus framework analysis using POETIC	4) What can online support forum posts reveal about the processes and experience of PR in BD in relation to the POETIC framework? Preceded by two exploratory RQs: 4a) What are the main topics that people with a self-reported BD diagnosis talk about in BD online support forums? 4b) With what meanings do Reddit users with a self-reported BD diagnosis use *recover* terms (i.e., recovery, (to) recover, recoverable)?



POETIC: Lived experience of personal recovery in bipolar disorder
New Tensions domain added to CHIME in green

P	**Purpose and meaning**	Meaning of mental illness experiences	Paid or voluntary work	Quality of life	Meaningful life and social roles
O	**Optimism and hope**	Belief in possibility of recovery	Positive thinking and valuing success	Hope-inspiring relationships	Having dreams and aspirations
E	**Empowerment**	Self-management & personal responsibility	Controversial role of medication	Control over life	
T	**Tensions**	Balancing acceptance with ambitions	Openness enables support, but also stigmatisation	Ambivalence around (hypo-) mania	
I	**Identity**	Rebuilding positive sense of self	Over-coming stigma	Dimensions of identity	
C	**Connectedness**	Support from others	Relationships	Peer support and support groups	Being part of the community

How people with a bipolar disorder diagnosis talk about personal recovery in peer online support forums

P	**Purpose and meaning**	Meaning of mental illness experiences	Work or formal education	Quality of life	Meaningful life and social roles	Spirituality	Meaningful life and social goals	Rebuilding of life	
O	**Optimism and hope**	Belief in possibility of recovery	Positive thinking and valuing success	Hope-inspiring relationships	Having dreams and aspirations				
E	**Empowerment**	Self-management & personal responsibility	Controversial role of medication	Control over life					
T	**Tensions**	Balancing acceptance with ambitions	Openness enables support, but also stigmatisation	Ambivalence around (hypo-) mania					
I	**Identity**	Rebuilding positive sense of self	Over-coming stigma	Dimensions of identity					
C	**Connectedness**	Support from others	Relationships	Peer support and support groups	Being part of the community				
X	**Not POETIC**	Other MH issues	Storytelling	Forum interaction	General discussion				
Colour key: category frequency		159	350	1000	1300	2000	4000	6500	

Figure 15 Overview of the key findings of the four empirical studies: POETIC review (Chapter 4), Reddit user characteristics study (Chapter 5), Reddit mood and posting behaviour study (Chapter 6), POETIC on Reddit study (Chapter 7)

8.2 Integration of findings

This section connects the findings of the individual studies to synthesise the main contributions and implications of this project for theory, research, and practice.

8.2.1 Contributions

This thesis made the following six main methodological and substantive contributions to health research, NLP, and corpus linguistics:

- The POETIC framework comprehensively captures the experience of PR in BD shared by people with lived experience both in previous research using interviews and focus groups as well as in online support forums. (POETIC review (Chapter 4), POETIC on Reddit study (Chapter 7))
- Peer online support forum posts revealed candid in-the-moment accounts of the lived experience of PR in BD that are unlikely to be retrieved via more traditional qualitative data collection methods. (POETIC on Reddit study (Chapter 7))
- Corpus framework analysis constitutes a methodological innovation, integrating corpus linguistics methods and qualitative framework analysis, that is useful to analyse large amounts of text data. (POETIC on Reddit study (Chapter 7))
- Consideration of ethical issues and involvement of people with lived experience throughout demonstrated how a PhD project can address these aspects within its time and resource limits. This is particularly novel for NLP and corpus linguistic research. (POETIC review (Chapter 4), Reddit user characteristics study (Chapter 5), Reddit mood and posting behaviour study (Chapter 6), POETIC on Reddit study (Chapter 7))
- Application of existing NLP tools provided the first information on the characteristics of a large sample of Reddit users who self-report a BD diagnosis. They are 52% feminine- and 48% masculine-gendered mainly young or middle-aged US-based adults who often report additional MH difficulties. (Reddit user characteristics study (Chapter 5))
- An exploratory study provided the first quantitative evidence on the online posting behaviour of people with a BD diagnosis as an important starting point for future research. It indicated a possible negativity bias of MH subreddit posts of users with a self-reported BD diagnosis. Posts in MH subreddits express more negative emotions than posts in other subreddits and users who experience more extreme mood are more likely to post in MH subreddits. (Reddit mood and posting behaviour study (Chapter 6))

8.2.2 Implications for theory

This thesis has several implications for theoretical models of PR and BD.

8.2.2.1 Presenting the first conceptual framework for PR specific to BD

POETIC as the first conceptual framework for PR specific to BD constitutes an important theoretical contribution of this thesis. It fills the gap in the PR literature that previously lacked a systematic description of the experience of PR in BD (Slade *et al.*, 2014; Van Weeghel *et al.*, 2019). The rigorous literature search for the POETIC review (Chapter 4) discovered an earlier systematic review of qualitative evidence on PR in BD by Lapsley et al. (2013), which PR research had not taken up since only one other publication besides the POETIC review cites this review to date[75]. In contrast, the POETIC review has already been cited twelve times since its publication in May 2021[76].

Part of the appeal of the POETIC framework may lie in its compact form and that it is based on the very well-known CHIME framework for PR in severe MH issues (Leamy *et al.*, 2011). The POETIC review demonstrated that PR in BD entails the same main processes as in other severe MH issues captured by CHIME (Section 0). But it also revealed 'a greater emphasis on self- management, medication, and socially meaningful roles such as work and parenting' (Jagfeld, Lobban, Marshall, *et al.*, 2021, p. 381), which the POETIC on Reddit study confirmed (Section 7.3.2). The POETIC review identified *Tensions* as a new PR domain that may be unique or at least particularly relevant in BD compared to other severe MH issues (Section 4.4.3). This entails negotiating tensions between PR domains (Balancing acceptance with ambitions and Openness enables support, but also stigmatisation) and Ambivalence around (hypo-)mania (Section 4.3.3.4). While the POETIC on Reddit study supports the existence of these tensions, the Tensions domain was less frequent than the other POETIC domains (Table 29). However, rather than deemphasising the importance of this domain, this may be an artefact of the corpus framework analysis approach. As Section 7.4.2 in the POETIC on Reddit study discusses, the keyword approach may have foregrounded more topic-like categories that single words more easily capture over the more complex theme-like categories in the Tensions domain that require more context. Importantly, the POETIC review revealed that all PR domains involved difficulties and losses, which the CHIME framework underemphasised (Section 4.4.2) (see also Stuart, Tansey and Quayle, 2017). This motivated the choice of POETIC, rather than the unconditionally harmonious CHIME, as new acronym to summarise the nuanced experience of PR in BD (see Jagfeld, Lobban, Marshall, *et al.*, 2021, p. 381).

8.2.2.2 Addressing limitations of previous PR research

This thesis also offers theoretical implications for the four main points of criticism of the concept of PR discussed in Section 1.3.5. First, PR had often been criticised as hard to grasp, vague concept (e.g., Bird *et al.*, 2014; McCabe *et al.*, 2018). Explicitly stating the PR definition underlying the thesis in Section 1.3.1, was a first step to address this issue. The POETIC review contributed to the concretisation of

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[75] https://scholar.google.com/scholar?cites=6924022199551753029&as_sdt=2005&sciodt=0,5&hl=de, last accessed on 13 May 2023

[76] https://scholar.google.com/scholar?cites=15293233126160308478&as_sdt=2005&sciodt=0,5&hl=de, last accessed on 13 May 2023

what PR means in BD with the comprehensive and compact POETIC framework (Figure 9). The POETIC on Reddit study provided further concrete operationalisations of PR in three ways: in the detailed coding guidelines to determine (1) the meaning of a *recover* term in context (Appendix G.3) (2) whether an online post is relevant for PR (Appendix G.6) and (3) in the automatic scoring of the PR relevance of online posts via a list of 562 PR terms (Section 7.2.3). While this thesis does not claim that these operationalisations are the only possible ways to define PR, stating them so explicitly allows for targeted, precise critique. All these resources are available for further work to use and adapt.

Secondly, the PR concept originates largely from ideas of white, Western researchers (Deegan, 1988) and is based on research conducted in wealthy, anglophone Western countries, lacking a wider cultural basis (Slade *et al.*, 2014, p. 17; Tse *et al.*, 2019). While this thesis hoped to gain perspectives from a more diverse range of individuals by collecting data from a large, international online forum, the Reddit user characteristics study (Section 5.4.3) revealed that most of the users lived in wealthy, anglophone, Western countries (see Section 8.3.2.2 below). Future research should address this by looking at online forums with a larger non-Western user base, such as Talklife[77], an international peer support forum for youth MH. Some previous research has explored cultural differences between Western (mainly American, British, Canadian) and non-Western (mainly Indian), users of this platform (Pendse, Niederhoffer and Sharma, 2019; Pruksachatkun, Pendse and Sharma, 2019), but not with a focus on BD or PR. The Recovery in the Bin collective pillories that the focus on Western views gave PR a neo-capitalistic spin to unduly focus on individual responsibility (Recovery in the Bin *et al.*, 2019). Nevertheless, the POETIC on Reddit study revealed some discussions of societal and systemic issues impacting on individuals' ability to experience PR around the term *environment* (Section 7.3.2.8).

Thirdly, by explicitly focusing on the lived experience of people with a BD diagnosis, this thesis filled a gap in PR research that had previously mostly focused on psychosis (Slade *et al.*, 2014; Van Weeghel *et al.*, 2019). Fourthly, the PR concept entails encouragement for positive risk-taking, which may pose problems for Western MH systems with legal responsibilities to prevent their clients from harming themselves or others (Slade, 2009; Holley, Chambers and Gillard, 2016). Self-management and personal responsibility in the Empowerment domain surfaced as one of the most frequently discussed POETIC categories both in the POETIC review (Section 4.3.3.3) and the POETIC on Reddit study (Section 7.3.2.3). Along with a recent longitudinal study from another PhD project (Mezes et al., 2021), this provides further evidence that positive risk-taking may be an important PR process that MH services should encourage and support.

8.2.2.3 Informing models of BD

Section 1.2.3 introduced the multifactorial bio-psycho-social model (Goodwin and Jamison, 2007) based on the diathesis (vulnerability)-stress model (Nuechterlein

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[77] https://www.talklife.com/

and Dawson, 1984; Lam, Jones and Hayward, 2010) that most Western health systems and research use to explain BD symptoms. Van Os et al. (2019) criticise the bio-psycho-social model as a mechanistic model of MH symptoms that ignores the spiritual or existential dimension, which is central in many peoples' lives. Both the POETIC review (Chapter 4) and the POETIC on Reddit study (Chapter 7). revealed how many people attributed spiritual or existential meanings to their MH experiences, particularly in the domains of Purpose & Meaning (Meaning of MH experiences, Spirituality), Optimism & Hope (Positive thinking and valuing success), and Identity (Rebuilding positive sense of self). These studies provide empirical evidence and compelling illustrative quotes for what van Os and colleagues (2019, p. 92) summarise as 'the work of reinventing and reintegrating oneself and one's life after experiencing the existential crisis that comes with mental illness'. Moreover, the participants in the POETIC review (Section 4.3.3.1) and the POETIC on Reddit study (Section 7.3.2.1) frequently discussed 'meaningful life' (Van Os *et al.*, 2019, p. 92) concerns, specifically meaningful life and social roles (reproductive decision making, parenting), and meaningful activities (paid or voluntary work, education). Therefore, this thesis supports the argument to 'extend the bio-psycho-social model with an existential domain' (Van Os *et al.*, 2019, p. 92) and provides qualitative evidence what this existential domain might mean for people living with BD.

8.2.3 Implications for research

This thesis also makes several contributions to the research methods in MH, corpus linguistics, and NLP. Mainly, the complete project constitutes a methodological innovation in MH research by demonstrating how to analyse large amounts of online support forum posts to study the lived experience of a complex aspect of MH. The research design consisting of a systematic review summarising previous research on (offline) data, quantitative studies that provide background on the online user characteristics and behaviour, and a final mixed-methods analysis of their online posts may constitute a useful blueprint to examine other MH RQs. The data selection in the POETIC on Reddit study (Section 7.2.3) proposes a method to narrow down large amounts of naturalistic data to study a complex and elusive phenomenon of interest such as PR. Finally, the findings of this study showed that online support forum posts can provide authentic and candid accounts of lived experiences of severe MH issues.

Additionally, this thesis provides valuable information on possible sampling biases for BD research that considers recruiting participants from Reddit. First, the Reddit user characteristics study showed that age, gender, country of origin, and comorbidity distributions of Reddit users with a self-reported BD diagnosis differ from Reddit users in general as well as from epidemiological statistics for BD, and also from participants in clinical studies who mainly recruited offline (Section 5.4.3). Second, the Reddit mood and posting behaviour study indicates that mainly users who may experience stronger mood symptoms tend to be active in MH support subreddits (Section 6.4.1.3). Therefore, posting study advertisements only in MH forums may miss potential participants that experience fewer BD symptoms. Third, the two exploratory studies in the POETIC on Reddit study (Appendices G.1 and G.2) showed that most posts in BD subreddits reflected a medical understanding of BD, focusing on medication, symptoms, professional treatment, and clinical recovery. This is in line with previous content analyses of BD online support forums from various countries (see Section 1.4.2.2.4.1). Thus, study advertisements in BD subreddits may mainly recruit people with a primarily clinical understanding of recovery.

Corpus framework analysis constitutes a novel method both for MH as well as corpus linguistic research. The combination of qualitative and quantitative corpus linguistic methods and qualitative framework analysis allows to analyse large amounts of text data within an existing framework. Compared to fully automatic NLP methods such as deep learning-based classification or topic modelling, this approach has two main advantages. First, rather than being a 'black box' or containing any random variation it is fully transparent in that the framework category frequencies deterministically trace back to specific parts of the input texts. Conversely, machine learning methods like topic modelling or neural network classifiers can also produce term groupings but learn these latent associations from the co-occurrences of the terms in all texts, which cannot be traced back to specific passages (e.g., Mohr and Bogdanov, 2013, p. 547). Moreover, the term groupings based on the same texts may change for every run of the system due to a different random initialisation of the distributions involved in the computation (Brookes and McEnery, 2019). Second, the manual coding forces the researcher to get immersed in the data to a larger degree and enables to firmly ground the analysis in the actual texts via illustrative quotes. Therefore, future studies of online and other text data such as therapy transcripts (e.g., Tay and Qiu, 2022) might find corpus framework analysis an effective tool, too. Furthermore, corpus framework analysis is a relevant contribution to recent methodological debates in corpus-assisted discourse analysis about the integration of not traditionally linguistic methods (e.g., Gillings, 2022).

The main contribution to NLP research lies in demonstrating how to incorporate strong considerations of ethical issues and involvement of people with lived experience throughout the whole project. While ethical considerations have been a core component of health research projects at least since the Declaration of Helsinki (The 18th World Medical Assembly, 1964), the NLP community only started to consider ethical issues in the last five to ten years (Hovy and Spruit, 2016; Hovy *et al.*, 2017; Proferes *et al.*, 2021). Institutional review boards had considered NLP studies of public online posts exempt from ethical approval for a long time (Benton, Coppersmith and Dredze, 2017, p. 1; Proferes *et al.*, 2021, p. 2), even for MH research topics (e.g., Park and Conway, 2017). Particularly the Reddit user characteristics study (Chapter 5) and the project proposal paper (Jagfeld, 2019) were instrumental in disseminating the project including discussions of the ethical considerations and involvement of people with lived experience to the NLP community. Both papers were presented at NLP conferences and are available in the ACL Anthology[78], the main open-access literature database for NLP research.

As a second contribution to NLP research, the project demonstrated how to apply NLP methods and systems to generate new knowledge in another research field,

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[78] https://aclanthology.org/

as evidenced by the Reddit user characteristics (Chapter 5), Reddit mood and posting behaviour (Chapter 6), and POETIC on Reddit (Chapter 7) study. Additionally, the Reddit user characteristics study presented a manual evaluation of the accuracy of previously available NLP systems for the prediction of Reddit user characteristics in a specific real-world use case (see Section 5.4.2).

Finally, the S-BiDD dataset comprising more than 20M Reddit posts of 20K people with a self-reported BD diagnosis and all derived corpora are available for future research (Jagfeld, Jones, *et al.*, 2022). This could be useful for MH researchers interested in other aspects of the lived experience of BD, linguistic researchers to study the language use and/or discourses of this population, and NLP researchers to build machine-learning models. However, all further research on the dataset should intend to benefit people living with BD and must adhere to the ethical guidelines set out in the data usage agreement[79].

8.2.4 Implications for practice

This project provides a deeper understanding of the lived experience of PR in BD and of Reddit users with a self-reported BD diagnosis. Both aspects have practical implications for people living with BD, their informal carers, and MH professionals.

8.2.4.1 Better understanding of the lived experience of PR in BD

The POETIC review (Chapter 4) and the POETIC on Reddit study (Chapter 7) identified the key issues relevant to PR in BD shared by people with lived experience in face-to-face interviews and focus groups as well as online, summarised in the POETIC framework. Both publications contain tables with illustrating quotes for the POETIC categories, which are a resource for everyone who wants to learn more about the experience of PR in BD. Candid accounts of positive examples of PR in BD in the language of people with lived experience may constitute positive examples that other people living with BD might be able to identify with and provide hope. Likewise, informal carers (relatives, friends) of people living with BD may find the framework and illustrative quotes helpful to understand what their loved one may experience. They might use parts of the framework as conversation starters with their loved one.

Similarly, MH professionals might find the POETIC framework and illustrative materials helpful to better understand their clients. They may also use it as starting points to collaboratively consider some of the aspects with their clients, for example in recovery-focused therapy (Jones *et al.*, 2015; Tyler *et al.*, 2022). This is also relevant in light of recent initiatives to educate MH professionals on the lived experience of severe MH issues such as the Understanding Psychosis and BD training for the UK National Health Service (Health Education England, 2020). Importantly, the POETIC framework acknowledges that difficulties and negative experiences are a natural part of PR in BD, which differs from the more

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[79] https://github.com/glorisonne/reddit_bd_mood_posting_mh/blob/main/data/DataUsageAgreement_SBiDDDataset.docx

unequivocally optimistic take on PR of the CHIME framework (Leamy *et al.*, 2011) it is based on. Therefore, this project implies that MH professionals should take caution to not introduce PR in an overly optimistic and simplistic way to their clients and reassure them that setbacks can also be part of the process.

The POETIC on Reddit study revealed sensitive issues that many individuals living with BD expressed they had not felt comfortable sharing with peers or MH professionals offline, such as sexuality, spirituality, and positive appraisals of (hypo-)mania (Section 7.4.1). One the one hand, this points to the important role that more anonymous peer online support spaces such as Reddit can take in peoples' PR. On the other hand, this highlights the importance for MH professionals to strive to create a therapeutic environment where clients feel comfortable to discuss such sensitive issues face-to-face, too.

8.2.4.2 Better understanding of Reddit users with a self-reported BD diagnosis

The Reddit user characteristics (Chapter 5), Reddit mood and posting behaviour (Chapter 6), and POETIC on Reddit (Chapter 7) study provide a better understanding of Reddit users with a self-reported BD diagnosis – who they are, their mood and posting behaviour, and what they talk about on Reddit. This information provides valuable context information for people living with BD who consider using Reddit as a source of information or support. Such information is also relevant for MH professionals working with clients who engage with Reddit or are interested in doing so. International BD experts recently highlighted a critical need to educate MH professionals about online support forums (Stefana *et al.*, 2020), to which the publications of this project contribute. Specifically, the Reddit mood and posting behaviour study (Chapter 6) found that Reddit users with a BD diagnosis who post in MH support subreddits may experience more mood symptoms than Reddit users with a BD diagnosis who only post in non-MH subreddits. This provides some initial evidence that MH subreddits may underrepresent people who are living well with BD. Additionally, exploratory study 1 in the POETIC on Reddit study (Appendix G.1) found that BD subreddit posts much more frequently discuss BD symptoms and professional treatment compared to non-medicalised topics such as self-management and PR. Therefore, it appears sensible for MH professionals to encourage their clients to engage with different sources of online and offline support to obtain a balanced picture of life with BD.

8.3 Strengths and limitations

This section discusses both the strengths and limitations of the research in this thesis with respect to methodology (Section 8.3.1), data collection (Section 8.3.2), analysis (Section 8.3.3), PPI (Section 8.3.4), ethics (Section 8.3.5), and dissemination (Section 8.3.6) and proposes how future work could address some of the limitations.

8.3.1 Methodology

8.3.1.1 Review of the pragmatic research paradigm

This project applied an interdisciplinary mixed-methods design that integrated qualitative and quantitative text analysis methods within a pragmatic research paradigm. A key methodological challenge of this research design is the integration of methods from different philosophical positions. Quantitative NLP methods, on the one hand, usually operate from a post-positivist standpoint, taking language samples at face value by counting and looking for group-level patterns, often ignoring individual differences and contextual factors. On the other hand, qualitative methods such as framework, thematic, or discourse analysis often take a more constructivist position in trying to understand an individual's lived experience by interpreting their account in a specific context (e.g., time, setting, questions asked), considering participant and researcher subjectivity. Pragmatism solves this issue of mixed-method research by deemphasising philosophical aspects (e.g., Morgan, 2007) and rather focusing on the practical consequences of the RQs and findings (Cherryholmes, 1992).

Pragmatism allows to justify methodological decisions based on empirical circumstances and pragmatic considerations (Danermark et al., 2002, p. 204). Pragmatic considerations justified several important methodological choices in this project such as selecting best-fit framework synthesis as methodology in the POETIC review (Chapter 4), collecting only Reddit data (Section 3.1.2.1), applying existing NLP tools rather than developing new ones to determine the characteristics of Reddit users and their mood in the Reddit user characteristics (Section 5.2.2) and Reddit mood and posting behaviour study (Section 6.2.3), and integrating qualitative framework analysis based on the POETIC framework with qualitative and quantitative corpus linguistic methods in the POETIC on Reddit study (Section 7.2.3).

Critiques of the pragmatic paradigm argue that it underestimates the importance of philosophical considerations on research (e.g., Maxwell and Mittapalli, 2010, p. 147). A more theory-heavy research paradigm such as critical realism could have stimulated a stronger and possibly fruitful engagement with the philosophical tensions between qualitative and quantitative methods but would have required more time. In conclusion, the pragmatist stance turned out to be beneficial to complete this interdisciplinary project with the allocated funding and time.

8.3.1.2 Review of validity threats

Following Maxwell (2012, Chapter 6) this project had identified validity threats for the four individual studies at the start (cf., Section 2.3). Encouragingly, the project could implement most of the planned strategies to address these threats that Table 10 summarised. Table 31 provides the remaining validity threats because the project could not implement the emphasised strategies due to time constraints. Future research should conduct these additional studies to test the validity of the associated findings and explore alternative explanations.

Table 31 Remaining validity threats after project completion

Validity threats, alternative explanations they leave open	Strategies for dealing with validity threats (*unimplemented strategies emphasised*)
Reddit user characteristics study (Chapter 5)	
Automatic methods to infer user characteristics may lack validity and produce misleading findings	• Manual evaluation of the automatic methods with users' public Reddit content • *Ask Reddit users to fill in questionnaires for their user characteristics and evaluate automatic methods against this* • Triangulate different methods to infer user characteristics
Reddit mood and posting behaviour study (Chapter 6)	
Findings may not be specific to Reddit users with a self-reported BD diagnosis	• *Repeat the analyses for Reddit users with other self-reported diagnoses (e.g., depression, borderline personality disorder, a chronic physical health issue)*
Findings may be specific to Reddit users with a self-reported BD diagnosis	• *Repeat the analyses for a more general sample of users who posted in BD subreddits but did not match the self-reported diagnosis patterns – however, expect them to be different because could contain undiagnosed people, carers, etc.*
Researcher subjectivity: Study may miss important associations (e.g., socioeconomic status) because of the choice of predictor variables based on what the review team thinks is important and what measures are readily available ('searching where the light is, not where the keys were lost')	• Justify choice of selected variables • *Repeat the analysis with a different sample of Reddit users who also fill in questionnaires that allow measurement of more variables*
Automatic emotion analysis method may lack validity and produce misleading findings	• Select widely used emotion analysis method with a strong body of psychometric research that backs up its validity • Discuss method limitations • *Triangulate results with other automatic emotion analysis methods*

Validity threats, alternative explanations they leave open	**Strategies for dealing with validity threats (*unimplemented strategies emphasised*)**
POETIC on Reddit study (Chapter 7)	
Thin data: Little reliable data about Reddit users (age, gender, country of residence, comorbidities, time since diagnosis, medication use, religious beliefs, etc.) - PR is a very subjective topic, and it may be difficult to make sense of some of peoples' experiences without much context of their lives; unclear to which population of people with BD the findings may generalise	• Automatically determine as many user characteristics as possible and compare to the samples in clinical studies • Try to find more user information by close reading of their other Reddit posts if needed • *Complementary interview study of Reddit users with a BD diagnosis*
Comparing the frequency of terms associated with PR vs clinical recovery (symptoms and their treatment) may not allow conclusions about the relative importance of these concepts for online forum users due to two reasons: Frequency may not be directly associated with importance and PR may be more difficult to capture via isolated terms than clinical recovery.	• Base conclusions on mix of qualitative and quantitative evidence • Review evidence for relationship between how frequently people mention something and how important it is for them (Boyd and Schwartz, 2020) • *Complement naturalistic online post analysis with qualitative interviews to ask people living with BD if PR is a relevant concept for them*

8.3.2 Data collection

Large-scale analysis of online support forum posts is novel in MH research. Several aspects of this way of data collection present both strengths and limitations.

8.3.2.1 Participant recruitment

The S-BiDD dataset consists of all Reddit posts of 19,685 users who self-reported having received a BD diagnosis from a MH professional on the platform. Three aspects of this way of participant recruitment deserve further discussion.

First, recruiting participants via self-reported diagnosis statements differs from most clinical research that screens participants via diagnostic interviews. There are several advantages to this approach: It allowed to screen everyone who had ever posted on Reddit if they reported a BD diagnosis and led to almost 20K eligible participants. Conducting diagnostic interviews with this many people would have been impossible for a single PhD student. Moreover, relying on the diagnostic judgment of MH professionals meant that the PhD student did not need training for conducting diagnostic interviews. Still, the approach yielded a well-defined sample of people who had received an official BD diagnosis and excluded self-diagnosed users or those who were unsure if they meet BD criteria. However, there are also disadvantages of this way of participant identification compared to diagnostic interviews: This approach did not check the veracity of the self-reported diagnoses, although it appears unlikely that someone would choose to label themselves with a stigmatised condition such as BD (Coppersmith, Dredze and Harman, 2014). Relying on self-reported diagnosis statements assumes that the MH professional who made the diagnosis properly applied DSM or ICD criteria, but this is not known for sure. Moreover, MH professionals who use the same DSM or ICD criteria do not always agree (see Section 1.2.5). Also, users who reported on Reddit that their BD diagnosis had been changed or revoked later on, were included in the dataset nevertheless, which is in line with BD constituting a lifetime diagnosis. Importantly, this approach omits people who might have experienced extreme mood but never sought a MH diagnosis or fall outside the boundaries of DSM or ICD criteria. As Section 1.2.5 discussed, MH diagnoses serve to group people with similar experiences but introduce arbitrary cut-offs. Including people based on self-reported experiences within a continuum-approach to MH would have been more in line with PR principles but infeasible for large-scale online data collection.

Second, selecting users who self-reported a diagnosis statement differs from other (mainly NLP) studies, which included all posts in BD subreddits (Gkotsis, Oellrich, *et al.*, 2016; Gkotsis *et al.*, 2017; Park and Conway, 2018; Tariq *et al.*, 2019; Thorstad and Wolff, 2019; Yoo, Lee and Ha, 2019; Kim *et al.*, 2020; Low *et al.*, 2020; Song and Kim, 2022). Self-reported diagnosis statements allow for more conceptual clarity and a more homogeneous sample as not everyone who posts in MH subreddits experiences MH issues (see Section 3.1.3). Additionally, this approach allowed to include users who had never posted in MH subreddits. This was important for the Reddit mood and posting behaviour study who then compared users who had posted in MH subreddits to those who had not (see Sections 6.2.6 and 6.3.3). On the downside, requiring a self-reported diagnosis statement on Reddit misses many users with a BD diagnosis who do not explicitly state it or do not state it in the form of one of these patterns (see also next paragraph). Still, the resulting dataset of 20M posts by 20K users was large enough such that a more inclusive but less precise approach did not appear more expedient.

Third, automatically identifying self-reported diagnoses has advantages and disadvantages compared to directly asking Reddit users whether they ever received a BD diagnosis from a MH professional. The approach checked every post ever made on Reddit until March 2019 against an extensive list of 145 diagnosis phrases with placeholders for 92 BD synonyms and 18 terms for health professionals. Although this allows for some language variation, it again misses diagnosed users who do not state their diagnosis at all or it in the form of one of these patterns. Also, this approach may occasionally produce false positives, such as considering ‘I am diagnosed with borderline personality disorders, but not bipolar disorder’ a self-reported BD statement. However, manual examination of all self-reported diagnosis statements of 100 users revealed only three users that the approach had incorrectly identified (Jagfeld, Lobban, Rayson, *et al.*, 2021, p. 6). Future work could estimate the recall of the self-reported diagnosis statement matching approach by conducting a survey of Reddit users that asks whether they received a BD diagnosis and checking whether they stated it in a public Reddit post that matches one of the patterns.

8.3.2.2 Data collection site: Reddit

The project collected the data from Reddit due to several reasons explained in Section 3.1.2.1. This section reviews some of these reasons in the context of their strengths and limitations. Reddit has a large and international user base and previous work (Cohan *et al.*, 2018; Sekulić, Gjurković and Šnajder, 2018) had demonstrated the feasibility of automatically identifying thousands of users with a self-reported BD diagnosis on this platform. While the project successfully identified almost 20K users, the Reddit user characteristics study revealed that more than 80% of them were from the US, more than 95% from English-speaking, and more than 98% from Western countries[80] (Section 5.4.3). Therefore, the views included in the POETIC on Reddit study (Chapter 7) comprise less geographic and cultural variety than hoped at the outset of the project. The project had also initially aimed to analyse data in different languages (Jagfeld, 2019). However, initial exploratory analyses revealed little non-English MH related content on Reddit and the project focused only on English posts subsequently. Only English self-reported BD diagnosis patterns were used for user identification and 97% of the S-BiDD dataset posts were in English (see Appendix G.1.3.1).

Compared to other peer online support platforms, such as commercial or charity run-online support forums, or closed Facebook groups posts, anyone can view public Reddit posts without a user account. Reddit posts are in the public domain and the site's Privacy Policy (Reddit Inc., 2022) permits their analysis and redistribution. Although the project had initially aimed to analyse data from several online sources, it then concentrated only on Reddit for the reasons provided in Section 3.1.2.1. While this allowed the project to study the S-BiDD dataset from different angles and in much depth, this also constitutes a major limitation in the generalisability of the findings. The present findings from one data collection site constitute useful starting points that future work looking at other peer online support spaces can compare against.

8.3.2.3 Online posts as naturalistic data

Online posts constitute naturalistic data that participants produced while being unaware that they were studied (Fielding, Lee, Blank, & Janetzko, 2016). Therefore, they can offer insights into 'an experience as it is lived rather than as it is enacted in the researcher constructed environment' (Seale, Charteris-Black, MacFarlane, & McPherson, 2010, p. 600) and overcome many of the limitations of more traditional and structured data collection methods (semi-structured interviews, focus groups, and questionnaires) such as interviewer bias (Briggs,

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[80] https://github.com/glorisonne/reddit_bd_user_characteristics/blob/master/output/user_countries.csv

1986) or constrained responses. However, naturalistic data also comes with three limitations or challenges. First, collecting data from participants that are unaware of being studied entails complex ethical consideration, which Section 8.3.5 discusses below. Second, since the participants did not produce the data in response to any prompts specific to the study aims, the data needed to be filtered for content relevant on PR in BD. Third, there was no way to directly engage with the participants and ask them to clarify or elaborate on any information from their posts. Therefore, future research might consider combining structured and naturalistic data collection methods either from the same (e.g., Coimbra-Gomes, 2021) or separate participants (e.g., Semino *et al.*, 2017).

8.3.2.4 Conclusions on data collection strengths and limitations

The data collection in this project comprises important strengths and limitations as discussed above. Most importantly, this project was the first to study PR in BD via naturalistic online content from people with lived experience of BD, which previous work had identified as a 'challenging task but a valuable critical step' (Stuart, Tansey and Quayle, 2017, p. 302). The data limitations have the following implications for the generalisability of the findings of the three studies based on the S-BiDD dataset: The findings of the Reddit user characteristics study (Chapter 5) only apply to Reddit users with a self-reported BD diagnosis and the characteristics of other peer online support forum users with a BD diagnosis may differ. The Reddit mood and posting behaviour study (Chapter 6) provides the first quantitative results on associations of mood and posting in BD support forums that future confirmatory studies of other forums need to test. The findings of the POETIC on Reddit study (Chapter 7) have some generalisability to PR experiences of people with a BD diagnosis in Western countries since they confirmed and complemented previous qualitative evidence synthesised in the POETIC review (Chapter 4), but further research should test this.

8.3.3 Data analysis

This project analysed data via qualitative health research, quantitative NLP, and qualitative and quantitative corpus linguistic methods. This approach exhibited both strengths and limitations. Importantly, it allowed the collection and analysis of more data than with a purely manual and qualitative approach. With more than 21M posts by almost 20K users, the S-BiDD dataset constitutes the largest dataset of online posts of people with a BD diagnosis so far (see Harvey *et al.*, 2022 and Section 1.4.2.2). However, integration of multiple approaches meant that the studies did not exhaust all affordances of one approach. The Reddit user characteristics (Section 5.2.2) and Reddit mood and posting behaviour study (Section 6.2.3) relied on existing pre-trained NLP methods rather than developing new models tailored to the study data, which a purely NLP approach might have done. The POETIC on Reddit study applied the corpus linguistic methods of key item, concordance, and collocation analysis (although the last one only to a limited extent) (Section 7.2.3), while a purely corpus linguistic project could have encompassed a more in-depth analysis of collocations and additionally of n-grams or lexical bundles. In terms of qualitative health research methods, both the POETIC review (Section 4.2.2.5) and the POETIC on Reddit study (Section 7.2.3) used deductive framework analysis. While this is a time-efficient approach and in line with the pragmatic paradigm, it introduces a bias compared to purely inductive data-driven approaches. Therefore, both studies complemented the deductive analysis with an inductive analysis of the data that the a priori frameworks could not accommodate.

Other discourse and linguistic analysis methods might have led to complementary findings and future work could explore the S-BiDD dataset with these. Particularly, systemic functional linguistics (Halliday & Matthiessen, 2014; see McDonald & Woodward-Kron (2016) and Abdo et al. (2019) for two applications to BD online support forum posts) in tandem with social actor theory (Van Leeuwen, 1996; Koller, 2009; Fairclough, 2013) could carve out more in detail who people with a BD diagnosis consider as actors in their PR and how their self-perceived agency might change over time. Such a study could apply automatic syntactic parsing to identify the arguments and modifiers of terms with the stem *recover* to identify the actors.

Furthermore, metaphor analysis (see Section 1.4.1.2) could be fruitful to provide another lens on the experience of PR in BD. Future research could explore metaphors around PR in BD to answer questions such as: How do metaphors differ between structured evidence from interviews or focus groups and more naturalistic data such as online posts? Do people who report more vs. less life satisfaction use different BD or recovery metaphors? Such research could build on the approach by Semino and colleagues (2017) who studied cancer and end of life metaphors in interviews and online forum posts. It could yield recommendations for MH professionals for how to talk about PR and provide inspiration for people living with BD similar to the ‘Metaphor menu for people living with cancer’ (MELC project, 2019).

8.3.4 Participatory and public involvement

Table 32 summarises the results of the PPI activities in this project and the impact they had on the PhD student and the project (GRIPP2 items 3 and 4, combined because the answers overlap significantly). The remainder of this section critically reflects on them (GRIPP2 item 5).

Table 32 Results and influence of PPI activities in this project

Month/ year	PPI methods (GRIPP2 item 2)	Results of PPI and influence on studies (GRIPP2 item 3 and 4)
03/19	Meet with Spectrum’s service user researcher who has lived experience of BD	This was the first opportunity for the PhD student to consciously talk to someone with lived experience of severe MH issues. It was reassuring to first talk to a service user researcher who has experience of sharing his story and knows how to protect himself. The service user researcher helped to set up the advisory panel consultation.

Month/ year	PPI methods (GRIPP2 item 2)	Results of PPI and influence on studies (GRIPP2 item 3 and 4)
05/19	Consult the Spectrum advisory panel (three participants with lived experience of BD in addition to the service user researcher) to get initial feedback on the project plan and aims	All panel members felt positive towards the project, welcomed its novelty, and were interested in the outcome. They pointed out some possible biases in the data such that people who are continuously struggling may be overrepresented in online support forum posts – a hypothesis that the project team then quantitatively explored in the Reddit mood and posting behaviour study (Chapter 6). Surprisingly for the PhD student, they would have liked the research to focus only on the UK rather than internationally. They were also concerned about including people in the dataset that did not have a 'genuine history' of MH issues (hospital admissions, taking medication) but said they had BD because it was in fashion. Overall, the panel provided a valuable first experience for the PhD student to present the project to a group of people with lived experience of BD.
10/19	Visit a local Bipolar UK support group (eight attendants) with the service user researcher and presenting the project	The eight mainly elderly attendants were positive towards the research project, although they were not familiar with online forums. It was an encouraging experience for the PhD student to connect with people with a BD diagnosis and hear that they valued the research.
09/20	Consult the Spectrum advisory panel (one participant, in addition to the service user researcher) to get feedback on the POETIC review findings (Chapter 4)	'[The panel] confirmed that the review results and implications resonated with their experiences and priorities. […] Their feedback did not lead to changes in the framework but introduced nuances to the manuscript' (Jagfeld, Lobban, Marshall, et al., 2021, p. 381)
05/21	Message the moderators of two large BD subreddits to get feedback on the project overall	Both responses were short. One was very positive and one very negative towards research on the forums' posts (see Figure 16). While yielding no suggestions for the data analysis as hoped, their responses illustrate the ethical dilemma of naturalistic online data collection. This interaction also demonstrated that more engagement with a non-academic

Month/ year	PPI methods (GRIPP2 item 2)	Results of PPI and influence on studies (GRIPP2 item 3 and 4)
		audience would require more time and funding than available for this project.
05/21	Pitch the project at a Young People's Involvement in Digital Mental Health Dragon's Den	The Dragon's Den was a fun opportunity to present the project in a different format and to young people for the first time. The two panel members who spoke up found the project very worthwhile, which was again motivating to hear. They also considered the potential benefits of the research to outweigh the ethical problems. They brought up that people may use Reddit less to connect with family and friends (compared to other social media platforms such as Facebook, WhatsApp), and so it may be a more impersonal data source in terms of ethics.
05/21	Talk to a lawyer with a bipolar I disorder diagnosis who lives in a US MH state facility about the project overall and plans for the Reddit mood and posting behaviour study (Chapter 6) and POETIC on Reddit study (Chapter 7)	The lawyer provided rich insights into his at times very distressing and dramatic personal experience of living with BD in the US. POETIC seemed to capture his experiences very well. He was grateful for a researcher to be interested in his story and research PR in BD. The interview was a touching encounter for the PhD student and contributed to a sense of doing meaningful work.
06 - 07/21	Consult with four volunteers with lived experience of BD and using social media in relation to their MH issues recruited via PeopleInResearch to get feedback on the initial results of the Reddit mood and posting behaviour study (Chapter 6) and plans for the POETIC on Reddit study (Chapter 7)	All volunteers, one man and three women, were UK-based and in their thirties to forties, three reported a bipolar II disorder diagnosis and several had a migrant background. The interviews provided valuable insights on the different usage patterns and reasons for engaging with online support forums. While most volunteers appeared stable and were very reflexive of their past experience, one volunteer appeared confused during the interview, and it was difficult to lead the discussion with her. A fifth volunteer cancelled the appointment on short notice due to a sudden bereavement and having to deal with financial difficulties. These two final interactions were examples of why it may be that people living relatively well with BD are often overrepresented in research. Difficult

Month/ year	PPI methods (GRIPP2 item 2)	Results of PPI and influence on studies (GRIPP2 item 3 and 4)
		life events or circumstances make it more difficult to find the time and headspace for a research interview. Being very unwell can impact on peoples' ability to share their thoughts and experiences in a way that is understandable to the researcher within the constraints of a brief consultation.
06/22	Consult with two of the volunteers recruited via PeopleInResearch on the final results of the Reddit mood and posting behaviour study (Chapter 6)	Overall, the results and implications resonated with both volunteers' experience of using online support forums and what they found important (see Section 6.3.5). The volunteers also confirmed that they were not concerned about potential for misuses of the research methods or misinterpretation of the results that could be harmful for people living with BD.
08/22	Consult with the same two volunteers as in 06/22 on the findings of the POETIC on Reddit study (Chapter 7)	Overall, both volunteers valued the results and agreed with the findings, but indicated limitations of the data, reflected in the discussion of the study (see Section 7.3.3).
11/22	Consult with Spectrum's service user researcher on the dataset name	The service user researcher confirmed the suspicion that the first idea for the dataset name could be seen as trivialising. The service user researcher regarded S-BiDD as 'most sensible' option.

Time and financial restrictions of the funding for this PhD project constrained the PPI activities in this project. Nevertheless, the PhD student consulted with people with lived experience of BD throughout the project, seeking feedback on every stage from research design to the interpretation of the findings and dissemination of the results (see Table 32). The infrastructure of the Spectrum Centre significantly supported this via the advisory panel of volunteers with lived experience of BD led by a service user researcher on an indefinite contract with the university.

The main limitation of PPI in this project was that it only comprised consultation, which some people regard as tokenistic (Arnstein, 1969). As Section 2.1.7 discussed, collaboration with people with lived experience or even a participatory action research design would have been more empowering and in line with PR principles (Rose *et al.*, 1998; Wallcraft, Read and Sweeney, 2003; Callard and Rose, 2010) but infeasible given the time and financial constraints of the project.

In hindsight it might have been better to try to recruit a more stable advisory board of volunteers with lived experience of BD and using social media at the start of the project. Also, more involvement of Reddit users with a BD diagnosis and the moderators of subreddits that mainly contributed to the dataset would have been desirable. Only some of the consulted volunteers had used Reddit specifically and all but one were UK-based, although most users in the S-BiDD dataset lived in the US. This could have given more credibility to the project to Reddit users and would have more easily allowed to disseminate the findings on MH subreddits with lesser fear of a negative backlash.

8.3.5 Ethical issues

Since analysing online support forum posts is relatively novel in MH research, considering the ethical issues of this was challenging as there was little ethical guidance available at the start of the project. Also, the research ethics committee of the Faculty of Health and Medicine at Lancaster University had fewer precedents for this project compared to more standard research protocols.

The main ethical concern in this project was around not seeking explicit consent from the Reddit users in the S-BiDD dataset. While ethical guidelines from the NLP and MH community at the start of the project regarded it as acceptable to waive explicit consent from online users to conduct research on their public posts (Benton, Coppersmith and Dredze, 2017; Williams, Burnap and Sloan, 2017; The British Psychological Society, 2021), this continues to be an ongoing debate (see Morant *et al.*, 2021). Importantly, none of the people with lived experience that offered feedback on the project in individual or group meetings raised any ethical concerns. They all regarded the benefits of this research to outweigh any potential risk of harm.

However, a direct message to the moderators of two large BD subreddits asking for feedback on the ongoing project elicited one very endorsing but also another very critical response (see Figure 16). The project team had carefully phrased the message to not indicate a request for consent from the forum since the ethically approved research protocol did not foresee this. Therefore, the negative response of the moderators of one forum did not halt the research but spurred the PhD student to consider their concerns. The moderators worried that research on the posts could ‘impact users and discourage honest posting’ (Figure 16). The project tried to minimise the likelihood of any direct impact on the participants by only sharing paraphrased quotes without any usernames or other identifying information. This made it very unlikely that any Reddit user would recognise their personal experience in the research outputs. As quoted in Section 3.4.1, the Reddit privacy policy explicitly states that much of the content on the site is ‘public and accessible to everyone, even without an account’, and even private content may become public, which users ‘should take that into consideration before posting’ (Reddit Inc., 2022). Therefore, users who post in BD subreddits should already be aware that their content is public and that researchers may analyse it, which may or may not have impacted on the honesty of their posting. Furthermore, one could argue that users who are concerned about the privacy of their posts would rather turn to non-public online support forums with more protective privacy policies and which require a sign up to view content or chose not to share their experiences online at all. However, according to the current state of research, it is unclear to what extend social media users are aware about the privacy policies of the sites they use (Ahmed, Bath and Demartini, 2017).

Large BD subreddit 1: 'Sorry for the late reply. As your study doesn't entail posting, you and your team are more the welcome to gather data from our subreddit. Don't forget we have a discord server too.
As to input, I'll bring it up with the rest of the moderators and get back to you.'

Large BD subreddit 2: 'Sorry we no longer allow studies or surveys. We are very very against anyone analyzing our posts, please consider how this might impact users and discourage honest posting. This isn't ethical research.'

Figure 16 Feedback of the moderators of two large BD subreddits in response to a direct message introducing the project (see Appendix H)

Therefore, future research should investigate the privacy expectations of MH subreddit users. Such a study could, for example, invite MH subreddit users to consent for researchers to analyse their posting behaviour and content before and after the start of the study. The study could then determine whether there are any changes based on whether a user had already known their posts were public prior to the start of the study. Researchers could complement this quantitative data with qualitative interviews of MH subreddit users' privacy expectations and opinions of research on Reddit. Importantly, the study should also interview users who did not consent to take part in the study as these may be the ones most likely critical of research on Reddit. Additionally, future research using public online posts might find it beneficial to incorporate more direct involvement of the online communities that produced the data from the beginning on to increase acceptability.

Ethical considerations at the project start had also identified a risk to encounter online posts that indicated a risk for the poster to harm themselves or others. In retrospect, the proposed strategy to only analyse posts that were at least three months old worked out well. While the close reading and coding of posts particularly in the POETIC on Reddit study (Chapter 7) indeed revealed such content, the temporal distance, and opportunities to discuss with colleagues protected against undue distress. The project team did not come across any posts indicating a risk of significant harm to others that required use of Reddit's reporting service.

8.3.6 Dissemination

Table 33 summarises the dissemination strategies envisioned before the beginning of the project in September 2018, along with the completed activities at the time of the final thesis publication (August 2023). Overall, the project realised most of the envisioned activities and reached each target group at least to some extent. Most activities targeted MH and NLP researchers, followed by MH professionals. So far, the PhD student has delivered 13 talks and four poster presentations associated with this project at local, national, and international academic events in the UK, mainland Europe, and the US (see Appendix I). Outreach to people living with BD and the wider public was more limited. Future work could translate the findings of this project into more accessible language and formats such as blog posts or a website.

Table 33 Dissemination of this project

Ideas before project start	Completed activities (May 2023) and future plans
People living with BD and informal carers	
Webpage to inform (informal carers of) people living with BD on the findings	While the PhD student did not set up a webpage, she tweeted about presentations and publications on her public Twitter profile[81] with graphical and text summaries of the results, aiming to be accessible for a wider non-academic audience. She was also a panellist for the Reddit World BD Day Ask me Anything in 2022[82] and 2023[83].
Talk to people with lived experience about the project and its findings	The PhD student talked to various people with lived experience throughout the project (see Section 8.3.4). These interactions were mainly for the purpose of consultation but always meant that the volunteers learned about the project and could use this knowledge for themselves or to pass on to their peers.
MH professionals	
Webpage targeted for professionals	The PhD student did not set up a webpage but posted about the research outputs on her public Twitter profile, also gaining several MH professionals as followers.
Organise workshops to inform on the findings	There has not been a stand-alone workshop on the project yet. However, the PhD student presented a poster and several talks at international clinical psychology conferences in the UK and US (see Appendix I) that many MH professionals attended. The PhD student also convened, chaired, and presented at a symposium at the BABCP 2023 conference on 'Talking about bipolar disorder and borderline personality disorder: Applying innovative large-scale language analysis approaches to lived experience'.
MH, NLP, and corpus linguistics researchers	
Present work at conferences	Yes (see Appendix I)

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[81] https://twitter.com/glorisonne

[82] https://www.crestbd.ca/2022/05/18/highlights-ama-2022-bipolar/

[83] https://talkbd.live/world-bipolar-day-2023/

Ideas before project start	Completed activities (May 2023) and future plans
Publish articles in proceedings and journals	Yes (Jagfeld, 2019; Jagfeld, Lobban, Marshall, *et al.*, 2021; Jagfeld, Lobban, Rayson, *et al.*, 2021)
Release the collected web data	The S-BiDD dataset is publicly available for research purposes after signing a data usage agreement (Jagfeld, Jones, et al., 2022) All programming code is publicly available under the GPL 3.0 open source license (Jagfeld, 2021a, 2022b, 2022a).
Wider public	
Research blog: explain the research in lay's terms, present at science slams, …	The PhD student did not set up a research blog but presented the project at the Young people's involvement in Digital Mental Health Dragons' Den in May 2021.

8.4 Personal reflections: dealing with challenges

This section reflects on some challenges in this project, following the outline of the three basic questions 'What worked well?', 'What did not work so well?', and 'What would I do differently if I were to do a similar project again'?. Different from other parts of this thesis, I write these personal reflections in the first person.

8.4.1 Anticipated challenges

In the application process for the PhD position, the supervisory team asked the applicants to prepare a five-minute presentation covering the questions: 'What are the key challenges that you would be likely to face in conducting the proposed research into talking about PR in BD? How would you overcome these and how would you maximise the impact of the work?'. Table 34 presents the three key challenges and strategies I had identified at this stage. At completion, I can say that I did indeed face these challenges and that the strategies worked well. Having anticipated these challenges and pre-planned ways to address them has certainly been helpful.

I particularly enjoyed the interdisciplinary dissemination activities, which often were a welcome change from drier research aspects. They provided opportunities to get creative (designing graphical abstracts, posters, presentations), meet new people and gain wider perspectives on the project, and to travel. Since there was only a limited research budget for this PhD, additional funding from Lancaster University's Centre for Corpus Research on Language (UCREL), Division of Health Research, Faculty of Health and Medicine, and Postgraduate College were vital to support the many external presentations of this project, for which I am very grateful.

Table 34 Key challenges and strategies to address them identified prior to the project start

Key challenge	Strategies to address the challenge
1. Get knowledgeable about BD: • Build up background knowledge on clinical psychology and BD	• Study relevant literature • Attend introductory courses in clinical psychology • Discuss with colleagues and fellow PhD students with backgrounds in psychology
2. Interdisciplinary working and publishing: • Get a feeling of how to argue, present and discuss results in clinical psychology Find important journals and conferences for the research	• Build on strategies for first key challenge • Present and discuss my preliminary results within the department • Consult with SHJ and FL
3. Data collection and corpus creation: • Corpus should be representative and large enough for statistical analysis • Data privacy and anonymity of authors and mentioned people in the data • Copyright or licensing of data to share with other researchers • Automatic filtering of relevant texts – ethical considerations	• Identify suitable sources: twitter hashtags/users, blogs, forums, comments below newspaper articles and Youtube videos, … • Study data collection procedures of similar endeavours • Consult with PER

8.4.2 Unexpected challenges

Additional challenges arose during the project that I had not anticipated prior to the start: the Covid-19 pandemic, having to engage with the philosophy of research, reflexivity, and conducting a research project of this size for the first time.

8.4.2.1 Navigating a PhD during the Covid-19 pandemic

During the second year of the project in early 2020, the Covid-19 pandemic disrupted nearly everyone’s life. Luckily, the data collection for the project had already been completed at this time such that data analysis did not have to consider the external impacts of the pandemic and lockdowns on the post content. The supervisory team quickly switched to virtual supervision meetings and since there were no essential in-person components to the project, the research continued more or less uninterrupted. During this time, I started to add in cartoons (often featuring Snoopy) or other little graphics at the beginning of the supervision agendas to share with the supervisory team what was currently going on for me more personally or emotionally in relation to the PhD. This turned out an effective way to replace the informal chit chat that would happen before and after in-person meetings. Additionally, I established virtual informal catch ups with other PhD students supervised within the Spectrum Centre that have continued in a roughly monthly rhythm until today. Although I could not meet my supervisors or colleagues in person for a large part of the project, I did not feel isolated because virtual supervision meetings and catch ups worked well for me.

During the lockdowns, I lived in spaces where I had to work and sleep in the same room. I found it more challenging to maintain boundaries between the project and my private life when I could see my working desk from my bed. Fortunately, I could delay close reading of online posts for the POETIC on Reddit study (Chapter 7), which sometimes contained distressing content (see Section 8.3.5), until after the lockdowns when I could again work on the PhD at an external place. An online workshop (*Focus on the Researcher: Dealing with Distressing Data*, 2021) had been helpful to prepare me for this task.

The pandemic did not require any changes to the research protocol, yet it impacted the PPI activities. While I had originally planned to consult with the Spectrum advisory panel in person at Lancaster University and connect with local BD support groups, the lockdowns meant that this was not possible for a large part of the project. Instead, I recruited volunteers online via PeopleInResearch, which I then interviewed in video calls. This meant that I could speak to people from a wider geographic area although all except one were UK residents. While I received very valuable insights into living with BD and helpful feedback on the project, having met the same people in person several times during the project maybe would have led to closer connections and deeper conversations. Still, hearing from people with lived experience of BD that they valued my research was very motivating for me and provided a direct sense of purpose. I am very grateful to everyone who talked about their MH experiences with me during this project for their time and trust.

The pandemic also had a strong impact on the dissemination activities that had to happen virtually for more than two years. While online presentations were a welcome substitute to nevertheless stay in touch with a wider audience, I noticed in hindsight that I only made new contacts during in-person events. In some online presentations, I found it harder to engage with the audience and presenting sometimes felt like talking into a void.

8.4.2.2 Getting to grips with research philosophy

Lancaster University's Division of Health Research expects that PhD theses specify the philosophical assumptions underlying the research. This was an aspect of research that I had not come across previously during my NLP studies. I found engaging with the philosophy of research while planning the project both very fascinating and challenging. It was a challenge for me to consolidate my new learnings in this field to a tangible stance for the project. As Section 2.1.7 expounded, I ultimately decided to base the project on the pragmatic research paradigm, which provides an epistemological middle way between completely objective and subjective stances (Morgan, 2007, p. 71).

8.4.2.3 Engaging with reflexivity

Reflexivity was another approach to research that was new for me. Reflexivity requires the researchers to reflect on how their personal goals, previous experiences, and skills might impact the project and its findings (Finlay and Gough, 2008). To make the researchers' positioning transparent, Section 2.4 addressed reflexivity for the whole thesis, and the POETIC review (Section 4.2.2.6) and POETIC on Reddit study (Section 7.2.2) contain study-specific reflexivity considerations. Looking back at my first reflexivity statement from May 2020 and my reflections on this in Section 2.4 from December 2020 when writing this chapter in February 2023 allowed me to see how my thinking had evolved. Particularly my initially positivist view that regarded subjective biases as a problem has developed into a more critical realist view with an appreciation of researcher subjectivity. I also asked my supervisors to revisit their reflexive statements after completion of the research in February 2023. They had nothing to add to my reflections summarised in this section.

Prior to starting this PhD, I heard the phrase 'Research is me-search' (see also Maso, 2003) at a work-life balance workshop for researchers, which has stuck with me since then. Indeed, while working on this project, I found that I could relate to some of the experiences shared by research participants. In these cases, reflexive journalling helped me to clarify what was going on, identify any changes I needed to make in the way how I approached the current task, and return to it in a more impartial way. Whenever I noticed a particular personal investment in some findings, I was careful to discuss them more thoroughly with people with lived experience and my collaborators to widen my perspective.

When embarking on a similar project again, I would write an initial reflexivity statement right at the start of the project and encourage my collaborators to do the same. I would also write intermediate reflexive statements more systematically to be able to continuously monitor and reflect on the impact of our subjective perspectives on our decisions.

8.4.2.4 Undertaking a large research project for the first time

When writing this discussion chapter and looking back at the project from its beginning, I realised one major challenge had been present throughout the project that I had not explicitly identified prior to the start. This 'elephant in the room' challenge was for me to conduct a research project of this length and scope for the first time. What seems to have worked very well is that I early on pinned down the conceptual and methodological basis of the project. I wrote the background on BD (Section 1.2), PR (Section 1.3), and research paradigms (Section 2.1) in the first year and then stuck to these definitions and choices. Additionally, completing the data collection in the first year of the project and then analysing the same data throughout proved to be efficient. Applying different methods in every study kept working on the project over several years interesting and allowed me to acquire many varied skills. But it also meant that I needed some time to deal with the new methodological challenges in each study. What I did not manage was to address all the research goals I had put down at the beginning of the project. Compared to the initial project proposal (Jagfeld, 2019), the completed project has a much narrower scope. This experience will certainly help me to set more realistic goals for future research projects.

8.5 Conclusion

This PhD thesis analysed personal recovery experiences that people with a self-reported BD diagnosis have shared in peer online support forums through integrating qualitative and quantitative health research, NLP, and corpus linguistic methods, while considering ethical issues and involving people with lived experience. A systematic review of previous qualitative evidence from interviews and focus groups resulted in the first framework for PR in BD, comprising the aspects Purpose & meaning, Optimism & hope, Empowerment, Tensions, Identity, Connectedness (POETIC). Automatic identification of users of the online discussion platform Reddit by matching self-reported BD diagnosis statements led to the S-BiDD dataset of 20K users and their more than 20M public online posts. Two quantitative studies using NLP methods determined the characteristics of the users in the S-BiDD dataset and associations between their mood and posting behaviour. They are mainly young or middle-aged US-based adults with an almost equal masculine-feminine gender distribution that often report additional MH comorbidities. Moreover, Reddit users with a self-reported BD diagnosis who exhibit more intense emotions in their posts, are more likely to post in MH support subreddits. A final study applied corpus framework analysis, a novel integration of qualitative framework analysis and qualitative and quantitative corpus linguistic methods, to analyse PR-related S-BiDD dataset posts with the POETIC framework. This showed that PR-related discussions in BD subreddits primarily focussed on three domains: Purpose & meaning (particularly reproductive decisions, work), Connectedness (romantic relationships, social support), and Empowerment (self-management, personal responsibility). The support forum data highlighted PR issues that exclusively or more frequently came up online compared to previous evidence from interviews and focus groups.

This thesis advances our knowledge of the experience of PR in BD. The findings support the notion that ‘living a satisfying, hopeful and contributing life’ (Anthony, 1993) is possible with a BD diagnosis. However, the findings paint a nuanced picture of the experience of PR in BD, which often also entails negative experiences, difficulties, and challenges. These findings constitute valuable information for people living with BD and their informal and formal carers. Additionally, future research can build on the new methods, findings, and the S-BiDD dataset that this thesis created. A better understanding of the concerns of people living with BD will hopefully contribute to more effective support.

Having considered the lived experience of PR in BD from 163 participants in previous qualitative research, 19,685 Reddit users, and 18 volunteers, this thesis concludes with another quote by the individual that it started with:

‘I consider my bipolar condition a gift to me. I have almost touched heaven in my mania, I have been plunged into the depth of despair in my depressions, but with the love and compassion that have been shown to me, I have weathered all the storms, and I believe I am equipped now to face any new challenges that life will inevitably put before me.' (Margaret Trudeau (2011, p. 342), in the afterword of her memoir 'Changing my mind')

List of abbreviations and acronyms

- **BD** Bipolar disorder
- **CHIME** Connectedness, Hope and optimism, Identity, Meaning and purpose, Empowerment
- **DSM** Diagnostic and Statistical Manual of Mental Disorders
- **GRIPP2** Guidance for Reporting Involvement of Patients and the Public short form
- **ICD** International Statistical Classification of Diseases and Related Health Problems
- **LIWC** Linguistic Inquiry and Word Count
- **MH** Mental health
- **NLP** Natural language processing
- **POETIC** Purpose and meaning, Optimism and hope, Empowerment, Tensions, Identity, Connectedness
- **PPI** participatory and public involvement
- **PR** Personal recovery
- **QPR** Questionnaire about the Process of Recovery
- **RQ** Research question
- **S-BiDD** dataset Self-reported bipolar disorder diagnosis dataset
- **SMHD** dataset Self-reported MH diagnoses dataset
- **tf-idf** term frequency-inverse document frequency
- **USAS** UCREL Semantic Analysis System

Appendices

A Reflexivity statements

A.1 Glorianna Jagfeld: My motivations and position in relation to recovery in extreme mood experiences (February 2020)

Having successfully studied NLP and published research in this field, I had always been excited about the affordances of programming to automatically process language data. For example, information retrieval and extraction methods allow to retrieve information from large collections that are infeasible to search manually. Likewise, statistical analysis of large amounts of texts can reveal language patterns that might not be noticed in manual investigations. At the same time, I felt increasingly frustrated with only developing tools that process language but not getting to use them to look at the content of this language and understand more about human experiences. This gave rise to my wish to conduct research at the intersection of computational linguistics and psychology.

I've always had a strong interest in psychology and mental health, perhaps due to my mother, aunt, and grandfather working as psychotherapists. Their presence in my family also made me grow up with the belief that seeing a psychotherapist when you're having mental health issues is just as normal as seeing the doctor when you've got a broken leg.

My interest in extreme mood experiences stems in part from my own experiences of less extreme mood fluctuations that I first became aware of as a student. While I was dealing with a longer period of low mood for the first time, a close family member revealed to me that she received psychological therapy for mood swings when I was a small child. Growing up I had never experienced her as ill in any way, instead she was highly functioning throughout and I regard her as a strong and independent woman who has been following her vocation. Thus, when I first heard about the concept of personal recovery in the advertisement of the PhD position that led to this thesis, this view on mental health issues resonated with me. Her journey through life is a personal example for me that it is possible to pursue a meaningful life alongside intense mood experiences and a continuing source of hope for myself.

Conversations with the Spectrum Centre's service user researcher and consultations of the centre's advisory panel of people with lived experience brought in the views of people with extreme mood experiences on this project. By discussing my observations and conclusions with my supervisors, other academics, and people with lived experience of bipolar disorder throughout working on this thesis, I aim to reflect on my preconceptions and to take action to mitigate these biases as far as possible.

A.2 Steven Jones (May 2020)

My interest in personal recovery in bipolar emerged from my academic work as a clinical researcher and my work as a clinical psychologist. In my clinical experience I grew increasingly concerned about the discrepancy between the values and goals of people living with bipolar and the often very directive approaches taken to their care. My involvement in the development of cognitive therapy for bipolar confirmed to me the importance of psychological aspects of bipolar disorder. However, a key limitation of this approach was that it started from the premise that the key issue to be addressed in bipolar disorder is problems with detections and coping with early warning signs of mania and depression. At the same time there was increasing interest in the concept of personal recovery both from service users and in terms of government policy. This led me to work on ways of measuring and facilitating personal recovery in bipolar with people with lived experience that move away from the emphasis of detection and coping with early signs as the necessary focus of research and treatment. I feel that personal recovery is an important concept in bipolar that can encompass a strengths and values approach to mental health. I am also aware that personal recovery can be a contentious term with some people seeing this as a way of rebranding services without changing them, and some people concerned that this focus fails to acknowledge the potentially serious life-threatening nature of the condition. My personal view is that it is the serious challenges associated with bipolar that make this approach so important to improve both understanding and care outcomes. There are also very different perspectives in relation to the nature of bipolar disorder and its causes internationally. In general, this term has had much more national and policy influence in the UK that US or Australia. It will therefore be of interest to see how people talk about personal recovery when not prompted by structured questioning and the extent to which this varies internationally.

A.3 Fiona Lobban (May 2020)

I have seen an incredibly important shift in the way in which mental health outcomes are conceptualised. We have moved away from a focus entirely on reducing symptoms, and relapses, towards one that increases a sense of personal recovery. In the UK and US (I am not sure about other countries?) this has been widely adopted right up to policy level but is astonishing in many ways.

Firstly, because everyone really struggles to understand what personal recovery actually means. Secondly because as an outcome measure it’s very hard to assess in any “objective” way – and such outcomes are general given more value in the kinds of scientific evidence that is used to inform services (i.e., randomised controlled trials). Thirdly, because there are no reliable interventions to improve personal recovery to date (some feasibility studies excluded). Finally, because in a society dominated by a capitalist model, the idea that one’s sense of leading a meaningful life (whatever that entails) is of more value than the ability to go to work, is surprisingly fabulous.

However, many people have argued that personal recovery is poorly understood by both patients and staff, and that as a result, recovery services will drift back to doing what they did before – which is trying to reduce clinical outcomes, sometimes at the expense of what is important to the individual. To address this, we really need to understand what personal recovery means to people – and one way to do this, whilst avoiding the demand characteristics of interviews, is to look at how people talk about personal recovery.

My expectations are that the data will all support the idea that people want to live a meaningful life, alongside symptom exacerbations if need be, and that the specifics of this will be very different for different people. However, I wonder if the term "recovery" will prove to be problematic for people, as this term is already widely used in lay language and means something very different i.e., getting over something "a return to a normal state of health, mind, or strength". In my mind this is very different to the concept of personal recovery – which is not about returning to anything, or necessarily reaching any kind of normality. I am interested to see what the data will show.

A.4 Paul Rayson (September 2020)

Your original prompt was "how our experiences may impact on our interpretation of your data and therefore supervision of your thesis" ...

My research background is in natural language processing and computational linguistics, where large bodies of naturally occurring text are automatically analysed by bespoke computer software and algorithms. Lancaster's take on this discipline in computer science has been heavily influenced by our long term close collaboration with academics in linguistics who have pioneered the methodology of corpus linguistics, the analysis of large corpora for linguistic purposes to describe or compare how language is used by different people or in different settings for varying purposes.

The linguists' manual analyses influence the algorithms embedded in the computer software and large amounts of manually annotated data are used to train machine learning algorithms to replicate and scale up the tagging. This is very much a descriptive approach, so not having a background previously in mental health discourse analysis, I try to approach the topic of Glorianna's PhD with an open mind about the potential results in relation to the concept of personal recovery. I am expecting the data to lead us in new unexpected directions, and I focus on improving methodologies to find the data we need and automatically analyse it in new and improved ways. During the work, I'm hoping to find out how widespread the personal recovery term itself is, and whether service users and professionals use other terminology for the same or similar concepts.

On a personal level, I have seen colleagues and friends struggle with their mental health, depression and anxiety, so am interested to see more discussion of this topic more widely within and beyond academia, particularly for awareness raising purposes.

B Details for 42 studies of BD research via language analysis of online posts

Table S1 Summary of articles describing BD research via language analysis of online posts

<table>
<tr><th>Field of publication; first author</th><th>Focus or aim(s) (topic category)</th><th>Data sources, date, language</th><th>Data size, number of users, user characteristics</th><th>Ethical considerations summary</th></tr>
<tr><td colspan="5">Text analysis as a tool for analyzing conversation in online support groups (Kramer, Fussell and Setlock, 2004)</td></tr>
<tr><td>Computer science; human computer interaction</td><td>Characterise nature of online support forum discourse and changes over time (Study BD online peer support)</td><td>US chatroom for BD peer-support, July 2002 - October 2003, English</td><td>80,136 chat messages, 267 users</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Content analysis via bespoke BD lexicon and LIWC (NLP)</td><td colspan="3">Key findings: Significant correlations with LIWC positive emotions: you, BD terms; negative emotions: BD terms, I, you; likelihood to mention BD terms decreases with chatroom membership length</td></tr>
<tr><td colspan="5">Social support and unsolicited advice in a bipolar disorder online forum (Vayreda and Antaki, 2009)</td></tr>
<tr><td>Qualitative health research; humanities and philology</td><td>Provision of social support in online forum (Study BD online peer support)</td><td>Moderated public Spanish-language online support forum for people with a diagnosis of BD and their friends and family hosted by Bipolar Web, March - May 2008, Spanish</td><td>14 initial posts with first comments, six presented example users</td><td>Elaborate discussion of consent: asked forum moderator for permission of data analysis, forum moderator posted prominent announcement of research in forum, researchers posted again</td></tr>
</table>

B: Details for 42 studies of BD research via language analysis of online posts

<table>
<tr><th>Field of publication; first author</th><th>Focus or aim(s) (topic category)</th><th>Data sources, date, language</th><th>Data size, number of users, user characteristics</th><th>Ethical considerations summary</th></tr>
<tr><td></td><td></td><td></td><td></td><td>in forum halfway through the study, only share translated excerpts with replaced usernames to preserve confidentiality and anonymity</td></tr>
<tr><td colspan="2">Method: Conversation analysis (health research)</td><td colspan="3">Key findings: New users often seem to ask for experiences or reassurance but first are directed to seek diagnosis and professional support to reinforce dominant biomedical view in the forum</td></tr>
<tr><td colspan="5">Cyber-support: An analysis of online self-help forums (online self-help forums in bipolar disorder) (Bauer <i>et al.</i>, 2013)</td></tr>
<tr><td>Psychiatry; psychology</td><td>Fields of interest and self-help mechanisms of forum users (Study BD online peer support)</td><td>Two BD self-help forums from Germany and Austria, 2006, German</td><td>2400 posts, 218 users, 59% feminine users</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Framework analysis, factor analysis (health research)</td><td colspan="3">Key findings: Main self-help mechanisms: disclosure, friendship, online-group cohesion, factors: group cohesion, emotional support, exchange of information); most discussed topics: social network, symptoms, medication, factors: illness related aspects, social aspects, financial and legal aspects</td></tr>
<tr><td colspan="5">Quantifying Mental Health Signals in Twitter (Coppersmith, Dredze and Harman, 2014)</td></tr>
<tr><td>NLP and clinical psychology; NLP</td><td>Diagnosis prediction from tweets, Twitter usage; differences in language use between users with different MH diagnoses</td><td>Tweets by users with self-reported MH diagnosis, 2008-2013, English</td><td>992K tweets, 394 users</td><td>Abstract recommends ethical discussion on balancing utility vs. privacy of MH online data,</td></tr>
</table>

<table>
<tr><th>Field of publication; first author</th><th>Focus or aim(s) (topic category)</th><th>Data sources, date, language</th><th>Data size, number of users, user characteristics</th><th>Ethical considerations summary</th></tr>
<tr><td></td><td></td><td></td><td></td><td>do not collect private tweets</td></tr>
<tr><td colspan="2">Method: Classification: logistic regression with n-gram, manually defined, and LIWC features, LIWC content analysis (NLP)</td><td colspan="3">Key findings: Binary classification users with BD vs. no MH diagnosis: 64% recall at 10% false alarms, 82% recall at 20% false alarms; LIWC: significant differences in posts of users with BD diagnosis vs. undiagnosed users: 1st person pronouns (I/we), anxiety; no differences: 2nd/3rd person pronouns, positive emotions, negative emotions, swear, anger</td></tr>
<tr><td colspan="5">Bad on the net, or bipolars’ lives on the web: Analyzing discussion web pages for individuals with bipolar affective disorder (Latalova <i>et al.</i>, 2014)</td></tr>
<tr><td>Medicine; psychiatry</td><td>Topics and needs of participants in BD peer support online forum, patterns of interaction, conformity of views with professional opinions</td><td>Three anonymous, non-professional Czech BD self-help forums, until March 2014, Czech</td><td>436 posts, ? users</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Qualitative content analysis (health research)</td><td colspan="3">Key findings: Community open to newcomers, information consistent with professionals' views; topics: diagnosis, treatment, specifically: sex, death, childhood, partner, alcohol, symptoms; communication: questions, story, sharing, comfort, advice, encouragement; little empty talk (nonsense), rejection, criticism; relationships: acceptance, support, closeness, sharing personal information; support medication</td></tr>
</table>

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(topic category)</th><th>Data sources,
date,
language</th><th>Data size,
number of users,
user characteristics</th><th>Ethical considerations summary</th></tr>
<tr><td colspan="5">From ADHD to SAD: Analysing the Language of Mental Health on Twitter through Self-Reported Diagnoses (Coppersmith <i>et al.</i>, 2015)</td></tr>
<tr><td>NLP and clinical psychology; NLP</td><td>Diagnosis prediction from tweets, differences in language usage between users with different MH diagnoses</td><td>Tweets by users with (manually checked) self-reported MH diagnosis, 2008-2015, at least 75% English tweets per user</td><td>720K tweets, 188 users, automatically estimate age and gender for control matching, but do not report characteristics distributions, report MH comorbidities</td><td>Ethics committee approved research</td></tr>
<tr><td colspan="2">Method: Classification: logistic regression with character n-gram features, LIWC content analysis, hierarchical clustering of language similarity (NLP)</td><td colspan="3">Key findings: Binary classification users with BD diagnosis vs. age- and gender-matched undiagnosed users: 63% recall at 10% false alarms; LIWC: significant differences in posts of users with BD diagnosis vs. undiagnosed users: function words, auxiliar verbs, cognitive mechanisms, health</td></tr>
<tr><td colspan="5">How Patients Contribute to an Online Psychoeducation Forum for BD: A Virtual Participant Observation Study (Poole, Smith and Simpson, 2015)</td></tr>
<tr><td>MH; public health</td><td>Forms of forum participation and relevant issues</td><td>Online forum for participants in BD internet-based psychoeducation intervention trial, March 2009 - September 2010, English</td><td>127 posts, 13 users, living in the UK, 53.8% feminine users</td><td>Ethics committee approved research, participants provided informed consent to use forum data in research, do not publish direct quotes because consent statement did not include this</td></tr>
</table>

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(topic category)</th><th>Data sources,
date,
language</th><th>Data size,
number of users,
user characteristics</th><th>Ethical considerations summary</th></tr>
<tr><td colspan="2">Method: Thematic analysis, discourse analysis (health research)</td><td colspan="3">Key findings: Themes: medication, employment, stigma, social support, coping strategies, insight and acceptance, the life chart, negative experiences of health care; personal narratives, emotive language and humour; seek and offer advice, offer encouragement, empathy</td></tr>
<tr><td colspan="5">Differentiating Sub-groups of Online Depression-Related Communities Using Textual Cues (Wang <i>et al.</i>, 2015)</td></tr>
<tr><td>Computer science; computer science</td><td>MH topic prediction from posts</td><td>Randomly sampled posts from seven LiveJournal communities focusing on BD, ? date, English</td><td>1,000 posts, ? users</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Classification via logistic regression with LIWC and topic modelling features (NLP)</td><td colspan="3">Key findings: Binary classification posts from BD vs. other MH communities: 77.6% accuracy, important features: LIWC: health, anger, family, death, topics: medication, specifically Seroquel, and BD</td></tr>
<tr><td colspan="5">Subconscious Crowdsourcing: A Feasible Data Collection Mechanism for Mental Disorder Detection on Social Media (Chang, Saravia and Chen, 2016)</td></tr>
<tr><td>Computer science; information systems</td><td>Diagnosis prediction from posts</td><td>All tweets from users with a manually checked self-reported BD diagnosis in their Twitter bio with at least 100 tweets and less than 50% tweets with hyperlinks or in non-English who follow one of 12 Twitter accounts with many users that propagates BD information, ? date, English</td><td>347,774 tweets, 278 users, employ lexicon-based age and gender prediction but do not report results</td><td>None mentioned</td></tr>
</table>

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<tr><td colspan="2">Method: Classification via random forests with tf-idf, LIWC, and manually defined user features (emotions, sentiment, age, gender, tweeting behaviour) (NLP)</td><td colspan="3">Key findings: Binary classification users with self-reported BD diagnosis vs. random users with tf-idf features: 96% precision; vs. BD professionals with user features: 72% precision</td></tr>
<tr><td colspan="5">The language of mental health problems in social media (Gkotsis, Oellrich, <i>et al.</i>, 2016)</td></tr>
<tr><td>NLP and clinical psychology; NLP</td><td>Distinguish MH subreddits based on lexical content, compute text quality, sentiment and emotions in subreddits</td><td>Reddit posts in MH subreddits (BD: r/bipolar, r/BipolarSOs, r/BipolarReddit), ? date, predominantly English</td><td>396,255 posts, ? users</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Classification: manually defined features, extraction of text quality measures, closed-vocabulary sentiment and emotion analysis (NLP)</td><td colspan="3">Key findings: BipolarSOs has higher lexical complexity than other subreddits, can reliably distinguish posts from different subreddits based on content, mainly negative sentiment in BD subreddits, but happiness in BipolarSO subreddit</td></tr>
<tr><td colspan="5">Member roles and identities in online support groups: Perspectives from corpus and systemic functional linguistics (McDonald and Woodward-Kron, 2016)</td></tr>
<tr><td>Discourse and communication studies; computer science and linguistics</td><td>Roles and identities of forum members</td><td>International BD peer support forum, 2001-2014, English</td><td>57K posts (8.4M words), 5.7K users, most from anglophone countries (US and UK)</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Frequency lists, systemic functional linguistics (corpus linguistics, linguistics)</td><td colspan="3">Key findings: Established compared to new members prefer: ‘having BD’ over ‘being bipolar’, using modals and imperatives, references to meta discourse, jargonisation, vague language</td></tr>
</table>

B: Details for 42 studies of BD research via language analysis of online posts

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<tr><th>Field of publication; first author</th><th>Focus or aim(s) (topic category)</th><th>Data sources, date, language</th><th>Data size, number of users, user characteristics</th><th>Ethical considerations summary</th></tr>
<tr><td colspan="5">A Framework for Classifying Online Mental Health-Related Communities With an Interest in Depression (Saha <i>et al.</i>, 2016)</td></tr>
<tr><td>Health informatics; data science</td><td>MH topic prediction from posts</td><td>Personal blogs from LiveJournal with BD topic category, ? date, English</td><td>About 86K posts, about 11K users</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Classification via logistic regression with LIWC and topic modelling features, single-task and multi-task models (NLP)</td><td colspan="3">Key findings: Multi-class classification posts with BD vs. other MH topic categories (multi-task model): 89.9% area under the curve; predictive features for BD: LIWC: sad, death, topic: cutting blood scars, depression meds anxiety disorder, heart pain inside</td></tr>
<tr><td colspan="5">MIDAS: Mental illness detection and analysis via social media (Saravia <i>et al.</i>, 2016)</td></tr>
<tr><td>Computer science; computer science</td><td>Diagnosis prediction from tweets</td><td>Tweets of people with self-reported BD (manually identified among followers of Twitter accounts that propagate BD information with large numbers of followers, community portals), ? date, English</td><td>? tweets, 278 users, employ lexicon-based age and gender prediction but do not report characteristics distributions</td><td>Anonymise usernames in dataset and presented examples to protect privacy</td></tr>
<tr><td colspan="2">Method: Classification: random forests with tf-idf and manually defined features (age, gender, polarity, Twitter social features) (NLP)</td><td colspan="3">Key findings: Binary classification users with BD vs. no MH diagnosis (tf-idf): 96% precision</td></tr>
<tr><td colspan="5">Multi-Task Learning for Mental Health using Social Media Text (Benton, Mitchell and Hovy, 2017)</td></tr>
<tr><td>NLP; computer science</td><td>Diagnosis prediction from posts</td><td>Same data as Coppersmith et al. (2015)</td><td>See Coppersmith et al. (2015), 76.1% feminine users for</td><td>None mentioned</td></tr>
</table>

Field of publication; first author	Focus or aim(s) (topic category)	Data sources, date, language	Data size, number of users, user characteristics	Ethical considerations summary
			manually annotated subsample across all MH issues	
Method: Classification: logistic regression with most frequent 1-5 gram features, neural networks (NLP)		**Key findings:** Multi-class classification users with BD vs. other MH diagnoses: <30% recall (10% false alarms)		
Characterisation of mental health conditions in social media using Informed Deep Learning (Gkotsis et al., 2017)				
Natural sciences, psychology, medicine and engineering; NLP	Automatically identify MH-related posts	Reddit posts in MH subreddits (BD: r/bipolar, r/BipolarSOs, r/BipolarReddit), June - August 2015, predominantly English	41,636 posts in BD subreddits, ? users	None mentioned
Method: Classification: logistic regression, support vector machines, neural networks (NLP)		**Key findings:** Binary classification MH vs. non-MH subreddit posts: 90% F-score; multi-class classification BD vs. other MH subreddit posts: 67% F-score, BD most frequently confused with depression subreddits posts		
'Being bipolar': A qualitative analysis of the experience of bipolar disorder as described in internet blogs (Mandla, Billings and Moncrieff, 2017)				
MH; psychiatry	Views of BD (symptoms, diagnosis, causes, treatment) by people with self-reported diagnosis	Posts from 12 blogging websites, ? date, English	45 posts, 22 users, gender: 68.2% feminine, 18.2% masculine; age: 22.7% 35-50, 31.8% > 50; country: 45.5% US, 4.5% South Africa	Did not seek ethical approval because blogs were public, anonymised posts

Field of publication; first author	Focus or aim(s) (topic category)	Data sources, date, language	Data size, number of users, user characteristics	Ethical considerations summary
			(differences to 100% unknown)	
Method: Thematic analysis (health research)		**Key findings:** Key BD symptoms: extreme and frequent mood fluctuations; rather broad, inclusive BD concept; medicalised model of BD consistent with drug company websites; positive aspects ascribed to personality; negative aspects externalised to BD		
SMHD: A Large-Scale Resource for Exploring Online Language Usage for Multiple Mental Health Conditions (Cohan et al., 2018)				
NLP; NLP	Collect dataset of social media posts of people with different self-reported MH diagnoses, examine linguistic differences between people with different/no diagnoses, develop text classifiers to infer people's diagnosis from their posts	Reddit posts (outside of MH subreddits and who do not mention MH issues) by users with self-reported MH diagnoses, June 2006 - December 2017, predominantly English	575K posts (26.2M words), 6.4K users, report MH comorbidities	Ethics statement: do not publish any data excerpts, do not contact users, replace usernames to protect privacy, only share data under usage agreement
Method: Classification: logistic regression, decision trees, support vector machines, neural networks, LIWC content analysis (NLP)		**Key findings:** Binary classification users with BD vs. no MH diagnosis: 51% F-score; LIWC: significant increases in posts of users with BD diagnosis vs. undiagnosed users: authenticity, words per sentence, dictionary words, total function words, total pronouns, personal pronouns, 1st person singular, 3rd person singular, prepositions, auxiliary verbs, common adverbs, conjunctions, common verbs, social processes, female references, cognitive processes, tentative, health, past focus, present focus; significantly decreased: numbers, leisure, money, netspeak		

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<tr><td colspan="5">Hierarchical neural model with attention mechanisms for the classification of social media text related to mental health (Ive <i>et al.</i>, 2018)</td></tr>
<tr><td>NLP; computer science</td><td>Automatically identify MH-related posts</td><td>Same as Gkotsis et al (2017)</td><td>See Gkotsis et al (2017)</td><td>Paraphrase post excerpts in article in line with ethical guidelines</td></tr>
<tr><td colspan="2">Method: Classification: different neural network models with word embedding features (NLP)</td><td colspan="3">Key findings: Multi-class classification posts from BD vs. MH subreddits (recurrent neural network with attention): 73% F-score</td></tr>
<tr><td colspan="5">Harnessing reddit to understand the written-communication challenges experienced by individuals with mental health disorders: Analysis of texts from mental health communities (Park and Conway, 2018)</td></tr>
<tr><td>Health research; biomedical and health informatics</td><td>Understand the impact of MH issues on written communication related to language impairment</td><td>Reddit posts from r/bipolar, January 2010 - May 2015, English</td><td>146,328 posts, 5,019 users</td><td>User privacy statement, research exempt from university's ethics committee, do not report user identifiable information to protect privacy</td></tr>
<tr><td colspan="2">Method: Automatic calculation of lexical diversity and readability, comparisons between MH subreddits and within users over time (NLP)</td><td colspan="3">BD posts had lower readability and lexical diversity than control subreddits, improvement of users over time</td></tr>
<tr><td colspan="5">Not Just Depressed: Bipolar Disorder Prediction on Reddit (Sekulić, Gjurković and Šnajder, 2018)</td></tr>
<tr><td>NLP; NLP</td><td>Diagnosis prediction from posts</td><td>Reddit comments (outside of MH subreddits and who do not mention MH issues) by users with self-reported</td><td>5M comments (163M words), 4,619 users</td><td>None mentioned</td></tr>
</table>

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<tr><td></td><td></td><td>BD diagnosis, 2005-2018, predominantly English</td><td></td><td></td></tr>
<tr><td colspan="2">Method: Classification: logistic regression, support vector machine, random forest with LIWC, emotion, bag of words, and manually defined Reddit features, LIWC content analysis (NLP)</td><td colspan="3">Key findings: Binary classification users with BD vs. no MH diagnosis (random forest): 86.3% F-score; LIWC: increases in posts of users with BD diagnosis vs. undiagnosed users: positive emotion, I; decrease: negative emotion, clout; more monthly variation in emotions for BD vs control users</td></tr>
<tr><td colspan="5">Analyzing Judgment in Bipolar Depression Patients’ Narratives Using Syntactic Patterns: A Corpus-Based Study (Abdo, Ali and Sarhan, 2019)</td></tr>
<tr><td>NLP; linguistics</td><td>Judgment types (appraisal theory)</td><td>MH support forum posts containing a self-reported BD diagnosis statement, ?, English</td><td>1.6M words, ? users</td><td>None mentioned</td></tr>
<tr><td colspan="2">Systemic functional linguistics, framework analysis (corpus linguistics, linguistics)</td><td colspan="3">Key findings: Most frequent judgment types: capacity (self-esteem), propriety (social sanction), more positive than negative judgment overall</td></tr>
<tr><td colspan="5">Ketosis and bipolar disorder: controlled analytic study of online reports (Campbell and Campbell, 2019)</td></tr>
<tr><td>Psychiatry; health research and computer science</td><td>Find evidence for effect of ketosis diet on mood stabilisation</td><td>Posts in ten BD forums with most members identified via Google search that mention ketogenic, vegetarian diet, or omega 3, ? date, English</td><td>259 posts, 274 users, 66.7% bipolar II disorder, 33.% bipolar I disorder for 24 users with reported subtype of BD diagnosis</td><td>Ethics statement: ethics committee accepted self-audit checklist, considered public posting as consent for data analysis, do not publish forum details or quotes to protect anonymity</td></tr>
</table>

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<tr><td colspan="2">Method: Manual deductive coding (outcome rating), significance tests (health research)</td><td colspan="3">Key findings: Significantly more reports of mood stabilisation or symptom remission for ketogenic diet than for other diets</td></tr>
<tr><td colspan="5">Tweeting your mental health: Exploration of different classifiers and features with emotional signals in identifying mental health conditions (Chen and Jackson, 2019)</td></tr>
<tr><td>Computer science; information management</td><td>Diagnosis prediction from tweets</td><td>Tweets by users with a self-reported BD diagnosis, November 2016 - February 2017, English</td><td>? tweets, 438 users</td><td>Only include public tweets, no private messages or protected user accounts</td></tr>
<tr><td colspan="2">Method: Classification: logistic regression, support vector machines, random forests, decision trees, naive bayes via LIWC, manually defined user behaviour, and lexicon-based emotion features (NLP)</td><td colspan="3">Key findings: Binary classification users with BD vs. randomly sampled users (logistic regression, LIWC, manually defined user behaviour features, lexicon-based emotions): 90.3% F-score</td></tr>
<tr><td colspan="5">Leveraging Linguistic Characteristics for Bipolar Disorder Recognition with Gender Differences (Huang et al., 2019)</td></tr>
<tr><td>Computer science; computer science</td><td>Diagnosis prediction from tweets (3 months prior to diagnosis)</td><td>Tweets with self-reported BD diagnosis including the diagnosis time, 2012-2018, predominantly English</td><td>1,819 tweets, 349 users, 66.2% feminine users</td><td>Ethics statement: model only intended as assistive tool (rather than offering diagnosis) if MH professional and patient agree to use it, personal user information de-identified to protect privacy</td></tr>
</table>

Field of publication; first author	Focus or aim(s) (topic category)	Data sources, date, language	Data size, number of users, user characteristics	Ethical considerations summary
Method: Classification: random forests with LIWC and bag of words features, neural networks with word embeddings and syntactic pattern features (NLP)		**Key findings:** Binary classification users with BD vs. no MH diagnosis (neural networks with syntactic pattern features): 91% F-score; first person singular pronouns 1.7 times more frequent in BD vs. control tweets		
Bipolar disorder, Genetic Risk, and Reproductive Decision-Making: A Qualitative Study of Social Media Discussion Boards (Sahota and Sankar, 2019)				
Qualitative health research; psychiatry	Reproductive decision-making	Reddit (r/bipolar and r/BipolarReddit), 2009-2013, English	9 threads, ? users	Did not seek ethical approval because consider it a textual analysis rather than human subject research, all posts are anonymous, public, and without identifying information
Method: Inductive coding consistent with grounded theory (health research)		**Key findings:** Central issue in reproductive decision-making: manageability of parenting children for people with BD diagnosis; past, present, future experiences or anticipations influence considerations		
Adapting Deep Learning Methods for Mental Health Prediction on Social Media (Sekulić and Strube, 2019)				
NLP; NLP	Diagnosis prediction from posts	Same data as Cohan et al. (2018) but different control user allocation	See Cohan et al. (2018)	Ethics statement: obtained data under usage agreement, do not attempt to contact users or link their information with other data

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<tr><td colspan="2">Method: Classification: logistic regression, support vector machines, neural networks (NLP)</td><td colspan="3">Key findings: Binary classification users with BD vs. no MH diagnosis: 67% F-score</td></tr>
<tr><td colspan="5">A Novel Co-Training-Based Approach for the Classification of Mental Illnesses Using Social Media Posts (Tariq <i>et al.</i>, 2019)</td></tr>
<tr><td>Computer science; computer science</td><td>Diagnosis prediction from posts</td><td>Up to 1,000 highest rated non-deleted Reddit submissions from r/bipolar and 5 highest-rated comments, ? date, English</td><td>1,000 or a bit less submissions, ? users</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Classification: random forests, support vector machine, naive bayes with tf-idf features (NLP)</td><td colspan="3">Key findings: Multi-class classification BD vs. other MH subreddit posts (random forests, naive bayes): 71% F-score</td></tr>
<tr><td colspan="5">Predicting future mental illness from social media: A big-data approach (Thorstad and Wolff, 2019)</td></tr>
<tr><td>Psychology; data science</td><td>Diagnosis prediction from posts (3 studies)</td><td>(1) Reddit posts from r/bipolar without MH issue mentions (2) Reddit posts by users who posted in r/bipolar, excluding posts in MH subreddits (3) Posts from (2) prior to first post in MH subreddit, 2012 - 2017, English</td><td>(1) 56,009 posts, ? users (2) ? posts, 6,109 users (3) ? posts, 4,513 users</td><td>Discussion of dual use, suggest to notify users about analysis of their posts</td></tr>
<tr><td colspan="2">Method: Classification via logistic regression with tf-idf features, open-vocabulary content</td><td colspan="3">Key findings: (1) Multi-class classification posts from BD vs. three other MH subreddits: 75% F-score (2) Multi-class classification users who posted in BD vs. other MH subreddits: 34% F-score (3) Multi-class classification users who posted</td></tr>
</table>

Field of publication; first author	Focus or aim(s) (topic category)	Data sources, date, language	Data size, number of users, user characteristics	Ethical considerations summary
analysis via clustering of most predictive features (NLP)		in BD vs. other MH subreddits only using posts prior to first MH subreddit post: 37% F-score		
Semantic network analysis for understanding user experiences of bipolar and depressive disorders on Reddit (Yoo, Lee and Ha, 2019)				
Computer science; interaction science	How do people with BD or depression diagnosis share their experiences and feelings in online communities; differences in post content from people with BD vs. depression diagnosis	Redddit (most popular posts in r/bipolar and r/depression subforums), most popular posts on 1 May 2018 (potentially dating back until 2005), predominantly English	2433 posts (BD), 2966 posts (depression), ? users	None mentioned
Method: Content analysis via semantic maps and LIWC (NLP)		**Key findings:** BD semantic network clusters: treatment after BD diagnosis, manic/depressive episodes, BD-related mental illness, symptoms and feelings, medication type and side effects, negative feelings and suicidal thoughts, cost of suffering and emotion, sleeping problems, episodes at night, and mood swings, school issues, time-related words; LIWC: BD vs. depression subreddits posts: more analytical thinking, lower authenticity, no differences for clout and emotional tone		
Mental illness and bipolar disorder on Twitter: implications for stigma and social support (Budenz *et al.*, 2020)				
MH; public health	Quantify the distribution of stigma and social support messaging about BD vs. other MH issues	Tweets with BD or MH keywords or hashtags, November 2016 - February 2017, English	6.7M tweets, 2M users (1.3M tweets by 40K users automatically analysed), ? country	None mentioned

<table>
<tr><th>Field of publication; first author</th><th>Focus or aim(s) (topic category)</th><th>Data sources, date, language</th><th>Data size, number of users, user characteristics</th><th>Ethical considerations summary</th></tr>
<tr><td colspan="2">Method: Manual content analysis, bag of words classifiers to predict stigma, support, topic, purpose of tweets (health research, NLP)</td><td colspan="3">Key findings: Support more prevalent than stigma, BD tweets compared to general MH tweets contained less displays of support, more of stigma</td></tr>
<tr><td colspan="5">Detection of Mental Health Conditions from Reddit via Deep Contextualized Representations (Jiang <i>et al.</i>, 2020)</td></tr>
<tr><td>NLP; computer science</td><td>Diagnosis prediction from posts</td><td>Reddit posts (in non-MH subreddits and who do not mention MH issues) by users with a self-reported BD diagnosis, ? date, English</td><td>5,819,000 posts, 11,186 users</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Classification: logistic regression with LIWC features and neural networks with word embedding features (NLP)</td><td colspan="3">Binary classification users with BD vs. other or no MH diagnosis (neural networks): 98.2% F-score, multi-class classification posts of users with BD vs. other or no MH diagnosis (neural networks): 61.5% F-score</td></tr>
<tr><td colspan="5">A deep learning model for detecting mental illness from user content on social media (Kim <i>et al.</i>, 2020)</td></tr>
<tr><td>Natural sciences, psychology, medicine and engineering; information science</td><td>Diagnosis prediction from posts</td><td>Reddit posts from r/bipolar, January 2017 - December 2018, English</td><td>41,493 posts, 14,372 users</td><td>University's ethics committee approved the research and imposed anonymisation process of posts</td></tr>
<tr><td colspan="2">Method: Classification: gradient boosting with tf-idf features vs. convolutional neural networks with word embedding features (NLP)</td><td colspan="3">Key findings: Binary classification posts from BD subreddit vs. other MH subreddits (neural network): 53.0% F-score</td></tr>
</table>

<table>
<tr><th>Field of publication; first author</th><th>Focus or aim(s) (topic category)</th><th>Data sources, date, language</th><th>Data size, number of users, user characteristics</th><th>Ethical considerations summary</th></tr>
<tr><td colspan="5">Natural Language Processing Reveals Vulnerable Mental Health Support Groups and Heightened Health Anxiety on Reddit during COVID-19: An Observational Study (Low <i>et al.</i>, 2020)</td></tr>
<tr><td>Health research; NLP and cognitive science</td><td>Characterise changes in MH subreddits during the initial stages of the Covid-19 pandemic</td><td>Reddit posts from r/BipolarReddit, November 2018 - 2019 (pre pandemic) and January - April 2020 (mid pandemic), English</td><td>1,500 - 2,700 randomly sampled pre-pandemic posts, 1,300 mid-pandemic posts, ? users, do not provide sample-specific user characteristics but state that Reddit users in general are predominantly American, masculine, and young</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Classification: logistic regression, support vector machine, decision trees with manually defined and lexicon-based features including LIWC and tf-idf, trend analysis via logistic regression, comparative automatic content analysis via clustering and topic modelling of pre- and mid-pandemic posts (NLP)</td><td colspan="3">Key findings: Multi-class classification BD vs. other (non-)MH subreddit posts (logistic regression): 81.1% F-score; features with positive coefficients: bipolar, manic, mania, lithium, mood, episod, psychiatrist, hospit, med and LIWC money; no negative semantic change by mid pandemic</td></tr>
<tr><td colspan="5">Characterizing the psychiatric drug responses of Reddit users from a socialomics perspective (Song and Xie, 2020)</td></tr>
<tr><td>Information science; information science</td><td>Measure drug effects (intended, side,</td><td>Reddit posts that mention 'bipolar disorder' from</td><td>1,460,447 posts, ? users</td><td>None mentioned</td></tr>
</table>

<table>
<tr><th>Field of publication; first author</th><th>Focus or aim(s) (topic category)</th><th>Data sources, date, language</th><th>Data size, number of users, user characteristics</th><th>Ethical considerations summary</th></tr>
<tr><td></td><td>psychological) via online posts</td><td>r/bipolar and r/bipolar2, ? date, English</td><td></td><td></td></tr>
<tr><td colspan="2">Method: Content analysis via semantic nets and word embeddings for LIWC features affect, cognitive, perceptual, social, personal concern, and lexicon-based side effects (NLP)</td><td colspan="3">Key findings: Lithium is the most frequent drug, heat stroke, high cholesterol, paranoia, and seizures may be newly detected side effects</td></tr>
<tr><td colspan="5">Emotion-based Modeling of Mental Disorders on Social Media (Guo, Sun and Vosoughi, 2021)</td></tr>
<tr><td>Computer science; computer science</td><td>Diagnosis prediction from posts via user emotional state</td><td>Reddit posts by users with self-reported diagnosis prior to first self-reported diagnosis statement, 2011 - 2019, English</td><td>? posts, 1,997 users</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Classification: logistic regression, support vector machines, random forests with emotion features from a neural network model, BERT neural network model (NLP)</td><td colspan="3">Key findings: Multi-class classification users with BD vs. depression or anxiety disorder or no MH diagnoses (BERT): 86.6% F-score; random forest model with emotion features compares comparably to neural network model with content features</td></tr>
<tr><td colspan="5">LiBRA: A Linguistic Bipolar Disorder Recognition Approach (Huang <i>et al.</i>, 2021)</td></tr>
<tr><td>Computer science; computer science</td><td>Diagnosis prediction from posts via syntactic patterns that works equally well for users with feminine and masculine gender identity</td><td>Same data as Huang et al. (2019)</td><td>See Huang et al. (2019)</td><td>Ethics statement: model only intended as assistive tool (rather than offering diagnosis) if MH professional and patient agree to use it, personal user information de-</td></tr>
</table>

<table>
<tr><th>Field of publication; first author</th><th>Focus or aim(s) (topic category)</th><th>Data sources, date, language</th><th>Data size, number of users, user characteristics</th><th>Ethical considerations summary</th></tr>
<tr><td></td><td></td><td></td><td></td><td>identified to protect privacy</td></tr>
<tr><td colspan="2">Method: Classification: random forests with tf-idf or LIWC features, neural networks with word-embedding features, graph-based model with syntactic features), open-vocabulary emotion analysis (NLP)</td><td colspan="3">Key findings: Binary classification users with BD vs. randomly sampled users (graph-based model with syntactic patterns): 91% F-score, model works better for feminine than masculine users, top-performing syntactic patterns seem to convey negative emotions (anger and sadness), 33-50% of LIWC categories significantly differ for tweets from feminine vs. masculine users</td></tr>
<tr><td colspan="5">Classification of mental illnesses on social media using RoBERTa (Murarka and Raleigh, 2021)</td></tr>
<tr><td>NLP; computer science</td><td>Diagnosis prediction from posts</td><td>Submissions from BD subreddits, ? date, English</td><td>3,009 posts, ? users</td><td>Remove URLs and usernames to publicly release data</td></tr>
<tr><td colspan="2">Method: Classification: various neural network models (NLP)</td><td colspan="3">Key findings: Multi-class classification users with BD vs. other or no MH diagnoses (RoBERTa, title and text): 86% F-score</td></tr>
<tr><td colspan="5">Predicting user emotional tone in mental disorder online communities (Silveira <i>et al.</i>, 2021)</td></tr>
<tr><td>Computer science; computer science</td><td>How do interactions in online support groups affect users' emotions?</td><td>Reddit posts from r/bipolar, 2017, English</td><td>15,825 submissions and their 136,824 comments, 11,363 users</td><td>State that models do not use any user features, hence can be implemented without harming their privacy</td></tr>
<tr><td colspan="2">Method: Predict emotional tone of last comment in thread by thread author from submission and comments via neural network with lexicon-based sentiment analysis features and word embeddings (NLP)</td><td colspan="3">Key findings: Emotional state improves through interaction: emotional tone of all comments (including last) is more positive than submission</td></tr>
</table>

<table>
<tr><th>Field of publication; first author</th><th>Focus or aim(s) (topic category)</th><th>Data sources, date, language</th><th>Data size, number of users, user characteristics</th><th>Ethical considerations summary</th></tr>
<tr><td colspan="5">Mental Illness Classification on Social Media Texts using Deep Learning and Transfer Learning (Ameer <i>et al.</i>, 2022)</td></tr>
<tr><td>Computer science; NLP</td><td>Diagnosis prediction from posts</td><td>Same data as Murarka et al. (2021)</td><td>See Murarka et al. (21) but state using 2,956 posts (rather than 3,009 in the dataset source)</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Classification: logistic regression, support vector machines, random forests, naive bayes, and various neural network models (NLP)</td><td colspan="3">Key findings: Multi-class classification users with BD vs. other or no MH diagnoses (RoBERTa with transfer learning): 80% F-score</td></tr>
<tr><td colspan="5">Bipolar disorder detection over social media (Kadkhoda <i>et al.</i>, 2022)</td></tr>
<tr><td>Computer science and medicine; computer science</td><td>Diagnosis prediction from tweets</td><td>Tweets by Twitter users with at least 100 tweets who stated ‘I was diagnosed with bipolar disorder’, January 2018 - April 2019, English</td><td>? tweets, 1000 randomly sampled users</td><td>None mentioned</td></tr>
<tr><td colspan="2">Method: Classification: logistic regression, support vector machines, random forests, decision trees, and others via tweet-based (sentiment, emotions, phonemes, phonetic associations) and user-based (sleep-wake cycles, tweets per day) features and modelling of within-user changes in a graph-based model (NLP)</td><td colspan="3">Key findings: Binary classification users with BD vs. randomly sampled users (decision tree, aggregate tweets on daily level): 85% F-score</td></tr>
</table>

Field of publication; first author	Focus or aim(s) (topic category)	Data sources, date, language	Data size, number of users, user characteristics	Ethical considerations summary
A computational approach to understand mental health from reddit: knowledge-aware multitask learning framework (Lokala *et al.*, 2022)				
Computer science; computer science	Diagnosis (MH issues as cardiovascular disease comorbidities) and gender prediction from posts	Posts from r/bipolar subreddit that also mention cardiovascular disease, ?, English	3,812 posts, 1,044 (1,128) users who wrote a submission (comment), 53.3% (42.2%) feminine users who wrote a submission (comment)	Ethical statement, discuss risks of their approach, remove sensitive information from data, publication only shares anonymised and paraphrased posts
Method: Classification: various neural network models (NLP)		**Key findings:** Multi-class classification users with BD vs. other MH diagnoses: 87% F-score; gender identification: 82% F-score (feminine), 78% F-score (masculine)		
Integrated entitymetrics analysis for health information on bipolar disorder using social media data and scientific literature (Song and Kim, 2022)				
Information management; information science	Analyse BD-related MH entities and their relationships in Reddit posts and scientific articles	Reddit posts from r/bipolar and r/bipolar2, November 2019 - January 2020, English	1,460,447 posts, ? users	None mentioned
Method: Content analysis via LIWC and lexicon- and rule-based health entity identification, network models of entities and relationships (NLP)		**Key findings:** Most prominent topics in Reddit posts: medication, side effects, affect, negative feelings towards taking BD medication, personal and social environment		

Field of publication; first author	Focus or aim(s) (topic category)	Data sources, date, language	Data size, number of users, user characteristics	Ethical considerations summary
Exploring Hybrid and Ensemble Models for Multiclass Prediction of Mental Health Status on Social Media (Zanwar *et al.*, 2022)				
NLP; computer science	Diagnosis prediction from posts	Subset of SMHD dataset (Cohan *et al.*, 2018), randomly sampled posts by distinct users	1,848 posts, 1,848 users	None mentioned
Method: Classification: various neural network models with manually defined and lexicon-based features including LIWC (NLP)		**Key findings:** Multi-class classification users with BD vs. other or no MH diagnoses (BERT model): 19.8% F-score		

C Ethical approval

Lancaster
University

Applicant: Glorianna Jagfeld
Supervisor: Steve Jones, Fiona Lobban, Paul Rayson
Department: Health Research
FHMREC Reference: FHMREC18066

03 May 2019

Dear Glorianna

Re: Talking about personal recovery in bipolar disorder

Thank you for submitting your research ethics application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC).** The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

As principal investigator your responsibilities include:

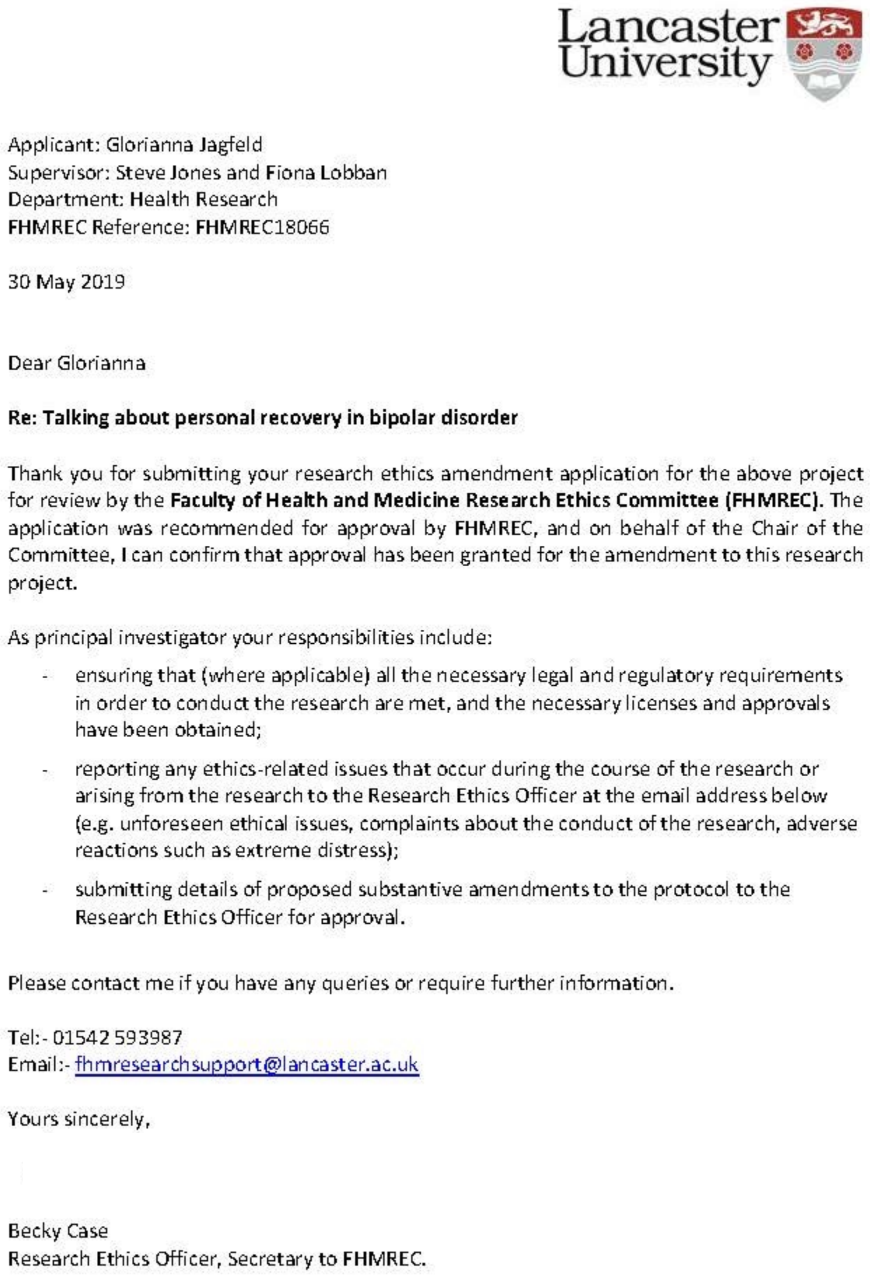
- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Becky Case
Research Ethics Officer, Secretary to FHMREC.



Lancaster University

Applicant: Glorianna Jagfeld
Supervisor: Steve Jones and Fiona Lobban
Department: Health Research
FHMREC Reference: FHMREC18066

30 May 2019

Dear Glorianna

Re: Talking about personal recovery in bipolar disorder

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC).** The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

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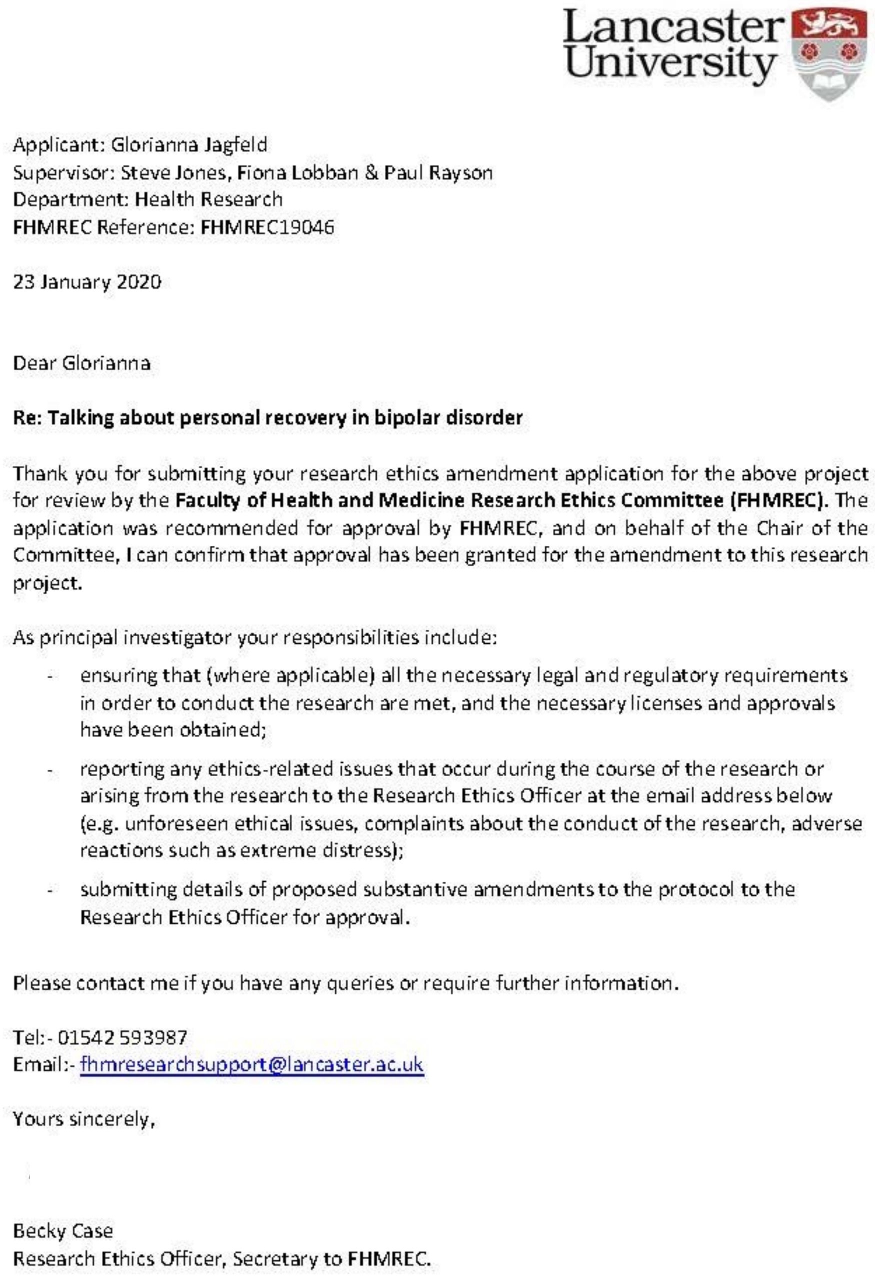
Yours sincerely,

Becky Case
Research Ethics Officer, Secretary to FHMREC.

C: Ethical approval



Lancaster University

Applicant: Glorianna Jagfeld
Supervisor: Steve Jones, Fiona Lobban & Paul Rayson
Department: Health Research
FHMREC Reference: FHMREC19046

23 January 2020

Dear Glorianna

Re: Talking about personal recovery in bipolar disorder

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC).** The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

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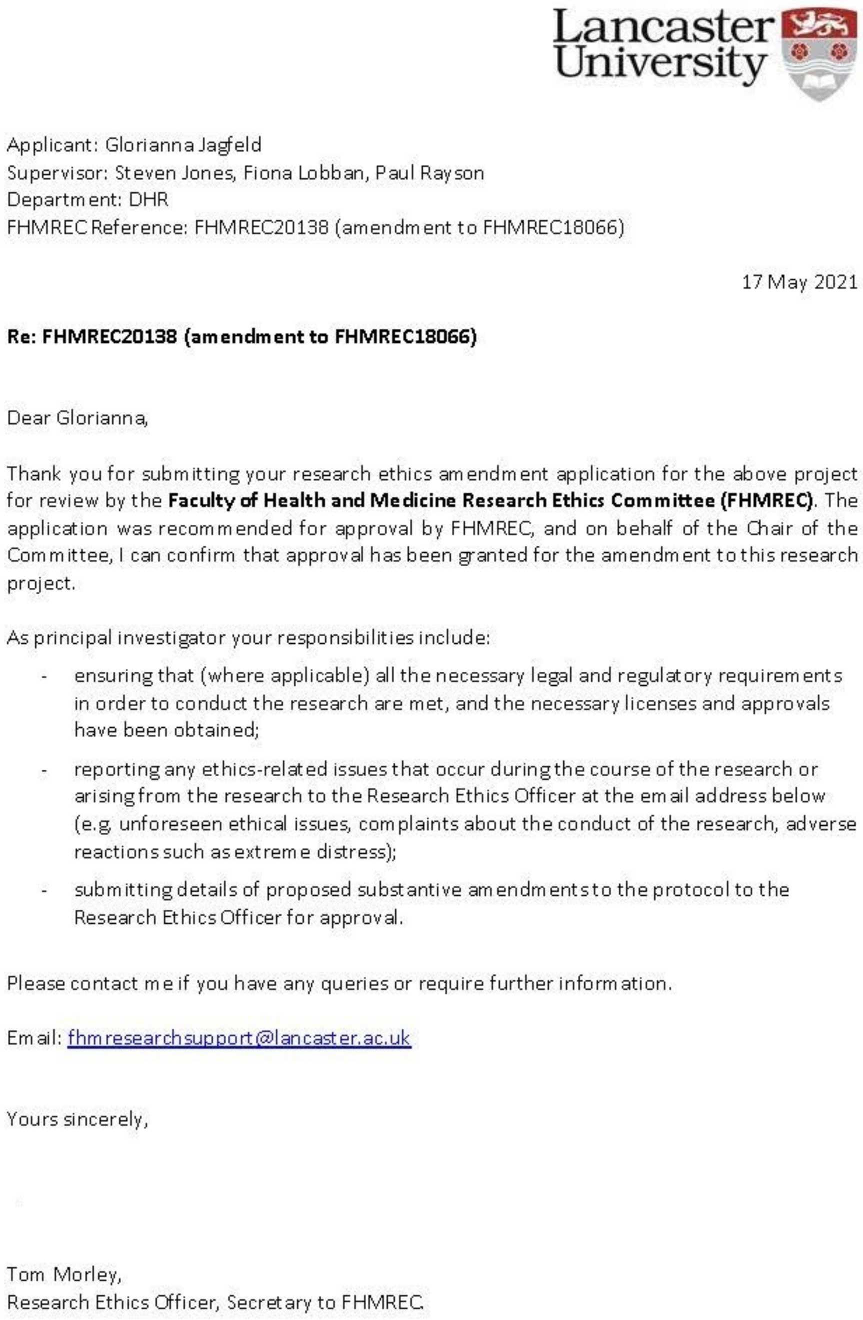
Please contact me if you have any queries or require further information.

Tel:- 01542 593987
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Becky Case
Research Ethics Officer, Secretary to FHMREC.

C: Ethical approval



Lancaster University

Applicant: Glorianna Jagfeld
Supervisor: Steven Jones, Fiona Lobban, Paul Rayson
Department: DHR
FHMREC Reference: FHMREC20138 (amendment to FHMREC18066)

17 May 2021

Re: FHMREC20138 (amendment to FHMREC18066)

Dear Glorianna,

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

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- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Email: fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

Tom Morley,
Research Ethics Officer, Secretary to FHMREC.

D Supplementary tables for the POETIC review (Chapter 4)

Table S2 Participant and study details of the twelve included articles (?: not reported or unknown)

Title, reference, country	Participant characteristics (age (mean+/-SD (range)))	Diagnosis, medication	Participant inclusion criteria	Research aims	Data collection, analysis	Recovery definition	Main themes
The process of recovery from bipolar I disorder: A qualitative analysis of personal accounts in relation to an integrative cognitive model (Mansell *et al.*, 2010), UK	**Participants:** 13 **Age:** 50.5+/-8.4 (33-61) **Gender:** female 9 **Ethnicity/nationality:** ? **Employment:** employed 9, unemployed 3, retired 1 **Qualification level:** postgraduate 3, degree 3, A-levels 3, GCE 4 **Other:** had psychotherapy 7	**Diagnosis:** BD I 13 **Medication:** 10	DSM-IV diagnosis of BD I, no relapse or hospitalization for at least 2 years	Characterize the personal experience of recovery in people with a diagnosis of BD	Semi-structured interviews, interpretative phenomenological analysis	Having remained free from relapse, and without hospitalization for at least 2 years (discussed as 'arbitrary' definition)	Ambivalent approaches: 1) Avoidance of mania 2) Taking medication 3) Prior illness versus current wellness 4) Sense of identity following diagnosis Helpful approaches: 1) Understanding 2) Life-style fundamentals 3) Social support and companionship 4) Social change
Implications for psychiatric care of the word "recovery" in people with bipolar disorder (Michalak *et al.*, 2012), Canada	**Participants:** 13 **Age:** median 41 **Gender:** female 10 **Ethnicity/nationality:** ? **Employment:** ? **Qualification level:** postsecondary degree/additional education 5, High School 8	**Diagnosis:** mixed sample of BD I and II **Medication:** ?	Self-reported diagnosis of BD I or II, age 19-65, fluent in English	Determine what the term recovery means to a sample of Canadians living with BD	Focus groups on research centre community engagement day,	Personal recovery does not by necessity require the full abatement of symptoms or complete restoration of functioning; rather, it refers to living a meaningful life	The meaning of recovery: 1) Rethinking the language of recovery 2) Shifting the framework 3) The art of managing BD 4) Understanding the journey: sense of self, the role of loss and acceptance, letting go of stigma

Title, reference, country	Participant characteristics (age (mean+/-SD (range)))	Diagnosis, medication	Participant inclusion criteria	Research aims	Data collection, analysis	Recovery definition	Main themes
					thematic analysis	beyond the restrictions of the illness.	
"Recovery" in bipolar disorder: How can service users be supported through a self-management intervention? A qualitative focus group study (Todd, Jones and Lobban, 2012), UK	**Participants:** 12 **Age:** 41.5 +/- 8.8 (29-56) **Gender:** female 5 **Ethnicity/nationality:** White British 11, other 1 **Employment:** full time 6, part time 2, voluntary 2, unemployed 2 **Qualification level:** ? **Other:** mean number of days since last episode 280	**Diagnosis:** BD I 8 (with rapid cycling 1), BD II 4 **Medication:** all	BD diagnosis by health professional, age 16-65	Explore how an opportunistically recruited group of service users with BD experience recovery and self-management to further understand how service users' recovery could be supported	Focus groups, thematic analysis	Process by which people can live fulfilling lives despite experiencing MH symptoms	1) Recovery is not about being symptom free 2) Recovery requires taking responsibility for your own wellness 3) Self-management: building on existing techniques 4) Overcoming barriers to recovery: negativity, stigma and taboo
Toward caring for oneself in a life of intense ups and downs: A reflexive-collaborative exploration of recovery in bipolar disorder (Veseth *et al.*, 2012), Norway	**Participants:** 13 **Age:** 47 +/- ? (27-65) **Gender:** Female 7 **Ethnicity/nationality:** ? **Employment:** full time 3, part time 3, disability pension 7 **Qualification level:** ? **Other:** relationship status: in relationship 9, single 4, socioeconomic status: none reported financial worries,	**Diagnosis:** mixed sample of BD I and II **Medication:** ?	(Were) receiving care for BD, identify as having had experiences of recovery from BD; exclusion: primary diagnosis of alcohol or substance	Investigate and explore the lived experiences of improvement in BD: What do individuals with BD do to promote their own recovery, and what challenges do they meet?	Open ended interviews, systematic text condensation modified in hermeneutic way,	Process of restoring a meaningful sense of belonging to one's community and positive sense of identity apart from one's condition while rebuilding a life despite or within the limitations	Towards caring for oneself in a life of intense ups and downs: 1) Handling ambivalence about letting go of manic states 2) Finding something to hang on to when the world is spinning around 3) Becoming aware of signals from self and others

Title, reference, country	Participant characteristics (age (mean+/-SD (range)))	Diagnosis, medication	Participant inclusion criteria	Research aims	Data collection, analysis	Recovery definition	Main themes
	years with BD symptoms: 18 (2-30)		abuse, inpatient or electro-convulsive treatment within previous 6 months		emphasising reflex-ivity	imposed by that condition	4) Finding ways of caring for oneself
The role of work in recovery from bipolar disorders (Borg *et al.*, 2013), Norway	Secondary analysis of data from Veseth et al. (2012)	See Veseth et al. (2012)	See Veseth et al. (2012)	Understand the role of work in recovery from BD and how people with BD deal with work-related challenges	Sec-ondary analysis, thematic and pheno-meno-logical analysis	Learning how to live a safe, dignified, full and self-determined life, at times in the face of the enduring symptoms of a serious mental illness	1) Many types of work – finding meaning and a focus 2) Helpful roles and contexts – to be much more than a person with an illness 3) Making work possible – the role of supportive relationships and supportive medications 4) The costs of working too much – finding a meaningful and healthy balance
I am Me! Experiencing Parenting While Dealing With One's Own Bipolar Disorder (Tjoflåt	**Participants:** 6 **Age**: 41 +/- ? (31-50) **Gender:** Female 5 **Ethnicity/nationality:** Norwegian all	**Diagnosis:** BD (not further speci-fied)	Whole or part-time caring for children under 18, BD diagnosis; exclusion:	Achieve insight into acquiring an understanding of parenting, while dealing with one's own BD	Semi-struc-tured inter-views, interpre-tative	May mean 'no longer having the need for services or taking medication' or 'taking back control of one's	1) Balancing BD and parenting 2) Need for support versus perceiving stigma 3) Dependence on their children

Title, reference, country	Participant characteristics (age (mean+/-SD (range)))	Diagnosis, medication	Participant inclusion criteria	Research aims	Data collection, analysis	Recovery definition	Main themes
and Ramvi, 2013), Norway	**Employment:** full or part time 3, national insurance 3 **Qualification level:** university/college degree 3, upper secondary school education 3 **Other:** relationship status: married 3, divorced 3	**Medication:** all	primary substance dependence or other primary mental diagnosis, inpatient or electro-convulsive treatment within previous 6 months, in severe mood episode		phenomenological analysis	life and achieving valued life goals such as work, housing, psychological well-being, and an improved quality of life’	4) Change and growth
Renegotiating identities: Experiences of loss and recovery for women with bipolar disorder (Fernandez, Breen and Simpson, 2014), Australia	**Participants:** 10 **Age:** 50.0 +/- 15.3 (29-68) **Gender:** female 10 **Ethnicity/nationality:** Australian all **Employment:** full time 1, part time 3, unemployed 3, retired 3 **Qualification level:** university degree 6 **Other:** relationship status: married 4, in relationship 2, separated/divorced 2, single 2	**Diagnosis:** BD I 7, BD II 2, cyclothymia 1 **Medication:** ?	BD diagnosis, undergoing therapeutic treatment, taking medication if indicated, participation consent from treating health professional;	Explore the experiences of loss, coping, and recovery in a community sample of people living with BD	Semi-structured interviews, constant comparative method	Personal process involving the ability to pursue life goals and aspirations regardless of the presence of symptoms	1) Identity bound by the diagnostic label 2) Multidimensional effects of the BD identity 3) Strategies for renegotiating identity

Title, reference, country	Participant characteristics (age (mean+/-SD (range)))	Diagnosis, medication	Participant inclusion criteria	Research aims	Data collection, analysis	Recovery definition	Main themes
			exclusion: severe depression (BDI-II > 28), manic symptoms (ASRM > 5), in hospital or psychiatric care				
Development and evaluation of recovery-focused cognitive–behavioural therapy for individuals with early bipolar disorder (Morrison *et al.*, 2016a), UK	**Participants:** 9 **Age:** 40.2 +/- 12.6 (24-61) **Gender:** Female 6 **Ethnicity/nationality:** White British all **Employment:** full time 3, employed not currently working 1, voluntary 2, unemployed 1, retired 1, student 1 **Qualification level:** postgraduate degree 2, degree 2, A-levels 2, GCSEs/diploma (secondary) 3 **Other:** relationship status: married 5, divorced 1, single 3	**Diagnosis:** BD I 8, BD II 1 **Medication:** 8	Diagnosed with BD I or II in previous 5 years, feel that can reflect on experience of recovery in BD, age 18-65; exclusion: experiencing major depression or mania within previous 2 months	Identify the range and nature of subjective recovery experiences in a group of individuals with recent onset BD	Interview with topic guide, interpretative phenomenological analysis	Subjective process	1) Mood experiences as understandable and manageable 2) Developing resources to self-manage health 3) Change in balance of care from perceived dependence on others to increased autonomy and independence 4) Access to personally meaningful activity 5) Recovery as lifelong process

Title, reference, country	Participant characteristics (age (mean+/-SD (range)))	Diagnosis, medication	Participant inclusion criteria	Research aims	Data collection, analysis	Recovery definition	Main themes
Living the life you want following a diagnosis of bipolar disorder: A grounded theory approach (Warwick, Tai and Mansell, 2019), UK	**Participants:** 12 **Age:** 49.6 +/- 11.4 (32-63) **Gender:** female 6 **Ethnicity/nationality:** ? (international sample) **Employment:** all (self employed 3) **Qualification level:** ?	**Diagnosis:** BD I 9, BD II 2, general medical condition/ Substance causing BD 1 **Medication:** 9	BD diagnosis, self-define as 'living the life they want', English speaking; exclusion: severe mood episode in last 4 years, in psychotherapy for comorbid diagnosis, severe learning disability diagnosis, psychotic experiences, known neurological/ organic basis for issues	Explore what factors or processes are involved to achieve recovery in BD, from the perspectives of those with personal experience	Interview with topic guide, grounded theory	Defined by the notion of 'being able to live the life you want' to capture a high level of attained functioning although being partially self-defined by participants	1) Support 2) Recognition of the problem 3) Believing that things can change and not giving up 4) Instinctive curiosity 5) Medication 6) Psychological therapy 7) Becoming the director of your own life 8) Changing how I think 9) Accepting who I am and how I feel 10) Looking after me
Resilience process in bipolar disorder from the views of	**Participants:** 15 **Age:** 42.9 +/- 12.0 (?-?) **Gender:** female 11	**Diagnosis:** mixed	In remission from BD I or BD II (CGI-	Explore the views of BD patients and	Semi-structured	Recovery in MH cannot be explained solely	Resilience as a dynamic process: 1) Antecedent conditions

Title, reference, country	Participant characteristics (age (mean+/-SD (range)))	Diagnosis, medication	Participant inclusion criteria	Research aims	Data collection, analysis	Recovery definition	Main themes
patients and health professionals (Echezarraga *et al.*, 2019), Spain	**Ethnicity/nationality:** ? **Employment:** employed 5, unemployed 10 **Qualification level:** postgraduate 3, university degree 8, secondary education 2, primary education 2 **Other:** relationship status: married/living together 7, with partner 1, single 6, divorced/separated 1 Had psychotherapy: 12	sample of BD I and II **Medication:** all	BP-M normal/minimal, BSDS >= 13), minimum resilience level (Resilience Scale-25 > 116), did not meet DSM-IV substance abuse disorder criteria in past four weeks	experienced clinicians on the resilience process experienced by people living with BD	inter-views and focus group, phenomenological thematic analysis	by psychopathology, psychosocial functioning, or symptomatic dimensions but also by personal changes in the attitudes, values, goals, and skills by which people can live fulfilling lives despite experiencing MH symptoms and vulnerabilities	2) Turning point 3) Making use of resilience assets and resources
Combining technical and expert-by-experience knowledge in the quest for personal recovery from bipolar disorder: A qualitative study (Tse *et al.*, 2019), Hong Kong	**Participants:** 32 **Age:** 46.3 +/- 11.3 (26-66) **Gender:** female 23 **Ethnicity/nationality:** Chinese all **Employment:** ? **Qualification level:** ? **Other:** years since diagnosis: 21.0 +/- 8.8 (5-37)	**Diagnosis:** BD (not further specified) **Medication:** ?	18 or older, ethnically Chinese, BD diagnosis by psychiatrist, receiving treatment from MH professional and formal peer support services	How do clients with BD seek, assess, and use technical and expert-by-experience knowledge (provided by peer support workers based on their own lived experience of mental	Inter-views with topic guide, thematic analysis	'Personal recovery' refers to the process of individual psychological adaptation to a disorder rather than a sole focus on the reduction of psychiatric symptoms and functional deficits	1) Making sense of the knowledge provided by MH professionals and peer support workers 2) Critical perspectives on technical and expert-by-experience knowledge 3) It is more than mere knowledge transfer: Role-modelling speaks louder

Title, reference, country	Participant characteristics (age (mean+/-SD (range)))	Diagnosis, medication	Participant inclusion criteria	Research aims	Data collection, analysis	Recovery definition	Main themes
				illness) to support their recovery process?			
The Meaning of Recovery: The Lived Experience of Patients with Bipolar Disorder in Turkey (Durgu and Dulgerler, 2020), Turkey	**Participants:** 28 **Age:** 37.0 +/- 12.6 (19-63) **Gender:** female 13 **Ethnicity/nationality:** ? **Employment:** unemployed 14, (self-)employed 10, student 2, retired 2 **Qualification level:** ? **Other:** years since BD onset: 13.3 +/- 9.6 (1-40) relationship status: single 16, married 10, divorced 2 Living: with parent(s) (+ sibling) 12, with spouse (+ child(ren)) 10, alone 3, other 3	**Diagnosis:** BD (not further specified) **Medication:** ?	DSM-5 BD diagnosis, being discharged at least once, 18 or older, able to provide consent, no other psychiatric diagnoses	Provide a deeper understanding of the lived experience of recovery of patients with BD	Interviews with open-ended questions, interpretative phenomenological analysis	Recovery is defined as a deep, individual, unique process of change in the attitudes, values, feelings, goals, skills and roles of the disabled person, and as a satisfying, hopeful, meaningful way of living by contributing to the environment chosen despite the limitations caused by the disease	1) Beginning of the journey 2) Route of the journey 3) A stop in the journey 4) Meaning of the journey

Table S3 CHIME codebook and article vote counts[84]

(Sub-) domain (CHIME index)	POETIC index	Description	Papers in this review	CHIME review papers
1 Connectedness	1	The sense of being connected to others (Bird et al., 2014), beyond individual's relationship, includes connections with society and feeling connected to others (Bird, 2015, p. 67), subsumes 'social inclusion' (Bird, 2015, p. 65).	12	86%
1.1 Peer support and support groups	1.1	Importance of peer support, received by attending organised groups, from contact with peer support workers, or informally, from friendships that developed among people with lived experience (Bird et al., 2014).	7	*45%*
1.1.1 Availability of peer support	N/A	Discussions of (un-)availability of peer support. [own]	1	25%
1.1.2 Becoming a peer support worker or advocate	N/A	Experiences of participants providing peer support themselves, e.g., by facilitating peer support groups. [own]	3	20%
1.2 Relationships	1.2	Supportive and collaborative personal relationships seen as having a positive impact on recovery. Having a range of personal relationships with others is critical to the recovery of a life worth living. (Bird et al., 2014, p. 647). Different from 1.3, these relationships are not tightly indexed on the MH issue (though they may emerge from it, e.g., friendships with other people using service), and relate to everyday social connectedness, feeling that you have friends and confidantes. [MS]	9	38%
1.2.1 Building upon existing relationships	N/A	Deepening of existing social relationships. [MS]	0	22%
1.2.2 Intimate relationships	N/A	Deepening of close/intimate (i.e., not just sexual) relationships. [MS]	2	10%

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[84] Codebook based on Bird et al. (2014) and Bird (2015), validated and supplemented by Mike Slade [MS]; POETIC index refers to Table S5, N/A for dropped subdomains; (Sub-)domain coverage: percentages among papers in the CHIME review validation phase (n=87) from Table DS2 in Leamy et al. (2011).

(Sub-) domain (CHIME index)	POETIC index	Description	Papers in this review	CHIME review papers
1.2.3 Establishing new relationships	N/A	Creation of new social relationships. [MS]	3	9%
1.3 Support from others	1.3	Relationships indexed on the MH issues, e.g., with workers (1.3.1) or supportive family (1.3.3) or friends or peers (1.3.4) which may be expressed through practical support (1.3.5). [MS]	12	61%
1.3.1 Support from professionals	1.3.1	Discussions of (lack of) support from services in recovery in general and of helpful (or unhelpful) interactions with specific professional groups (therapists, psychiatrists, community nurses). [own]	10	48%
1.3.2 Supportive people enabling the journey	N/A	[not used]	0	31%
1.3.3 Family support	1.3.2	Family providing practical or emotional support or external feedback on how they perceive mood or behaviour of individual. [own]	9	30%
1.3.4 Friends and peer support	1.3.3	Friends providing practical or emotional support or external feedback on how they perceive mood or behaviour of individual. [own]	4	21%
1.3.5 Active or practical support	1.3.4	Anyone (including services) providing help with daily life, e.g., managing chores, getting visits in hospital, organise hospital stay and transition to home (Bird, 2015, p. 68). If practical support is provided by family/friends, this is double coded in 1.3.3 or 1.3.4 as well. [MS]	6	5%
1.4 Being part of the community	1.4	Feeling of being part of the wider community, could include membership in different communities, e.g., religious, local community, service-related etc. (Bird, 2015, p. 81)	5	40%
1.4.1 Contributing and giving back to the community	N/A	Participants contributing to society, e.g., by supporting others or research. [own]	2	24%

(Sub-) domain (CHIME index)	POETIC index	Description	Papers in this review	CHIME review papers
1.4.2 Membership of community organisations	N/A	[not used]	0	15%
1.4.3 Becoming an active citizen	N/A	[not used]	0	13%
2 Optimism and hope	2	Having hope for recovery, can be in terms of various aspects: less symptoms, better social, occupational functioning, quality of life. [own] Includes experiencing a reawakening of hope after despair. Subdomains emphasise the idea that recovery is an active process, rather than something that is ‘done to’ the person (Bird et al., 2014). Illustrates that recovery requires self-determination (Bird, 2015, p. 69).	8	79%
2.1 Belief in possibility of recovery	2.1	Belief (disbelief) that recovery is possible. [own]	6	34%
2.2 Motivation to change	N/A	[not used]	0	17%
2.3 Hope-inspiring relationships	2.2	Presence of hope-inspiring relationships, could be with family, friends and professionals or with a higher power, engender a belief that recovery is possible. Also contains the opposite: evidence how professionals can reduce hope and belief in recovery (Bird et al., 2014). Includes role models that provide hope for future: hear about success of others, learn from other people's recovery stories (Bird, 2015, p. 69).	5	14%
2.3.1 Role-models	N/A	Role models that provide hope for future: hear about success of others, learn from other people's recovery stories (Bird, 2015, p. 69).	3	9%
2.4 Positive thinking and valuing success	2.3	Having an optimistic view of life (bad things will get better), gratefulness for life, setting (small goals) and value progress, little successes. [own]	6	11%
2.5 Having dreams and aspirations	2.4	Aiming for more (better job, quality of life) than one has in the present. [own] Affective state (feeling of life worth living, having dreams of good future). Concrete cognitive goals coded in 4.4 ‘Meaningful social and life goals’.	3	8%
3 Identity	3	How individuals see themselves or think they are perceived by others. [own]	12	75%

(Sub-) domain (CHIME index)	POETIC index	Description	Papers in this review	CHIME review papers
3.1 Dimensions of identity	3.1	Individuals see themselves as more than their diagnosis. Identity not unitary, multiple dimensions important (e.g., sexual, ethnic, cultural). Mental health services/professionals need to value different identity dimensions and treat person as individual, not label (Bird et al., 2014, p. 648). Difference to 3.3: Maintain or develop positive sense of self/place in world. E.g., person with unlovability schema due to upbringing who identifies this being replaced with more positive sense of self coded here, not 3.3. [MS]	8	9%
3.1.1 Culturally specific factors	N/A	[not used]	0	8%
3.1.2 Sexual identity	N/A	Regarding sexuality as important part of identity. [own]	1	2%
3.1.3 Ethnic identity	N/A	[not used]	0	5%
3.1.4 Collectivist notions of identity	N/A	[not used]	0	7%
3.2 Rebuilding or redefining positive sense of self	3.2	Recovery involves redefining or regaining a positive sense of self. Includes viewing the process of recovery as involving some transformation of identity (discovering a new ‘me’) as well as the opposite: holding on to the aspiration of reclaiming one’s prior social identity and sense of self. (Bird et al., 2014)	12	66%
3.2.1 Self-esteem	3.2.1	[collapse with 3.2.3] [MS]	4	24%
3.2.2 Acceptance	3.2.2	Includes both accepting one's self and being accepted by others (Bird, 2015, p. 69). Compared to 4.1.1 ‘accepting and normalising the illness’ this subdomain is more holistic (accepting oneself) and less specific to having a MH diagnosis. [own]	8	24%
3.2.3 Self-confidence and self-belief	3.2.1	[collapse with 3.2.1] [MS] Participants talking about lack or rebuilding of self-confidence, self-belief or self-esteem as affecting their recovery.	9	13%

(Sub-) domain (CHIME index)	POETIC index	Description	Papers in this review	CHIME review papers
3.3 Over-coming stigma	3.3	Regain a positive sense of self by overcoming stigma, society needs to support notion of recovery, too, and let go of stigma (Bird et al., 2014). Relates specifically to marginalised identities, including but not limited to MH (so also includes e.g., gender, sexuality, class). [MS]	9	46%
3.3.1 Self-stigma	3.3.1	Internalised stigma (Bird, 2015, p. 70), individuals feeling less capable because of the negative messages they associate with their diagnosis. [own]	2	31%
3.3.2 Stigma at a societal level	3.3.2	External stigma, includes MH professionals actively working with community to reduce stigma (Bird, 2015, p. 70)	7	37%
4 Purpose and meaning	4	Broad subdomain of having the goal of living a meaningful and purposeful life whatever that means to the person (Bird et al., 2014), goal of recovery is to find framework that explains experience (Bird, 2015, p. 70)	12	66%
4.1 Meaning of mental illness experiences	4.1	Understanding or finding meaning in one's mental illness experience, can range from spiritual or religious meanings through to adoption of a medical view of mental illness. Giving meaning normalises the experience and can have positive implications (e.g., increased acceptance and reduced self-stigma) (Bird et al., 2014). Includes people trying to make sense of diagnosis/symptoms due to past life experiences (e.g., trauma) [own].	11	34%
4.1.1 Accepting or normalising the illness	4.1.1	De-emphasise, normalise, relativise illness (Bird, 2015, p. 71). Individuals accept/recognise/realise they have a MH problem (insight) prior to taking action. [own] Insight is coded here if the individual uses this explanatory framework. [MS]	10	25%
4.2 Spirituality (including development of spirituality)	4.2	Connecting with a higher power and developing spirituality, often aids to develop an understanding of their experience and provides a source of support and encouragement. Includes organised religion or a specific faith as well as spirituality in abstract terms (Bird, 2015, p. 71)	2	41%
4.3 Quality of life	4.3	Broad subdomain, process and outcome, importance to have basic needs met (adequate housing and financial support) (Bird, 2015, p. 71). Includes generic mentions of 'quality of life' as important for people [own]. Also: people saying their general experience of living has improved, might be due to material changes ('getting a job meant I had my first secure housing') or psychological/behavioural changes ('my life improved as I was able to accept I need to ask for help when my mood worsens') [MS]	12	65%
4.3.1 Well-being	4.3.1	Wellbeing as important aspect of a meaningful life, contrasted with 5.1.1.5 Self-management/Maintaining good physical health and wellbeing, which focuses on specific strategies to maintain wellbeing, not necessarily giving wellbeing a meaning. [own]	2	31%

(Sub-) domain (CHIME index)	POETIC index	Description	Papers in this review	CHIME review papers
4.3.2 Meeting basic needs	N/A	[not used]	0	21%
4.3.3 Paid or voluntary work or work related activities	4.7	Importance and impact of paid work or voluntary work. Paid work or voluntary work provides routine, connection to daily life, identity different from illness, but can also pose a risk factor due to causing stress. Symptoms can impair work performance. [own]	11	22%
4.3.4 Recreational and leisure activities	4.3.2	Hobbies and recreational activities support recovery by providing distraction from MH issues or sense of productivity, e.g., reading, relaxing, gardening, crafts, singing. [own]	6	9%
4.3.5 Education	4.3.3	Embracing lifelong learning, going to and valuing a Recovery College, getting past fears of ‘education’ or ‘feeling thick’ to engage in self-development – so both formal education and informal shift of attitude towards learning. [MS]	6	8%
4.4 Meaningful social and life goals	4.4	Goal setting in areas outside of MH services, predominantly change of residence and getting a job or take up further education (Bird, 2015, p. 71). Compared to 4.5 Meaningful life and social roles, which is about more long-term ‘roles’, contains more focused goals such as getting a promotion, a degree. 2.5 is more of a feeling (life worth living, for first time had dreams of a good future) and 4.4 more articulated goals (less affective, more cognitive). [MS]	6	17%
4.4.1 Active pursuit of previous or new life or social goals	N/A	[not used]	0	17%
4.4.2 Identification of previous or new life or social goals	N/A	[not used]	0	9%

(Sub-) domain (CHIME index)	POETIC index	Description	Papers in this review	CHIME review papers
4.5 Meaningful life and social roles	4.5	Activities and occupations that make life meaningful, essentially the same ones as for people without MH problems (Bird et al., 2014). Life making more sense through re-framing of experience as meaningful, social role of mother/father being reengaged with, finding value in supporting others. Work (paid or voluntary formal employment) is coded at 4.3.3 instead.	7	46%
4.5.1 Active pursuit of previous or new life or social roles	N/A	[not used]	0	46%
4.5.2 Identification of previous or new life or social roles	N/A	[not used]	0	39%
4.6 Rebuilding of life	4.6	Having a purpose or a reason to get up each day, can include volunteering (Bird et al., 2014, p. 649)	6	23%
4.6.1 Resuming with daily activities and daily routine	N/A	[not used]	2	14%
4.6.2 Developing new skills	N/A	Developing skills (personal, professional) that one did not pursue prior to diagnosis [own].	1	9%
5 Empowerment	5	How individuals achieve empowerment, many subthemes focus on MH services, but theme also includes becoming an empowered citizen (Bird, 2015, p. 72)	12	91%
5.1 Personal responsibility	5.1	Individuals take responsibilities for their own recovery, professionals need to allow this (Bird, 2015, p. 72); being able to get on with day-to-day life, even when symptoms are present, includes maintaining good physical and MH, using self-management strategies, accessing self-help (Bird et al., 2014)	12	91%
5.1.1 Self-management	5.1.1	Individuals attend to both physical and MH themselves (includes coping strategies, self-help materials, seeking professional help) (Bird, 2015, p. 72)	12	69%

(Sub-) domain (CHIME index)	POETIC index	Description	Papers in this review	CHIME review papers
5.1.1.1 Coping skills	N/A	Coping with stressful life events (death of loved one, financial hardship, trauma), coping with life challenges (might include MH but also e.g., interpersonal, financial) [MS]. 5.1.12 is specifically about new approaches to self-management of symptomatology [MS].	4	29%
5.1.1.2 Managing symptoms	N/A	Strategies people employ themselves to alleviate their symptoms once they notice them. [own]	9	25%
5.1.1.3 Self-help	N/A	Self-help in relation to symptoms. Compared to 5.1.1.2, which is more behavioural, self-help is more attitudinal, valuing inter-dependence, using proactive strategies. Not a big distinction so may frequently be double coded. [MS]	7	14%
5.1.1.4 Resilience	N/A	Resilience in relation to stressful life events. While 5.1.1.1 is about dealing with challenges when experienced, 5.1.1.4 is about becoming more resilient so fewer challenges are experienced: E.g. I used to be very upset when people ignored me and I'd have to hide myself away (5.1.1.1), but now I choose to view other people as just preoccupied with their own problems so they're not really ignoring me (5.1.1.4). [MS]	1	29%
5.1.1.5 Maintaining good physical health and well-being	N/A	Self-management strategies that directly target physical health or that are physical in nature (exercise, sleep, diet). [own]	8	14%
5.1.2 Positive risk-taking	5.1.2	Taking risks, accepting challenges, leaving one's comfort zone, not specific to care planning context [own]; Particularly in the context of care planning and goal setting. MH professionals need to allow individuals to take positive risks as it promotes feelings of personal responsibility (Bird, 2015, p. 73).	5	20%
5.2 Control over life	5.2	Being involved in decision-making and having some say in one's care and treatment, particularly where medication and hospitalisation are concerned; Positive risk taking in context of care planning and goal setting; helpful if supported by professionals (Bird et al., 2014). Feeling in control over life or symptoms, including, but not limited to, in relation to services. [own]. 5.1.2 is trying new things even when they might go wrong, 5.2 is feeling in control of life, experiencing agency. [MS]	10	90%
5.2.1 Choice	5.2.1 Understandable	Getting information about one's MH diagnosis and treatments from professionals/services (Bird, 2015, p. 72). Being offered a range of treatment options and more actively negotiating what's wanted. Does not include people getting knowledgeable about their diagnosis themselves (could just be increased compliance	3	36%

(Sub-) domain (CHIME index)	POETIC index	Description	Papers in this review	CHIME review papers
	mood empowers	and buying of expert's explanatory model), though yes if this leads to initiation of more shared decision-making conversation. [MS]		
5.2.1.1 Knowledge about illness	N/A	Individuals becoming knowledgeable about their diagnosis, either by getting information from professionals/services, and/or by seeking information online, from books, peers themselves and/or by gaining their own lived experience. [own] -- but only if this leads to discussions around treatment.	0	20%
5.2.1.2 Knowledge about treatments	N/A	Individuals desire or get information about treatment options from professionals. [own]	1	8%
5.2.2 Regaining independence and autonomy	5.2.2	Regain independence by less relying on services or receiving support that increases independence (financial support to buy things, move to own housing). [description not checked by MS]	4	26%
5.2.3 Involvement in decision-making	5.2.3	Individuals feel their preferences are considered for treatment decisions. [own]	11	26%
5.2.3.1 Care planning	N/A	Making decisions about what care, support, and therapy from services to access when. [own]	11	40%
5.2.3.1.1 Crisis planning	N/A	[not used]	0	8%
5.2.3.1.2 Goal setting	N/A	[not used]	0	14%
5.2.3.1.3 Strategies for medication	5.3	Any discussions around taking or not taking medication for one's MH issues. [own]	7	29%
5.2.3.1.4 Medication not whole solution	5.3	Discussions of medication not effectively reducing symptoms, having negative side effects, or not being helpful for socio-occupational or PR goals. [own]	9	13%

(Sub-) domain (CHIME index)	POETIC index	Description	Papers in this review	CHIME review papers
5.2.4 Access to services and interventions	5.2.4	Services can(not) be accessed. In contrast, 1.3.1 Support from professionals is about support from professionals as part of services in general and whether they are orwhat is perceived helpful about it. [own]	4	15%
5.3 Focussing upon strengths	N/A	Adopting roles that are built around one's personal strengths and resources (Bird et al., 2014); includes utilising strengths/resources of the context/community (Bird, 2015, p. 73).	1	16%

Table S4 Codebook and article vote counts for inductive new themes and subdomains

Theme	Description	Articles
1.3.1.2 Therapy	Discussions of how therapy was helpful or not in PR.	5
5.1.1.1 Always vigilant	Perceived need/burden of having to always stay vigilant of mood, monitor mood and behaviour and micro-manage (increase/decrease activity). Captures negative aspects such as loss of levity/easiness/light-heartedness/innocence in life. Increased self-awareness is a cause of stress or constant worry.	8
5.1.1.2 Knowing oneself	Knowing oneself, what stresses/relaxes oneself, how one is likely to react to certain situations, what one likes and dislikes, becoming clear about values and goals in life. Includes two aspects: 1) Acquiring experience-based competence. Highlights the need to try out strategies oneself, and learn what works for oneself personally, takes time, trial and error, needs perseverance. 2) Becoming/being aware of own behaviour and mood and/or accepting/trusting that feelings pass.	11
5.1.1.3 Lifestyle changes towards routine, balance, calmness	Maintaining a balanced, regular, structured daily life as a preventative measure to encourage mood stability or live a calm life, avoid stress as trigger of extreme moods.	7

Theme	Description	Articles
5.2.1 Understandable mood empowers	Acquiring theoretical knowledge on emotion/mood, cognitive processes (e.g. emotions are unstable, temporal) enables better understanding of oneself and of self-management techniques, and ultimately feeling more in control of mood. Different from 5.2.1.1 Knowledge about illness (does not refer to shared decision making in care), and *5.1.1.2 Knowing oneself (non-individual information, can be provided in psychoeducation as true on population-level).	6
5.3 Controversial role of medication	Role of medication in recovery, discussions of benefits, disadvantages, and experiences with coming off medication.	12
6 Tensions	Participants need to negotiate tensions between PR processes and in their dealing with (hypo-)mania.	12
6.1 Balancing acceptance with ambitions	Tension between accepting limitations due to MH issues to reduce stress and live a manageable life on the one hand and having ambitions or goals to work towards to and not giving up the hope of achieving things meaningful for oneself on the other hand. Negotiating the question: what can I expect of myself?	10
6.2 Openness enables support and stigmatisation	Tension between having to disclose MH issues to professionals or family/friends to get support with the risk of experiencing stigma. Informal level: Openly/naturally talking about ones BD enables more connectedness with others, more support and less need to hide a part of oneself but also makes one vulnerable to negative judgments, lack of comprehension. Formal level: Different experiences or evaluations of receiving the diagnosis. For some it is helpful explanation for experiences and enables access to treatment, for others it is unhelpful and adds stigma.	10
6.3 Ambivalence around (hypo-)mania	Perception and personal meaning of mania/elated mood varies between individuals: Some participants like and miss mania due to improved creativity and energy. Others dislike or fear elated states due to irritability, danger of losing control. Many are ambivalent about elated states due to these opposing experiences.	8

Table S5 Further quotes for the POETIC framework

Name[85]	Example quotes
1 Connectedness	
1.1 Peer support and support groups	Support groups provided a lot of laughter, camaraderie, and a sense of connection with "like-minded people." […] "You feel, 'I am not an oddity; I am just one of many others who are traveling the same road.' That feeling that I am not the only one."(Fernandez, Breen and Simpson, 2014) Two participants were critical of support groups. For example, one stated that support groups "tend to stop progression in a sense. You become institutionalized" (Fernandez, Breen and Simpson, 2014) I shared with the peer worker what I had experienced. We had common ground; we had empathy for each other. We felt that we had the same issue so there was no hierarchy and I was able to speak my mind freely. (Tse *et al.*, 2019)
1.2 Relationships	All participants described experiences of relationship loss. Four reported divorcing because of the strains that BD put on their marriage. (Fernandez, Breen and Simpson, 2014) I feel sometimes that I'm not consistent with my friends ::: if I'm maybe feeling a bit down I may not be in contact with them or if I'm feeling quite anxious. So I don't feel it's always ::: cos of consistency y'know, but I think they understand that mostly (Mansell *et al.*, 2010) "If I feel something wearing me down, being with him or her because they aren't in a good place, I back off and try to look after myself" (Veseth *et al.*, 2012)
1.3 Support from others	
1.3.1 Support from professionals	… I mean in hospital I just remember at my lowest, … there was one particular nurse who I really kind of clicked with […], who really helped me… but the interaction between us, seemed to really helped me come out of my … initial shell … […]so I remember him very distinctly because it's a catalyst that situation […] whether there are other factors, as well that obviously go together too and that's the catalyst
* 1.3.1.1 Therapy	when I when I saw it through the lens of the CBT I could see where I was… thinking poorly or thinking catastrophe when there was really no need to […] one thing I really appreciated the first day I met with her and was talking through my experiences is that she validated a lot of what I was experiencing (Warwick, Tai and Mansell, 2019) … the first time I did it, I was like hypomanic, so it was like a different approach and I am like I do not really need this, it just did not feel like it was doing much, whereas this time round, […] I was

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[85] * indicates subdomains and themes differing from CHIME

	in a better place, I was more more stable I reckon (Warwick, Tai and Mansell, 2019)
1.3.2 Family support (CHIME 1.3.3)	Two participants reported that their family and friends were “in denial” about the BD diagnosis and chose to ignore it. For example, one woman described her mother saying, “Well it is not my problem, it is your problem. Why should I have to change my life to fit in your situation?” (Fernandez, Breen and Simpson, 2014) Several found their partners' assistance in noticing signs was beneficial (Warwick, Tai and Mansell, 2019) I try to get others to observe me as well; I ask the children about certain situations and whether I’m interpreting them correctly (Mansell *et al.*, 2010)
1.3.3 Friends and peer support (CHIME 1.3.4)	I remember [a friend] saying [about me], “Some days [she] wants to talk, other days she just needs to be quiet.” That struck me so much. I will never forget that because I wrote [it] down after. She knows when I need to be quiet and she knows when I need to talk. You know, it is such a wonderful friend that can do that. (Fernandez, Breen and Simpson, 2014) Another participant thought that it was better to socialize with her friends when she was not symptomatic, revealing that her friends “could see well [me] for birthdays and celebrations, but sick [me] would get her own help; she would look after herself.” (Fernandez, Breen and Simpson, 2014)
1.3.4 Active or practical support (CHIME 1.3.5)	Participants also commented on the practical and emotional support they received from friends. For example, one participant stated, “They used to come and do the washing for me, bring me homemade bread, and look after the family.” (Fernandez, Breen and Simpson, 2014) All of the participants stated that they periodically wished to receive additional support in caring for their children […]: I had a serious diagnosis, but I didn’t understand it, and perhaps neither did my therapists or my doctor. I was alone with my children, I was manic and psychotic and we didn’t get any help. Had they understood it and had my children been in kindergarten, it would have helped, both for my children and me ... it’s quite as simple as that (Tjoflåt and Ramvi, 2013)
1.4 Being part of the community	One participant stated that he ‘used to be someone who would retreat from things’, a sentiment that was mirrored by the majority of participants. Participants generally ‘feel more in touch with human beings’ and have a more positive approach towards others, which is reflected by increased interaction with others. (Mansell *et al.*, 2010)
2 Hope	
2.1 Belief in possibility of recovery	I am a strong person and I can get through this and I will do whatever it takes (Todd, Jones and Lobban, 2012) I think I'm a positive person...I was self-confident, I knew that I could make it, that I was worthy, then, that's why I still went on trying (Echezarraga *et al.*, 2019)

2.2 Hope-inspiring relationships (CHIME 2.3)	… the respectful psychiatrist I've had, whom I've had sporadic meetings with, but more frequently now. That he all the time has acknowledged that it was crucial for me to be working. (Borg *et al.*, 2013) I think a lot of this was learning from my peers that the … you know if there is a relapse that that's part of the recovery you know that its not a perfectly straight forward road all the time … (Warwick, Tai and Mansell, 2019) PSWs [peer support workers] are role models showing us what could happen in 5 or 6 years and set my mind at ease (Tse *et al.*, 2019)
2.3 Positive thinking and valuing success (CHIME 2.4)	Overall, [in] dealing with my losses I have always been a very determined, persistent, tenacious person, so even when I was climbing the great mountain of my disease and people said, "You are not going to do this, and you are not going to do that, or you should not do this," I was thinking, "I am going to do whatever it is I want to do!" (Fernandez, Breen and Simpson, 2014) I am gonna rack my brains if there's any other magic things I can tell you, but I just think, do the things you enjoy I think and you know, do things you enjoy if you can, and value your time, always value what you are doing and be, be present with what you are doing (Warwick, Tai and Mansell, 2019)
2.4 Having dreams and aspirations (CHIME 2.5)	Maren worked three days a week at the time of her interview, but was hoping to work full-time. Even though it could be difficult to work and stay concentrated and motivated for her job, she was one of those who found it helpful to make an effort, have strenuous days and simply be in a setting where she had to use her intellect and cognitive capacity. She felt it was helpful to be challenged. (Borg *et al.*, 2013)
3 Identity	
3.1 Dimensions of identity	the illness isn't all of me, but at times it feels like it (Mansell *et al.*, 2010) what they were and what they did was solely interpreted in light of their bipolar disorder, such as "people set labels on my feelings." (Tjoflåt and Ramvi, 2013) I know for me the end result of recovery is really not having to talk about the fact that I'm bipolar anymore, that it doesn't define who I am, that I'm living well […] (Michalak *et al.*, 2012)
3.2 Rebuilding or redefining positive sense of self	I would say that it isn't necessarily going back to who you were, but it's developing a new life, it's transforming, growing… and rebuilding a whole new life. So there is hope but it's moving forward as opposed to trying to get the past back. That's my interpretation of recovery. (Michalak *et al.*, 2012)
3.2.1 Self-esteem, self-confidence and self-belief (CHIME 3.2.1 + 3.2.3)	I am not worse than other persons, even though I am ill; so when I am not really myself due to my illness, I think that I am just as worthy as others, am I not? (Tjoflåt and Ramvi, 2013) It is very difficult, particularly when you have been episodic many times. After a while you begin to doubt yourself and you lose that kind of tenacity and nerve to do things: "I am going to go and work here or I am going to do this degree." You know, everyone needs that sort of leap where they say, "Maybe I cannot, but I am going to

	do it anyway," and then they do it. But I think maybe for a bipolar person that has fallen down so many times, after a while you start to think, "Maybe I am overreaching." (Fernandez, Breen and Simpson, 2014)
3.2.2 Acceptance	This acceptance, however, might well take courage and determination, because many of the participants experienced their psychological life as overwhelmingly stormy. (Veseth *et al.*, 2012) "I have accepted the fact that I am more unusual, that I have a brain that is exceptionally different. I would not say better than anybody else's, I do not think, but it is different." (Fernandez, Breen and Simpson, 2014)
3.3 Over-coming stigma	
3.3.1 Self-stigma	So the de-shaming was huge. And I did a lot of that kind of de-shaming work with my therapist and I just couldn't really get that with my psychiatrist cause it was a different kind of care there. (Michalak *et al.*, 2012) I was quite taken aback I think the…with the diagnosis more than anyone else was, so … getting through, getting rid of that self stigma was a big stepping stone (Warwick, Tai and Mansell, 2019)
3.3.2 Stigma at a societal level	"You have got this big stamp on your forehead that everyone else sees….All this stuff about equality in our society is just a load of rubbish." (Fernandez, Breen and Simpson, 2014) I find out about a lot of weird rumours going around and people talking; the manic phases are exciting, but it affects the children . . . they don't deserve it, but both they and I have been hurt." (Tjoflåt and Ramvi, 2013)
4 Purpose and meaning	
4.1 Meaning of mental illness experiences	I think some of the work I did with the psychologists when I got under the EI team allowed me to make a bit of sense of perhaps from some of the things that had happened early on in my life. There were some quite traumatic events early on in my life . . . I guess maybe some of the things that had happened to me previously in life had given me a lot of beliefs that perhaps were brought to the fore when I was, when my mood was kind of all over the place. (Morrison *et al.*, 2016a) A lot of people I know with bipolar are included in this, are very much perfectionists and blame themselves when things aren't going right and I've sort of, I've tried to stop [laughs] worrying about every little detail of things. (Morrison *et al.*, 2016a)
4.1.1 Accepting or normalising the illness	while the label of bipolar disorder engendered mixed feelings, participants reported that accepting one has a problem and seeking information about it was helpful (Mansell *et al.*, 2010) I had to reflect, analyse why my life was like a boat at the mercy of the waves … and I realised that I could not go on like this, because so much instability was hurting me so much … and from the moment when you become aware that you cannot go on like that, you begin to emerge from it [BD] a little (Echezarraga *et al.*, 2019)

4.2 Spirituality	All participants discussed developing hope and belief in change being possible. This arose from seeing peers who “had a life” (P34) or from holding onto faith-based beliefs (Warwick, Tai and Mansell, 2019)
4.3 Quality of life	Most participants stressed the importance of shifting the framework from one of illness to wellness; an emphasis on quality of life, including happiness and engagement with life. And, as one individual stated, “[this] is a shift in the framework.” (Michalak *et al.*, 2012)
4.3.1 Well-being	awareness of how to remain well as being ‘on a mundane level’ prior to his start of recovery, which have now been shifted to the forefront of his life. (Mansell *et al.*, 2010)
4.3.2 Recreational and leisure activities (CHIME 4.2.4)	When I get out of hospital, I will buy crayons. I’ll paint like children. (Durgu and Dulgerler, 2020) I take care of my bird. Looking after animals is a good thing, it makes me feel happy; I talk to my bird if I am bored… A small aquarium is enough to calm me down. ” (Durgu and Dulgerler, 2020)
4.3.3 Education (CHIME 4.3.5)	The rejection of certain aspects of information provided to them by professionals and within the literature on bipolar disorder was, for many participants, part of the process in the utilization of personal methods for staying well, as participants’ own experiences with these methods sometimes negated the information provided via other avenues. (Mansell *et al.*, 2010) I am also very, quite curious about things and so, my first instinct whenever I find out about anything is to do loads and loads of research and I so I went to the library [laughing] and I did loads of research about bipolar disorder and things like that (Warwick, Tai and Mansell, 2019)
4.4 Meaningful social and life goals	I would say taking a university degree and using it in a qualified position has been most .. . I believe, most important. (Borg *et al.*, 2013) “I do not really care about studying in the depression. It does not mean anything for me anymore. I do not know why I am doing it.” (Fernandez, Breen and Simpson, 2014) having targets and and reaching them, ticking them off, is a big part in recovery (Warwick, Tai and Mansell, 2019)
4.5 Meaningful life and social roles	Several parents had had suicidal thoughts, but they felt that the love and responsibility they had for their children had saved their lives: “Without my children, I would not be here, it’s that simple; thinking about them saved my life, that I’m convinced of.” (Tjoflåt and Ramvi, 2013) “they [children] have been in need of me when they have been growing up, but now I have seen how much I have needed them, too. It’s been very important for me having to discipline myself; lunch packets, laundry, and all those things” (Veseth *et al.*, 2012)
4.6 Rebuilding of life	I would say that it isn’t necessarily going back to who you were, but it’s developing a new life, it’s transforming, growing… and rebuilding a whole new life. So there is hope but it’s moving

	forward as opposed to trying to get the past back. That's my interpretation of recovery. (Michalak *et al.*, 2012) I think when I came out of hospital I was maybe 2 stone overweight, which I never really was before … it was good to kind of socialize with, sort of build-up friendships again, maybe make new ones as well…to be in that sort of cycle when you are you are actually motivated to go out and do something because its planned already, its already structured into your week what you are doing … (Warwick, Tai and Mansell, 2019)
* 4.7 Paid or voluntary work (CHIME 4.3.3)	"I really care for that job .. . I feel that if I lose it, I have nothing." (Borg *et al.*, 2013) For many of the participants the amount of time spent at work was important. Some had been involved in ordinary full-time work, but had chosen to give it up due to stressful work conditions or because they felt it could not be combined with persistent symptoms. Others reduced their working hours in order to have a more flexible day and fill it with other activities. This also permitted the necessary rest and balancing of one's energy during the day. (Borg *et al.*, 2013) Employment was considerably affected by mood changes. The participants thought that their medication affected their memory and cognitive functioning in the workplace. For many, not being able to function as they once did made it "terrible," "difficult," and "hard" to perform in the workplace. Consequently, some participants described being forced to take sick leave because they struggled to perform their duties while "operating on very little fuel." (Fernandez, Breen and Simpson, 2014). It reminded me that I can do all that stuff, I was beginning to wonder at what point if my brain was completely fried and all the things I was able to do ten years ago, if I could still do that at all in terms of being professional about things, and understanding finances and erm company structures and all that sort. (Morrison *et al.*, 2016a) I feel the best I I have done, in all my life, [laughs] and that is I can put it to a change of career, and doing what I absolutely love doing rather than previously when … I quite enjoyed what I was doing but it wasn't really fully in line with … my values actually. (Warwick *et al.*, 2019)
5 Empowerment	
5.1 Personal responsibility	
5.1.1 Self-management	
* 5.1.1.1 Always vigilant	participants were acutely aware of their prodromes and explained how they counteracted even slight changes in mood, sleep, thoughts, and energy levels (Mansell *et al.*, 2010) Another participant thought that she could not be her "usual jolly self" because she feared others would perceive her as being symptomatic of mania. Consequently, she thought she had become

	more “serious” and “less spontaneous,” and she “[thought] twice” about her actions. (Fernandez, Breen and Simpson, 2014) trust that certain feelings would pass rather than lead to an episode (Warwick *et al.*, 2019)
* 5.1.1.2 Knowing oneself	Gradually I’ve gotten to know myself quite well, and I know that the mania is … It hurts physically being in that condition. I feel a distaste in my body. For example, my oral cavity: I feel a stress arising there. It’s not easy to explain, but it’s like I detect this myself (Veseth *et al.*, 2012) The participants described how they had explored ways of living over the years with the coexistence of work and activities and persistent symptoms of bipolar disorder. They had expended a great amount of effort in finding the proper balance between rest and activity, being on their own or being sociable, and in being open for trial and error when it came to coping with the impact of the mood swings on their daily life. (Borg *et al.*, 2013)
* 5.1.1.3 Lifestyle changes towards routine, balance, calmness	participants stressed the importance of reducing their workload in order to better facilitate a ‘work-home, work-social life balance’ (Mansell *et al.*, 2010) I um put up a sign on my desk and it was um on the this sign it said focus, order, balance and simplicity, which I called fobs, F.O.B.S, so I could remember focus, order, balance, and simplicity (Warwick, Tai and Mansell, 2019) I believe that an orderly life is essential. That is, an orderly life, physical exercise, the environment, the family environment, the social environment you have (Echezarraga *et al.*, 2019)
5.1.2 Positive risk-taking	Self-management is about using the madness to cure the madness … as long as the risk isn't too high, as long as you survive the risk, then do it, that is the way to self-management – one small step”. (Todd, Jones and Lobban, 2012) Individuals showed a willingness and persistence to experiment until something worked, even when this required substantial effort or going against advice. (Warwick, Tai and Mansell, 2019)
5.2 Control over life	
* 5.2.1 Understandable mood empowers	Advice from expert professionals regarding treatment options and ways of managing symptoms was described as valuable. (Warwick, Tai and Mansell, 2019) This process of making mood experiences understandable enabled participants to develop a stronger sense that such experiences could also be managed rather than having a ‘life of their own’ (Morrison *et al.*, 2016a) Similarly, another participant described the lack of information about her diagnosis and treatment: “I did not really understand what I had; nobody really told me that I had anything, really. They gave me pills to take [but] they did not explain what they were for.” (Fernandez, Breen and Simpson, 2014)

5.2.2 Regaining independence and autonomy	It seems a bit silly, but […] I got DLA when I first got diagnosed and that was with the help of someone from like CAB and that was massive because… that gave me more independence because it meant that I could go out and buy just small things.. and I know it sounds a bit ridiculous but like that, being able to have that was massive. (Morrison *et al.*, 2016a)
5.2.3 Involvement in decision-making	Adopting the patient identity resulted in a loss of power, autonomy, and independence. For some, the patient identity mirrored aspects of a parent–child relationship, as evidenced by the use of the term "fatherfigure psychiatrist". (Fernandez, Breen and Simpson, 2014) … central role of the individual in managing care from diverse sources (including medication, therapy, family, support groups, psychoeducation, etc.) to enhance mood stability and mental health (Morrison *et al.*, 2016a)
5.2.4 Access to services and interventions	Access to practical support was critical in the earlier stages of recovery when travel or financial constraints could have been a barrier. This included close proximity of services, access to support groups or a professional, financial support, or employers accommodating leave and phased returns to work. (Warwick, Tai and Mansell, 2019) participants were mindful that, when a relapse occurs, focus shifts to a clinical recovery from the current episode being experienced, and services may be required (Todd, Jones and Lobban, 2012)
* 5.3 Controversial role of medication (formerly 5.2.3.1.3 and 5.2.3.1.4)	"Seroquel has been the answer" (Fernandez, Breen and Simpson, 2014) I'm on really good medications and they work for me, you know. But that's only a small piece of the puzzle and I think we have to, recovery has to start looking at not just a patient going to a psychiatrist. That's not recovery, you know? That doesn't, isn't probably going to bring about recovery unless you have strong family support or a loving spouse. (Michalak *et al.*, 2012) A former girlfriend of mine … when I was still on medication … she pointed out that it was dulling my senses … which I found a valuable insight, and as a result of that … I began to think about getting off my medication, which I did … by agreement with a G.P. and my psychiatrist. It was many years ago now – eight, nine … but that was sort of a very pivotal thing … very useful (Mansell *et al.*, 2010).
* 6 Tensions	
* 6.1 Balancing acceptance with ambitions	I mean from what I've read there's always going to be ups and downs eventually, so I guess it's just remaining mindful that, yeah I have been ill and I'm probably more, more than the average person, more susceptible to becoming ill again so I've got to watch out for it and just yeah take it easy and look after myself. (Morrison *et al.*, 2016a) One participant adhered to medication but resisted relinquishing all control. Instead, she explained, "The bad side for me would be to lower my standards, lower my expectations of myself, get around with the Seroquel shufflers and just accept myself in that role." (Fernandez, Breen and Simpson, 2014)
* 6.2 Openness enables	many indicated that "letting go of stigma" (i.e., removing internalized stigma) was necessary for recovery. Some indicated

support and stigmatisation	this could result in feeling okay about having BD, which allows for self-disclosures, reduced isolation and connection with others. (Michalak *et al.*, 2012) changing from being closed and noncommunicative with others to taking the initiative and being open, yielded positive effects. This allowed them to get the personal and parenting help they wanted, and it seemed as if they were perceived in a different and more positive way. (Tjoflåt and Ramvi, 2013) Participants also reported a loss of control when their family, friends, or work colleagues engaged in symptom surveillance: I have actually had friends say, “Are you symptomatic? You are talking a lot. Maybe you have got some mania?” (Fernandez, Breen and Simpson, 2014) My boss was really worried that I might have been becoming unwell and, unfortunately, she contacted my psychiatrist before I got there. That was such a breach of confidentiality and just triggered a whole lot of stuff for me….My boss had said I was wearing different clothes, so it is this fear of, I cannot look different, I cannot wear different things, I cannot have a lot of money or act in certain ways. (Fernandez, Breen and Simpson, 2014) The need for support on the one hand, and the experiencing of stigma on the other, highlights the fact that external aspects of support could be experienced as both strengthening and inhibiting for the parents and the family (Fernandez, Breen and Simpson, 2014) Others were grateful for no longer being alone in noticing the symptoms. Many viewed receiving a diagnosis as a key event because it allowed access to the correct medication and treatment (Warwick, Tai and Mansell, 2019) Those who had received a later diagnosis viewed the years without a diagnosis as positive, as they were unaware of negative messages and had even socially recovered without realising it (”[…] I can see that I was very ill when I was younger but now able to work and hold down a job for a considerable period of years and I've learnt how to be in recovery…without even realising I was terribly ill”.) (Todd, Jones and Lobban, 2012)
* 6.3 Ambivalence around (hypo-)mania	“I think the mania part was that I would stretch myself until I felt like I was hanging on to a windowsill with my fingertips, ready to drop any time.” (Fernandez, Breen and Simpson, 2014) some participants said that they sometimes thought about the exciting and creative aspects of mania, and whether there could ever be a place for them in their current lives as well individuals, as participants often believed that they overcompensated in the monitoring of stimulating thought processes for fear of relapsing into mania. (Mansell *et al.*, 2010) most participants communicated a thirst for these states. This craving was commonly described as more challenging when life was hard and stressful. Mania or hypomania can be experienced as a break from the grayness and dysphoria of everyday life, or sometimes from feelings of being overwhelmed by stress. (Veseth *et al.*, 2012)

E Supplementary materials for the Reddit user characteristics study (Chapter 5)

E.1 Further method details

E.1.1 Age and gender: Language use

Tigunova et al.'s (2019) HAMCNN-attn model predicts an age group[86] and gender for Reddit users with at least ten posts based on their up to 100 most recent posts. Separate HAMCNN-attn models were trained on the RedDust dataset (Tigunova *et al.*, 2020) with the HAM open-source implementation[87] with the hyper-parameters specified by Tigunova et al. (2020) (128 CNN filters of size 2, attention layer with 150 units, 70 training epochs). Likely due to random seed variation, our trained age model had an area under the curve score of 0.80 compared to 0.88 in Tigunova et al. (2020). Our trained gender model had 84.9% accuracy on the RedDust test set compared to 86.0% reported by Tigunova et al. (2020).

E.1.2 Age: Hybrid method

Two corrections were applied prior to the Hybrid method: The first author checked all users with a self-reported average posting age below 16 or above 60. Age at account creation predictions younger than 13 by the Language use approach were discarded as Reddit requires an age of at least 13 when signing up.

E.1.3 Country

The Reddit country inference method (Harrigian, 2018) initially was a proprietary project but later the first author, Keith Harrigian, rebuilt it for the public release[88] used in this work. Therefore, the training data and model performance, provided by Keith Harrigian in personal email communication on 5 March 2021, slightly differ from the original publication. The training data consists of 56,853 automatically location-labelled users (top five: 68.8% US, 9.4% Canada, 7.0% UK, 3.3% Australia, 1.0% Germany), of which 8.2% were identified based on self-reported locations in r/AmateurRoomPorn and the remainder by self-reported locations in reply to 'Where are you from?' questions (Harrigian, 2018). Label precision was 97.6% in a manual evaluation of 500 users[89].

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[86] younger than 14, 14-23, 24-45, 46-65, 66+, relative to the user's most recent post

[87] https://github.com/Anna146/HiddenAttributeModels

[88] https://github.com/kharrigian/smgeo

[89] https://github.com/kharrigian/smgeo#dataset-noise

The ‘Global’ (as opposed to US only) model was used to predict user locations, which achieves 35.6% accuracy at 100 miles in 5-fold cross validation, equal to the originally reported performance in Harrigian (2018). Overall country-level accuracy is 81.9% and is generally higher for users with more training data (95.1% US, 65.1% Canada, 82.8% UK, 44.1% Australia, 41.1% Germany).

E.1.4 Gender: Username method

Wang and Jurgens (2018, p. 38) trained their long short-term memory gender inference model on 80% of 4,900,250 Twitter and 367,495 Reddit usernames, automatically labelled with self-reported masculine or feminine gender identity. Following them, the present work assumes usernames to perform masculine gender for model predictions of 0.1 or lower, and feminine for 0.9 or higher. This model and setting achieved 0.92 precision with 0.18 recall in 10% held-out Twitter and Reddit username test data (Wang and Jurgens, 2018, Figure 5 in supplementary material).

E.2 Visual results summary

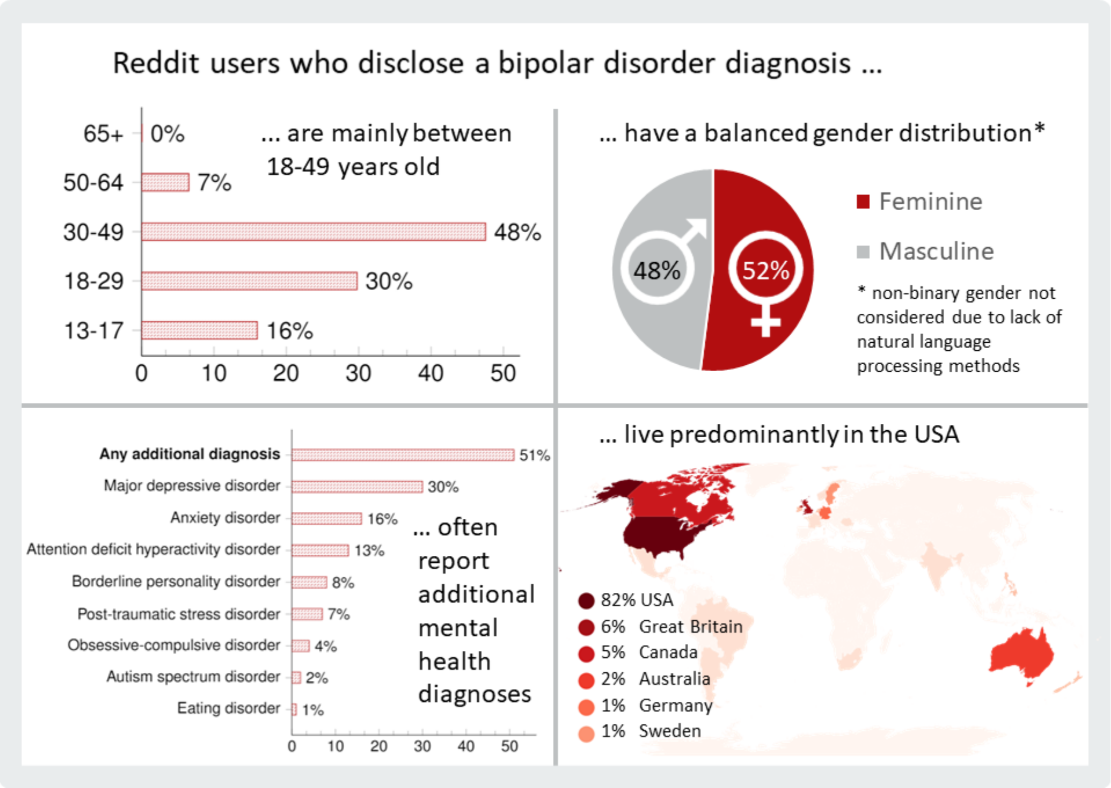

Figure S1 Visual summary of the characteristics of Reddit users who self-report a BD diagnosis

F Supplementary materials for the Reddit mood and posting behaviour study (Chapter 6)

F.1 Details on the creation of the bipolar disorder and mental health subreddit lists

The following steps led to the list of 158 MH subreddits, of which 37 are specific to BD:

- Starting point: three-level hierarchical topic-categorisation of 30K subreddits by snoopsnoo.com (Orionmelt, 2017): 20 first-, 141 second-, 529 third-level topics; snoopsnoo.com manually categorised subreddits based on subreddit descriptions and posts. Health and NLP research (e.g., Buntinx-Krieg *et al.*, 2017; Al-Khatib *et al.*, 2020) has used this taxonomy previously.
- The MH subreddit list was manually compiled from subreddits categorised in Lifestyle/Health, Lifestyle/Health/Depression and Anxiety, and Lifestyle/Health/Recovery.
- MH-related subreddits from the SMHD dataset[90] were added to this list.
- Subreddits from the MH list were categorised as BD-specific if according to their description they exclusively focused on BD.
- Subreddits in which people with a self-reported BD diagnosis had posted that contained *bipolar* in their name, had more than 10K posts, or contained a BD diagnosis post or a post with a BD mention were added to the BD or MH subreddit list if appropriate.

F.2 Method details for the logistic regression model with controls and LIWC variables

F.2.1 Rationale for model selection

A logistic regression model was most appropriate to address RQ 3 because it reveals which predictors significantly impact on the outcome and their effect sizes. While more complex models may yield higher accuracy, they are more difficult to interpret and therefore not suitable to address RQ 3.

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[90] https://ir.cs.georgetown.edu/data/smhd/mh_subreddits.txt

F.2.2 Model estimation

The logistic regression model was fitted via the R (R Core Team, 2022, Windows version 4.1.0) glm function with the following specification:

model.liwc_w_controls <- glm(*posted in MH* ~ age + gender + active_days + activity + posemo + anxiety + anger + sadness + first_pers_sg, data = df, family = binomial(link="logit"))

This corresponds to describing the probability of a user having posted in MH subreddits via the following equation in vector notation:

$$p(posted\ in\ MH) =$$

$$\frac{1}{1+e^{-(\beta_0+\beta_1\text{age}+\beta_2\text{gender}+\beta_3\text{active\_days}+\beta_4\text{activity}+\beta_5\text{posemo}+\beta_6\text{anxiety}+\beta_7\text{anger}+\beta_8\text{sadness}+\beta_9\text{first\_pers\_sg})}}$$

The model parameters β_0 (intercept) and predictor coefficients $\beta_1 - \beta_9$ are fitted via maximum likelihood estimation.

The model was estimated using all 10,158 users which met the eligibility criteria and for which age and gender information was available. The outcome variable *posted in MH* was imbalanced with 7,846 (77.2%) of users having posted in MH subreddits (*posted in MH* = 1) and 2,312 (22.8%) of users only having posted in non-MH subreddits (*posted in MH* = 0). As Figure S2 shows, the fitted model outperforms the majority class baseline that always predicts posted in MH = 1 for every user in the dataset for all recall levels except 1.0. Balancing the outcome variable by randomly subsampling 2,312 users with *posted in MH* = 1 only changed the intercept but not the predictor coefficients substantially, as expected.

The model was used to estimate the impact of each predictor on the outcome for the known users.

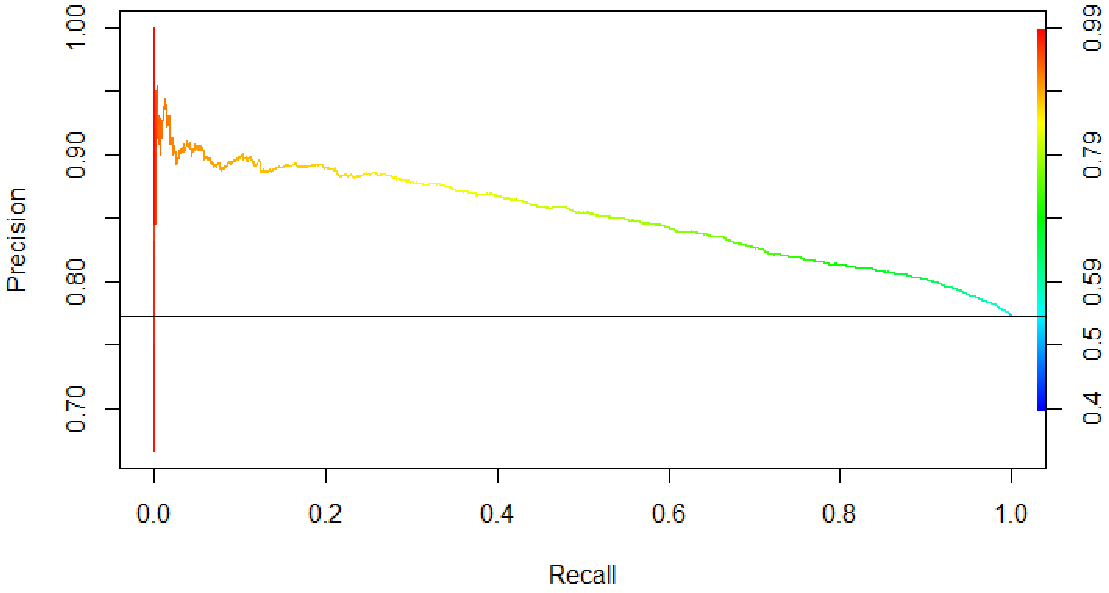

Figure S2 Precision-recall plot for the glm regression model with controls and LIWC variables applied to the 10,158 users it was estimated on

F.3 Assumptions checking for the logistic regression model with controls and LIWC variables

F.3.1 Overview of logistic regression model assumption checks

Assumptions for logistic regression were checked according to Field, Miles and Field (2012, sec. 323). As summarised in Table S6, most assumptions were met satisfactorily. Future work could try to address the lack of a linear relationship between some predictors in the model by applying more complex models with splines or nonlinear transformations of the predictors.

Table S6 Logistic regression model assumption checks

Assumption	Check results	Met?
Independence of errors	Given the study design, all cases (the users) are independent, as only a single measurement per user is used for each variable.	✓
No multicollinearity	Some multicollinearity is present in the model, but it is well below empirical thresholds for potentially harmful collinearity (see Appendix F.3.2).	✓
Linear relationship between continuous predictors and the logit of the outcome variable	All predictors except for age, and active_days showed a linear relationship with the logit of the outcome variable (see Appendix F.3.3).	(✓)

Assumption	Check results	Met?
Enough cases for all independent variable combinations	Could not be checked via crosstabulation since all variables except gender were continuous. However, no unreasonably inflated standard errors were detected (Field, Miles and Field, 2012, p. 324).	✓

F.3.2 Multicollinearity

According to Table S7, there is little to no relationship between most predictors in pairwise comparisons. Weak to medium positive correlations (0.2 < Spearman's rho ≤ 0.5) exist between anxiety, sadness, and feminine gender; first-person pronoun use, positive emotion, anxiety, and feminine gender; anger and masculine gender and activity. Additionally, there is a weak negative correlation between anger and first-person-pronoun use as well as active days and activity. The variance inflation factor (VIF) of all predictors in the model is well below the empirical critical threshold of 10 and the mean VIF of 1.13 is only marginally above the empirical threshold of 1 (Field, Miles and Field, 2012, p. 298). Belsley et al.'s (1980) condition number kappa κ of 21.79 (calculated via collin.fnc from the languageR package) is within the range of medium collinearity of $6 < \kappa < 30$ and below the ≥ 30 threshold of potentially harmful collinearity that Baayen (2008, p. 182) suggests.

Table S7 Pairwise correlations (Spearman's rho) of predictive variables and variance inflation factor (VIF)

	anxiety	sadness	anger	1st pers. sg	age	gender	active days	activity	VIF
posemo	-0.03	0.09	-0.16	0.25	-0.06	-0.17	-0.05	-0.11	1.08
anxiety		0.24	0.04	0.21	-0.03	-0.27	-0.13	0.03	1.12
sad			0.16	0.18	0.00	-0.15	-0.04	0.06	1.12
anger				-0.22	-0.04	0.24	0.06	0.27	1.08
1st pers. sg.					-0.10	-0.41	-0.14	-0.19	1.31
age						0.00	-0.13	0.11	1.04
gender							0.15	0.11	1.27
active days								-0.21	1.10
activity									1.07

F.3.3 Testing for linearity of the logit

The linear relationship between continuous predictors and the outcome variable *posted in MH* was tested following Field, Miles and Field (2012, p. 343) by adding the natural logarithm of all continuous predictors to the model. According to Field, Miles and Field (2012, p. 344), a predictor is linearly related to the logarithm of the outcome if the logarithmic predictor term is not significant. As Table S8 shows, this is the case for all predictors except age and active days.

Table S8 Results for the glm regression model including controls and LIWC variables and logarithmic terms for continuous predictors

<table>
<tr><th>Model with controls and LIWC variables</th><th>Est/Beta</th><th>SE</th><th>z</th><th>P</th></tr>
<tr><td>(Intercept)</td><td>-1.49</td><td>0.54</td><td>-2.75</td><td>0.01</td></tr>
<tr><td>age</td><td>-0.05</td><td>0.05</td><td>-1.00</td><td>0.32</td></tr>
<tr><td>gender</td><td>-0.79</td><td>0.06</td><td>-13.93</td><td><.001</td></tr>
<tr><td>active days</td><td>0.01</td><td>0.00</td><td>8.96</td><td><.001</td></tr>
<tr><td>activity</td><td>0.33</td><td>0.04</td><td>8.99</td><td><.001</td></tr>
<tr><td>posemo</td><td>0.23</td><td>0.10</td><td>2.28</td><td>0.02</td></tr>
<tr><td>anxiety</td><td>0.85</td><td>0.17</td><td>5.12</td><td><.001</td></tr>
<tr><td>anger</td><td>-0.47</td><td>0.14</td><td>-3.45</td><td><.001</td></tr>
<tr><td>sadness</td><td>0.50</td><td>0.17</td><td>2.88</td><td>0.004</td></tr>
<tr><td>1st pers. sg.</td><td>0.60</td><td>0.19</td><td>3.22</td><td>0.001</td></tr>
<tr><td>log_age</td><td>0.00</td><td>0.00</td><td>-8.35</td><td><.001</td></tr>
<tr><td>log_active days</td><td>-0.10</td><td>0.01</td><td>-8.64</td><td><.001</td></tr>
<tr><td>log_activity</td><td>-0.06</td><td>0.03</td><td>-1.79</td><td>0.07</td></tr>
<tr><td>log_posemo</td><td>0.00</td><td>0.30</td><td>0.00</td><td>1.00</td></tr>
<tr><td>log_anxiety</td><td>0.25</td><td>0.10</td><td>2.43</td><td>0.01</td></tr>
<tr><td>log_anger</td><td>-0.02</td><td>0.24</td><td>-0.07</td><td>0.95</td></tr>
<tr><td>log_sadness</td><td>-0.21</td><td>0.07</td><td>-3.05</td><td>0.002</td></tr>
<tr><td>log_1st pers. sg.</td><td>-1.49</td><td>0.54</td><td>-2.75</td><td>0.01</td></tr>
<tr><td colspan="5">Model fit</td></tr>
<tr><td rowspan="2">Pseudo R²</td><td colspan="2">Hosmer and Lemeshow</td><td>Cox and Snell</td><td>Nagelkerke</td></tr>
<tr><td colspan="2">0.064</td><td>0.066</td><td>0.101</td></tr>
<tr><td colspan="5">Key: p-values for fixed effects calculated using Satterthwaite’s approximations.
Model equation: <i>posted in MH</i> ~ age + gender + active days + activity + posemo + anxiety + anger + sadness + 1st pers. sg. + log_posemo + log_anxiety + log_anger + log_sadness + log_1st pers. sg. + log_age + log_active days + log_activity, family = binomial(link="logit")
N = 10,031 subjects = total observations (126 subjects omitted because the mean of one of their LIWC scores is zero, so the log is undefined)</td></tr>
</table>

F.4 Probability calculation for the gender coefficient

The 0.56 intercept coefficient represents odds of exp(0.56) = 1.75 which in turn represents an overall probability of posting in MH subreddits of $P = \frac{1.75}{1+1.75} = 0.64$ which is our models’ best estimate for the grand mean for the data. Using our model coefficients, the log odds of feminine users posting in MH subreddits is 0.56 + 0.79 = 1.35 and for masculine users is 0.57 – 0.79 = -0.23. The odds of posting in MH subreddits for each gender are exp(1.35) = 3.86 for feminine and exp(-0.23) = 0.79 for masculine. The probability of posting in MH subreddits for feminine users is $\frac{3.86}{1+3.86} = 0.79$ and for masculine users is $\frac{0.79}{1+0.79} = 0.44$. Therefore the -0.79 beta coefficient represents an estimated 13% increase in the likelihood to post in MH subreddits for feminine users compared to the grand mean and a 20% decrease for masculine users. In other words, feminine users are 33% more likely to post in MH subreddits than masculine users. This change in the likelihood to post in MH subreddits is reflected in differences between the actual sample means feminine = 0.84 and masculine = 0.69 around the actual sample grand mean 0.77.

F.5 Regression results for subsampled dataset with gender-balanced outcome groups

For gender balancing, a random sample of users with the over-represented gender in the outcome group was selected to match the sample size of the underrepresented gender, i.e., 896 users with masculine gender identity were randomly selected from the total of 1,416 users with masculine gender identity who never posted in MH subreddits (see Table S9). Like for the unbalanced dataset, the logistic regression model including the LIWC variables had a better fit than the model with only the control predictors, also for the gender-balanced dataset (Table S10). As Table S11 shows, the results for the gender-balanced sample did not change substantially compared to the results of the original sample in Table 27. Specifically, the effect of positive emotion stayed almost exactly the same (95% CI [0.03 - 0.08]). The effects of sadness and anxiety decreased in significance level from $P < .001$ to $P = .002$ and slightly in effect size: The 95% CI of the anxiety coefficient decreased to [0.20–0.83] from previously [0.32–0.91] and sadness to [0.13–0.62] from previously [0.18–0.63].

Table S9 Sample sizes according to outcome and gender before and after balancing for gender

posted in MH	**Gender**	**Before gender balancing**	**After gender balancing**
posted in MH = 0	feminine	896	896
	masculine	1,416	896
posted in MH = 1	feminine	4,696	3,150
	masculine	3,150	3,150
Total sample size (n users)		10,309	8,092
% of users with *posted in MH* = 1		77.2	77.9

Table S10 Model fit comparison for controls only and controls with LIWC variables for gender-balanced dataset

Model name	Nested/ simpler Model	Predictors added	Model fit				LRT against nested	
			AIC	BIC	LL	df	df	X2
Controls	-	age, gender, active days, activity	8465	8500	-4227	8087		
Controls + LIWC	Controls	posemo, anxiety, anger, sadness, 1st pers. sg.	8418	8488	-4119	8082	5	56.34, *P* <.001

Table S11 Results for the glm regression model including controls and LIWC variables for gender-balanced dataset

Model Controls + LIWC	Est/Beta	SE	95% CI	z	*P*	Odds ratio (exp(coeff))	
						Est/ Beta	95% CI
(Intercept)	0.15	0.19	-0.23 – 0.53	0.78	0.43	1.16	0.80 – 1.70
age	-0.0005	0.003	-0.01 – 0.01	-0.18	0.86	1.00	0.99 – 1.01
gender	0.06	0.06	-0.06 – 0.18	0.91	0.36	1.06	0.94 – 1.19
active days	0.0003	0.00003	0.0003 – 0.0004	10.16	<.001	1.00	1.00 – 1.00
activity	-0.01	0.01	-0.02 – 0.01	-1.18	0.24	0.99	0.98 – 1.01
posemo	0.06	0.01	0.04 – 0.08	4.98	<.001	1.06	1.04 – 1.09
anxiety	0.51	0.16	0.20 – 0.83	3.17	0.002	1.67	1.23 – 2.31
anger	-0.07	0.05	-0.16 – 0.02	-1.55	0.12	0.93	0.85 – 1.02
sadness	0.38	0.12	0.13 – 0.62	3.04	0.002	1.46	1.15 – 1.87
1st pers. sg.	0.02	0.02	-0.02 – 0.05	0.84	0.40	1.02	0.98 – 1.05

Model fit			
Pseudo R^2	Hosmer and Lemeshow	Cox and Snell	Nagelkerke
	0.019	0.019	0.030
Key: p-values for fixed effects calculated using Satterthwaite's approximations. Confidence Intervals have been calculated using the Wald method. Model equation: glm(*posted in MH* ~ age + gender + active days + activity + posemo + anxiety + anger + sadness + 1st pers. sg., family = binomial(link="logit"))			

F.6 Supplementary tables

Table S12 Top ten subreddits with most posts in the S-BiDD dataset for subreddits in the BD or MH subreddit list, and subreddits not in the MH subreddit list

BD subreddits (n=36, 564,160 posts)		**MH subreddits (without BD) (n=116, 618,165 posts)**		**Non-MH subreddits (n=49,195, 20,225,268 posts)[91]**	
Subreddit	% BD sub reddit posts	Subreddit	% MH sub reddit posts	Subreddit	% non-MH subreddit posts
bipolar	70.39	stopdrinking	13.04	AskReddit	14.49
BipolarReddit	24.66	depression	11.82	politics	1.98
bipolar2	4.10	raisedby narcissists	11.37	funny	1.69
BipolarSOs	0.53	ADHD	8.57	pics	1.56
bipolarart	0.08	BPD	8.26	Random_Acts_Of_Amazon	1.41
cyclothymia	0.07	Suicide Watch	4.39	todayilearned	1.09
bipolar_irl	0.05	aspergers	4.39	AdviceAnimals	1.05
bipolarpoets	0.02	Anxiety	4.17	WTF	1.05
bipolar_r4r	0.02	crippling alcoholism	3.49	AskWomen	0.93
Bipolar Creativity	0.01	proED	2.82	news	0.92

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[91] The number of non-MH subreddits is the number of unique subreddits in which users in the dataset posted that are not in the MH subreddit list. The users in the dataset only posted in 36 of the 37 pre-identified BD-specific subreddits and in 116 of the 121 not BD-specific subreddits in the MH subreddit list.

Table S13 Descriptive statistics and between user differences for users in the regression model

	Posted in MH subreddits		Never posted in MH subreddits		Difference[92]		
	mean	std	mean	std	*P*	effect size	effect size inter pre tation
age	29.22	9.31	29.47	9.82	2.28[a]	-0.03[a]	Very small
gender	0.4	0.49	0.61	0.49	<.001[a]	-0.43[a]	Small
active days	1292.08	883.97	1130.44	889.61	<.001[a]	0.18[a]	Very small
activity	1.44	2.52	1.85	4.79	<.001[b]	-0.16[b]	Very small
pos-emo	3.63	0.88	5.61	2.35	<.001[b]	0.17[b]	Very small
anxiety	0.36	0.19	0.3	0.16	<.001[a]	0.16[a]	Very small
anger	0.79	0.41	1.09	0.62	<.001[a]	-0.15[a]	Very small
sadness	0.44	0.21	0.43	0.22	<.001[b]	0.14[b]	Very small
1st pers. sg.	6.35	1.86	5.54	1.75	<.001[a]	0.21[a]	Small

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[92] a: independent t-test , Cohen's d; b: Welch's t-test, Glass' delta

G Supplementary materials for the POETIC on Reddit study (Chapter 7)

G.1 Supplementary Report 1: Exploratory study 1: Main topics in bipolar disorder subreddits

G.1.1 Summary

Exploratory study 1 investigated 'What are the main topics that people with a self-reported BD diagnosis talk about in BD online support forums?'. It consisted of an automatic content analysis of a 20M word corpus built from randomly sampled S-BiDD dataset posts in BD subreddits, followed by manual coding. The resulting topics in order of frequency were MH symptoms, Professional treatment, Personal narratives, Recovery and self-management, and Recurrences and routines. MH symptoms and Professional treatment were each about ten times more frequent than all other topics.

G.1.2 Motivation

Content selection is necessary when working with naturalistic data as not all Reddit posts by people with a BD diagnosis state something about their PR experiences. However, understanding what issues beyond PR people with a BD diagnosis discuss on Reddit, helps to contextualise discussions about PR on this platform. In addition, a broad-scale content analysis of the online posts can determine how prevalent or 'niche' the topic is on the platform. Therefore, the first exploratory study investigated 'What are the main topics that people with a self-reported BD diagnosis talk about in BD online support forums?'.

G.1.3 Methods

Figure S3 shows a flow chart of the corpus construction and analysis detailed in the following.

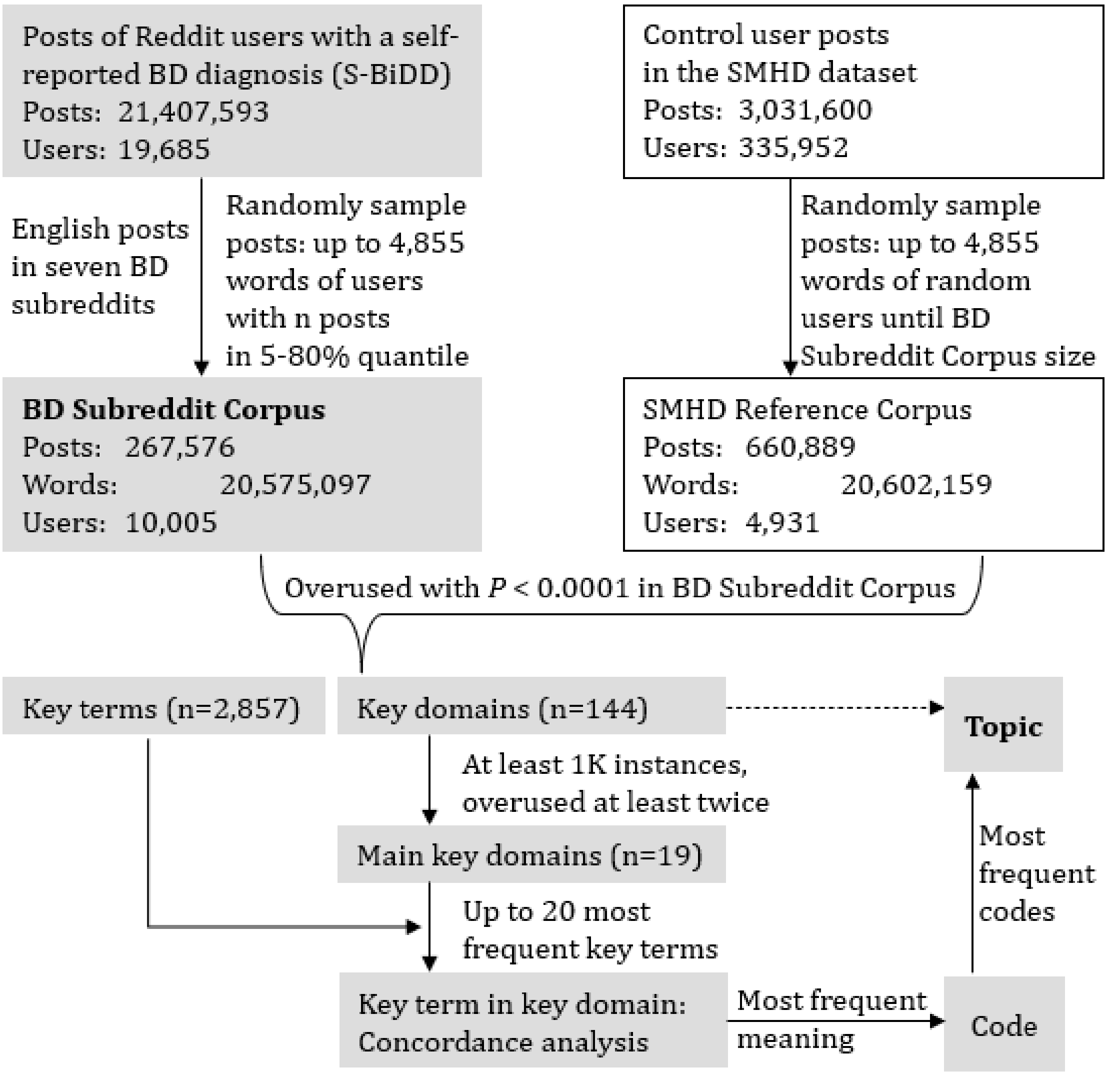

Figure S3 Corpus construction and analysis flow chart

G.1.3.1 Corpus construction

The BD Subreddit Corpus constructed for this exploratory study consists of 20M words representative for English posts in seven BD subreddits[93] by people with a self-reported diagnosis of BD from randomly sampled dataset[94] posts. Precisely, the 5% of identified user accounts with fewest words in BD subreddits were removed (less than 76 words, 5% quantile) and posts of the 20% of user accounts who had posted most were downsampled until 4,855 words were reached or exceeded (80% quantile). Only English posts were analysed as 97% of the dataset posts are in this language as determined via the python-based automatic language detection system langid.py (Lui and Baldwin, 2012). Post wordcount was

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[93] r/Bipolar, r/BipolarReddit, r/bipolar2, r/bipolarSOs, r/bipolarart, r/cyclothymia, r/manicdepression

[94] The BD Subreddit Corpus includes 34,995 comments from April and May 2019. The S-BiDD dataset contains only posts up until March 2019, to be consistent with the submissions (thread starts), which were only available up until this month when the dataset was created.

determined via NLTK's (version 3.4.1) TwitterTokenizer (Bird, Loper and Klein, 2009).

To identify key terms (words or phrases) and key semantic domains (see Appendix G.1.3.2), a reference corpus was constructed from Reddit posts of the control users in the SMHD dataset by Cohan et al. (2018). These users never mentioned MH-related terms on Reddit or posted in MH-related subreddits. Up to 4,855 words of randomly sampled SMHD control users with at least 76 words were included until the SMHD Reference Corpus reached the same number of words as the BD Subreddit Corpus.

G.1.3.2 Automatic content analysis via key semantic domains

USAS (Rayson *et al.*, 2004), an NLP tool for automatic content analysis, served to annotate words and phrases in the corpus with semantic domains. USAS assigns semantic domains to words and multi-word units using a manually created lexicon (Piao *et al.*, 2005) and word sense disambiguation rules (Rayson *et al.*, 2004). USAS requires input that is word-segmented (tokenised) and tagged with parts of speech by CLAWS (Garside and Smith, 1997). USAS domains are hierarchically organised with 21 top-level domains, e.g., 'Food and farming', 'Psychological actions, states, and processes' (see Table S14) and 232 second- and third-level domains. Key terms (words and multiword phrases as identified by USAS) and key domains were identified by calculating which terms and USAS domains were statistically significantly overused[95] in the BD Subreddit Corpus compared to the SMHD Reference corpus.

Table S14 USAS top-level domains

A: general and abstract terms	I: money and commerce in industry	Q: language and communication
B: the body and the individual	K: entertainment, sports and games	S: social actions, states and processes
C: arts and crafts	L: life and living things	T: time
E: emotion	M: movement, location, travel and transport	W: world and environment
F: food and farming	N: numbers and measurement	X: psychological actions, states and processes
G: government and public	O: substances, materials, objects and equipment	Y: science and technology
H: architecture, housing and the home	P: education	Z: names and grammar

---

[95] Log likelihood statistic (Rayson and Garside, 2000), $P<.0001$ with Bonferroni correction for n=490,364 comparisons (number of combined unique terms, part of speech tags, and USAS domains in the BD Subreddit and SMHD Reference Corpus)

G.1.3.3 Manual analysis of key terms in key semantic domains

Since the USAS domain hierarchy intends to capture a general interpretation of the world, it can lack specificity for analysing corpora from a specialised domain (Hunt and Brookes, 2020, p. 85). Therefore, main key domains[96] were analysed in more detail following a standard corpus linguistic approach of keyword concordance analysis (Baker, 2010, p. 135; Hunt and Brookes, 2020, p. 85). The contexts of the up to 20 most frequent key terms in each key domain were explored via the SketchEngine[97] concordance view. Based on this, codes were inductively assigned to reflect the explicit/surface meaning of the key terms in context and subsequently grouped into broader inductive domain-specific topics, following a conventional content analysis approach (Hsieh and Shannon, 2005). Each key term was assigned to one code based on its most frequent meaning and each USAS domain was assigned to one topic aggregated from the most frequent codes of the key terms tagged with this domain. This was difficult in some cases where key terms or words tagged with the same USAS domain referred to different aspects of living with BD, such as 'mental health' appearing predominantly in the context of 'mental health symptoms' but also in 'mental health services' (referring to treatment). Therefore, the topic frequencies represent approximations rather than exact values.

G.1.4 Results

G.1.4.1 Corpus statistics

The BD Subreddit Corpus comprises 267,576 posts with a total of 20,575,097 words by 10,005 users. The SMHD Reference Corpus consists of 660,889 posts with a total of 20,602,159 words by 4,931 users (see Table S15). There are two striking differences: First, the vocabulary size in the reference corpus is almost three times as large as in the BD Subreddit Corpus. This is probably due to the more diverse range of topics expected in the reference corpus compared to the BD Subreddit Corpus that is restricted to a narrow set of subreddits. Second, posts in the BD Subreddit Corpus have more than twice the number of words than in the SMHD Reference Corpus. This aligns with Cohan *et al.* (2018) who reported that the posts of all user groups with MH diagnoses, including BD were substantially longer compared to the posts of undiagnosed control users from which the SMHD Reference Corpus was sampled.

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[96] at least 1K occurrences and overused at least twice (log ratio (Hardie, 2014) ≥ 1.0) in the BD Subreddit Corpus compared to the SMHD Reference Corpus

[97] https://www.sketchengine.eu/

Table S15 BD Subreddit Corpus and SMHD Reference Corpus statistics (SD: standard deviation)

Corpus	Users	Terms[98] (hapax legomena)	Words	Posts	Mean +/- SD words/ user	Mean +/- SD posts/ user	Mean +/- SD words/ post
BD sub-reddit corpus	10,005	156,285 (58%)	20,575,097	267,576	2,056 +/- 1,839	27 +/- 30	77 +/- 114
SMHD Reference Corpus	4,931	404,506 (66%)	20,602,159	660,889	4,178 +/- 1,166	134 +/- 73	31 +/- 33

Figure S4 shows the number of words and Figure S5 the number of posts per user in the BD Subreddit and SMHD Reference Corpus. The peaks in the number of users with around 5K words in both corpora are due to the sampling of posts for each user until 4,855 words were reached. Other than that, the data follow exponential distributions. This is in line with the 90-9-1 principle in online support forums which states that only 1% of superusers produce the majority of the forum content, while a further 9% of users supply the rest and the remaining 90% of users only observe the content without actively participating (Carron-Arthur, Cunningham and Griffiths, 2014; Van Mierlo, 2014).

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[98] according to USAS

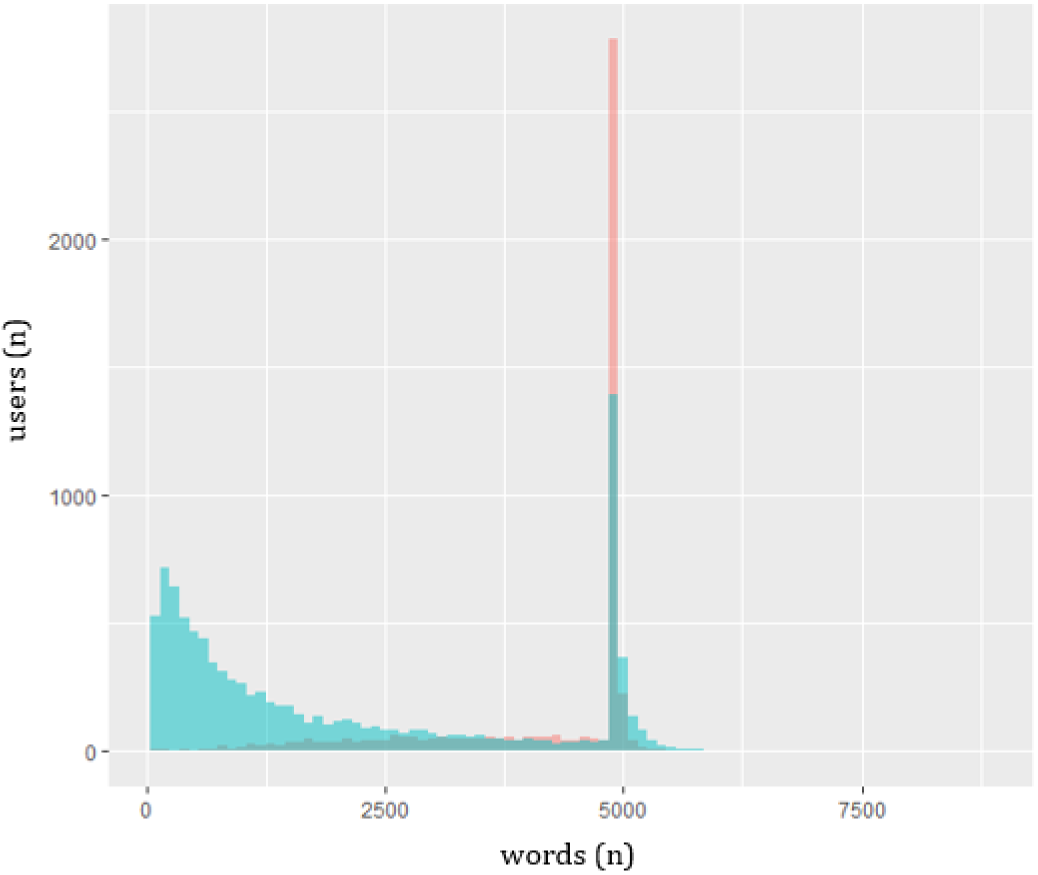

Figure S4 Histogram for words per user in the BD Subreddit Corpus (blue) and SMHD Reference Corpus (red)

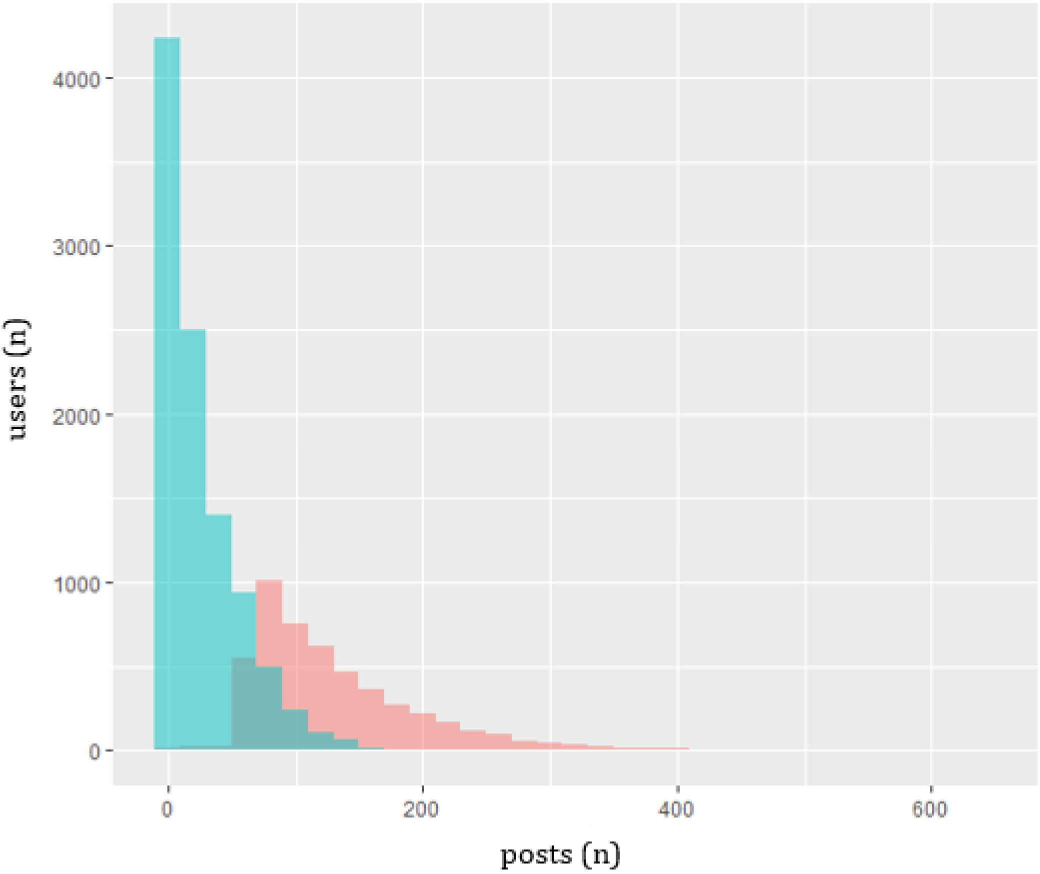

Figure S5 Histogram for posts per user in the BD Subreddit Corpus (blue) and SMHD Reference Corpus (red)

G.1.4.2 Analysis of key terms in key semantic domains

Comparison of the BD Subreddit Corpus with the SMHD Reference Corpus yielded 3,201 key terms[99] and 141 USAS key domains[100] that were significantly overused in the BD Subreddit Corpus. Manual analysis of the most frequent key terms in the 19 main key domains resulted in five BD-related topics: MH symptoms, Professional treatment, Recovery and self-management, Personal narratives, and Recurrences and routines (see Table S16).

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[99] https://github.com/glorisonne/reddit_bd_recovery/blob/main/exploratory_study_1/BD%20Subreddit%20Corpus_key%20terms.csv

[100] https://github.com/glorisonne/reddit_bd_recovery/blob/main/exploratory_study_1/BD%20Subreddit%20Corpus_key%20domains.csv

Table S16 BD-specific topic grouping and manually analysed key terms in the 19 main key domains in the BD Subreddit Corpus

USAS domain	Fre-quency	Most frequent overused key terms (up to 20)
1. MH symptoms (420,697 mentions)		
1.1. BD-specific (306,854 mentions)		
1.1.1 Mania (181,432 mentions)		
B2- Disease	154833	mania (14110), disorder (11915), symptoms (10542), side effects (7338), crazy (5836), illness (5354), mental illness (4700), pain (4230), hurt (3809), sick (3741), adhd (3716), psychotic (3049), psychosis (2975), hypo (2255), side effect (1970), hallucinations (1894), paranoid (1880), disease (1815), paranoia (1759), patients (1549)
X5.2++ Interest, energy, excitedness	24684	manic (23,061), obsessive (588), addict (237), obsessively (195), fixated (88), on the manic side (29), manics (20)
A1.3- Lack of caution	1915	impulsive (925), reckless (410), rash (196), impulsively (175)
1.1.2 Depression (77,356 mentions)		
E4.1- Sad	77356	depression (24772), depressed (14809), depressive (6885), sad (3827), cry (2334), upset (1953), crying (1790), suffering (1389), in a state (1227), regret (1160), miserable (1111), trauma (851), cried (849), sadness (767), embarrassed (642), suffered (599), embarrassing (592), depressions (524)
1.1.3 Extreme mood and mood swings (48,066 mentions)		
E1 Emotional actions, states, processes	35880	mood (13462), moods (4007), feel (3889), emotions (3658), emotional (2863), mood swings (1672), moody (353), compassion (304), vibes, affective (199), tone (197), temper (178), self-control (151)
A6.3+ Comparing: variety	8856	mixed (3722), combination (1620), spectrum (785), erratic (274), combinations (235)
N5.1+++ Entirety: maximum	3330	extreme (2705), extremes (330), as much as possible (264)
1.2 Other MH issues (78,968 mentions)		
E6- Apprehension, confidence	49169	anxiety (13863), care (3869), stress (3545), worried (3177), anxious (3177), worry (2876), trouble (2404), PTSD (1746), concerned (1353), nervous (1232), stressful (1180), concern (831), concerns (798),

USAS domain	Frequency	Most frequent overused key terms (up to 20)
		worrying (546), caring (529), worries (323), dysphoric (319)
E5- Trepidation, courage, surprise	29799	psych (5645), scared (4118), fear (2482), scary (2205), afraid (2124), terrified (1445), panic (1166), terrifying (657), freaking out (598), scares (544), freaked out (472), freak out (471), fears (424), alarm (362), dread (306)
1.3 General (25,350 mentions)		
A5.1-- Evaluation: bad	9525	worse (9100), exacerbated (130), exacerbate (119), exacerbates (67), exacerbating (55)
B2 Health and disease	9114	mental health (5674), health (2647), Medicaid (160), wellness (158), asymptomatic (29)
X1 Psychological actions, states, processes	6711	mind (4831), psychological (419), sanity (326), state of mind (314), anhedonia (146), psychologically (91)
2. Professional treatment (208,346 mentions)		
B3 Medicines and medical treatment	208346	diagnosed (20740), doctor (17524), medication (17498), psychiatrist (12949), diagnosis (11955), therapist (9910), therapy (8953), hospital (6837), treatment (6450), medications (5657), drugs (5362), doctors (4539), drug (4193), prescribed (3900), medical (3245), medicine (3169), pills (3002), medicated (2507), DR (2352), antidepressants (2190)
3. Personal narratives (34,925 mentions)		
L1+ Life and living things	34925	life (31481), alive (1473), lives (1297)
4. Recovery and self-management (34,583 mentions)		
A2.1- Affect: modify, change	14216	stable (7866), stability (1876), stabilize (600), stabilized (515), stabilizing (266), left alone (125), rut (104), stabilizes (72), stabilise (46)
X5.1+ Attention	10295	focus (4057), attention (1316), focused (811), focusing (601), Mindfulness (600), concentrate (576), concentration (454), mindful (292), concentrating (133), vigilant (119), acutely (47)
B2+ Health	7753	healthy (3620), recovery (908), recover (502), recovering (342), well being (184), recovered (184), well-being (103), snap out of it (124), wellbeing (103), healthily (56)

USAS domain	Fre-quency	Most frequent overused key terms (up to 20)
X9.2 Ability: success	2319	cope (1888), coped (66)
5. Recurrences and routines (24,818 mentions)		
N6 Frequency or rate of recurrence	24818	sometimes (15822), at times (1417), on and off (598), n't ever (556), twice a day (520), once a week (449), once a day (275), once a month (270), off and on (145)

While mentions of core BD symptoms (*mania, depression*, and *extreme moods*) were frequent key terms in the BD Subreddit Corpus, other frequent key terms referred to other MH concerns, mainly *anxiety*, addiction, and attention deficit hyperactivity disorder. The Professional treatment topic consisted of the single USAS domain B3: 'Medicines/medical treatment'. Based on the key term frequencies, *medication(s)* or *meds* (n=57,981 mentions) prescribed by a *doctor* (n=17,524) or *psychiatrist* (n=12,949) appear as the most frequently discussed treatment, compared to far less mentions of *(psycho-)therapy* or *therapies* (n=9,246) offered by a *therapist* (n=9,910). The keyword *life* often appeared in Personal narratives ('for my whole life').

Notably, posts in the BD Subreddit Corpus mentioned Recovery and self-management far less frequently than MH symptoms and Professional treatment. To illustrate this, the USAS domain B2: 'Health and disease' distinguishes ill-health (B2-) and good health (B2+). B2- (n=154,833) contributed to the MH symptoms topic with terms such as *mania, disorder*, and *symptoms*. The twenty times less frequent B2+ domain (n=7,753) contributed to the Recovery and self-management topic with terms such as *recovery* and *wellbeing*. Temporal terms on frequency or rate of recurrence indicated routines, e.g., medication or self-care regimes.

G.1.5 Discussion

Via an automatic content analysis with subsequent manual analysis of key words, phrases, and content domains, this study found that people with a self-reported BD diagnosis most frequently talk about MH symptoms and professional treatment in BD subreddits. About ten times less frequently, they discuss their personal narratives, recovery and self-management, and recurrences and routines.

G.1.5.1 Involvement of people with lived experience

After completion of this exploratory study, five volunteers with lived experience of BD and using online support forums recruited via PeopleInResearch were interviewed in June-July 2021. They confirmed the finding that the focus in BD online support forums is on symptoms and professional treatment, although one volunteer was surprised by how few mentions there were of positive experiences and recovery. All volunteers were familiar with the term recovery in relation to BD, but they had their personal preferences about how to talk about living with BD and recovery, using a variety of other terms, e.g., 'living a normal life', 'feeling better', 'improvement'. All volunteers were very supportive of the research, and none raised ethical concerns.

G.1.5.2 Limitations

While the automatic content analysis approach taken in this study allowed to analyse as many as 20M of words, two limitations of the USAS tool need to be pointed out. First, like virtually any automatic tool, USAS can make mistakes. USAS achieved 91% precision on general topic conversation transcripts (Rayson *et al.*, 2004), but this does not necessarily translate to online posts in the specific MH domain. However, the concordance analysis of key terms in the main key domains did not reveal frequent miscategorisations.

Second, since USAS is based on static dictionaries, it cannot assign a semantic domain to words that are not in its dictionaries. In the BD Subreddit Corpus, USAS could not assign a semantic domain to only 1.87% of term instances. GJ manually examined the 66 untagged terms with a frequency of at least 500 instances (accounting for 37.64% of untagged tokens) and proposed suitable USAS categories. USAS developers Paul Rayson and Andrew Wilson checked these assignments, which can be used to extend the USAS dictionary[101]. The analysis revealed that most of them were psychotropic drug brand names (e.g., *Lamictal, Seroquel, Latuda*). Other frequently untagged instances were medication dosages that were not properly segmented by the tokeniser (e.g., *100mg*). Few instances were diagnosis abbreviations, e.g., *bp2, BPD*, and Reddit-specific terms such as *Reddit, subreddit*. Most of the examined untagged words would fall into the USAS domains B3 (Medical treatment) and B2- (Disease), which were the two most frequent domains in the BD Subreddit Corpus already. Therefore, it can be confidently concluded that incomplete coverage of the USAS tool did not distort the results of this study and that re-tagging the corpora with complete coverage would likely not change the conclusions.

G.2 Supplementary Report 2: Exploratory study 2: Usage of *recover* terms by people with a bipolar disorder diagnosis

G.2.1 Summary

Exploratory study 2 examined how Reddit users with a self-reported BD diagnosis use *recover* terms. Three coders coded the meaning of 377 instances of the eight most frequent word forms of recovery (i.e., recovery, recover, … = *recover* terms) in the *recover* corpus consisting of 57K S-BiDD dataset posts with at least

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[101] https://github.com/glorisonne/reddit_bd_recovery/blob/main/data/BDSubredditCorpus_UntaggedTerms_ProposedTags.csv

one *recover* term. Overall, 43% of the instances denoted MH recovery, 23% recovery from physical health issues, 14% recovery from difficult life events, and 20% other meanings. Of the MH recovery instances, 66% described clinical recovery, whereas only 17% clearly denoted PR. Only 7.4% *recover* term instances related to BD, another 7.4% to PR, and only 1.3% to PR in BD. This indicated that Reddit users with a self-reported BD diagnosis seem to more readily associate topics such as alcohol addiction or recovery from physical health issues with 'recovery', rather than PR in BD. Also, Reddit users with a BD diagnosis almost exclusively used *recover* terms in relation to BD in BD subreddits.

G.2.2 Motivation

Although the research literature and MH systems widely adopt the term 'recovery' (e.g., World Health Organization Regional Office for Europe, 2005; Amering and Schmolke, 2011; Department of Health (UK), 2011), Michalak et al. (2012) and McCabe et al. (2018), among others, criticise the term as ambiguous between a clinical recovery vs. PR understanding. Qualitative studies have evidenced diverse understandings of the term by people with lived experience of severe MH issues (McCabe *et al.*, 2018), and BD specifically (Michalak *et al.*, 2012).

Michalak et al. (2012, p. 174) identify 'a lack of precision about what the term recovery represents and entails' as a challenge in clinician-client communication and conclude that a 'one size fits all' approach may not be linguistically appropriate for describing outcomes in people with mental illness' (2012, p. 176). To complement and extend the existing qualitative evidence, the second study will for the first time yield quantitative evidence on the question 'With what meanings do Reddit users with a self-reported BD diagnosis use *recover* terms (i.e., recovery, (to) recover, recoverable)?'.

G.2.3 Methods

G.2.3.1 Corpus construction

Table S17 displays the three steps that led to the *recover* corpus. Initially, English[102] posts that contained at least one term instance (token) matching *recover* (e.g., recovery, recovered, irrecoverable) were selected from the S-BiDD dataset[103]. Although *recover* appeared frequently as part of proper names, these deserve a separate study as the present RQ focuses on lexical uses. Therefore, proper names (subreddit names, e.g., *opiatesrecovery, edrecovery*, usernames and product names, e.g., *MoistureCover, RecoverIT*) were manually removed. Also, the matched term *precoverage* that did not have *recover* as stem was removed. This led to a list of 98 *recover* content terms[104] to select posts in the second step.

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[102] according to automatic language identification via langid.py (Lui and Baldwin, 2012)

[103] URLs in all S-BiDD dataset posts were automatically replaced with the placeholder subURLaddress (see https://github.com/glorisonne/reddit_bd_mood_posting_mh/blob/main/replace_urls.py).

[104] https://github.com/glorisonne/reddit_bd_recovery/blob/main/exploratory_study_2/recover_content_terms.csv

Finally, the number of posts for one user who had posted disproportionally many posts (n=3,997) (see Figure S6) was downsampled to the number of posts of the user with the second must number of posts (n=540) posts to create the *recover* corpus.

Table S17 *recover* corpus creation

Posts	Users	Subreddits	Sentences	Tokens	Unique *recover* terms
1. All English S-BiDD dataset posts with at least one token that matches *recover*					
61,553	9,119	4,125	795,911	12,786,617	241
2. After selecting only posts with at least one *recover* content term					
60,716	9,098	4,097	787,893	12,668,640	150
3. *recover* corpus: after downsampling user with disproportionally many posts					
57,259	9,098	4,087	755,220	12,190,378	145
Posts from *recover* corpus for manual coding of *recover* instances					
332	302	180	4,738	77,163	9

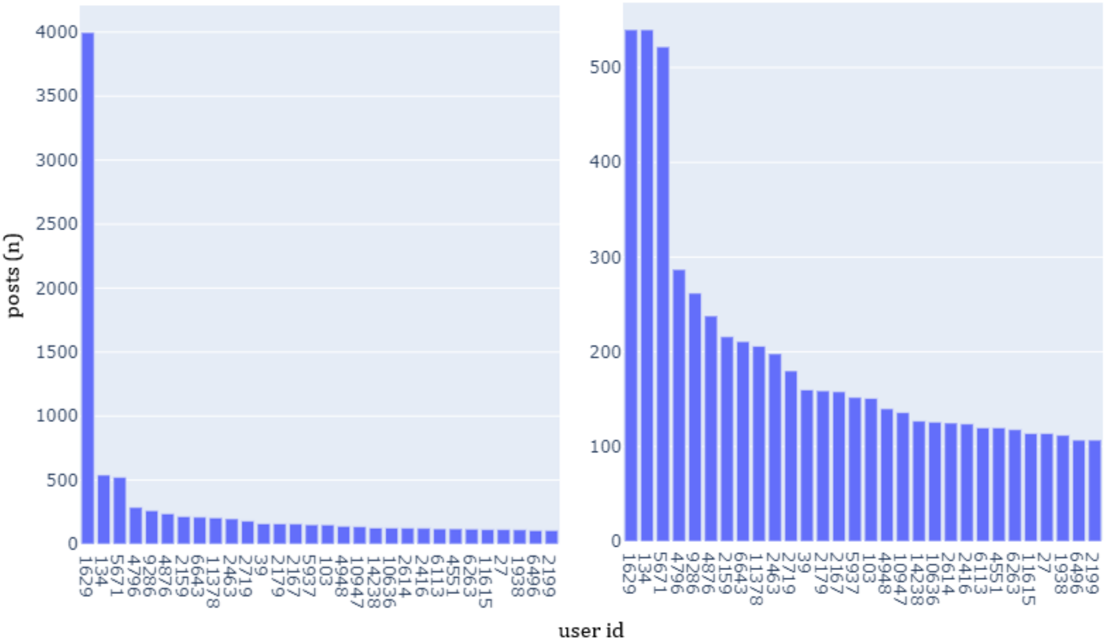

Figure S6 Number of posts that contain a *recover* content term for top 30 users before (left) and after (right) downsampling posts of user 1626

For manual coding, a random sample of 0.5% of the posts in the *recover* corpus was selected. Since only 15 *recover* term instances in the random sample appeared in BD-specific subreddits, 35 randomly selected instances from BD-specific subreddits were added. Additional randomly selected instances were added from the corpus for *recover* terms (see Section G.2.3.2) that had less than five instances in the initial 0.5% sample.

G.2.3.2 Manual coding

Eight *recover* terms that corresponded to standard English terms[105] and appeared at least 100 times in the corpus (see Table S19) were manually coded for their meaning. The codebook (see Appendix G.3) consisted of the nine main categories shown in Table S23, including MH recovery, recovery from physical health issues, recovery from difficult live situations, and retrieving things. The study team agreed on these categories based on Oxford dictionary meanings of the *recover* terms, clinical definitions and operationalisations of personal and clinical recovery (i.e., the Questionnaire about the process of recovery (Neil *et al.*, 2009)), and initial explorations of the data. For instances identified as denoting MH recovery coders additionally distinguished between PR and clinical recovery, the MH condition in relation to which the recover term was used, and whether the recovery was from a discrete MH episode or seen as long-term.

The coding spreadsheet presented each *recover* term instance and its sentence and post context. GJ coded all 377 instances. In a pilot to gauge feasibility of the task, PER coded 62 instances and SHJ 29 of these. Subsequently, PER and SHJ each coded half of the remaining 315 instances, such that at least two coders coded every instance. After agreement calculation, GJ considered the thread context from reddit.com (if available) if there was not enough information in the post alone. The coding team resolved all disagreements in discussion.

G.2.4 Results

Table S18 displays the top ten subreddits in the S-BiDD dataset that contain most posts with a *recover* content token. Two are BD-specific (*Bipolar, BipolarReddit*), three are related to other MH issues (*BPD, depression, raisedbynarcissists*), two are about substance abuse (*stopdrinking, OpiatesRecovery*), and three are not MH-specific (*AskReddit, relationships, Fitness*).

Table S18 Top ten subreddits with most posts in the *recover* corpus

Subreddit	Posts in *recover* corpus (n)	*recover* corpus posts out of all subreddit posts (%)
AskReddit	5208	0.18
bipolar	2688	0.68
stopdrinking	2639	3.27
BipolarReddit	1293	0.93
BPD	1029	2.01
relationships	964	0.56
OpiatesRecovery	804	9.12
raisedbynarcissists	778	1.11
depression	654	0.89

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[105] terms listed in the Oxford dictionary (lexico.com) or their correctly inflected variants, e.g., recoveries

Subreddit	Posts in *recover* corpus (n)	*recover* corpus posts out of all subreddit posts (%)
Fitness	583	1.16

The *recover* corpus comprises 57,535 posts by 9,101 users in 4093 subreddits (758,037 sentences with 12,229,902 tokens). It contains 162 unique terms that match *recover*, of which 14 are standard English such as recovery, recovers, the remaining ones correspond to proper names that appeared in posts who also contained whitelisted *recover* content terms, e.g., redditorsinrecovery, spelling mistakes, e.g., recoverd, recoverying, or word segmentation issues, e.g., recovery](suburladdress (see Table S19).

Table S19 *recover* terms in the *recover* corpus with at least three instances (boldface: standard English terms)

Rank	Term	Frequency	Rank	Term	Frequency
1	**recovery**	**32431**	16	recoverd	10
2	**recover**	**15460**	**17**	**unrecovered**	**8**
3	**recovering**	**10389**	18	edrecovery	8
4	**recovered**	**7171**	**19**	**recoverer**	**7**
5	**recovers**	**822**	**20**	**recoverability**	**6**
6	**recoveries**	**264**	21	soberrecovery.com	5
7	**recoverable**	**194**	22	recoverying	5
8	**unrecoverable**	**124**	23	recovery/	5
9	recovery-	34	24	recover-	5
10	redditorsinrecovery	31	25	recover--	4
11	**irrecoverable**	**23**	26	celebraterecovery	4
12	recovery](suburladdress	19	**27**	**recoverers**	**4**
13	opiatesrecovery	17	28	recovery--	3
14	smartrecovery.org	13	29	dinosaursinrecovery	3
15	**irrecoverably**	**11**			

G.2.5 Coding the meanings of *recover* terms

As Table S20 shows, both coder pairs achieved moderate to good agreement in coding the overall meaning of *recover* term instances (top left), and even good to very good agreement when only considering the instances where both coders assigned a definite code (not ‘Cannot determine’) (bottom left). In deciding whether *recover* term instances pertained to a PR or clinical recovery notion coders only reached a fair level of agreement even when only considering instances where they decided for one code or the other. Conversely, determining the MH issue for MH recovery instances seemed relatively uncontroversial and both coder pairs achieved good to very good agreement. In coding whether the *recover* term pertained to long-term recovery vs. recovery from an episode, one annotator pair achieved good agreement, while the other only agreed poorly.

Discussions of disagreements showed that particularly for ‘Recovery type’ the consistently low agreement for both coder pairs in the blind coding was due to two factors: First, inferring this information about the subjective state of the post author for an isolated instance of a *recover* term often lacked context. Some posts were very short and there was no opportunity to ask the author. This lack of context gave rise to diverging judgments based on the individual reading of the coder with their personal backgrounds. Importantly, most of the disagreements could be resolved in discussion. The team could not agree on the recovery type for only 16.7% of the MH recovery *recover* term instances (see ’Cannot determine’ in Table S23).

Table S20 Gwet's AC$_1$ and its standard error (SE), Cohen's kappa (k) and observed agreement (P$_0$) for the coding of the meaning of recover terms

Coders	n	AC$_1$, SE	k	P$_0$	n	AC$_1$, SE	k	P$_0$	n	AC$_1$, SE	k	P$_0$	n	AC$_1$, SE	k	P$_0$
	Meaning				Recovery type				MH issue				Duration			
	All				Both coders agree on MH recovery											
GJ + PER	220	0.820, 0.028**	0.78**	0.836	85	0.335, 0.083	0.17	0.518	85	0.807, 0.045**	0.77**	0.824	85	0.268, 0.083	0.02$^+$	0.459
GJ + SHJ	186	0.623, 0.039*	0.53*	0.661	77	0.363, 0.086	0.09	0.519	77	0.840, 0.045**	0.81***	0.857	77	0.703, 0.065*	0.28$^+$	0.753
	Both coders did not code 'Cannot determine'				Both coders agree on MH recovery and did not code 'Cannot determine'											
GJ + PER	203	0.885, 0.024***	0.85***	89.7	61	0.52, 0.11$^+$	0.37$^+$	72.1	71	0.89, 0.04***	0.86***	90.1	66	0.28, 0.13	0.03	57.6
GJ + SHJ	159	0.746, 0.038**	0.65**	77.4	61	0.43, 0.12$^+$	0.18	65.6	63	0.928, 0.035***	0.91***	93.7	68	0.787, 0.068**	0.34$^+$	83.8

Table S20 note: See Table S21 for definitions of the agreement measures and Table S22 for their benchmarking.

Table S21 Inter-rater agreement measures

Name	**Equation**[106]	**Comment**
	Two coders: coder 1, coder 2 Total coded cases: N Number of classes: z Frequency that coder 1 assigned class i and coder 2 assigned class j: $f_{i,j}$ Frequency of coder 1 assigning class i: $f_{i\cdot} = \sum_{j=1}^{z} f_{i,j}$ Frequency of coder 2 assigning class i: $f_{\cdot i} = \sum_{j=1}^{z} f_{j,i}$	
Raw agreement (P_0)	$P_0 = \frac{\sum_{i=1}^{z} f_{i,i}}{N}, P_0 \in [0,1]$	Not corrected for chance agreement P_e, P_0 *100 = % of agreed cases
Cohen's kappa (k) (Cohen, 1960)	$k = \frac{P_0 - P_e}{1 - P_e}, P_e = \frac{\sum_{i=1}^{z} f_{i\cdot} * f_{\cdot i}}{N^2}$ $k \in [-1,1]$	Inaccurate for skewed and imbalanced label distributions (Dettori and Norvell, 2020)
Gwet's AC_1 (Gwet, 2014b)	$AC_1 = \frac{P_0 - P_e}{1 - P_e}$ $P_e = \frac{\sum_{i=1}^{z} \pi_i * (1 - \pi_i)}{z-1}, \pi_i = \frac{f_{i\cdot} + f_{\cdot i}}{2}$ $AC_1 \in [-1,1]$	Recommended as most reliable inter-rater agreement measure for categories in discourse analysis by Brezina (2018a, p. 269) and as more reliable than kappa in clinical research by Dettori and Norvell (2020)

Table S22 Benchmarking of k and AC_1 according to Altman's (1991) scale

k or probability that the true agreement strength level of AC_1, SE is the one associated with the value or one that is better is above 0.95[107]	**Agreement strength level**
0.8-1	Very good***
0.6-0.8	Good**
0.4-0.6	Moderate*
0.2-0.4	Fair$^+$
<0.2	Poor

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[106] Implementation: https://github.com/glorisonne/reddit_bd_recovery/blob/main/agreement.R

[107] The k value directly maps to the agreement strength level where k≥lower value of the respective range. For AC_1 and its standard error, the cumulative probability is calculated for each agreement strength level that the value falls into that category. The agreement strength level is the most likely range to which the estimate belongs, when the cumulative probability crosses a certain threshold (Dettori and Norvell, 2020, p. 500). Following Gwet (2014a) this threshold was set to 95%.

G.2.6 Distribution of the meanings of *recover* terms

Table S23 shows the percentages of coded *recover* term instances in each of the categories overall and according to subreddit type (BD-specific, non-BD MH-focused, non-MH-related[108]). As could be expected, Reddit users with a BD diagnosis more frequently refer to MH recovery with *recover* terms in subreddits specific to BD (80.0%) or other MH issues (84.0%) than in subreddits not related to MH issues (28.9%), where a physical health meaning is equally likely (28.5%). Still, even in MH specific subreddits, 16%-20% of *recover* term instances bear a non-MH-related meaning (recovery from physical health issues or difficult life events, or retrieving things). For MH recovery instances, a clinical recovery denotation is much more frequent (66.0%) compared to PR (17.3%), with little differences between subreddits with and without MH focus.

Table S23 Meanings of *recover* terms in Reddit posts of people with a self-reported BD diagnosis

Category	Description	% total (n=377)	% BD sub reddits (n=50)	% MH sub reddits (n=50)	% non-MH sub reddits (n=277)
MH recovery	**Recovery from/in MH issues**	**43.0**	**80.0**	**84.0**	**28.9**
- Clinical recovery (% MH recovery)	Measured by discrete, predefined, clinician-observed outcomes (e.g., symptoms + functioning)	66.0	75.0	73.8	57.5
- PR (% MH recovery)	**Living a satisfying, hopeful, contributing life even with limitations of MH issues; self-defined, individual, process**	**17.3**	**12.5**	**11.9**	**14.3**
- Cannot determine (% MH recovery)	Cannot distinguish between clinical recovery and PR	16.7	12.5	14.3	20.0
Physical health	Return to normal health/strength by overcoming a physical health issue (e.g., childbirth, surgery)	22.8	12.0	2.0	28.5
Life event	Overcoming a difficult life event/situation that did not cause a diagnosable MH issue (e.g., breakup, job loss)	14.1	6.0	10.0	16.3

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[108] See Jagfeld (2022c) for the lists of BD and MH-specific subreddits.

Category	Description	% total (n=377)	% BD sub reddits (n=50)	% MH sub reddits (n=50)	% non-MH sub reddits (n=277)
Animal or plant	Animals or plants regaining health or strength	2.7	0.0	0.0	3.6
Inanimate	Inanimate agent (e.g., economy, PC operating system) regaining prosperity/resuming normal functioning	3.7	0.0	0.0	5.1
Retrieve	Regain possession or control of something stolen or lost	8.0	0.0	4.0	10.1
Energy	Remove/extract an energy source or industrial chemical for use, reuse, or waste treatment (e.g., sulphur recovery)	0.3	0.0	0.0	0.4
Proper noun	The *recover* term is (part of) a proper noun, e.g., Refuge Recovery	1.9	0.0	0.0	2.5
Other	Any other meaning or cannot determine meaning	3.5	2.0	0.0	4.7

As Table S24 shows, Reddit users with a self-reported BD diagnosis most frequently use *recover* term mentions in a MH recovery sense in relation to addiction (40.1%), predominantly alcohol. Only 17.3% of the instances refer to BD. As could be expected, a higher share (67.5%) of the instances refer to BD in BD subreddits. Interestingly, people with a BD diagnosis never used *recover* terms in relation to BD in non-BD-specific MH subreddits, but mainly in relation to addiction or eating disorders. More than a third of the MH recovery instances in BD subreddits were in relation to a specific MH episode, while almost all instances in other subreddits referred to longer term recovery.

Table S24 Coded MH issues and duration of *recover* term instances with a MH recovery meaning

Diagnosis	% all sub reddits (n=162)	% BD sub reddits (n=40)	% MH sub reddits (n=42)	% non-MH sub reddits (n=80)
Addiction (ADD)	40.1	15.0	38.1	53.8
- Alcohol (% of ADD)	53.8	33.3	87.5	44.2
- Other drugs (% of ADD)	24.6	33.3	12.5	27.9
- Other (multiple, sex) (% of ADD)	21.5	33.3	0.0	27.9
BD	**17.3**	**67.5**	**0.0**	**1.3**

Diagnosis	**% all sub reddits (n=162)**	**% BD sub reddits (n=40)**	**% MH sub reddits (n=42)**	**% non-MH sub reddits (n=80)**
Eating disorders	14.2	0.0	28.6	13.8
Major depressive disorder	5.6	0.0	11.9	5.0
Borderline personality disorder	3.1	0.0	9.5	1.3
Other (anxiety disorder, post-traumatic stress disorder, psychotic disorder, self-harm, multiple, cannot determine)	19.8	17.5	11.9	25.0
Duration (whether from a discrete episode or long-term)				
Episode	13.0	35.0	0.0	8.8
Long-term	74.1	52.5	90.5	76.3
Cannot determine	13.0	12.5	9.5	15.0

G.2.7 Discussion and limitations

The second exploratory study sought to determine with what meanings Reddit users with a self-reported BD diagnosis use *recover* terms. Overall, only 7.4% (n=28) *recover* term instances were in relation to BD and another 7.4% in relation to PR, and only 1.3% (n=5) in relation to PR in BD. This indicates that Reddit users with a self-reported BD diagnosis probably more readily associate other topics with *recover* terms, such as alcohol addiction or recovery from physical health issues. The coding also showed that Reddit users with a BD diagnosis almost exclusively use *recover* terms in relation to BD in BD subreddits, but mostly in a clinical recovery sense. Therefore, the main study only considered posts in BD subreddits, but employed additional search and exclusion terms to select posts relevant for PR in BD.

There are two limitations of this study. First, the coders were part of the study team and therefore might have been implicitly biased in their coding by expectations of the outcome. However, this study was exploratory, so no hypotheses were tested or confirmed. Second, the interrater agreement was rather low for some subtasks, particularly for determining the underlying recovery notion of a *recover* term instance used in relation to MH issues. Importantly, the agreement rose to a fair level when omitting instances where at least one of the coders could not determine the recovery notion. Moreover, for all but 17% of the instances the team could agree on the recovery notion in the subsequent discussion. This indicates that inferring the recovery notion for a single *recover* term instance from the limited context of a post is difficult and not always possible.

G.3 Supplementary Document 1: Codebook for meanings of *recover* terms

For each instance of a *recover* term, you are provided with its immediate context (the sentence in which it appeared), the full post in which it appeared and the subreddit in which it was posted. See Table S25 for the coding sheet outline.

Table S25 Coding sheet outline

Post ID	Subreddit	Term	Word number in sentence	Sentence	Post	Meaning	MH issue	Duration	Comment
1	Rabbits	recovered	16	I was trying to get her to move on all her four legs when she recovered.	[full post text]	Animal or plant			
2	bipolar	recover	23	I'm currently recovering from my latest manic episode.	[full post text]	Clinical recovery	BD	episode	

Based on only the information present in the coding sheet, please code the **meaning** of the *recover* term according to the codebook in Table S26 using the boldfaced codes in the first column. If there is more than one *recover* term in the post, please only code the meaning for the highlighted instance based on the sentence and the number of the term in the sentence.

If the *recover* term is used in relation to MH (**MH recovery**), please use the additional guidance in Table S27 to distinguish **Clinical recovery and PR**. Please also specify all **MH issues** that the *recover* term is used in relation to according to Table S30.

For **Clinical recovery**, please specify whether the *recover* term is used in relation to a specific episode or for longer term recovery (**duration**) according to Table S31.

Please document the reasons for your decisions in the **comment** column.

Table S26 Codes for meanings of recovery, recover, recoverable, irrecoverable

Code	Description	Example quotes (paraphrased posts or dictionary entries[109])	Code source
Recovery in or from MH issues			
Clinical recovery Clinical + socio-functional recovery in severe MH issues	Clinical recovery consists of discrete outcomes that clinicians can observe objectively, such as current depressive, psychotic, or manic symptoms, vocational and social functioning, and service use and treatment aspects (e.g., time since last hospital admission, taking medication or being in psychotherapy) (Torgalsbøen, 1999; Liberman and Kopelowicz, 2002); Can apply to an individual episode or relapse.	1. r/Random_Acts_of_Amazon I was diagnosed with bipolar, PTSD and Anorexia a year ago. My boyfriend cheated on me with his ex partner on our anniversary. I self harmed every day, multiple times a day. Now, I am properly medicated for my mental health issues. I am still going through recovery for my eating disorder due to a recent relapse. For our 2 year anniversary, my boyfriend gave me a promise ring. I have also been free of self harm for 6 months! I am happy as my world has turned around! 2. r/neuroscience Can the brain recover from depression and does this change its structure?	Clinical & theoretical
PR PR in severe MH issues	'Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even with the limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness' (Anthony,	1. r/depression 4 years ago I was at my lowest and lost everything, but somehow I've managed to build a new life and I'm again considered 'successful'. The open wound of depression in my brain has healed to a scar. I don't need therapy or medication but I feel like I can't just erase that part of me. Does anyone have a recovery-from-depression stories from which I could learn how to deal with this? 2. I committed suicide and died but then was brought back in to a coma. This was such a slow and painful psychological recovery but now it's been about 3 years and this has certainly shaped my life to enjoy	Clinical & theoretical

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[109] https://www.dictionary.com/browse/recovery

Code	Description	Example quotes (paraphrased posts or dictionary entries[109])	Code source
	1993). Broader scope than an individual episode/relapse.	everything in life and to make me one of the happiest people in the world.	
MH recovery	Recovery in or from MH issues. Only assign if cannot distinguish between clinical recovery and PR	1. I switched from college education to drug business for a few months. Luckily, I was able to recover and get my priorities straight and graduate, but for a time, I felt as though I'd given up my entire life to my dependence on the substances. 2. The first time I couldn't continue working due to mental health issues, I took a medical leave. The second time, I just resigned. I have yet to recover.	Clinical & theoretical
Regaining health or strength			
Life event Human recovering from difficult life event or situation	Overcoming a difficult life event/situation that didn't cause a severe MH issue	1. I'm still sort of recovering from the break up. 2. Recovering cookie-addict 😉	Data
Physical health Human Clinical recovery from physical health issues	Return to normal state of health and strength by overcoming a physical health issue	1. When I give my body rest and healthy food, it seems to recover quicker. 2. r/Casualima: How long was recovery after ECT treatment before you were back to yourself?	Clinical & theoretical
Animal or plant Recovery of animals, plants	Animals or plants regaining health or strength	After the road accident, the family dog Barko is back at home and he looks all set to make a full recovery.	Theoretical
Inanimate Recovery of inanimate objects or concepts	Economy, market, operating system (recovery mode) regaining prosperity/resuming normal functioning Note: Only assign Inanimate if not Retrieve.	Make sure the device is turned off, then turn it on again. Upon startup, hold Cmd+R to boot into recovery mode. r/SamandTolki: How did their marriage recover, or did it ever truly recover? His reputation never recovered after he lost his title.	Dictionary

Code	Description	Example quotes (paraphrased posts or dictionary entries[109])	Code source
Other meanings			
Retrieve Retrieve or find again	The action or process of regaining possession or control of something stolen or lost, includes data/file recovery Test: You can replace 'recover*' in the sentence with 'retrieve' or 'regain'.	1. r/bipolar: I was hoping so much I could recover a small sliver of my sanity. 2. I have seen reps at my Apple Store actually refer customers out to third - party data recovery services. **Note: Retrieve takes precedence over 'Inanimate', even if the actor who is retrieving/regaining something [here the service] is inanimate.**	Data & dictionary
Energy recover energy or substances	The process of removing or extracting an energy source or industrial chemical for use, reuse, or waste treatment. ('sulphur recovery')	1. While silver recovery systems remove most of the chemical, other dangerous solvents are used to clean film-developing machinery. 2. The draft document deals with waste minimisation, recycling, and energy recovery.	Dictionary
Proper noun	The *recover* term forms part of a proper noun	Have you heard of Refuge Recovery? They don't meet in person very often but they've also got phone meetings in addition.	Data
Other Other or unclear	Any other meaning not captured by the codes above or cannot determine meaning due to lack of context or meaning is ambiguous between codes; please specify		

Table S27 Criteria to distinguish clinical recovery and PR based on Slade (2009, p. 35)

Clinical recovery	Example	PR	Example
Outcome or state, dichotomous	DSM-5 or ICD-11 diagnosis specifiers for clinical recovery status: partial remission, full remission	Journey or process, on a continuous scale	The Bipolar Recovery Questionnaire (Jones, Mulligan, *et al.*, 2013) measures self-reported responses on 10-cm visual analogue scales from strongly disagree to strongly agree (0-100).
Observable, objective	Agreement of clinician ratings for the same	Subjective	See QPR questions in Table S28, where

Clinical recovery	Example	PR	Example
Often clinician-rated	individual is a criterium for the reliability of clinical recovery or socio-occupational functioning scales (e.g., Goldman, Skodol and Lave, 1992)	Self-reported	individuals self-define what ‘purpose’ means in their lives (item 6)
Same criteria across individuals		Individual, idiosyncratic meaning	

To enable a more structured distinction between clinical and PR, please check if the content in relation to the *recover* term in the post refers to aspects of any of the QPR items listed in Table S28 and follow the decision guidance in Table S29. Assign only ‘MH recovery’ in case you cannot determine whether the user uses *recover* in a clinical recovery or PR sense (please provide a comment in this case).

Table S28 QPR items (Neil et al., 2009)[110]

1	I feel better about myself
2	I feel able to take chances in life
3	I am able to develop positive relationships with other people
4	I feel part of society rather than isolated
5	I am able to assert myself
6	I feel that my life has a purpose
7	My experiences have changed me for the better
8	I have been able to come to terms with things that have happened to me in the past and move on with my life.
9	I am basically strongly motivated to get better.
10	I can recognise the positive things I have done.
11	I am able to understand myself better
12	I can take charge of my life.
13	I can actively engage with life
14	I can take control of aspects of my life
15	I can find the time to do the things I enjoy

Table S29 Clinical recovery vs. PR code decision based on the QPR

Item status	Paraphrased example	Code
User does not relate an aspect of any QPR item to recovery	1. r/depression One meds combination made me feel SO GOOD Except I gained 20 pounds in a month. Nothing has worked as good as this combo. I can't imagine	Clinical recovery (likely in absence of

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[110] reproduced with Professor Tony Morrison’s permission

Item status	Paraphrased example	Code
	how I would act without meds, they're so important to recovery from depression. 2. As far as recovery goes, I'm on medication I hate but which works and I'm not in therapy. *[recovery only seen as equivalent to treatment]*	other evidence based on QPR items)
User indicates that they are not interested in at least one QPR item in relation to recovery or they indicate that at least one QPR item is not relevant to their view of recovery	I don't cate about anything at this point in my life, I just want to recover from this crippling feeling of anxiety. *[artificial example since there was no case in the data]*	Clinical recovery (in absence of the user endorsing aspect(s) of at least one QPR item in relation to recovery)
User associates wish to do or hope to reach at least one QPR item with recovery	I've been very depressed for a long time but I really wish to recover and feel like my life has a purpose again.	PR
User indicates that they (or someone else) partly or fully feel (able to) do or experience at least one QPR item and consider themselves (or this someone) in recovery	I committed suicide and died but then was brought back in to a coma. This was such a slow and painful psychological recovery but now it's been about 3 years and this has certainly shaped my life to enjoy everything in life and to make me one of the happiest people in the world. *[fulfils, e.g., QPR 10, 15]*	PR
User indicates some aspects of QPR items in relation to recovery, but personal evaluation is unclear	r/BPD: CBT, DBT, meditation and mindfulness have helped me a lot. I've read about people in recovery from BPD. It isn't impossible but it's damn hard work. *[cognitive and dialectical behavioural therapy, meditation and mindfulness may have positive effects for many QPR dimensions (e.g. QPR 11) but the author is not explicit in what ways they have helped them, could still be seen only in relation to borderline personality disorder symptoms]*	Unclear – label as 'MH recovery' and provide comment

Table S30 MH issues for coding of *recover* instances

MH issue	Code	Examples and scope
Addiction	ADD	Please specify type: Alcohol -A Other drugs -D Sex -S Other (specify, e.g., gambling)
Anxiety disorder	AD	Social anxiety, panic disorder, generalised anxiety disorder, panic attacks
Attention deficit hyperactivity disorder	ADHD	ADHD
Autism spectrum disorder	ASD	Autism, asperger syndrome
Bipolar disorder	BD	Any type (bipolar I disorder, bipolar II disorder, Bipolar spectrum disorder, cyclothymia)
Borderline personality disorder	BPD	Borderline
Eating disorder	ED	Anorexia, bulimia
Major depressive disorder[111]	MDD	Depression, major depression, dysthymia
Obsessive-compulsive disorder	OCD	OCD, skin picking
Post-traumatic stress disorder	PTSD	PTSD
Psychotic disorder	PD	Schizophrenia, schizoaffective disorder
Multiple	Multiple	MDD+AD, ED+MDD (comment)
Other	Other	Please specify (self-harm, suicidal ideation/attempt, other personality disorders, other MH diagnoses …)

Table S31 Criteria to distinguish recovery from an episode vs. longer term recovery

Type	Code	Example
Recovery from an episode Mood episodes: depressed, (hypo-)manic Other episodes: psychotic	Epi sode	r/BipolarReddit: So far, I've had an 7 month break from depression, after 5 months of growing mania with final eruption, and my 3 months of post-mania **recovery**

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[111] Depressive episodes can occur as part of both BD and major depressive disorder. Please label instances of "recovery from depression" as concerning the MH issue BD if the user additionally mentions a BD diagnosis or BD symptoms (high mood, mixed mood) in the post and as major depressive disorder otherwise.

Type	Code	Example
		2. r/bipolar The **recovery** from mania is usually worse than recovering from depression.
Persistent symptom remission over a longer period of time, not mentioned in relation to a specific episode	Long-term	r/stopdrinking: In early **recovery**, I was more isolated. I became more willing to take risks and socialise with people (if alcohol was not the main focus) with more sober time under my belt.
Cannot determine whether meant in relation to an episode or long-term	Other	

G.4 Supplementary Document 2: Construction of the PR terms list

Candidate PR terms were generated from four sources: First, articles included in the POETIC review (Table S2) (n=12, 75,553 words) were compared to excluded articles (n=80, 409,877 words) that fulfilled all inclusion criteria (qualitative study reporting only experiences of people with a BD diagnosis) except a PR focus. Keywords (log likelihood > 10.83, *P*<.0001) were identified by comparing the article texts of included vs. excluded studies via the corpus linguistic software tool Wmatrix 4 (Rayson, 2008). To do so, the full paper text without abstract, tables, figures, and appendices were converted from pdf to txt via Science Parse[112] with manual post-correction. Three excluded articles were only available as images and not included because an additional optical character recognition step was regarded as not time efficient.

Second, keywords for each POETIC domain were identified by comparing the quotes coded into each POETIC domain in the review to the quotes coded into all other domains (see Table S32). Third, keywords (log likelihood > 10.83, *P*<.0001) were identified in MH recovery posts from exploratory study 2 that only contained *recover* term instances coded as PR (n= 26, 6,368 words) by comparing them against posts that only contained *recover* term instances coded as clinical recovery (n=89, 13,790 words).

Table S32 Corpus sizes and keywords for quotes coded in each POETIC domain from articles included in the POETIC review[113]

Domain	Words	Words reference (coded in any other domain)	Keywords (min freq 1, LL>6.63)	Overused keywords (min freq 2, LL>6.63)
1 Purpose and Meaning	8,237	33,316	19	13

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[112] https://github.com/UCREL/science_parse_py_api

[113] freq: frequency, LL: log likelihood

Domain	Words	Words reference (coded in any other domain)	Keywords (min freq 1, LL>6.63)	Overused keywords (min freq 2, LL>6.63)
2 Optimism and hope	2,650	37,021	25	19
3 Empowerment	14,968	26,946	42	20
4 Tensions	6,490	33,968	29	17
5 Identity	5,777	34,724	22	16
6 Connectedness	9,221	32,047	41	20

Fourth, the concordances of keywords that appeared in at least two included articles or PR posts by at least two users were manually examined with the corpus-linguistic software tool AntConc (Anthony, 2005) to identify additional words and phrases indicative of PR. Using two different corpus linguistic tools was necessary because Wmatrix 4 does not allow to sort concordances of keywords according to their left and right context, while Antconc does not report the frequency of keywords in the reference corpus. All wordcounts are reported according to Wmatrix.

Finally, the study team selected the terms indicative of PR from the candidates and extended the list with terms informed by their expert knowledge, and spelling and phraseological variants (e.g., self-esteem and self esteem, forgive yourself and forgive herself).

G.5 Supplementary Document 3: Tf-idf weighted cosine similarity to score the personal recovery relevance of Reddit posts

Given a vocabulary[114] of size N with i representing one term of the vocabulary, a post p is represented by the vector x of length N according to its bag of words with one hot encoding[115]:

$$x_i = \begin{cases} 1 \; if \; vocabulary \; term \; i \; appears \; in \; p \\ 0 \; else \end{cases}$$

Analogously, the PR terms are represented by the vector y, also of length N:

$$y_i = \begin{cases} 1 \; if \; vocabulary \; term \; i \; appears \; in \; the \; PR \; terms \; list \\ 0 \; else \end{cases}$$

---

[114] In this study, the vocabulary consists of the unique lemmas in all posts. The posts were pre-processed such that spaces in all phrases in the PR terms list were replaced by underscores, so they are represented as a single term in the posts (e.g., "believe in myself" → believe_in_myself).

[115] This explanation follows Jurafsky and Martin (2018, p. 112 ff.).

The PR score of the post p is calculated as the cosine similarity between the tf-idf weighted vector representation $\bar{x}$ of the vector representation x and the tf-idf weighted vector representation $\bar{y}$ of the PR terms list vector representation y:

PR score (x) = $cosine(\bar{x}, \bar{y}) = \frac{\sum_{i=1}^{N} \bar{x}_i * \bar{y}_i}{\sqrt{\sum_{i=1}^{N} \bar{x}_i^2} * \sqrt{\sum_{i=1}^{N} \bar{y}_i^2}}$

The tf-idf weighted vector representation $\bar{z}$ of a vector z and a particular post p is calculated by multiplying the vector entry for each vocabulary term i with its associated weight $w_{i,p}$: $\bar{z} = w_{i,p} * z_i$.

The weights consist of the multiplication of the term frequency $tf_{i,p}$ of vocabulary term i and the inverse document frequency idf_i of term i: $w_{i,p} = tf_{i,p} * idf_i$, where the frequency of term i that appears $count(i,p)$ times in a post p is defined as follows:

$$tf_{i,p} = \begin{cases} 1 + \log_{10} count(i,p) \ \ if\ count(i,p) > 0 \\ 0\ else \end{cases}$$

The inverse document frequency of term i that appears in df_i posts out of a collection of M posts (traditionally called documents) is $idf_i = \log_{10} \frac{N}{df_i}$.

G.6 Supplementary Document 4: Codebook to determine personal recovery relevance of Reddit posts

In this coding task, you will assess if Reddit posts are relevant for PR.

G.6.1 Coding task overview

Q1) Given a Reddit post, ask yourself, does the post indicate that their author ('user' in the following) can be regarded as being in PR, i.e., do they share experiences relevant to their PR in the post? Yes/No

Please consider Q1 carefully using the PR guidelines detailed in Appendix G.6.2.

Q2)[116] Ask yourself: how confident am I about my answer to Q1? Give yourself a rating on a scale from 1 to 5:

- 1: not confident at all
- 2: slightly confident
- 3: somewhat confident
- 4: fairly confident

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[116] Guidelines adapted from confidence rating in Troiano, Padó and Klinger (2021).

- 5: completely confident

For Q2, please go for your immediate reaction to the post – avoid over-thinking.

Table 35 shows the outline of the complete coding sheet.

To answer 'yes' to 'PR relevant' 1. BD and 2. Personal experience must be both 'yes' and at least one of 3-5 must be 'yes'.

To answer 'no' to 'PR relevant' either 1. BD or 2. Personal experience must be 'no' or (if 1-2 are both 'yes') all of 3-5 must be 'no'.

Table 35 Coding sheet outline

	Post	**PR relevant**	**Confidence**	**1. BD**	**2. Personal experience**	**3. Living well with BD**	**4. Personal understanding of BD**	**5. Meaningful life**
Possible values	I feel …	yes/no	1/2/3/4/5	yes/no	yes/no	yes/no	yes/no	yes/no

G.6.2 Personal recovery guidelines

G.6.3 Definition of personal recovery

Please use this definition of PR to guide your decision: 'Recovery is a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even with the limitations caused by the illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness' (Anthony, 1993).

G.6.4 Stages of personal recovery

Please include only users from the 'Contemplation' phase onwards (see Table S33).

Table S33 Stages of PR (Leamy et al., 2011, p. 449)

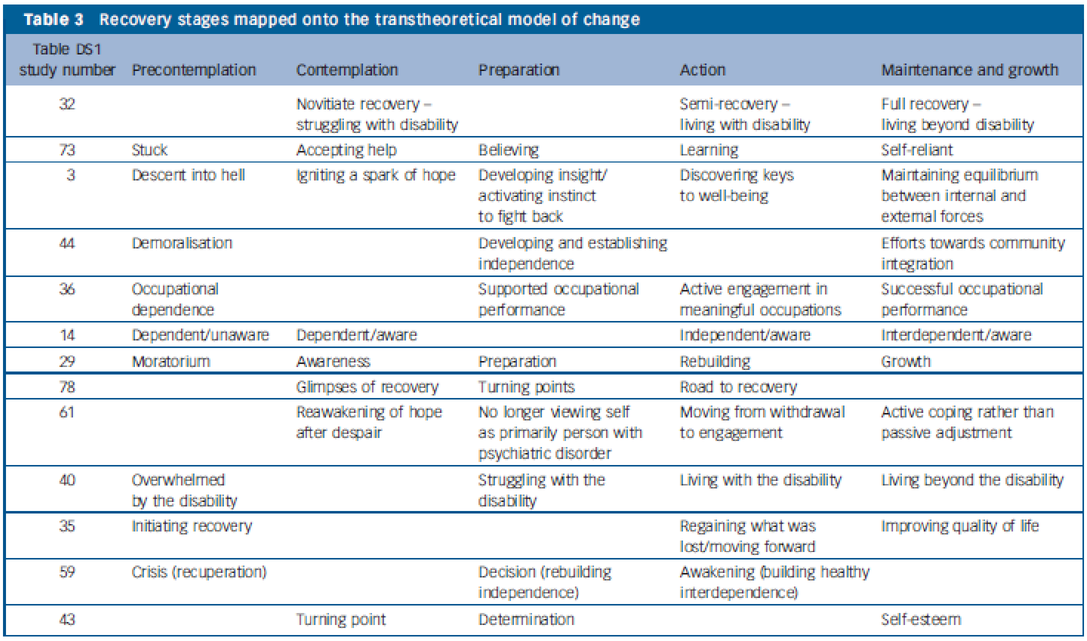

Table 3 Recovery stages mapped onto the transtheoretical model of change

Table DS1 study number	Precontemplation	Contemplation	Preparation	Action	Maintenance and growth
32		Novitiate recovery – struggling with disability		Semi-recovery – living with disability	Full recovery – living beyond disability
73	Stuck	Accepting help	Believing	Learning	Self-reliant
3	Descent into hell	Igniting a spark of hope	Developing insight/ activating instinct to fight back	Discovering keys to well-being	Maintaining equilibrium between internal and external forces
44	Demoralisation		Developing and establishing independence		Efforts towards community integration
36	Occupational dependence		Supported occupational performance	Active engagement in meaningful occupations	Successful occupational performance
14	Dependent/unaware	Dependent/aware		Independent/aware	Interdependent/aware
29	Moratorium	Awareness	Preparation	Rebuilding	Growth
78		Glimpses of recovery	Turning points	Road to recovery	
61		Reawakening of hope after despair	No longer viewing self as primarily person with psychiatric disorder	Moving from withdrawal to engagement	Active coping rather than passive adjustment
40	Overwhelmed by the disability		Struggling with the disability	Living with the disability	Living beyond the disability
35	Initiating recovery			Regaining what was lost/moving forward	Improving quality of life
59	Crisis (recuperation)		Decision (rebuilding independence)	Awakening (building healthy interdependence)	
43		Turning point	Determination		Self-esteem

G.6.5 Inclusion and exclusion criteria

Table S34 explains the inclusion and exclusion criteria, see Table S35 for example posts with explanations.

Yes: 1 + 2 + at least one of 3, 4, 5 are met
No: Everything else

Criteria 3-5 are based on the POETIC framework for PR in BD (Jagfeld, Lobban, Marshall, *et al.*, 2021), see Figure 9 for an overview of the domains and categories.

Table S34 Inclusion and exclusion criteria for PR relevant

Rank	Criterium	Include (PR relevant = yes)	Exclude (PR relevant = no)
1	BD	User shares experiences related to their BD diagnosis	User mainly focuses on experiences related to other issues or MH diagnoses
2	Personal experience	User shares their own personal experience	User gives general advice to others, not speaking from their own experience User makes a general comment User asks question without providing own experience
3	(Hope for) living	User expresses that they (hope to) live well with	Users express no hope in living well with BD, only talk about negative aspects and

Rank	Criterium	Include (PR relevant = yes)	Exclude (PR relevant = no)
	well with BD	BD (which might include experiencing symptoms)	difficulties. According to Leamy et al. (2011) they could be seen as in the ‘Precontemplation’ phase of the PR process, but here only include users who are at least in the ‘Contemplation’ phase
4	Personal (non-medical) interpretation of BD	User expresses understanding their BD experiences in a personal framework, e.g., regarding mood as on a continuum and/or they express empowerment with respect to managing their moods and treatment choices	User expresses clinical understanding of their BD experiences, regard themselves as ‘ill’ and their experiences as fundamentally different from people without a BD diagnosis
5	Meaningful life vs. treating symptoms	User talks about (issues with) living a meaningful life, this can include, e.g., meaningful activities, live goals or roles, relationships, questioning or redefining their identity, negotiating tensions in living with BD	User only talks about or seeks advice in relation to treating symptoms.

Table S35 Paraphrased example posts for PR relevance criteria

Include	Exclude
1. Experiences in relation to BD	**Experiences mainly not in relation to BD**
I honestly do NOT know how I would get through this without my husband, and he's the most supportive person I can imagine and then some. He even remembers things like the patterns of my moods so I can tell my doc, since he knows I can't remember crap. I know it's tough on him, but he's fantastic about trying to remember that when I'm irritable it *isn't* directed deliberately at him. He's also developed a great repertoire of tricks for cheering me up (when possible), easing my anxiety about things, and	I went down a very similar path with my ex, I have bipolar and PTSD from sexual assault, and after we graduated we were long distance. When we were together I always had no interest in it, I couldn't feel anything, and so I would drink to feel ok enough to do it. I wanted the intimacy, but couldn't deal with the physical part. I also felt like I 'had to do it' when he came to visit because it was so rare. Ultimately, he knows me well and saw pretty easily what I was doing, and we had a bunch of fights about it. He was

Include	Exclude
just trying to make things easier in general. Second to him, definitely my mother. But then, she's the one I inherited the bipolar from, so she more than understands. I feel incredibly lucky to have two such supportive people in my life.	extremely upset because he felt like I was 'drugging myself' to be with him, when he would have been fine and supportive without the sex, as much as he wanted it, because he was a respectable guy. We broke up but it's fine now, we talk occasional I can say from experience this did not work well for me. It stopped working and I drank/smoked more and more until it became a problem, I would drink a lot but some days because of my meds I would blackout after one drink. It scared me so I stopped drinking the day he broke up with me, I'm a year and a half sober now *Comment: Main focus is not BD but trauma-linked self-medication*
	I am a 2 fifth a night Addict diagnosed Bipolar.. and I don't Give a fuck I still get up next day and go to this place I call a job.. and I still function.. When that stops happening I'll quit. *Comment: Main focus is on relationship to drinking (which indicates PR), but not BD*
2. Share own personal experience	**General advice, comment, or question without own experience**
I was discharged by my therapist this week! BP2, diagnosed in Feb 2013. It was rough, you all know how it is. I knew I was getting depressed a lot but I had no idea how bad it was. A near suicide led me to talk to someone. Making that call was the hardest thing I have ever done. Today I feel great! No more racing negative thoughts. I still get depressed now and then but it's nothing like before. My therapist and I both believe I have the tools to make it through episodes on my own. I will still see my Pdoc regularly and I'll always be on meds. If I ever feel that it's getting too much to handle I can call the therapist anytime to schedule an appointment. It feels	This is probably going to sound weird, and I don't know anything about your situation so I'm speaking generally, but it's only worth being in a relationship if it's healthy for both people. If the non-BP person isn't getting what they need or the relationship is hurting them emotionally, then they have every right to leave. Relationships are completely voluntary, and if your SO isn't treating you well because of personality/attitude/whatever (bipolar aside), then that's not healthy. Why should BP guilt that person into staying? I'm sure it sounds terrible, but I guess it's important to remember that a non-bipolar partner has feelings and

Include	Exclude
great knowing that I pulled through this! *Comment: indicates empowerment*	needs, too, and sometime that need involves being gone. *Comment: Giving general advice*
	I would be willing to do an interview as well. Bipolar I and currently in college. *Comment: General comment*
	Intranasal ketamine is pretty well-established for treatment-resistant depression and seems to be useful in some cases for bipolar, but I'm looking for personal experiences with the treatment. Due to unrelated medical issues, I'm kind of running out of options for the bipolar, which is a real shame. *Comment: Asking a question without sharing own experiences*
	I apologize if my post seems mean spirited, but I have dealt with Bipolar stigma for eight years. The stigma against Bipolar Disorder is vicious and abhorrent. Your post simply furthers the stigma against people with Bipolar Disorder. I wish that you would rewrite your entire post in a manner that is less stigmatizing. Additionally, it would be good if you could explain exactly what you want from us. Do you just want to vent? Do you want feedback from people who have experienced similar circumstances? Do you want advice? The purpose of your post is completely unclear, and that is one of the reasons that it seems to be a troll post. *Comment: Asking a question without sharing details of own experiences*
3. (Hope) for living well	**Express no hope for living well with BD**
* working shifts before 8 am WILL make you cycle. Instead of telling people you have bipolar, tell them you have insomnia and the sleeping pills you take make you useless before then (75% true). * it's almost	One of the worst things about this... ...is that no matter what you do, what lifestyle change you make, or what medication you're on, you're still going to cycle. You will always be bipolar, you'll always be on the up and

Include	Exclude
impossible to hear when I'm down but bipolar is about cycles. I will be down, I will be stable, I will be up. It will always change, which is good and bad. But I've gotten INFINITELY BETTER at recognizing where I am in the cycles and have treatment that works for me. * three years ago I was in the hospital and suicidal, now I'm moving to England to attend a top 10 university for a program I'm passionate about and have done things I never thought I would do, like hold down a job and travel on my own. **You never know what tomorrow will be like.** *Comment: Purpose and meaning: education/life goals, living well despite symptoms*	down. I recently started taking long walks and I feel great emotionally, but I still feel depression coming, and coming hard. Sorry if this seems morbid, just letting out how I feel. *Comment: Trying to live well but also lacking hope about this (Precontemplation phase)*
	Made so many enemies. Considering dropping out of school and moving away. Throughout my entire school life, I have made many enemies by just being stupid and manic. Dated and fucked all the wrong people. Then made enemies with them after bc I'm unstable. Then their friends hate me. And the new girls and past girls they dated hate me. Also I'm so confrontational when manic that I burned bridges with shitty friends but in the worst way possible. And today I got mistaken for my ex's new girlfriend (who hates me) at school by someone close to my ex. Not sure if they're fucking with me. Have been avoiding campus for 6 weeks and every time I've been there is an awkward interaction that literally sends me into a serious suicidal and irrational spiral. Almost killed myself a week ago after the last interaction. Feel stupid but kind of want to drop out. Maybe move away. I only have a year left but these 6 weeks have been UNBEARABLE. I think if I stay any longer I might just actually follow

Include	Exclude
	through and kill myself. Reaping the consequences of my actions suuuucks. Didn't realize my behavior is because I was bipolar until I got diagnosed recently. Now painfully self aware and ashamed. Has anyone experienced something like this before? It's so hard on me because I already want to kill myself on the daily anyway and now these stressors have exacerbated it by 100x. *Comment: This seems to be someone in a crisis about the consequences of mood driven behaviour, not PR because main options considered here seem to be suicide and leaving school, not living a meaningful life with BD*
4. Personal understanding of their BD experiences	**Understanding of their BD experiences only in frame of clinical diagnosis**
That sucks. I can't think of anyone in my life who doesn't know. Well, except Facebook, I'm not out on Facebook, but they're mainly people I don't really talk to, I just spy on them lol. I don't think most of the people I've told researched it like my bestie did, but they listen when I explain what it's like. I usually use the odometer analogy- most healthy people are between 60 & 120. 60 is sad, it's like the day your mother died. Bipolar people can sometimes sit between 0 & 60 - that's depression. Most people understand depression without a lengthy explanation. 120 is happy, like your wedding day or the birth of your first child. Bipolar people can go from 120 - 180. 180 you think you're god. In between 120 and 180 you can be hypersexual, hyperactive, talk a million miles an hour, start a thousand projects you're never going to finish, be a fitness fanatic, never sleep, come up with brilliant ideas, some actually brilliant, some clearly	I'm very much in the same boat as you, even right down to being 30 right now and having had no idea what the heck was going on with me since adolescence and earlier even. I also think my bipolar is more in line with type II in terms of percentages of depression versus (hypo)mania, although I'm dxed type one simply because I have had two full blown manic episodes - although they were triggered by an antidepressant medication and quitting alcohol, and I don't think they would happen that way without a 'trigger'. At any rate, I agree, it's intense (yet sort of vindicating and a relief) to find out why I'm the way I am... not just a failure or someone not coping with the normal human condition, but rather, someone with a specific illness causing me to have extremes of moods and a baseline level of emotion that's mildly depressed at best. *Comment: User expresses clinical understanding of their BD symptoms, regards themselves as ill*

Include	Exclude
delusional, be charismatic, be the life of the party, indulge a little too much in the party and end up addicted to drugs and alcohol, and depending where you are on the spectrum, either kick ass at work by putting in 60 extra hours a week or get yourself fired for running into the office naked wielding a butter knife and screaming that the CIA are infiltrating the systems. There's a spectrum and not all bipolar people reach 180, so not everyone gets to the naked butter knife/ believing you're god stage. Personally, I have bipolar 1, so theoretically I can get there, but I haven't yet. People with bipolar 2 can only get to like 150 maybe. *Comment: User clearly seems to have a personal understanding that makes sense to them. They Contextualise their experience on a continuum – not binary (vs. what they have is some qualitative different illness to people without a BD diagnosis)*	
5. Talk about meaningful life or activities	**Talk about treating symptoms only**
Energy levels. Just a little background. I've been diagnosed as Bipolar 2 since I was 13 (now 20 (male)). I haven't had medication in a few years as I haven't had insurance and still don't. So more often than not I just have to deal with my moods and ride them out. I work as a valet at a pretty nice downtown hotel and am constantly running to get cars and talking to people who want to check in and valet with us. It's so draining. Today was one of those days where I just did not want to deal with any of the people at all but bit the bullet until I was off the clock. My girlfriend (20) wanted to go out tonight with a friend to go see a movie (she had planned this a week in advance) and I agreed at first. I got home today and just felt like shit. I	SSRI/SNRIs trigger rapid cycling for me. I was on Zoloft and Pristiq at different times. I would get hypomanic at first and then wind up all over the place. I had bad anxiety on Pristiq especially. My pdoc wants to keep me off all antidepressants due to my history of cycling, but that may not be the case for you. We are now exploring low dose Abilify with Lamictal.

Include	Exclude
really did not want to do anything. I just want to sit down all day and stare at the wall and listen to the hum of the air conditioner. I know it's a waste of time and counterproductive and could possibly further my depression during the day but I can't find the energy to care or to change it. How do you find the energy to get up and do things even when you don't want to? I know for work I do because I need the money. I feel bad for not going with my girlfriend but I'm really not up to it. And at least I'll be able to make it up to her another day where as with work, if I got fired I wouldn't. (I'm trying to make a point, but I'm very terrible at expressing it.) She told me she was mad at me for not wanting to go and she thinks I don't want to spend time with her. I do want to I just can't find it in me to go when I know I won't enjoy my night with them so why have me be a bother to them? She thinks me going out would make it better but I feel like I'd just want to be back at home, alone. So how do you guys do it? And how do your SO's, family, friends react to you when you are like this? I suppose this is kind of a rant but I just wanted some other opinions. Thank you guys. *Comment: User seems to struggle with relationships, connection, and work – PR in the sense of seeing the importance of these.*	
I love this subreddit Hi everyone, I was formally diagnosed with BP2 at age 16. (27 now). I showed early signs and even ended up in anger management at age 6. Once diagnosed, I felt better Fast forward 10 years.. I'm on mood stabilizer (lamictal). During manic episodes, I cut myself off of it thinking I'm 'cured'. I end up treating people around me like shit including my husband who is	

Include	Exclude
so so supportive. Manic episodes just make me so big headed. I rage and tell him he doesn't deserve me, I'm too good for him, he will never find someone like me.. meanwhile he literally did nothing except say hello (Haha ._.) Now I'm back on lamictal and have been for about a year, but I randomly keep overthinking my diagnosis. I keep thinking I was misdiagnosed because I'm not manic, don't have paranoia ect. It feels weird even telling ppl I have bipolar bc I feel like they dont believe me because so many people use the term so freely to explain frequent mood changes Reading posts here really helps me see that I am correctly diagnosed, I'm thinking this way because the meds are working and I'm level-headed, and "normal" people have bipolar. So anyways, just wanna say thx. I appreciate everyone's post. It makes me feel like I'm not alone *Comment: This post mixes clinical and PR perspectives – clinical recovery as they talk about medication and the importance of formal diagnosis, but also PR as they talk about the importance of their relationship and how it is strained by BD issues – therefore it fulfils (5) and is included – generally, it is ok if a post mixes perspectives as long as it contains some PR-relevant aspects according to criteria 3-5*	
	Does not meet any of 3-5
	Im bipolar 2. I had a psychologist who always downplayed my symptoms. If I said "mania", she would say, "Ah ah, HYPOmania." When I ended up in the hospital after leaving my boyfriend to become a porn star, she was fired. Dumb bitch. The only difference between 1 and 2 is that 1 has psychosis so.... *Comment: Complaints about treatment*

<table>
<tr><th>Include</th><th>Exclude</th></tr>
<tr><td></td><td><i>but does not indicate living a meaningful life</i></td></tr>
<tr><td colspan="2">Borderline case, low confidence – could be decided either PR relevant = yes or no</td></tr>
<tr><td colspan="2">My last hypomanic I opened up to a friend who is going through a messy break up... I told her she was beautiful, an amazing person that I used to fancy. That my wife used to be very jealous of her (so I made sure I never organised to see her without other people present). If I'd stopped there it would have been awesome. I then proceeded to send massive amounts of increasingly odd messages her way until I realised I was hypomanic a few days later. Then I apologised for my behaviour and resisted messaging her for a few days until I thought I had broken the back of the episode... I hadn't. I used the dying throws of the episode to further embarrass myself by trying to explain my bipolar to her in a very hypomanic way. I then brought a pot of pinkest pink paint for her (because if she was a colour she would be pinkest pink... it made sense to my borderline manic mind at the time). As far as hypomanic episodes go it was mild and I didn't do myself any long term physical or financial damage. The only damage is I think my friend is now a bit creeped out by me and I've damaged that relationship in a possibly irreparable way. Thankfully my friend lives a reasonable distance away and isn't interested in me or I could be writing about a whole bigger regret.
<i>Comment: This seems to be an account of a relationship being messed up in a hypomanic episode – in telling this one could infer that the user sees the value of relationships (fulfilling 5) – maybe lean towards "include"</i></td></tr>
</table>

G.7 Supplementary Document 5: Quote selection and paraphrasing method

GJ selected the quotes and checked whether a Google search for the paraphrased quote (with and without the additional search term 'reddit') would retrieve the original post in the top ten search results. If this was the case, the quote was shortened or paraphrased until the modified post no longer came up in the search results. Paraphrasing followed the method outline in Berry et al. (2017). CH checked the original quotes for suitability to illustrate the categories and compared the original quotes and the paraphrases to make sure the paraphrases were meaning and style preserving.

G.8 Supplementary Document 6: Methodological considerations and details on generating the key lemmas

Baker (2004, pp. 354–55) discusses some advantages and disadvantages of using lemmas instead of wordforms in keyword analyses. Analysing key lemmas could bring out aspects that might not show up in a key word analysis if individual wordforms of the same lemma (e.g., meditate, meditated, meditating) are too infrequent on their own. On the other hand, analysing key lemmas would mask diverging trends for individual wordforms of the same lemma. This would be the case, if, for example, meditate was significantly overused in one corpus, whereas meditating was overused in the other corpus because these differences would cancel out in the aggregated frequency for the lemma 'meditate'. This study analysed key lemmas to emphasise analysing content and extend vocabulary coverage rather than focusing on more fine-grained linguistic differences.

Lemmas in #LancsBox 6.0 are pairs of a lemma and part of speech tag, e.g., need_v for need as a verb vs. need_n for need as a noun. Both lemmas and part of speech tags are automatically assigned via TreeTagger (Schmid, 1994). TreeTagger performs lemmatisation by a look-up in a manually created dictionary, therefore the lemmatisation accuracy should be near perfect[117]. For wordforms that are not contained in the dictionary, the wordform is assigned as fallback. TreeTagger achieved 86.6% part of speech tagging accuracy on a social media data test set consisting of Twitter messages and online chat dialogues (Horsmann, Erbs and Zesch, 2015), which might be comparable to the PR-BD corpus.

The 5% dispersion threshold for key lemmas was set in analogy to Hunt and Brookes (2020) who required keywords to appear in 5% of their posts, however a per-post threshold was too restrictive for the PR-BD corpus.

There are no general recommendations in corpus linguistics for the relative size of the reference corpus to the target corpus. Brezina (2018b, pp. 81–82) argues that the larger the reference corpus the more reliable are the keywords, particularly since a larger reference corpus has a lower likelihood of containing zero instances of target corpus terms by chance. Rayson and colleagues (2004, p. 11) showed that at a log likelihood significance level of $P<.0001$ the chi-squared statistics for identifying keywords is reliable for expected word frequencies of 1/100000 or higher for a target corpus size of 1M words and a reference corpus size of 1M, 5M or 10M words. Therefore, given the 1.3 M-word PR-BD Corpus, the Reference Corpus' size of 4.7M words was deemed acceptable.

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[117] e-mail communication with TreeTagger developer Helmut Schmid on 23 February 2022

G.9 Supplementary figure and tables

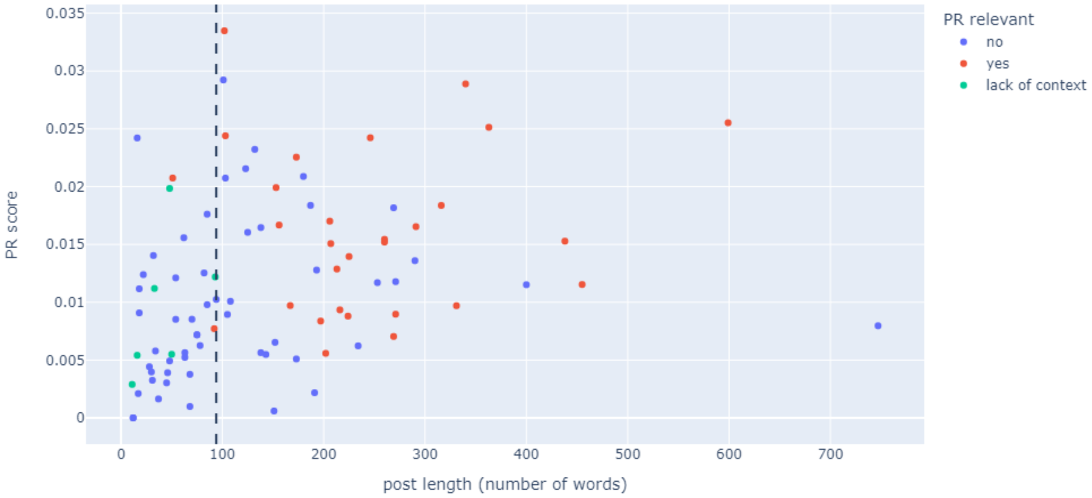

Figure S7 PR-relevance for 90 posts by length and cosine similarity score with the PR terms list[118]

Figure S7 note: The dashed line at 94 words is the maximum length of posts for which PR relevance could not be determined due to a lack of context.

Table S36 Gwet's AC$_1$ and its standard error (SE), Cohen's kappa (k) and observed agreement (P$_0$) (see Table S21 for definitions) between GJ and CH for coding the PR relevant of posts; benchmarking of AC$_1$ and k according to Altman's (1991) scale: $^{+}$fair, *moderate, **good level of agreement (see Table S22)

	n	AC$_1$, SE	k	P$_0$
Pilot	20	0.55^{+}, 0.19	0.43*	0.75
Main	100	0.57*, 0.08	0.51*	0.77
Main confident (both 3,4, or 5)	62	0.77**, 0.08	0.71**	0.87

Table S37 Manual coding results for PR relevance

PR relevant	Yes	No	Lack of context/ cannot decide
90 posts (GJ coded, SHJ audited)	29	55	6

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[118] List of all 210 post ids with PR relevance codes: https://github.com/glorisonne/reddit_bd_recovery/blob/main/post_ids/posts_PR_relevant_post_ids.csv

PR relevant	Yes	No	Lack of context/ cannot decide
120 posts (GJ + CH coded), ≥ 94 words	37	78	5
Total (% of 210)	66 (31.4%)	133 (63.3%)	11 (5.2%)

Table S38 Precision, recall, and instances that were correctly included (true positives (TP)), incorrectly included (false positives (FP)), incorrectly excluded (false negatives (FN)), and corpus sizes for cutoffs of the PR terms similarity score (boldface: selected cutoff)

Quan-tile	Cut off PR>x	Precision TP/(TP+FP)	Recall TP/(TP+FN)	TP	FP	FN	Posts	Users	Words[119]
		Posts with at least 94 words (n=167), manually coded as PR relevant (n=64) or not (n=103)					All posts (n=83,216)		
	-1.000	0.38	1	64	103	0	48182	8001	12480368
1	0.005	0.42	1	64	89	0	42451	7607	11551321
2	0.007	0.45	0.98	63	78	1	38223	7278	10731293
3	0.009	0.46	0.88	56	65	8	33365	6834	9678076
4	0.011	0.48	0.78	50	55	14	27999	6274	8417562
5	0.013	0.51	0.69	44	43	20	22985	5653	7141678
6	0.015	0.51	0.62	40	38	24	18354	4991	5853576
7	0.017	0.48	0.45	29	32	35	14296	4296	4686913
8	0.02	0.5	0.33	21	21	43	9627	3336	3224916
9	**0.025**	**0.59**	**0.2**	**13**	**9**	**51**	**4462**	**1982**	**1505419**
	0.027	0.5	0.11	7	7	57	3174	1556	1060175
	0.029	0.55	0.09	6	5	58	2220	1176	740910
	0.031	0.6	0.05	3	2	61	1534	878	497546
10	0.071	N/A	0.0	0	0	64			

Table S39 Reference corpus sizes (not about PR in BD) for various cutoffs of the PR terms similarity score (boldface: selected cutoff)

Quantile	Cutoff PR<x	Precision	Recall	TP	FP	FN	Posts	Users	Words[120]
		Manually coded posts (n = 167)					All posts (n= 83,216)		
1	0.005	1	0.14	14	0	89	5731	2629	929047
2	0.007	0.96	0.24	25	1	78	9959	3686	1749075
3	0.009	0.83	0.37	38	8	65	14817	4594	2802292
4	0.011	0.77	0.47	48	14	55	20183	5446	4062806
5	**0.013**	**0.75**	**0.58**	**60**	**20**	**43**	**25197**	**6075**	**5338690**

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[119] wordcounts according to spacy tokenization (Honnibal *et al.*, 2020, version 3.0.6), differing from the wordcount reported in the main text according to LancsBox' tokenisation via TreeTagger

[120] wordcounts according to spacy tokenization (Honnibal *et al.*, 2020, version 3.0.6), differing from the wordcount reported in the main text according to LancsBox' tokenisation via TreeTagger

Quantile	Cutoff PR<x	Precision	Recall	TP	FP	FN	Posts	Users	Words[120]
6	0.015	0.73	0.63	65	24	38	29828	6591	6626792
7	0.017	0.67	0.69	71	35	32	33886	6984	7793455
8	0.02	0.66	0.8	82	43	21	38555	7399	9255452
9	0.025	0.65	0.91	94	51	9	43720	7778	10974949
10	0.071	0.62	1	103	64	0	48182	8001	12480368

Table S40 Key lemmas coded into POETIC categories

Domain/ category	Fre-qency	Key lemmas (% of key lemma coded into category)[121]
Connect-edness	**15709**	
1.1 Peer support and support groups	2711	group* 67%, support_n 47%, share_v 40%, insight 33%, personal 30%, community 27%, member 23%, hope_n 23%, perspective 20%, helpful 20%, offer_v 17%, connect 13%, support_v 13%, resource 13%, friendship 7%, learn 7%, positive 7%, recovery 7%, cure_v 7%, grateful 7%, responsible 7%, encourage* 7%, position* 7%, provide* 7%, step_n* 7%, social 3%, decision 3%, opportunity 3%, involve 3%, family 3%, chance 3%, girlfriend 3%, strength 3%, trauma 3%, live 3%, supportive 3%, kid 3%, motivation 3%, enjoy 3%, life 3%, degree 3%, skill 3%, education 3%, effort* 3%, struggle_n* 3%, teach* 3%
1.2 Relation ships	6884	relationship 73%, friendship 53%, partner_n 50%, boyfriend 50%, engage 40%, forgive* 40%, marriage* 40%, girlfriend 37%, marry 33%, wife 30%, deserve* 30%, our* 30%, live 27%, father_n 27%, maintain* 27%, social 23%, connect 23%, open_adj 23%, mom 23%, family 20%, close_adj 20%, mother 20%, guilty 20%, sexual 17%, involve 17%, chance 17%, member 17%, choose* 17%, deal_v 13%, perspective 13%, improve 13%, supportive 13%, kid 13%, husband 13%, dad 13%, daughter 13%, responsibility 13%, struggle_n* 13%, accept 10%, offer_v 10%, progress 10%, challenge 10%, healthy 10%, son 10%, guilt 10%, responsible 10%, brother* 10%, effort* 10%, position* 10%, step_n* 10%, develop 7%, success 7%, trauma 7%, share_v 7%, activity 7%, capable 7%, support_v 7%, enjoy 7%, grateful 7%, life 7%, skill 7%, pursue 7%, childhood* 7%, forward_adv* 7%, quality* 7%, decision 3%, opportunity 3%, strength 3%, possibility 3%, parent_n 3%, child 3%, positive 3%, risk_n 3%, community 3%, stability 3%, motivation 3%, recovery 3%, confidence 3%, study_v 3%, college 3%, personal 3%, choice 3%, dream_n 3%, routine 3%, education 3%, active 3%, adult* 3%, baby* 3%, encourage* 3%, group* 3%, grow* 3%, raise_v* 3%, schedule* 3%, seek* 3%, yourself* 3%

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[121] *: new key lemma, not a PR term

Domain/ category	Fre-qency	Key lemmas (% of key lemma coded into category)[121]
1.3 Support from others	5955	supportive 63%, seek* 60%, support_v 57%, husband 50%, professional 47%, support_n 47%, active 40%, provide* 37%, wife 33%, resource 30%, offer_v 30%, educate* 30%, family 27%, mother 27%, care_n 27%, member 27%, partner_n 23%, helpful 23%, mom 23%, son 23%, encourage* 23%, girlfriend 20%, trauma 20%, grateful 20%, step_n* 20%, teach* 20%, boyfriend 17%, engage 17%, shame_n 17%, insight 17%, responsible 17%, accept 13%, perspective 13%, belief 13%, marry 13%, study_v 13%, social 10%, connect 10%, possibility 10%, live 10%, child 10%, positive 10%, community 10%, manage 10%, dad 10%, daughter 10%, pursue 10%, adult* 10%, brother* 10%, effort* 10%, marriage* 10%, position* 10%, develop 7%, decision 7%, involve 7%, exercise_n 7%, cope 7%, share_v 7%, motivation 7%, capable 7%, skill 7%, recover 7%, environment* 7%, group* 7%, quality* 7%, struggle_n* 7%, opportunity 3%, success 3%, deal_v 3%, strength 3%, learn 3%, open_adj 3%, progress 3%, close_adj 3%, parent_n 3%, recovery 3%, life 3%, challenge 3%, god 3%, money 3%, father_n 3%, choice 3%, lifestyle 3%, education 3%, guilty 3%, bear_v* 3%, choose* 3%, deserve* 3%, grow* 3%, schedule* 3%
1.4 Being part of the community	159	connect 7%, community 7%, society 7%, involve 3%, activity 3%, positive 3%, husband 3%, helpful 3%, money 3%, member 3%, active 3%, effort* 3%, maintain* 3%
Optimism & hope	**3525**	
2.1 Belief in possibility of recovery	1346	cure_v 27%, hope_n 23%, manage 20%, progress 17%, recover 17%, live 13%, recovery 13%, life 10%, deserve* 10%, risk_n 7%, career* 7%, forward_adv* 7%, accept 3%, success 3%, deal_v 3%, exercise_v 3%, strength 3%, community 3%, stability 3%, confidence 3%, society 3%, challenge 3%, adult* 3%, educate* 3%, future* 3%, quality* 3%, raise_v* 3%, struggle_n* 3%
2.2 Hope-inspiring relation ships	671	successful* 27%, strength 13%, dad 13%, father_n 13%, encourage* 13%, success 10%, share_v 10%, hope_n 10%, recovery 7%, mother 7%, brother* 7%, social 3%, involve 3%, chance 3%, connect 3%, shame_n 3%, perspective 3%, possibility 3%, live 3%, parent_n 3%, boyfriend 3%, cure_v 3%, grateful 3%, challenge 3%, mom 3%, daughter 3%, resource 3%, guilty 3%, childhood* 3%, raise_v* 3%
2.3 Positive thinking and valuing success	1202	opportunity 37%, grateful 37%, strength 27%, progress 27%, forward_adv* 23%, success 17%, positive 17%, enjoy 17%, hope_n 13%, guilt 13%, learn 10%, challenge 10%, choose* 10%, effort* 10%, future* 10%, teach* 10%, connect 7%, encourage* 7%, our* 7%, successful* 7%, social 3%, accept 3%, shame_n 3%, perspective 3%, friendship 3%, trauma 3%, open_adj 3%, cope 3%, partner_n 3%, community 3%, capable 3%, helpful 3%, society 3%, god 3%, active 3%, pursue 3%,

Domain/ category	Fre-qency	Key lemmas (% of key lemma coded into category)[121]
		forgive* 3%, grow* 3%, maintain* 3%, quality* 3%, raise_v* 3%, seek* 3%, yourself* 3%
2.4 Having dreams and aspirations	306	dream_n 27%, future* 23%, hope_n 7%, pursue 7%, forward_adv* 7%, successful* 7%, deal_v 3%, possibility 3%, open_adj 3%, stability 3%, active 3%
Identity	**3405**	
3.1 Dimensions of identity	528	sexual 20%, belief 10%, accept 7%, strength 7%, life 7%, social 3%, chance 3%, girlfriend 3%, share_v 3%, supportive 3%, cure_v 3%, society 3%, adult* 3%, future* 3%
3.2 Rebuilding or redefining positive sense of self	1640	confidence 40%, forgive* 37%, guilt 27%, deserve* 23%, shame_n 20%, yourself* 17%, strength 13%, learn 13%, grow* 13%, guilty 10%, successful* 10%, decision 7%, accept 7%, success 7%, capable 7%, responsibility 7%, childhood* 7%, effort* 7%, forward_adv* 7%, future* 7%, step_n* 7%, social 3%, family 3%, deal_v 3%, exercise_v 3%, perspective 3%, share_v 3%, improve 3%, live 3%, insight 3%, motivation 3%, manage 3%, marry 3%, support_v 3%, cure_v 3%, study_v 3%, job 3%, enjoy 3%, hope_n 3%, society 3%, care_n 3%, personal 3%, goal 3%, support_n 3%, healthy 3%, dream_n 3%, lifestyle 3%, sexual 3%, responsible 3%, active 3%, pursue 3%, adult* 3%, baby* 3%, bear_v* 3%, encourage* 3%, our* 3%, quality* 3%
3.3 Overcoming stigma	1237	stigma 80%, shame_n 23%, society 23%, personal 13%, responsible 10%, bear_v* 10%, social 7%, open_adj 7%, share_v 7%, belief 7%, close_adj 7%, child 7%, community 7%, helpful 7%, money 7%, daughter 7%, education 7%, choose* 7%, educate* 7%, environment* 7%, group* 7%, decision 3%, involve 3%, accept 3%, family 3%, diet_n 3%, partner_n 3%, supportive 3%, positive 3%, risk_n 3%, professional 3%, mother 3%, capable 3%, grateful 3%, member 3%, responsibility 3%, graduate 3%, guilty 3%, active 3%, adult* 3%, baby* 3%, brother* 3%, career* 3%, deserve* 3%, forward_adv* 3%, future* 3%, raise_v* 3%, step_n* 3%, struggle_n* 3%, yourself* 3%
Purpose & meaning	**16469**	
4.1 Meaning of mental illness experiences	1593	childhood* 40%, sexual 37%, trauma 27%, insight 27%, grow* 23%, accept 20%, dad 17%, father_n 13%, environment* 13%, family 10%, deal_v 10%, positive 10%, dream_n 10%, guilt 10%, our* 10%, involve 7%, shame_n 7%, society 7%, challenge 7%, choose* 7%, raise_v* 7%, struggle_n* 7%, develop 3%, connect 3%, perspective 3%, open_adj 3%, belief 3%, kid 3%, child 3%, community 3%, motivation 3%, marry 3%, mother 3%, grateful 3%, relationship 3%, personal 3%, choice 3%,

Domain/ category	Fre-qency	Key lemmas (% of key lemma coded into category)[121]
		pursue 3%, baby* 3%, brother* 3%, deserve* 3%, provide* 3%, seek* 3%
4.2 Spirituality	1153	god 70%, belief 37%, life 10%, teach* 10%, connect 7%, cure_v 7%, care_n 7%, quality* 7%, raise_v* 7%, develop 3%, trauma 3%, possibility 3%, close_adj 3%, activity 3%, insight 3%, positive 3%, mother 3%, capable 3%, study_v 3%, enjoy 3%, grateful 3%, personal 3%, guilt 3%, pursue 3%, baby* 3%, environment* 3%, future* 3%, yourself* 3%
4.3 Quality of life	2634	hobby 70%, improve 40%, money 23%, parent_n 17%, marry 17%, enjoy 13%, social 10%, exercise_v 10%, activity 10%, husband 10%, manage 10%, job 10%, wife 10%, degree 10%, adult* 10%, quality* 10%, decision 7%, involve 7%, success 7%, girlfriend 7%, engage 7%, learn 7%, live 7%, close_adj 7%, kid 7%, life 7%, personal 7%, skill 7%, resource 7%, routine 7%, recover 7%, education 7%, responsible 7%, guilty 7%, active 7%, grow* 7%, maintain* 7%, develop 3%, family 3%, connect 3%, exercise_n 3%, offer_v 3%, progress 3%, partner_n 3%, community 3%, professional 3%, boyfriend 3%, stability 3%, mother 3%, capable 3%, cure_v 3%, relationship 3%, dad 3%, goal 3%, mom 3%, healthy 3%, dream_n 3%, lifestyle 3%, sexual 3%, pursue 3%, bear_v* 3%, brother* 3%, career* 3%, educate* 3%, environment* 3%, forward_adv* 3%, marriage* 3%, our* 3%, provide* 3%, raise_v* 3%, teach* 3%
4.4 Meaningful life and social goals	687	goal 27%, dream_n 10%, progress 7%, community 7%, money 7%, pursue 7%, step_n* 7%, yourself* 7%, decision 3%, involve 3%, success 3%, manage 3%, capable 3%, life 3%, hobby 3%, care_n 3%, degree 3%, lifestyle 3%, graduate 3%, education 3%, career* 3%, grow* 3%
4.5 Meaningful life and social roles	5769	kid 57%, parent_n 53%, daughter 53%, baby* 53%, child 50%, son 47%, bear_v* 43%, raise_v* 37%, chance 30%, environment* 30%, decision 27%, mom 27%, grow* 23%, risk_n 20%, society 20%, father_n 20%, challenge 17%, develop 13%, perspective 13%, possibility 13%, capable 13%, life 13%, choice 13%, responsible 13%, childhood* 13%, our* 13%, provide* 13%, struggle_n* 13%, family 10%, care_n 10%, dad 10%, choose* 10%, future* 10%, opportunity 7%, deal_v 7%, open_adj 7%, cope 7%, partner_n 7%, husband 7%, stability 7%, marry 7%, mother 7%, support_v 7%, helpful 7%, healthy 7%, guilty 7%, adult* 7%, deserve* 7%, forgive* 7%, position* 7%, successful* 7%, yourself* 7%, involve 3%, connect 3%, girlfriend 3%, offer_v 3%, share_v 3%, boyfriend 3%, motivation 3%, study_v 3%, grateful 3%, relationship 3%, god 3%, wife 3%, support_n 3%, dream_n 3%, resource 3%, guilt 3%, sexual 3%, recover 3%, effort* 3%, marriage* 3%, quality* 3%, seek* 3%
4.6 Rebuilding of life	218	deal_v 3%, capable 3%, life 3%, skill 3%, recover 3%

Domain/ category	Freqency	Key lemmas (% of key lemma coded into category)[121]
4.7 Paid or voluntary work or work-related activities or formal education	4415	graduate 77%, college 77%, job 70%, degree 63%, career* 60%, study_v 47%, education 47%, position* 43%, capable 27%, successful* 27%, teach* 27%, opportunity 23%, professional 20%, pursue 20%, community 17%, enjoy 17%, offer_v 13%, skill 13%, responsibility 13%, struggle_n* 13%, chance 10%, learn 10%, possibility 10%, progress 10%, support_v 10%, wife 10%, choice 10%, dream_n 10%, recover 10%, effort* 10%, quality* 10%, schedule* 10%, decision 7%, accept 7%, success 7%, engage 7%, improve 7%, risk_n 7%, motivation 7%, manage 7%, guilty 7%, adult* 7%, deserve* 7%, environment* 7%, provide* 7%, raise_v* 7%, open_adj 3%, stability 3%, recovery 3%, helpful 3%, grateful 3%, hope_n 3%, life 3%, relationship 3%, challenge 3%, dad 3%, money 3%, goal 3%, member 3%, routine 3%, sexual 3%, responsible 3%, active 3%, baby* 3%, brother* 3%, childhood* 3%, choose* 3%, forward_adv* 3%, future* 3%, maintain* 3%, yourself* 3%
Empowerment	**8994**	
5.1 Self-management and personal responsibility	6396	diet_n 83%, lifestyle 80%, routine 80%, schedule* 73%, exercise_n 70%, exercise_v 67%, cope 60%, skill 53%, responsibility 53%, maintain* 47%, healthy 43%, goal 37%, learn 33%, develop 30%, effort* 30%, step_n* 30%, yourself* 30%, activity 27%, active 27%, positive 23%, choose* 23%, improve 20%, recovery 17%, care_n 17%, deal_v 17%, manage 17%, hobby 17%, environment* 17%, teach* 17%, success 13%, stability 13%, cure_v 13%, challenge 13%, social 10%, belief 10%, life 10%, choice 10%, guilt 10%, responsible 10%, pursue 10%, adult* 10%, forward_adv* 10%, decision 7%, accept 7%, connect 7%, perspective 7%, trauma 7%, progress 7%, live 7%, child 7%, capable 7%, study_v 7%, helpful 7%, enjoy 7%, personal 7%, money 7%, resource 7%, sexual 7%, bear_v* 7%, our* 7%, provide* 7%, quality* 7%, struggle_n* 7%, successful* 7%, opportunity 3%, chance 3%, engage 3%, strength 3%, shame_n 3%, possibility 3%, open_adj 3%, close_adj 3%, husband 3%, boyfriend 3%, motivation 3%, dad 3%, wife 3%, education 3%, guilty 3%, career* 3%, encourage* 3%, forgive* 3%, group* 3%, position* 3%, seek* 3%
5.2 Control over life	1309	educate* 47%, resource 33%, choice 30%, helpful 20%, education 20%, learn 13%, manage 13%, recovery 10%, effort* 10%, teach* 10%, develop 7%, decision 7%, provide* 7%, seek* 7%, involve 3%, connect 3%, deal_v 3%, strength 3%, perspective 3%, share_v 3%, progress 3%, improve 3%, close_adj 3%, activity 3%, risk_n 3%, community 3%, professional 3%, marry 3%, capable 3%, study_v 3%, job 3%, challenge 3%, care_n 3%, personal 3%, money 3%, active 3%, pursue 3%, adult* 3%, choose* 3%, encourage* 3%, forgive* 3%, forward_adv* 3%, step_n* 3%, yourself* 3%
5.3 Controversial	1289	risk_n 23%, possibility 20%, quality* 20%, cure_v 17%, professional 13%, recovery 13%, baby* 13%, exercise_n 10%, close_adj 10%, dream_n 10%, develop 7%, accept 7%, success

Domain/ category	**Freqency**	**Key lemmas (% of key lemma coded into category)**[121]
role of medication		7%, chance 7%, exercise_v 7%, offer_v 7%, cope 7%, improve 7%, stability 7%, lifestyle 7%, routine 7%, raise_v* 7%, involve 3%, connect 3%, diet_n 3%, open_adj 3%, positive 3%, community 3%, motivation 3%, confidence 3%, mother 3%, capable 3%, study_v 3%, job 3%, helpful 3%, grateful 3%, hope_n 3%, life 3%, relationship 3%, challenge 3%, care_n 3%, personal 3%, goal 3%, choice 3%, degree 3%, responsibility 3%, responsible 3%, pursue 3%, brother* 3%, choose* 3%, forward_adv* 3%, grow* 3%, maintain* 3%, our* 3%, position* 3%, provide* 3%, seek* 3%, step_n* 3%
Tensions	**1796**	
6.1 Balancing acceptance with ambitions	395	opportunity 7%, care_n 7%, schedule* 7%, develop 3%, accept 3%, success 3%, strength 3%, boyfriend 3%, stability 3%, study_v 3%, job 3%, hope_n 3%, challenge 3%, goal 3%, responsibility 3%, resource 3%, pursue 3%, our* 3%, struggle_n* 3%, yourself* 3%
6.2 Openness enables support and stigmatisation	1137	open_adj 30%, close_adj 20%, stigma 17%, adult* 17%, share_v 13%, supportive 13%, accept 7%, friendship 7%, belief 7%, personal 7%, member 7%, choose* 7%, encourage* 7%, struggle_n* 7%, develop 3%, social 3%, opportunity 3%, success 3%, chance 3%, offer_v 3%, possibility 3%, live 3%, positive 3%, motivation 3%, manage 3%, job 3%, helpful 3%, grateful 3%, life 3%, society 3%, challenge 3%, care_n 3%, dad 3%, choice 3%, sexual 3%, baby* 3%, career* 3%, deserve* 3%, educate* 3%, future* 3%, group* 3%, position* 3%, provide* 3%, raise_v* 3%
6.3 Ambivalence around (hypo-)mania	264	confidence 10%, progress 7%, motivation 7%, enjoy 7%, perspective 3%, possibility 3%, live 3%, husband 3%, manage 3%, god 3%, goal 3%, choice 3%, dream_n 3%, skill 3%, sexual 3%, encourage* 3%
Not POETIC	**9302**	
X.1 Other MH issues	5840	motivation 50%, stability 43%, recover 43%, activity 37%, confidence 37%, money 37%, guilty 37%, involve 33%, brother* 33%, friendship 30%, trauma 30%, risk_n 30%, bear_v* 30%, marriage* 30%, engage 27%, deal_v 23%, shame_n 20%, society 20%, father_n 20%, guilt 20%, forward_adv* 20%, future* 20%, quality* 20%, struggle_n* 20%, possibility 17%, social 17%, cope 17%, child 17%, insight 17%, enjoy 17%, god 17%, goal 17%, healthy 17%, decision 13%, family 13%, chance 13%, live 13%, belief 13%, kid 13%, marry 13%, challenge 13%, personal 13%, degree 13%, dream_n 13%, encourage* 13%, our* 13%, success 10%, exercise_v 10%, strength 10%, close_adj 10%, recovery 10%, manage 10%, life 10%, hobby 10%, mom 10%, choice 10%, son 10%, member 10%, responsible 10%, pursue 10%, career*

Domain/ category	**Fre-qency**	**Key lemmas (% of key lemma coded into category)**[121]
		10%, group* 10%, yourself* 10%, connect 7%, girlfriend 7%, diet_n 7%, perspective 7%, improve 7%, parent_n 7%, positive 7%, boyfriend 7%, mother 7%, cure_v 7%, study_v 7%, hope_n 7%, daughter 7%, childhood* 7%, choose* 7%, educate* 7%, forgive* 7%, grow* 7%, provide* 7%, seek* 7%, step_n* 7%, develop 3%, opportunity 3%, exercise_n 3%, offer_v 3%, open_adj 3%, progress 3%, partner_n 3%, husband 3%, professional 3%, capable 3%, support_v 3%, relationship 3%, dad 3%, responsibility 3%, education 3%, adult* 3%, baby* 3%, deserve* 3%, environment* 3%, position* 3%, successful* 3%
X.2 Story telling	2187	girlfriend 20%, college 20%, brother* 20%, dad 17%, graduate 17%, childhood* 17%, close_adj 13%, mother 13%, adult* 13%, develop 10%, deal_v 10%, offer_v 10%, parent_n 10%, recover 10%, encourage* 10%, decision 7%, family 7%, possibility 7%, open_adj 7%, activity 7%, husband 7%, boyfriend 7%, recovery 7%, marry 7%, cure_v 7%, money 7%, wife 7%, healthy 7%, choice 7%, son 7%, member 7%, daughter 7%, responsible 7%, career* 7%, grow* 7%, position* 7%, raise_v* 7%, successful* 7%, involve 3%, accept 3%, chance 3%, diet_n 3%, learn 3%, share_v 3%, live 3%, kid 3%, child 3%, positive 3%, risk_n 3%, community 3%, motivation 3%, confidence 3%, study_v 3%, job 3%, enjoy 3%, life 3%, stigma 3%, mom 3%, dream_n 3%, guilt 3%, baby* 3%, deserve* 3%, effort* 3%, forward_adv* 3%, future* 3%, marriage* 3%, provide* 3%, seek* 3%, step_n* 3%
X.3 Forum interaction	1074	care_n 13%, stability 10%, healthy 10%, marriage* 10%, opportunity 7%, exercise_n 7%, strength 7%, professional 7%, recovery 7%, relationship 7%, environment* 7%, maintain* 7%, raise_v* 7%, yourself* 7%, chance 3%, shame_n 3%, perspective 3%, progress 3%, partner_n 3%, live 3%, parent_n 3%, activity 3%, positive 3%, boyfriend 3%, mother 3%, capable 3%, cure_v 3%, enjoy 3%, grateful 3%, challenge 3%, personal 3%, dad 3%, wife 3%, mom 3%, father_n 3%, degree 3%, son 3%, skill 3%, pursue 3%, baby* 3%, brother* 3%, childhood* 3%, deserve* 3%, encourage* 3%, future* 3%, grow* 3%, our* 3%, position* 3%, schedule* 3%, seek* 3%
X.4 General discussion	201	society 7%, social 3%, perspective 3%, partner_n 3%, hope_n 3%, care_n 3%, mom 3%, adult* 3%, environment* 3%, future* 3%, our* 3%

Table S41 Categories assigned to key lemmas based on 30 coded concordance lines each

	Key lemma[122]	Freq	Coded categories with percentage
1	life	4732	4.5 13%, 2.1 10%, 4.2 10%, 5.1 10%, X.1 10%, 1.2 6%, 3.1 6%, 4.3 6%, 1.1 3%, 1.3 3%, 4.4 3%, 4.6 3%, 4.7 3%, 5.3 3%, 6.2 3%, X.2 3%
2	family	1988	1.3 26%, 1.2 20%, X.1 13%, 4.1 10%, 4.5 10%, X.2 6%, 1.1 3%, 3.2 3%, 3.3 3%, 4.3 3%
3	job	1831	4.7 70%, 4.3 10%, 3.2 3%, 5.2 3%, 5.3 3%, 6.1 3%, 6.2 3%, X.2 3%
4	relationship	1777	1.2 73%, X.3 6%, 4.1 3%, 4.3 3%, 4.5 3%, 4.7 3%, 5.3 3%, X.1 3%
5	live	1614	1.2 26%, 2.1 13%, X.1 13%, 1.3 10%, 4.3 6%, 5.1 6%, 1.1 3%, 2.2 3%, 3.2 3%, 6.2 3%, 6.3 3%, X.3 3%, X.2 3%
6	yourself*	1450	5.1 30%, 3.2 16%, X.1 10%, 4.4 6%, 4.5 6%, X.3 6%, 1.2 3%, 2.3 3%, 3.3 3%, 4.2 3%, 4.7 3%, 5.2 3%, 6.1 3%
7	our*	1416	1.2 30%, 4.5 13%, X.1 13%, 4.1 10%, 2.3 6%, 5.1 6%, 3.2 3%, 4.3 3%, 5.3 3%, 6.1 3%, X.3 3%, X.4 3%
8	learn	1400	5.1 33%, 3.2 13%, 5.2 13%, 2.3 10%, 4.7 10%, 1.1 6%, 4.3 6%, 1.3 3%, X.2 3%
9	parent_n	1275	4.5 53%, 4.3 16%, X.2 10%, X.1 6%, 1.2 3%, 1.3 3%, 2.2 3%, X.3 3%
10	child	1243	4.5 50%, X.1 16%, 1.3 10%, 3.3 6%, 5.1 6%, 1.2 3%, 4.1 3%, X.2 3%
11	support_n	1238	1.1 46%, 1.3 46%, 3.2 3%, 4.5 3%
12	Kid	1146	4.5 56%, 1.2 13%, X.1 13%, 4.3 6%, 1.1 3%, 4.1 3%, X.2 3%
13	deal_v	1141	X.1 23%, 5.1 16%, 1.2 13%, 4.1 10%, X.2 10%, 4.5 6%, 1.3 3%, 2.1 3%, 2.4 3%, 3.2 3%, 4.6 3%, 5.2 3%
14	manage	934	2.1 20%, 5.1 16%, 5.2 13%, 1.3 10%, 4.3 10%, X.1 10%, 4.7 6%, 3.2 3%, 4.4 3%, 6.2 3%, 6.3 3%
15	mom	845	4.5 26%, 1.2 23%, 1.3 23%, X.1 10%, 2.2 3%, 4.3 3%, X.2 3%, X.3 3%, X.4 3%
16	care_n	827	1.3 26%, 5.1 16%, X.3 13%, 4.5 10%, 4.2 6%, 6.1 6%, 3.2 3%, 4.4 3%, 5.2 3%, 5.3 3%, 6.2 3%, X.4 3%
17	healthy	811	5.1 43%, X.1 16%, 1.2 10%, X.3 10%, X.2 6%, 4.5 6%, 3.2 3%, 4.3 3%
18	accept	733	4.1 20%, 1.3 13%, 1.2 10%, 3.1 6%, 3.2 6%, 4.7 6%, 5.1 6%, 5.3 6%, 6.2 6%, 2.1 3%, 2.3 3%, 3.3 3%, 6.1 3%, X.2 3%
19	group*	717	1.1 66%, X.1 10%, 1.3 6%, 3.3 6%, 1.2 3%, 5.1 3%, 6.2 3%
20	college	715	4.7 76%, X.2 20%, 1.2 3%
21	cope	665	5.1 60%, X.1 16%, 1.3 6%, 4.5 6%, 5.3 6%, 2.3 3%

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[122] *: new key lemma, not a PR term

	Key lemma[122]	Freq	Coded categories with percentage
22	husband	649	1.3 50%, 1.2 13%, 4.3 10%, 4.5 6%, X.2 6%, 1.4 3%, 5.1 3%, 6.3 3%, X.1 3%
23	mother	609	1.3 26%, 1.2 20%, X.2 13%, 2.2 6%, 4.5 6%, X.1 6%, 3.3 3%, 4.1 3%, 4.2 3%, 4.3 3%, 5.3 3%, X.3 3%
24	social	599	1.2 23%, X.1 16%, 1.3 10%, 4.3 10%, 5.1 10%, 3.3 6%, 1.1 3%, 2.2 3%, 2.3 3%, 3.1 3%, 3.2 3%, 6.2 3%, X.4 3%
25	Dad	574	4.1 16%, X.2 16%, 1.2 13%, 2.2 13%, 1.3 10%, 4.5 10%, 4.3 3%, 4.7 3%, 5.1 3%, 6.2 3%, X.1 3%, X.3 3%
26	partner_n	572	1.2 50%, 1.3 23%, 4.5 6%, 2.3 3%, 3.3 3%, 4.3 3%, X.1 3%, X.3 3%, X.4 3%
27	decision	566	4.5 26%, X.1 13%, 1.3 6%, 3.2 6%, 4.3 6%, 4.7 6%, 5.1 6%, 5.2 6%, X.2 6%, 1.1 3%, 1.2 3%, 3.3 3%, 4.4 3%
28	money	565	X.1 36%, 4.3 23%, 3.3 6%, 4.4 6%, 5.1 6%, X.2 6%, 1.3 3%, 1.4 3%, 4.7 3%, 5.2 3%
29	share_v	499	1.1 40%, 6.2 13%, 2.2 10%, 1.2 6%, 1.3 6%, 3.3 6%, 3.1 3%, 3.2 3%, 4.5 3%, 5.2 3%, X.2 3%
30	Goal	485	5.1 36%, 4.4 26%, X.1 16%, 3.2 3%, 4.3 3%, 4.7 3%, 5.3 3%, 6.1 3%, 6.3 3%
31	boyfriend	469	1.2 50%, 1.3 16%, X.1 6%, X.2 6%, 2.2 3%, 4.3 3%, 4.5 3%, 5.1 3%, 6.1 3%, X.3 3%
32	support_v	464	1.3 56%, 1.1 13%, 4.7 10%, 1.2 6%, 4.5 6%, 3.2 3%, X.1 3%
33	Wife	464	1.3 33%, 1.2 30%, 4.3 10%, 4.7 10%, X.2 6%, 4.5 3%, 5.1 3%, X.3 3%
34	personal	441	1.1 30%, 3.3 13%, X.1 13%, 4.3 6%, 5.1 6%, 6.2 6%, 1.2 3%, 3.2 3%, 4.1 3%, 4.2 3%, 5.2 3%, 5.3 3%, X.3 3%
35	father_n	435	1.2 26%, 4.5 20%, X.1 20%, 2.2 13%, 4.1 13%, 1.3 3%, X.3 3%
36	helpful	434	1.3 23%, 1.1 20%, 5.2 20%, 3.3 6%, 4.5 6%, 5.1 6%, 1.4 3%, 2.3 3%, 4.7 3%, 5.3 3%, 6.2 3%
37	choice	433	5.2 30%, 4.5 13%, 4.7 10%, 5.1 10%, X.1 10%, X.2 6%, 1.2 3%, 1.3 3%, 4.1 3%, 5.3 3%, 6.2 3%, 6.3 3%
38	supportive	421	1.3 63%, 1.2 13%, 6.2 13%, 1.1 3%, 3.1 3%, 3.3 3%
39	god	416	4.2 70%, X.1 16%, 1.3 3%, 2.3 3%, 4.5 3%, 6.3 3%
40	positive	414	5.1 23%, 2.3 16%, 1.3 10%, 4.1 10%, 1.1 6%, X.1 6%, 1.2 3%, 1.4 3%, 3.3 3%, 4.2 3%, 5.3 3%, 6.2 3%, X.2 3%, X.3 3%
41	close_adj	412	1.2 20%, 6.2 20%, X.2 13%, 5.3 10%, X.1 10%, 3.3 6%, 4.3 6%, 1.3 3%, 4.2 3%, 5.1 3%, 5.2 3%
42	degree	401	4.7 63%, X.1 13%, 4.3 10%, 1.1 3%, 4.4 3%, 5.3 3%, X.3 3%
43	hope_n	390	1.1 23%, 2.1 23%, 2.3 13%, 2.2 10%, 2.4 6%, X.1 6%, 3.2 3%, 4.7 3%, 5.3 3%, 6.1 3%, X.4 3%
44	seek*	389	1.3 60%, 5.2 6%, X.1 6%, 1.2 3%, 2.3 3%, 4.1 3%, 4.5 3%, 5.1 3%, 5.3 3%, X.2 3%, X.3 3%
45	son	387	4.5 46%, 1.3 23%, 1.2 10%, X.1 10%, X.2 6%, X.3 3%

	Key lemma[122]	**Freq**	**Coded categories with percentage**
46	stability	386	X.1 43%, 5.1 13%, X.3 10%, 4.5 6%, 5.3 6%, 1.2 3%, 2.1 3%, 2.4 3%, 4.3 3%, 4.7 3%, 6.1 3%
47	dream_n	376	2.4 26%, X.1 13%, 4.1 10%, 4.4 10%, 4.7 10%, 5.3 10%, 1.2 3%, 3.2 3%, 4.3 3%, 4.5 3%, 6.3 3%, X.2 3%
48	chance	369	4.5 30%, 1.2 16%, X.1 13%, 4.7 10%, 5.3 6%, 1.1 3%, 2.2 3%, 3.1 3%, 5.1 3%, 6.2 3%, X.2 3%, X.3 3%
49	develop	363	5.1 30%, 4.5 13%, X.2 10%, 1.2 6%, 1.3 6%, 5.2 6%, 5.3 6%, 4.1 3%, 4.2 3%, 4.3 3%, 6.1 3%, 6.2 3%, X.1 3%
50	grow*	358	4.1 23%, 4.5 23%, 3.2 13%, 4.3 6%, X.1 6%, X.2 6%, 1.2 3%, 1.3 3%, 2.3 3%, 4.4 3%, 5.3 3%, X.3 3%
51	exercise_n	347	5.1 70%, 5.3 10%, 1.3 6%, X.3 6%, 4.3 3%, X.1 3%
52	enjoy	345	2.3 16%, 4.7 16%, X.1 16%, 4.3 13%, 1.2 6%, 5.1 6%, 6.3 6%, 1.1 3%, 3.2 3%, 4.2 3%, X.2 3%, X.3 3%
53	step_n*	341	5.1 30%, 1.3 20%, 1.2 10%, 1.1 6%, 3.2 6%, 4.4 6%, X.1 6%, 3.3 3%, 5.2 3%, 5.3 3%, X.2 3%
54	skill	335	5.1 53%, 4.7 13%, 1.2 6%, 1.3 6%, 4.3 6%, 1.1 3%, 4.6 3%, 6.3 3%, X.3 3%
55	struggle_n*	334	X.1 20%, 1.2 13%, 4.5 13%, 4.7 13%, 1.3 6%, 4.1 6%, 5.1 6%, 6.2 6%, 1.1 3%, 2.1 3%, 3.3 3%, 6.1 3%
56	open_adj	332	6.2 30%, 1.2 23%, 3.3 6%, 4.5 6%, X.2 6%, 1.3 3%, 2.3 3%, 2.4 3%, 4.1 3%, 4.7 3%, 5.1 3%, 5.3 3%, X.1 3%
57	choose*	330	5.1 23%, 1.2 16%, 2.3 10%, 4.5 10%, 3.3 6%, 4.1 6%, 6.2 6%, X.1 6%, 1.3 3%, 4.7 3%, 5.2 3%, 5.3 3%
58	community	329	1.1 26%, 4.7 16%, 1.3 10%, 1.4 6%, 3.3 6%, 4.4 6%, 1.2 3%, 2.1 3%, 2.3 3%, 4.1 3%, 4.3 3%, 5.2 3%, 5.3 3%, X.2 3%
59	risk_n	321	X.1 30%, 5.3 23%, 4.5 20%, 2.1 6%, 4.7 6%, 1.2 3%, 3.3 3%, 5.2 3%, X.2 3%
60	diet_n	320	5.1 83%, X.1 6%, 5.3 3%, X.2 3%, 3.3 3%
61	improve	318	4.3 40%, 5.1 20%, 1.2 13%, 4.7 6%, 5.3 6%, X.1 6%, 3.2 3%, 5.2 3%
62	member	307	1.3 26%, 1.1 23%, 1.2 16%, X.1 10%, 6.2 6%, X.2 6%, 1.4 3%, 3.3 3%, 4.7 3%
63	daughter	297	4.5 53%, 1.2 13%, 1.3 10%, 3.3 6%, X.1 6%, X.2 6%, 2.2 3%
64	perspective	295	1.1 20%, 1.2 13%, 1.3 13%, 4.5 13%, 5.1 6%, X.1 6%, 2.2 3%, 2.3 3%, 4.1 3%, 5.2 3%, 6.3 3%, 3.2 3%, X.4 3%, X.3 3%
65	stigma	293	3.3 80%, 6.2 16%, X.2 3%
66	future*	289	2.4 23%, X.1 20%, 2.3 10%, 4.5 10%, 3.2 6%, 2.1 3%, 3.1 3%, 3.3 3%, 4.2 3%, 4.7 3%, 6.2 3%, X.2 3%, X.3 3%, X.4 3%
67	responsibility	284	5.1 53%, 1.2 13%, 4.7 13%, 3.2 6%, 3.3 3%, 5.3 3%, 6.1 3%, X.1 3%
68	resource	283	5.2 33%, 1.3 30%, 1.1 13%, 4.3 6%, 5.1 6%, 2.2 3%, 4.5 3%, 6.1 3%

	Key lemma[122]	Freq	Coded categories with percentage
69	career*	279	4.7 60%, X.1 10%, 2.1 6%, X.2 6%, 3.3 3%, 4.3 3%, 4.4 3%, 5.1 3%, 6.2 3%
70	lifestyle	265	5.1 80%, 5.3 6%, 1.3 3%, 3.2 3%, 4.3 3%, 4.4 3%
71	forward_adv*	262	2.3 23%, X.1 20%, 5.1 10%, 1.2 6%, 2.1 6%, 2.4 6%, 3.2 6%, 3.3 3%, 4.3 3%, 4.7 3%, 5.2 3%, 5.3 3%, X.2 3%
72	offer_v	259	1.3 30%, 1.1 16%, 4.7 13%, 1.2 10%, X.2 10%, 5.3 6%, 4.3 3%, 4.5 3%, 6.2 3%, X.1 3%
73	success	247	2.3 16%, 5.1 13%, 2.2 10%, X.1 10%, 1.2 6%, 3.2 6%, 4.3 6%, 4.7 6%, 5.3 6%, 1.3 3%, 2.1 3%, 4.4 3%, 6.1 3%, 6.2 3%
74	guilt	241	3.2 26%, X.1 20%, 2.3 13%, 1.2 10%, 4.1 10%, 5.1 10%, 4.2 3%, 4.5 3%, X.2 3%
75	maintain*	239	5.1 46%, 1.2 26%, 4.3 6%, X.3 6%, 1.4 3%, 2.3 3%, 4.7 3%, 5.3 3%
76	society	237	3.3 23%, 4.5 20%, X.1 20%, 1.4 6%, 4.1 6%, X.4 6%, 2.1 3%, 2.3 3%, 3.1 3%, 3.2 3%, 6.2 3%
77	routine	233	5.1 80%, 4.3 6%, 5.3 6%, 1.2 3%, 4.7 3%
78	involve	232	X.1 33%, 1.2 16%, 1.3 6%, 4.1 6%, 4.3 6%, 1.1 3%, 1.4 3%, 2.2 3%, 3.3 3%, 4.4 3%, 4.5 3%, 5.2 3%, 5.3 3%, X.2 3%
79	graduate	228	4.7 76%, X.2 16%, 3.3 3%, 4.4 3%
80	recovery	227	5.1 16%, 2.1 13%, 5.3 13%, 5.2 10%, X.1 10%, 1.1 6%, 2.2 6%, X.2 6%, X.3 6%, 1.2 3%, 1.3 3%, 4.7 3%
81	schedule*	224	5.1 73%, 4.7 10%, 6.1 6%, 1.2 3%, 1.3 3%, X.3 3%
82	girlfriend	220	1.2 36%, 1.3 20%, X.2 20%, 4.3 6%, X.1 6%, 1.1 3%, 3.1 3%, 4.5 3%
83	activity	220	X.1 36%, 5.1 26%, 4.3 10%, 1.2 6%, X.2 6%, 1.4 3%, 4.2 3%, 5.2 3%, X.3 3%
84	exercise_v	218	5.1 66%, 4.3 10%, X.1 10%, 5.3 6%, 2.1 3%, 3.2 3%
85	marry	213	1.2 33%, 4.3 16%, 1.3 13%, X.1 13%, 4.5 6%, X.2 6%, 3.2 3%, 4.1 3%, 5.2 3%
86	provide*	210	1.3 36%, 4.5 13%, 1.1 6%, 4.7 6%, 5.1 6%, 5.2 6%, X.1 6%, 4.1 3%, 4.3 3%, 5.3 3%, 6.2 3%, X.2 3%
87	raise_v*	209	4.5 36%, 4.1 6%, 4.2 6%, 4.7 6%, 5.3 6%, X.2 6%, X.3 6%, 2.1 3%, 2.2 3%, 2.3 3%, 3.3 3%, 4.3 3%, 6.2 3%, 1.2 3%
88	opportunity	207	2.3 36%, 4.7 23%, 4.5 6%, 6.1 6%, X.3 6%, 1.1 3%, 1.2 3%, 1.3 3%, 5.1 3%, 6.2 3%, X.1 3%
89	brother*	207	X.1 33%, X.2 20%, 1.2 10%, 1.3 10%, 2.2 6%, 3.3 3%, 4.1 3%, 4.3 3%, 4.7 3%, 5.3 3%, X.3 3%
90	deserve*	207	1.2 30%, 3.2 23%, 2.1 10%, 4.5 6%, 4.7 6%, 1.3 3%, 3.3 3%, 4.1 3%, 6.2 3%, X.1 3%, X.2 3%, X.3 3%
91	educate*	204	5.2 46%, 1.3 30%, 3.3 6%, X.1 6%, 2.1 3%, 4.3 3%, 6.2 3%
92	successful*	199	2.2 26%, 4.7 26%, 3.2 10%, 2.3 6%, 2.4 6%, 4.5 6%, 5.1 6%, X.2 6%, X.1 3%

	Key lemma[122]	**Freq**	**Coded categories with percentage**
93	professional	191	1.3 46%, 4.7 20%, 5.3 13%, X.3 6%, 3.3 3%, 4.3 3%, 5.2 3%, X.1 3%
94	friendship	190	1.2 53%, X.1 30%, 1.1 6%, 6.2 6%, 2.3 3%
95	progress	190	2.3 26%, 2.1 16%, 1.2 10%, 4.7 10%, 4.4 6%, 5.1 6%, 6.3 6%, 1.3 3%, 4.3 3%, 5.2 3%, X.1 3%, X.3 3%
96	trauma	188	X.1 30%, 4.1 26%, 1.3 20%, 1.2 6%, 5.1 6%, 1.1 3%, 2.3 3%, 4.2 3%
97	teach*	186	4.7 26%, 1.3 20%, 5.1 16%, 2.3 10%, 4.2 10%, 5.2 10%, 1.1 3%, 4.3 3%
98	sexual	184	4.1 36%, 3.1 20%, 1.2 16%, 5.1 6%, 3.2 3%, 4.3 3%, 4.5 3%, 4.7 3%, 6.2 3%, 6.3 3%
99	study_v	181	4.7 46%, 1.3 13%, 5.1 6%, X.1 6%, 1.2 3%, 3.2 3%, 4.2 3%, 4.5 3%, 5.2 3%, 5.3 3%, 6.1 3%, X.2 3%
100	recover	180	X.1 43%, 2.1 16%, 4.7 10%, X.2 10%, 1.3 6%, 4.3 6%, 4.5 3%, 4.6 3%
101	motivation	178	X.1 50%, 1.3 6%, 4.7 6%, 6.3 6%, 1.1 3%, 1.2 3%, 3.2 3%, 4.1 3%, 4.5 3%, 5.1 3%, 5.3 3%, 6.2 3%, X.2 3%
102	effort*	178	5.1 30%, 1.2 10%, 1.3 10%, 2.3 10%, 4.7 10%, 5.2 10%, 3.2 6%, 1.1 3%, 1.4 3%, 4.5 3%, X.2 3%
103	belief	177	4.2 36%, 1.3 13%, X.1 13%, 3.1 10%, 5.1 10%, 3.3 6%, 6.2 6%, 4.1 3%
104	hobby	177	4.3 70%, 5.1 16%, X.1 10%, 4.4 3%
105	baby*	174	4.5 53%, 5.3 13%, 1.2 3%, 3.2 3%, 3.3 3%, 4.1 3%, 4.2 3%, 4.7 3%, 6.2 3%, X.1 3%, X.2 3%, X.3 3%
106	strength	170	2.3 26%, 2.2 13%, 3.2 13%, X.1 10%, 3.1 6%, X.3 6%, 1.1 3%, 1.2 3%, 1.3 3%, 2.1 3%, 5.1 3%, 5.2 3%, 6.1 3%
107	challenge	168	4.5 16%, 5.1 13%, X.1 13%, 1.2 10%, 2.3 10%, 4.1 6%, 1.3 3%, 2.1 3%, 2.2 3%, 4.7 3%, 5.2 3%, 5.3 3%, 6.1 3%, 6.2 3%, X.3 3%
108	environment*	168	4.5 30%, 5.1 16%, 4.1 13%, 1.3 6%, 3.3 6%, 4.7 6%, X.3 6%, 4.2 3%, 4.3 3%, X.1 3%, X.4 3%
109	possibility	166	5.3 20%, X.1 16%, 4.5 13%, 1.3 10%, 4.7 10%, X.2 6%, 1.2 3%, 2.2 3%, 2.4 3%, 4.2 3%, 5.1 3%, 6.2 3%, 6.3 3%
110	adult*	165	6.2 16%, X.2 13%, 1.3 10%, 4.3 10%, 5.1 10%, 4.5 6%, 4.7 6%, 1.2 3%, 2.1 3%, 3.1 3%, 3.2 3%, 3.3 3%, 5.2 3%, X.1 3%, X.4 3%
111	marriage*	161	1.2 40%, X.1 30%, 1.3 10%, X.3 10%, 4.3 3%, 4.5 3%, X.2 3%
112	shame_n	159	3.3 23%, 3.2 20%, X.1 20%, 1.3 16%, 4.1 6%, 2.2 3%, 2.3 3%, 5.1 3%, X.3 3%
113	capable	158	4.7 26%, 4.5 13%, 1.2 6%, 1.3 6%, 3.2 6%, 5.1 6%, 2.3 3%, 3.3 3%, 4.2 3%, 4.3 3%, 4.4 3%, 4.6 3%, 5.2 3%, 5.3 3%, X.1 3%, X.3 3%
114	education	157	4.7 46%, 5.2 20%, 3.3 6%, 4.3 6%, 1.1 3%, 1.2 3%, 1.3 3%, 4.4 3%, 5.1 3%, X.1 3%
115	responsible	156	1.3 16%, 4.5 13%, 1.2 10%, 3.3 10%, 5.1 10%, X.1 10%, 1.1 6%, 4.3 6%, X.2 6%, 3.2 3%, 4.7 3%, 5.3 3%

	Key lemma[122]	Freq	Coded categories with percentage
116	engage	155	1.2 40%, X.1 26%, 1.3 16%, 4.3 6%, 4.7 6%, 5.1 3%
117	bear_v*	155	4.5 43%, X.1 30%, 3.3 10%, 5.1 6%, 1.3 3%, 3.2 3%, 4.3 3%
118	encourage*	155	1.3 23%, 2.2 13%, X.1 13%, X.2 10%, 1.1 6%, 2.3 6%, 6.2 6%, 1.2 3%, 3.2 3%, 5.1 3%, 5.2 3%, 6.3 3%, X.3 3%
119	confidence	153	3.2 40%, X.1 36%, 6.3 10%, 1.2 3%, 2.1 3%, 5.3 3%, X.2 3%
120	cure_v	147	2.1 26%, 5.3 16%, 5.1 13%, 1.1 6%, 4.2 6%, X.1 6%, X.2 6%, 2.2 3%, 3.1 3%, 3.2 3%, 4.3 3%, X.3 3%
121	guilty	147	X.1 36%, 1.2 20%, 3.2 10%, 4.3 6%, 4.5 6%, 4.7 6%, 1.3 3%, 2.2 3%, 3.3 3%, 5.1 3%
122	childhood*	147	4.1 40%, X.2 16%, 4.5 13%, 1.2 6%, 3.2 6%, X.1 6%, 2.2 3%, 4.7 3%, X.3 3%
123	forgive*	147	1.2 40%, 3.2 36%, 4.5 6%, X.1 6%, 2.3 3%, 5.1 3%, 5.2 3%
124	active	141	1.3 40%, 5.1 26%, 4.3 6%, 1.2 3%, 1.4 3%, 2.3 3%, 2.4 3%, 3.2 3%, 3.3 3%, 4.7 3%, 5.2 3%
125	insight	140	1.1 33%, 4.1 26%, 1.3 16%, X.1 16%, 3.2 3%, 4.2 3%
126	pursue	140	4.7 20%, 1.3 10%, 5.1 10%, X.1 10%, 1.2 6%, 2.4 6%, 4.4 6%, 2.3 3%, 3.2 3%, 4.1 3%, 4.2 3%, 4.3 3%, 5.2 3%, 5.3 3%, 6.1 3%, X.3 3%
127	grateful	139	2.3 36%, 1.3 20%, 1.1 6%, 1.2 6%, 2.2 3%, 3.3 3%, 4.1 3%, 4.2 3%, 4.5 3%, 4.7 3%, 5.3 3%, 6.2 3%, X.3 3%
128	connect	136	1.2 23%, 1.1 13%, 1.3 10%, 1.4 6%, 2.3 6%, 4.2 6%, 5.1 6%, X.1 6%, 2.2 3%, 4.1 3%, 4.3 3%, 4.5 3%, 5.2 3%, 5.3 3%
129	quality*	136	5.3 20%, X.1 20%, 4.3 10%, 4.7 10%, 1.2 6%, 1.3 6%, 4.2 6%, 5.1 6%, 2.1 3%, 2.3 3%, 3.2 3%, 4.5 3%
130	position*	134	4.7 43%, 1.2 10%, 1.3 10%, 1.1 6%, 4.5 6%, X.2 6%, 5.1 3%, 5.3 3%, 6.2 3%, X.1 3%, X.3 3%

Table S42 POETIC framework descriptions (reproduced from Jagfeld, Lobban, Marshall, et al. (2021, Appendix B & C)) and paraphrased quotes (see Appendix G.7)

POETIC index, domain/ category	*Description* and paraphrased illustrative quotes
4 Purpose and meaning	*Broad subdomain of having the goal of living a meaningful and purposeful life whatever that means to the person, goal of recovery is to find framework that explains experience*
4.1 Meaning of mental illness experiences	*Understanding or finding meaning in one's mental illness experience, can range from spiritual or religious meanings through to adoption of a medical view of mental illness. Giving meaning normalises the experience and can have positive implications (e.g., increased acceptance and reduced self-*

POETIC index, domain/ category	*Description* and paraphrased illustrative quotes
	stigma). Includes people trying to make sense of diagnosis/symptoms due to past life experiences (e.g., trauma). “Did you also find positive elements in negative symptoms of our illness? Before I received treatment I experienced a very strong critical voice during depression, but it actually drove me to improve myself. It would motivate me to put more effort into everything and make extreme changes. Now that I receive treatment, I can still identify areas in my life where I might improve, but I don't feel the same motivation. I seem to be happy to live a mediocre life. Does anyone else feel like this, too? Do you have any strategies to overcome this?” “I've developed two explanations as to why I was chosen to have bipolar. 1. There are tons of people that are bipolar/depressed/etc., and it is a godsend to meet someone that not only understands, but has dealt with it and can help. 2. This is sort of a religious thing, but maybe you can get something out of it anyway. I'm a Buddhist practitioner, so karma comes into play here. With all if this terrible crap I've had to deal with, I'm at least thankful that I am expending so much negative karma in a single lifetime. Getting this out of the way now means that I'm getting it over with.” “As a teacher, I find myself really good at spotting, helping understanding students with anxiety, low self esteem, depression and the ones being bullied. I have a much better feel with them, than colleagues, who haven't experienced mental health problems and often, these children seek me.”
4.7 Paid or voluntary work or formal education	*Importance and impact of paid work or voluntary work. Paid work or voluntary work provides routine, connection to daily life, identity different from illness, but can also pose a risk factor due to causing stress. Symptoms can impair work performance.* “I want medication to improve my concentration - is that selfish? When I'm normal or before my hypomania gets out of control, I am excellent at my job, but during depressive and mixed episode I only perform at the most basic levels. So I can hold down my job but I would like to excel. I feel guilty asking my doctor for medication to improve my concentration; on the other hand I think these issues are due to my bipolar, so it is alright wanting to treat it like anything else.” “Bipolar folks at college: how do you cope with settling into college life after living at home?”
4.3 Quality of life	*Broad subdomain, process and outcome, importance to have basic needs met (adequate housing and financial support). Includes generic mentions of “quality of life” as important for people. Also: people saying their general experience of living has improved, might be due to material changes (“getting a job meant I had my first secure housing”) or psychological/behavioural changes (“my life improved as I was able to accept, I need to ask for help when my mood worsens").* “Besides, it's no measure of health to be well adjusted to a profoundly sick society.” “Now the sleep thing is happening again. I also have a job. It's a great job in a pharmacy I like, but some days I just cannot get out of fucking bed.

POETIC index, domain/ category	***Description* and paraphrased illustrative quotes**
	And when I say some days, I mean most. About 8 months ago my boss had to pull my health insurance because I wasn't netting 20 hours a week. [...] I have no health insurance so I cannot see a doctor. Well, I could, but it would cost quite a bit of money out-of-pocket, money which I don't have because I work so few hours. A vicious cycle is happening. I haven't been able to afford my meds so I stopped them a few months ago. At that point, I wasn't convinced they were doing anything anyway, but couldn't see a doctor to get adjusted or re-diagnosed." "Mental health professionals call me 'high functioning' because I've got a job and something looking like a social life. Others with chronic (mental) health issues I know would love to be as 'put together' as I am, so I agree on that. However, I need a lot of resources and faking to keep this up. On days when getting out of bed feels almost impossible, I do my best to paint on a smile and get through the day. I am grateful for everything I can do given my bipolar disorder, but no one sees how hard it is to keep going as if everything was okay, how 'high functioning' feels inside."
4.5 Meaningful life and social roles	*Activities and occupations that make life meaningful, essentially the same ones as for people without MH problems. Life making more sense through re-framing of experience as meaningful, social role of mother/father being reengaged with, finding value in supporting others. Work (paid or voluntary formal employment) is coded at 4.3.3 instead.* "I wouldn't wish bipolar disorder on my worst enemy, let alone could I bear to pass it on to anyone. I've got other reasons, too. I'm terrified of the thought of having to come off my medication for at least nine months, particularly with the hormonal changes and stress of parenting. I see my suicide risk going up and I'm scared I'd be so selfish and end my child's life as well. [...] I've considered it all and having kids just doesn't seem possible for me." "My parents had no idea how to handle my teenage depression and bipolar. [...] I feel like I'm better equipped to help my son deal with his emotions and negative behaviors than my parents ever were bc I've been though it and the therapy. [...] It's all a process and every day is a new challenge, bit that doesn't mean that you can't be a good parent."
4.2 Spirituality	*Connecting with a higher power and developing spirituality, often aids to develop an understanding of their experience and provides a source of support and encouragement. Includes organised religion or a specific faith as well as spirituality in abstract terms.* "Spiritual or psychosis? During my highs, one thing that always happens to me is that I get highly euphoric and expansiveness. I experience moments of intense connectedness to the world around me, almost as if the surroundings and I merge into one being. [...] Talking to my new therapist, I told her how these moments were intensely spiritual to me. To my surprise, she told me that they were bordering on psychotic. Would you all say the same? I'm not sure when one is high enough to become psychotic. I've also heard occasional voices and see random patterns in my visual field. Should I tell my doctors? I don't know what to do, I don't want to lose this beautiful spiritual connection to nature."

POETIC index, domain/ category	***Description* and paraphrased illustrative quotes**
	“I meditate and visualize angel wings enfolding me and being flooded with radiating loving light. I realise this sounds quite bipolar. To talk about this part of my inner world to a psychiatrist would require a lot of trust for me. I have always had this active imagination, as if there was another presence just out of reach. I think of it as something I do privately. As long as it does not negatively affect my everyday life, it should not concern anyone.”
4.4 Meaningful social and life goals	*Goal setting in areas outside of MH services, predominantly change of residence and getting a job or take up further education. Compared to 4.5 Meaningful life and social roles, which is about more long-term ‘roles’, contains more focused goals such as getting a promotion, a degree. 2.5 is more of a feeling (life worth living, for first time had dreams of a good future) and 4.4 more articulated goals (less affective, more cognitive).* “There is no such thing as a life wasted. [...] The value of a life is up to the person who possesses that life and no amount of outside influence changes that. [...] Bipolar isn't going to cause me to waste my life bipolar is just a thing I have. I interpret my life as meaningful because I choose to do things that I value. Bipolar has had a tremendous negative impact on my life but because I spend my time doing what I value it can never be wasted.” “I'm not a bad guy, but … I did so many horrible things, made bad choices for myself and my family, recklessly spent our money, so we ended up homeless and had to move in with my parents. No medication will ever enable me to forgive myself, I think. I just hope they can make me stable enough, so I can go to school, find a job, and make progress towards my dreams. Maybe one day I can be the man my kids and wife need. I want my family back.”
4.6 Rebuilding of life	*Having a purpose or a reason to get up each day, can include volunteering.* ”I might be capable of maintaining a kind of normal life, yet, I don't know how to do it. I'm not in crisis anymore, but there is no normal that I can return to. […] TLDR; now stable, but worried I've been unstable too long to change my lifestyle.” “So the day program meant I went home at night and on the weekends and dealt with those daily living skills. If I was overwhelmed or confused etc. I'd have the day program therapists to help.”
2 Optimism and hope	*Having hope for recovery, can be in terms of various aspects: less symptoms, better social, occupational functioning, quality of life [own]. Includes experiencing a reawakening of hope after despair. Subdomains emphasise the idea that recovery is an active process, rather than something that is ‘done to’ the person. Illustrates that recovery requires self-determination.*
2.1 Belief in possibility of recovery	*Belief (disbelief) that recovery is possible.* “There's someone on there saying that even if things are good right now and I'm optimistic currently, one day I will realize that being optimistic just can't happen. That I can't overcome bipolar and can only manage it. Everyone faces set backs and people with bipolar are no different. The difference between me and people who think you'll never win is that I keep trying.”

POETIC index, domain/ category	*Description* and paraphrased illustrative quotes
	“You can think you're cured, other people think they're an astronaut, or God or whatever makes them happy in whatever moment. From a medical perspective bipolar is a *chronic* illness, not an *acute* illness. So there's technically no 'cure', only lessening of episodes, or periods of no episodes. Now it is technically feasible that you're experiencing a very long period of remission, or symptoms so slight it actually seems that your bipolar is 'cured' as far as *you 're* concerned, and- that's great actually. Feeling better is feeling better, no matter how it comes about. You could be in the middle of long manic/hypomanic episode where you feel so wonderfully great that you're 100% convinced your cured, when you're just feeling wonderful due to the course of the illness itself.”
2.3 Positive thinking and valuing success	*Having an optimistic view of life (bad things will get better), gratefulness for life, setting (small goals) and value progress, little successes.* “I think the problem here is how you or I or OP measure success. You have to develop your own baseline and go from there. [...] My best days are when I choose life over death. That's a celebration for me and I grow from it. My bipolar and BPD make my life unbearable at times and hard at most. But it is what it is. [...] I just choose...albeit with the help of consistent effort, consistent support, an immense amount of education, exposure, and resources to view it positively.” “I hate bipolar, yes I do, but you know what? Bipolar has taught me what real love looks like. It looks like loving the same person when I'm manic, depressed, stable, anything. Bipolar has taught me humility and how to swallow my pride when I fucked up a friendship because of an outburst. Bipolar has taught me to appreciate every single good moment I have. Bipolar taught me that I was a god damned fucking warrior every single day of my life fighting a battle I didn't even know existed.”
2.2 Hope-inspiring relation-ships	*Presence of hope-inspiring relationships, could be with family, friends, and professionals or with a higher power, engender a belief that recovery is possible. Also contains the opposite: evidence how professionals can reduce hope and belief in recovery. Includes role models that provide hope for future: hear about success of others, learn from other people's recovery stories.* “Now im thinking about vlogging about my journey w/ Bipolar disorder. Getting personal on selfmanagement and not only the depressive stuff. But I hope to encourage others by showing them you can still live life to the fullest potential.” “My grandmother had pretty bad bipolar disorder, so does my dad and at least two other cousins. My father is extremely successful and in a loving marriage with my mom. [...] my father is an amazing man who understands my illness like no one else. My dad is my inspiration! [...] I know my dad's experience is not universal but it gives me hope.”
2.4 Having dreams and aspira-tions	*Aiming for more (better job, quality of life) than one has in the present [own]. Affective state (feeling of life worth living, having dreams of good future). Concrete cognitive goals coded in 4.4 "meaningful social and life goals".* “Never let bipolar disorder determine who you are. It is a challenge to live with sometimes, but I believe you can still achieve your hopes and

POETIC index, domain/ category	***Description* and paraphrased illustrative quotes**
	ambitions even if it takes some more effort. I plan to keep pursuing my dream, I hope you can find and follow your passions. feel free to PM me if you want to chat or have questions. Good luck on the road ahead, stay strong and never give up.” “For example, this week I have been completely reorganizing and cleaning my house, car, and life, and I find it fun and engaging. I am not avoidant of tasks, phone calls, people. My mind is clear and liberated from the many burdens of depression. Most of my thoughts are richly positively and focus on the future and the present-- none of the wretched ruminating from before. I am able to talk myself down from intense emotions. I'm able to forgive myself.”
5 Empowerment	*How individuals achieve empowerment, many subthemes focus on MH services, but theme also includes becoming an empowered citizen.*
5.1 Self-management & personal responsibility	*Individuals take responsibilities for their own recovery, professionals need to allow this; being able to get on with day-to-day life, even when symptoms are present, includes maintaining good physical and MH, using self-management strategies, accessing self-help.* *“I can experience regular emotions now and it's incredible.”* “I've always been super interested in science and I'm not happy with the outputs of the pharma industry. They only care about profit and no one ever fully recovering. Without medication, I had to be my own scientist. I started tracking my mood, sleep, period, diet, anything that seemed relevant. I subtracted and added factors that seemed to have an effect on me. I've much improved, but it's still a work in progress.” “I'm diagnosed with rapid-cycling bipolar and my sexual needs are pretty demanding. Now that I am taking medication and more stable, swinging and BDSM with my boyfriend basically solved my issues. I want to spend the rest of my life with my boyfriend, but we both agree that you can't always expect one other person to complete you in every way.”
5.3 Controversial role of medication	*Role of medication in recovery, discussions of benefits, disadvantages, and experiences with coming off medication.* “There is, of course, concerns with safety of mood stabilizer medication while pregnant. From what I understand, there is a risk of cleft lip with lamotrigine. I can tell you people with bipolar disorder do end up having babies. It comes down to weighing the risks of medications versus the pros. It can be more damaging to the baby to not take medication and have mood swings.” “Care for your wellbeing my ass! How are we supposed to exercise, diet, sleep, when the meds fuck everything all up? loved keeping fit but ever since I'm on lithium, I feel exhausted when I exercise. It also reduced my sleep quality, I got even skinner because I eat less and I feel dumber. Still, my doc says lithium is the gold standard and advises against exploring other meds.” “If you stop taking your medication, you will relapse. This isn’t possible, it’s certain. If your psychiatrist says you need the medication, you should take it. I’m unsure about the legal side, but I’m convinced we have an ethical obligation to take responsibility for our mental health. The most

POETIC index, domain/ category	***Description* and paraphrased illustrative quotes**
	basic thing we can do to protect ourselves and our loved ones is to cooperate with the doctors.”
5.2 Control over life	*Being involved in decision-making and having some say in one’s care and treatment, particularly where medication and hospitalisation are concerned; Positive risk taking in context of care planning and goal setting; helpful if supported by professionals. Feeling in control over life or symptoms, including, but not limited to, in relation to services. 5.1.2 is trying new things even when they might go wrong, 5.2 is feeling in control of life, experiencing agency.* “Again and again, there comes a point in therapy where the therapist suggests incredibly inappropriate things based on their idealised idea of living life. Like getting a roommate when they do not understand how much I value my own space as an introvert. Of course I resist these suggestions, which they then interpret as me sabotaging my recovery. I welcome suggestions, but in the end, I have to make the decisions for myself.” “Educate yourself, your family and friends on your diagnosis, and then educate yourself even more, because we'll never fully get it. Stay away from people who want to stigmatise you without understanding your condition. Seek a doctor, know your triggers and symptoms, and advocate for yourself.”
6 Tensions	*Participants need to negotiate tensions between PR processes and in their dealing with (hypo-)mania.*
6.1 Balancing acceptance with ambitions	*Tension between accepting limitations due to MH issues to reduce stress and live a manageable life on the one hand and having ambitions or goals to work towards to and not giving up the hope of achieving things meaningful for oneself on the other hand. Negotiating the question: what can I expect of myself?* “I was forced to come to terms with the fact that being an attorney would likely never be a sustainable, healthy career choice for me, and that was such an ego blow; however, being a paralegal sets me up with a more reliable and less intense schedule with far less client contact, and I still get to work in a field that values my skills (albeit with less remuneration than would be provided were I an attorney).” “Journeys and progress are rarely linear. Expectations do little for us but lead to disappointment. Possibility is a different story. It means we are open to alternatives and are more adaptable in our thinking- which generally leads fewer instances of feeling stuck.”
6.2 Openness enables support and stigmatisation	*Tension between having to disclose MH issues to professionals or family/friends to get support with the risk of experiencing stigma. Informal level: Openly/naturally talking about ones BD enables more connectedness with others, more support and less need to hide a part of oneself but also makes one vulnerable to negative judgments, lack of comprehension. Formal level: Different experiences or evaluations of receiving the diagnosis. For some it is helpful explanation for experiences and enables access to treatment, for others it is unhelpful and adds stigma.*

POETIC index, domain/ category	***Description* and paraphrased illustrative quotes**
	“Having bipolar doesn't somehow delegitimize every emotion I now have. I usually don't respond well if someone tells me to "take my meds" in an emotional situation. People in my life know not to use that as a weapon. It's not an open topic for discussion and I've set that boundary with everyone in my life.” “Nearly a year after my bipolar diagnosis, I'm finally open about it - it was the best decision. It has allowed me to find the people who are truly there for me and it has strengthened many relationships and widened my support network. It's awesome - I've turned something society considers isolating into an opportunity for support and connection. There are always going to be crappy people, but they would have been that way anyways, even if they didn't know about your bipolar.”
6.3 Ambivalence around (hypo-) mania	*Perception and personal meaning of mania/elated mood varies between individuals: Some participants like and miss mania due to improved creativity and energy. Others dislike or fear elated states due to irritability, danger of losing control. Many are ambivalent about elated states due to these opposing experiences.* “I miss my joyful hypomanias, I must admit, but I realise the positive experiences are rare and mostly prevent me from getting any real work done.” “Mania is also part of my problem. There's no way back if I let it drag me. I know it doesn't last forever, I'll see the consequences of my delusional actions and then go downhill and get depressed. But I find it so hard to not engage. Mania is this really cool friend, I love hanging out with her, I feel good all the time, everything is beautiful, I love everyone and everyone loves me. This time, I want to stay on earth, I don't want to do it again. Can anyone relate? Has anyone successfully escaped mania before?” “Some might discourage this, but I used my bipolar to my advantage in my studies. I found a way to focus my hypomania, getting almost obsessed with the subject. I managed to 'control' my hypomania as a study superpower and to shut it off after the test. I could also shut it off at night to sleep.”
3 Identity	*How individuals see themselves or think they are perceived by others.*
3.2 Rebuilding or redefining positive sense of self	*Recovery involves redefining or regaining a positive sense of self. Includes viewing the process of recovery as involving some transformation of identity (discovering a new ‘me’) as well as the opposite: holding on to the aspiration of reclaiming one’s prior social identity and sense of self.* “In the past year, I've learned to let go. I've been cleaning out my belongings and trying to get all of my responsibilities handled (I've been procrastinating, of course...). I've let go of friends and family who aren't supportive of me and are unhealthy for me and my illness. I've let go of some old dreams. I've learned that I'm stronger than I think, but that I tell people that I'm fine when I'm not. I've learned that leaning on loved ones for support is okay, and being vulnerable can lead to growth. I've stopped hiding so much, especially from myself. I try to accept the cycles of being bipolar, and I try to enjoy the moments that make everything worthwhile.”

POETIC index, domain/ category	*Description* and paraphrased illustrative quotes
	“You feel guilty and you feel you deserve it. You should have acted differently and yet you haven't. That's only part of being human and especially of being bipolar... To think in terms of deserving is pointless - you deserve a healthy brain & fair change in life, but you will never have that. "Deserved" guilt will not prevent future mistakes. Only experience, rationality, reflection and insight will stop them. Practice mindfulness and radical self-acceptance. Be as kind to yourself as you would be to me for making such mistakes. You're handling this deadly disease as best as you can.” “Personally, I've always encouraged self-care. Being overly critical about our decisions and disability can just make things worse. The fact is, this is a chronic illness. And it's not easy.”
3.3 Overcoming stigma	*Regain a positive sense of self by overcoming stigma, society needs to support notion of recovery, too, and let go of stigma. Relates specifically to marginalised identities, including but not limited to MH (so also includes, e.g., gender, sexuality, class).* “I think a non-aggressive approach would be the best way to deal with this. It might be very tempting to argue with the person and say, "You have no idea what I'm going through!" or "You're stupid if you can't understand this!", but when you take a step back, acting like that will only further this person's belief that you are unstable and unable to fit into the normal fabric of society. I'm sorry if this sounds harsh, but although we are afflicted with bipolar disorder, we need to blend into a society that has certain expectations of behavior. Rebelling against those expectations might be satisfying in the short term, but could be devastating in the long term.” “Being bipolar puts us at high risk of ending up in the meat grinder that is American Justice, where it's OK for the police to execute a homeless man with an M16 for "camping without a permit". With access to adequate treatment and an end to extreme law enforcement abuses, we would be a much smaller share of the homeless population. Our share of the homeless and incarcerated has more to do with the state of medical science, as well as how our society is structured and conducts itself than our abilities.” “I don't use the label (yet). I use the words depression, anxiety and panic, and 'manic episode'… If the person is not bipolar and has no clue what a manic episode is (I.e. most everyone else) then they don't have the stigma attached and are just a bit more supportive and less scared and freaked out... Kind of like calling yourself a freethinker instead of atheist, or using 'plant based diet' instead of vegan. Just sidesteps stigma and stereotypes so you can have a real discussion.”
3.1 Dimensions of identity	*Individuals see themselves as more than their diagnosis. Identity not unitary, multiple dimensions important (e.g., sexual, ethnic, cultural). Mental health services/professionals need to value diff. identity dimensions and treat person as individual, not label. Difference to 3.3: Maintain or develop positive sense of self/place in world. E.g., person with unlovability schema due to upbringing who identifies this being replaced with more positive sense of self coded here, not 3.3.*

POETIC index, domain/ category	*Description* and paraphrased illustrative quotes
	"But really, bipolar is just... you. It's nice to be on drugs and more stable, but I'm not cured. Bipolar is just part of me. Not always a pleasant part, but it's not going to go away. You might as well embrace it." "Thanks so much for the tips on the bipolar part and for bringing up the LGBTQ aspect in detail. I'm very lucky that I am applying to a progressive program that is dedicated to educating students from a social justice-forward perspective in order to serve the very diverse schools here in San Francisco. So, I'm definitely looking forward to sharing my perspective as a lesbian (who cannot "pass" as straight), and continuing to advocate for others in my community whose experiences aren't necessarily like my own."
1 Connect-edness	*The sense of being connected to others, beyond individual's relationship, includes connections with society and feeling connected to others, subsumes "social inclusion".*
1.3 Support from others	*Relationships indexed on the MH issues, e.g., with workers (1.3.1) or supportive family (1.3.3) or friends / peers (1.3.4) which may be expressed through practical support (1.3.5).* "Well, the first thing I might say is the best thing you can do when you decide you want to be there to support someone with a mental illness is to step up your self care regime. [...] Because, unfortunately, the world is not set up to support the supporters. And that shit's fucked. We need you guys and everyone is better off when you can be there for us, but if someone is struggling with regular crises you gotta put your own oxygen mask on before you can be there for someone else." "My girlfriend has been with me through my bipolar for about five years. She can be very therapeutic to talk to ..."
1.2 Relation-ships	*Supportive and collaborative personal relationships seen as having a positive impact on recovery. Having a range of personal relationships with others is critical to the recovery of a life worth living. Different from 1.3, these relationships are not tightly indexed on the MH issue (though they may emerge from it, e.g., friendships with other people using service), and relate to everyday social connectedness, feeling that you have friends and confidantes.* "It may be difficult to find someone who is willing to cope with bipolar among 'normal' people pursuing 'normal' life goals. I had the best dating experiences with 'alternative' crowds (tabletop gamers, new age, artists, BDSM, the polyamorous community)." "Will anyone be able to love me? Can I be in a relationship or will I be single forever?"
1.1 Peer support and support groups	*Importance of peer support, received by attending organised groups, from contact with peer support workers, or informally, from friendships that developed among people with lived experience.* "Psychotherapy taught me how to overcome my own trauma in a lifelong process and others with similar trauma offered so much solidarity to me." "Are there any other "high functioning" bipolar people here who feel like they don't belong anywhere? I can't really relate to others in my bipolar

POETIC index, domain/ category	*Description* and paraphrased illustrative quotes
	support group with similar symptoms, neither to my peers at school, although I perform at a similar level." "I didn't feel supported in this subreddit. The validity of my bipolar diagnosis was questioned, and it was implied that it wasn't bad, so I didn't deserve to post here. I am strong enough to write this now because I hope it starts a discussion for a more supportive environment here. Our bipolar experiences are all different and that should be accepted."
1.4 Being part of the community	*Feeling of being part of the wider community, could include membership in different communities, e.g., religious, local community, service-related etc.* "Never give up! If you're not able to go to school/study for one day, it's okay, try tomorrow and see if you can do better. I totally feel you with the friend thing, what helped me here I set my goal lower. I no longer wanted to make a friend but engage in social activities with people and see where it leads." "I work as a representative in Social Security disability hearings, helping people with physical and mental disabilities obtain government benefits. Despite or because of that, I firmly believe that it's best for us to try our best to be productive members of society, even if only to give purpose and motivation for recovery and coping. This group has helped me stay stable."

Table S43 Content that did not fit into POETIC: new inductive category descriptions and quotes

Category	*Description* and illustrative quotes
X Not POETIC	*Content not related to PR and/or the user's own lived experience (talking about someone else's experiences or in general terms)*
X.1 Other MH issues	*General discussions of MH issues (mostly but not always BD-specific, symptoms, genetics and heredity, treatment, diagnosis, societal issues, scientific research) that are not directly related to PR or users' own experiences* "My father has bipolar and 2/3 of his offspring, too. His father, growing up at the beginning of the 20th century, was considered "crazy". My father's sister also had mental health issues, and I know of at least two cousins on his side that have bipolar." "The first step is a proper diagnosis. Based on the symptoms you describe and your family history, you might very well have bipolar, but only a mental health professional can confirm this." "Update and burnt bridges Yesterday I posted here about the realization that I've entered a manic episode. I drove 600 miles to see an online friend after breaking up with my boyfriend. I told no one where I was going. Aside from my family and this guy, I've destroyed all my relationship in the past days. I hate it - when I get this way, I become so impulsive and insensitive and I end up feeling super guilty afterwards. I would love to feel normal one day! Positive note: I am safe."

X.2 Story telling	*Storytelling of users' own or others' past or present situation without PR relevance* "This is a very long post, I have the need to tell everything here because I think you will understand me better than other people. I (F/29) had, like many of you I guess, a horrible childhood and teenage years. My family couldn't understand me at all. First time I went to therapy I was 5. I continued with therapy from 5-10, 13-20, 23 and still going." "Frankl This book really spoke to me as it was the first book I read after being diagnosed with Bipolar II. Frankl was a holocaust survivor who had studied neurology and psychiatry before being taken away from his family." "Within the past WEEK, my gf broke up with me, a cousin of mine passed away to cancer after some partial neglect of my unsupportive family, my grandmother is affected by her death because she feels responsible, I dislocated my shoulder after having a terrible fight on the phone with my gf, my close friend relapsed and overdosed on benzos (she's alive but I went to her house to help her out and she was a mess), and those who I've asked to be close questioned my intentions, and my job has reached an all time level of stress. I don't know what to do."
X.3 Forum inter-action	*Direct interactions between forum users (giving/asking for advice, providing example from own life without PR relevance, commenting on another user's situation, congratulating, wishing well, criticising another user)* "Your post itself seems more like a troll post rather than an actual post from a parent of a Bipolar child. If I had problems with the law, I sincerely doubt that my parents would seek help from random people on the internet." "Misdiagnosed with bipolar, but wanted to thank you guys. I've seen a different psychiatrist, and it's become clear to both him and me that my previous bipolar 2 diagnosis was incorrect, and what I actually have is cyclical depression. However, I wanted to thank you guys for being such a supportive community. I really felt like I had a place I belonged for a while, and I felt like there were people going through what I was at the time, making me feel less alone." "There's a lot to unpack here. First of all, she ain't your girlfriend. She's your ex-girlfriend. I ain't trying to rub it in, but her decision must be respected. It sounds like y'all's relationship was rough from the start. It would've been better if it had ended much sooner."
X.4 General discus-sion	*General discussions of not directly MH-related issues (human behaviour, media, society)* "Everyone hurts people... normal people hurt people. We subscribe to social conventions as women because we're told to." "The majority of the world rules, and runs all important aspects of survival in society. The minority rich, politicians and government are just that small and figureheads."

Table S44 Key lemmas that are not PR terms (*) contributing existing and new aspects of the PR experience

Key lemma	Existing aspect(s) (similar PR terms)	New aspect(s)
childhood*		coming to terms with (traumatic) childhood experiences, collocates: traumatic, trauma,

Key lemma	Existing aspect(s) (similar PR terms)	New aspect(s)
		abuse, ptsd - making sense of MH experiences
encourage*		encouraging others to do something (e.g., seek help) - giving advice / interaction
environment*		focus on structural/societal circumstances rather than individual (work environment, (un-)supportive environment, family environment) + reproductive decision making (environment for child to grow up)
adult*		life stage: people who are young adults talk about transition/differences between life as child vs. adult; being/behaving like an adult seen as providing for oneself, mature dealing with emotions, taking responsibility for own MH
baby*		reproductive decision making
raise_v*		reproductive decision making
bear_v*		reproductive decision making, genetics
educate*	112/204 instances are reflexive (educate yourself)	non-reflexive instances: educating others (family, friends, society) - relationships/stigma
grow*	personal growth (growth, growth process) - rebuilding/redefining positive sense of self	221/358 instances are "grow up" - childhood experiences - meaning of MH issues + reproductive decision making
teach*	empowerment (learn), job/work (teaching as job/career)	educating others
our*	relationships (collocations: relationship, son, marriage, family, daughter, child)	group identity: people with BD (collocations: brain, life, ability, illness, emotion, mind, experience, disorder, gene, problem, condition, mood), society in general (collocations: society, community)
choose*	self-management & personal responsibility/Empowerment (choice, collocations: people, life, own, tell, behaviour, medication)	negotiating individual responsibility for BD (collocations: illness, bipolar, disorder) + reproductive decision making (collocations: kid, parent, child)

Key lemma	Existing aspect(s) (similar PR terms)	New aspect(s)
forgive*	72/147 instances reflexive (forgive yourself)	non-reflexive instances: others forgive the user, user forgives others - relationships
provide*	others provide support/care/love	reproductive decision making (provide for a child)
struggle_n*	recovery as dynamic/active process (2/334 instances through struggle, make it through, get/work through)	symptoms
quality*	quality of life (65/136 instances), relationships (quality time), Identity (personal qualities), controversial role of medication (impact on quality of life)	symptoms: sleep quality
forward_adv*	active recovery process (move forward, push forward, step forward, active process) + relationships / meaningful life and social goals (look forward)	
brother*	family relationship (mother, father, mom, dad, daughter, son, aunt, uncle, niece, nephew, grandchild, relative)	
career*	meaningful life & social roles (work, job, occupation, promotion, degree)	
position*	meaningful life & social roles (work, job, occupation, promotion, degree)	
future*	optimism & hope (good future - this PR term does not appear, but 36% of future instances are coded in Optimism & Hope domain)	
successful*	Optimism & hope (success)	
group*	peer support (335/717 instance are 'support group')	
deserve*	relationship (problems) (collocations: relationship, support), rebuilding/redefining positive sense of self ("deserving better") (feel good about yourself, collocations: happiness, good)	
marriage*	relationship (relationship, spouse, partner, boyfriend, girlfriend, husband, wife, hubby, bf, gf)	

Key lemma	Existing aspect(s) (similar PR terms)	New aspect(s)
step_n*	self-management (comfort zone, work through, change process, seek help, active process)	
effort*	self-management (make it through, through struggles), work	
schedule*	self-management (routine)	
maintain*	self-management (routine, maintain health, maintain healthy)	
seek*	support from others (178/389 instances are 'seek help'), remainder about seeking treatment, medication, second opinion	
yourself*	self-management (take care of yourself - self-care) + rebuilding/redefining positive sense of self (forgive yourself)	

Table S45 PR terms that were underused in the PR-BD corpus compared to the reference corpus (freq: frequency)

Term	Freq PR-BD	Freq Reference	Dispersion	LL	P	LR	Comment
doctor	1246	6659	3.1	202.1	<.001	-0.6	medical MH professional
high mood	1	5	13.3	0.1	1	-0.5	symptom
mania	948	4395	21.6	63.3	<.001	-0.4	symptom
manic	1512	6267	20.9	34.1	<.001	-0.2	symptom
pdoc	297	1737	2.1	73.9	<.001	-0.7	medical MH professional
psychiatrist	974	4548	0.1	68.6	<.001	-0.4	medical MH professional
race	93	344	0.4	0.2	1	-0.1	race_n (identity-aspect) overused, race_v (not PR-related) underused
sleep	1279	4620	9.1	0.7	1	0.0	symptom

Table S46 PR terms that did not appear in the PR-BD corpus

Group: Frequency	PR terms (lemmatised)
Content covered by other key lemmas: 30	*brush yourself off, come off antipsychotic, find your own recovery, find your own route, find something to hang on to, find the proper balance, find way of care, find way of live, make it up to yourself, stand on your own foot, access to service, crisis planning, service user, share decision-make, handle ambivalence, handle distress, hope-inspire, rebuild life, self-belief, self-educate, social role, social success, meaningful activity, meaningful for you, meaningful role, meaningful task, personally meaningful, pivotal moment, pivotal step, pivotal thing*
Recovery journey characteristics: 12	*active process, change process, dynamic process, growth process, idiosyncratic process, individualized process, process of acceptance, process of recovery, subjective process, unique process, journey of recovery, recovery journey*
Spelling mistake: 2	progess, pyhsical activity
Islamic faith: 1	*Islamic* Other belief-oriented PR terms are all overused: *Christian, Jewish, Buddhist, Catholic, Protestant, atheist*, however *Muslim* and *Hindu* (not in the PR terms list but related to Islamic faith) are overused in the PR-BD corpus, so discussions of Islamic faith are not entirely absent
Collectivist identity: 1	*collectivist* It is unclear whether the absence of collectivist indicates the absence of collectivist notions or discussions about different societal norms from the PR-BD corpus or whether the term is just too formal for Reddit. The PR term *individual* is about equally frequent in the PR-BD and reference corpus.

H Message to bipolar disorder subreddit moderators

Subject: Feedback on research project looking at recovery experiences in bipolar on Reddit

Dear [subreddit name] moderators,

First of all, I'd like to thank you for maintaining one of the largest subreddits for bipolar disorder on Reddit that is a source of support and information for many people.

My name is Glorianna Jagfeld, I'm a PhD student at the Spectrum Centre for Mental Health Research at Lancaster University in the UK. Together with my three supervisors/professors – Steven Jones & Fiona Lobban (clinical psychology) and Paul Rayson (computer science) – we're doing research on personal recovery in bipolar disorder. One of the strengths of the Spectrum Centre is the innovative use of technology (e.g. development of online interventions). Additionally, it is very important for us that our research contributes to improving the lives of people who experience extreme moods or psychosis. Therefore, we seek input from people with lived experience of mental health issues. The research ethics committee of the Faculty of Health and Medicine at Lancaster University has approved of our research.

We are looking at the experiences that people publicly share on Reddit as an alternative source of information to personal interviews. The aim of the research is to inform psychological interventions that can support recovery and wellbeing in bipolar disorder.

Since we want to ensure as much as possible that our research has a positive impact on people living with bipolar disorder, we would like to engage with Reddit users who are living with bipolar disorder. Particularly, **we are looking for 2-3 individuals who are happy to spend 1-2 hours on discussing two of our studies** (as detailed below) with me. This could be either via asynchronous Reddit messages/email or in an audio/video call via Microsoft Teams or zoom and we offer a reimbursement of $15/hour.

We would be particularly keen on hearing from you as moderators as you certainly will have a lot of experience with what is going on in your subreddit. We would also be very grateful to hear about any quick comments you may have on our studies. If none of you were available for a more detailed exchange, we would like to ask for your kind permission to post our request for volunteers in your subreddit.

I'm looking forward to hearing from you as your considerations could add significantly to the value of our research project and contribute to the development of better support and care for people living with bipolar disorder.

I’m happy to provide further information on the project.
You can reply to this message or contact me via email at g.jagfeld@lancaster.ac.uk.

Best wishes,
Glorianna Jagfeld

Glorianna Jagfeld at Lancaster University:
https://www.lancaster.ac.uk/people-profiles/glorianna-jagfeld
Spectrum Centre for Mental Health Research:
https://www.lancaster.ac.uk/health-and-medicine/research/spectrum/

Study details

We are looking for feedback on the findings of a study which we are currently completing (study 1) and for suggestions for another study which we are currently planning (study 2).

Study 1 (nearly completed) - looking for feedback

We’ve identified several thousand Reddit user accounts who publicly posted that they have a diagnosis of bipolar disorder. Many of them also posted in [subreddit name]. To understand a bit more about the contexts in which people post to this subreddit, we first want to see whether people’s mood influences how many posts they make in mental health-related subreddits like [subreddit name].

For this, we measured positive and negative affect, anxiety, sadness, anger in terms of the frequencies of certain words (e.g. ‘happy’, ‘laugh’, ‘disappointed’) in users’ public Reddit post over a week and predicted with a statistical model (linear regression) how many posts they would make in the next week. We found that mean emotion levels did not impact the subsequent posting frequency, so people were not more likely post in mental health-related subreddits when they expressed particularly sad or happy feelings in their Reddit posts. However, people were much more likely to post in mental health-related subreddits when they expressed more variation in the emotions in their Reddit posts, so when they made both happy *and* sad posts in a week or very anxious and non-anxious posts. Is this something that resonates with your experiences as moderators/your own experience that people do not necessarily tend to post when they are up or down but particularly when they experience lots of changes in their emotional state?

Study 2 (planning stage) - looking for input

‘Recovery’ is quite a controversial term in the context of severe mental health issues and people are likely to have different opinions on what constitutes recovery for them. These might also differ from the definitions that mental health services use. Therefore, in this study we plan to look at specifically the terms ‘recovery’ and ‘to recover’ and how people with a self-reported bipolar disorder diagnosis use them on Reddit. A first observation is that ‘recovery’ seems to be very much associated with recovery from alcohol abuse and less so with recovery in bipolar disorder. Additionally, we would like to explore with what terms people living with bipolar disorder write about living well on Reddit, for example if they describe this as ‘being happy’ or ‘stable’ or achieving specific aims… We are also hoping for suggestions on what kinds of phrases people might use based on your own experience (as moderators).

I Talks and posters associated with this thesis

Glorianna Jagfeld was the presenter for all talks and poster presentations.

Jagfeld, G., Lobban, F., Rayson, P. and Jones, S.H. (July 2023) 'Integrating health research, natural language processing, and corpus linguistics to analyse peer online support forum posts on personal recovery in bipolar disorder', *talk at the British Association for Behavioural and Cognitive Psychotherapies 51th Annual Conference* in the symposium 'Talking about bipolar disorder and borderline personality disorder: Applying innovative large-scale language analysis approaches to lived experience' (convenor and chair: Jagfeld, G.), Cardiff, UK.

Jagfeld, G., Humphreys, C., Lobban, F., Rayson, P., Jones, S.H. (September 2022) 'Talking about personal recovery in bipolar disorder: Text analysis of public peer online support forum posts', *poster at the Society for Research in Psychopathology Annual Meeting*, Philadelphia, US.

Jagfeld, G., Humphreys, C., Rayson, P., Lobban, F. and Jones, S.H. (August 2022) 'Corpus Framework Analysis: Integrating computational linguistics, corpus linguistics, and clinical psychology to analyse online posts on personal recovery in bipolar disorder', *talk at the 6th Corpora & Discourse International Conference (CADS)*, Bertinoro, Italy.

Jagfeld, G., Humphreys, C., Rayson, P., Lobban, F. and Jones, S.H. (July 2022) 'Talking about personal recovery in bipolar disorder: Integrating natural language processing, corpus linguistics and health research to analyse peer online support forum posts', *talk at the British Association for Behavioural and Cognitive Psychotherapies 50th Annual Conference*, London, UK.

Jagfeld, Davies, R., Boyd, R., Lobban, F., Rayson, P. and Jones, S.H. (July 2022) 'An exploratory analysis of the relationship of posting in peer online support forums and trait mood in bipolar disorder', *talk at the British Association for Behavioural and Cognitive Psychotherapies 50th Annual Conference*, London, UK.

Jagfeld, G. (March 2022) 'Corpus framework analysis: integrating computational linguistics, corpus linguistics, and clinical psychology to analyse Reddit posts on personal recovery in bipolar disorder', *talk in the Lancaster UCREL Corpus Research Seminar Series,* online.

Jagfeld, G., Lobban, F., Rayson, P. and Jones, S.H. (July 2021) 'Bipolar disorder and recovery on Reddit: a corpus linguistic analysis', *talk at the Corpus Linguistics International Conference*, online.

Jagfeld, G., Lobban, F., Rayson, P. and Jones, S.H. (June 2021) 'Understanding who uses Reddit: Profiling individuals with a self-reported bipolar disorder diagnosis', *talk at the 7th Workshop on Computational Linguistics and Clinical Psychology*, online.

Jagfeld, G. (May 2021) ‘Talking about personal recovery in bipolar disorder’, *pitch at the Young People’s Involvement in Digital Mental Health Dragons’ Den*, online.

Jagfeld, G., Lobban, F., Marshall, P. and Jones, S.H. (March 2021) ‘CHIME becomes POETIC: Personal recovery in bipolar disorder - systematic review and "best fit" framework synthesis of qualitative evidence’, *talk at the British Psychological Society Division of Clinical Psychology Annual Conference 2021*, online.

Jagfeld, G. (May 2020) ‘Talking about lived experience in bipolar disorder: a corpus linguistic analysis of Reddit social media posts’, *talk in the Lancaster UCREL Corpus Research Seminar Series*, online.

Jagfeld, G., Jones, S.H., Lobban, F. and Rayson, P. (February 2020) ‘Talking about lived experience in bipolar disorder: a corpus linguistic analysis of social media posts’, *talk at the workshop ‘Patients’ Changing Agency in the Tension of digital and non-digital Health Communication’*, Hamburg, Germany.

Jagfeld, G. (July 2019) ‘A computational linguistic study of personal recovery in bipolar disorder’, *poster at the 57th Annual Meeting of the Association for Computational Linguistics: Student Research Workshop*, Florence, Italy.

Jagfeld, G. (June 2019) ‘PhD project: Talking about personal recovery in bipolar disorder’, *talk in the Lancaster University Division of Health Research student-run presentations series*, Lancaster, UK.

Jagfeld, G., Jones, S.H., Rayson, P. and Lobban, F. (May 2019) ‘How do people describe personal recovery experiences in bipolar disorder in structured and informal settings?’, *poster at the Advances in Data Science 2019 Meeting*, Manchester, UK.

Jagfeld, G., Jones, S.H., Lobban, F. and Rayson, P. (April 2019) Talking about personal recovery in bipolar disorder, *talk at the Healthcare Text Analytics Conference*, Cardiff, UK

Jagfeld, G. (April 2019) ‘Talking about personal recovery in bipolar disorder’, *runner-up prize for best poster at the Lancaster University Faculty of Health and Medicine Postgraduate Research Symposium*, Lancaster, UK.

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