

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

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Abstract

Background

Personal recovery, living a satisfying, hopeful life alongside symptoms, has become an increasingly valued aim across mental health care agendas internationally. However, there is little understanding of how people experience personal recovery alongside the mood challenges characteristic of a bipolar disorder diagnosis. Personal recovery frameworks have been developed for populations with mixed psychiatric diagnoses, predominantly psychotic disorders.

Methods

This systematic review of qualitative data used the widely adopted personal recovery processes Connectedness, Hope and optimism, Identity, Meaning and purpose, Empowerment (CHIME) in a “best fit” framework synthesis to understand personal recovery experiences in bipolar disorder. Included studies were coded with deductive framework analysis based on the CHIME processes and inductive thematic analysis for aspects beyond the a priori framework.

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 personal recovery in bipolar disorder, 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 personal recovery framework tailored for bipolar disorder is directly applicable to clinical practice with personal recovery objectives. It highlights the need for professionals to introduce personal recovery in a realistic and balanced way to address recent criticism by service user organisations of personal recovery as overly optimistic.

Keywords: bipolar disorder, personal recovery, recovery, qualitative research, meta-synthesis, framework synthesis

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 bipolar disorder 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). Bipolar disorder is associated with a high risk of suicide (Novick et al., 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 (Akers et al., 2019; Coryell et al., 1998; Goldberg and Harrow, 2004; Tohen et al., 2003) and satisfaction within these domains (Goldberg and Harrow, 2005).

Personal recovery in severe mental health issues and bipolar disorder

Clinical recovery in severe mental health issues (SMHIs) is usually clinician-assessed in terms of symptom severity and socio-occupational functioning (Lieberman and Kopelowicz, 2002; Torgalsbøen, 1999). Alternatively, from the 1980s on, initiatives by people with lived experience of SMHIs started advocating the importance of outcomes that each individual defines as relevant to them and their self-reported life satisfaction (Anthony, 1993; Deegan, 1988). Anthony (1993) defined the concept of personal recovery as ‘a way of living a satisfying, hopeful life even with the limitations caused by the illness’. Given this broad definition, personal recovery 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 mental health policies internationally since the beginning of this century (e.g., Department of Health (UK), 2009; Department of Health and Ageing (Australia), 2009; Mental Health Commission of Canada, 2012; President’s New Freedom Commission on Mental Health (US), 2003; World Health Organization Regional Office for Europe, 2005).

A large-scale systematic literature review led to a conceptual framework for personal recovery in SMHIs, comprising the five main recovery processes Connectedness, Hope and optimism, Identity, Meaning and purpose, and Empowerment (CHIME) (Leamy et al., 2011). The evidence considered in the review predominantly concerned psychotic disorder and to a much smaller extent major depressive disorder and bipolar disorder². A recent scoping review of personal recovery 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, p. 178) conclude “[s]triking gaps in our knowledge relate to how personal recovery processes take place in people with mood disorder”. Indeed, ongoing mood instability and dealing with the upsurge of elated moods often constitute special challenges for people diagnosed with bipolar disorder compared to other SMHIs (Jones et al., 2010; Lapsley et al., 2013).

Therefore, this review seeks to develop a conceptual framework for personal recovery specific to bipolar disorder based on CHIME in a “best fit” framework synthesis (Carroll et al., 2013, 2011). “Best

² 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 bipolar disorder (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 bipolar disorder in any article.

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 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 bipolar disorder-specific experiences.

The concept of subjective quality of life in bipolar disorder (Morton et al., 2018a; Murray et al., 2017), 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 personal recovery. Structured measures of quality of life (Murray and Michalak, 2012) and personal recovery (Jones et al., 2013) in bipolar disorder are associated but not mutually redundant (Murray et al., 2017). Further, a systematic review found that the studies on quality of life in bipolar disorder so far lack a coherent definition of the term (Morton et al., 2017). Thus, to ensure conceptual clarity, inclusion criteria in this review required articles to explicitly focus on personal recovery experiences as part of the research question or provide a definition of personal recovery (see Section ‘Eligibility criteria’). This specificity also sets the present review apart from a previous qualitative evidence synthesis on personal recovery in bipolar disorder (Lapsley et al., 2013), which included any qualitative study of people with a bipolar disorder diagnosis with a psychosocial focus. Moreover, growing clinical use of the personal recovery concept warrants an updated review.

Aim

This review aims to answer: ‘What do we know about the experience of personal recovery of individuals diagnosed with bipolar disorder from qualitative evidence?’

Method

The review protocol was pre-registered on PROSPERO³. Reporting of this review follows guidelines for systematic reviews (PRISMA-P (Moher et al., 2015)) and qualitative evidence syntheses (ENTREQ (Tong et al., 2012)).

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 bipolar disorder diagnoses. Second, CHIME is well established with more than 1000 citations⁴ and applications in a randomised controlled trial of a pro-recovery intervention (Slade et al., 2015, 2011), 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 personal recovery measures. In contrast, extensions such as “difficulties” proposed by Stuart, Tansey and Quayle (2017) have had limited impact to date.

³ https://www.crd.york.ac.uk/PROSPERO/display_record.php?RecordID=136978

⁴ 1059 citations according to Google Scholar on 10.4.2019.

Searches and screening

Search strategy

In line with guidance for framework synthesis, this review adopted a comprehensive search strategy. PICOS (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 01/1980 until present in the initial search on 21.6.19 and the update on 14.10.20. The lower time limit was set to the publication year of DSM-III (American Psychiatric Association, 1980), which more precisely operationalised the definition of bipolar disorder compared to previous versions. The final query consisted of the four concepts bipolar disorder, personal recovery, 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 personal recovery was difficult to operationalise, additionally all articles citing the most widely cited personal recovery 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 protocol⁵.

Eligibility criteria

Articles included in this review state personal or subjective recovery experiences in their research questions or aim or otherwise provide a personal recovery definition and discuss their qualitative results within a personal recovery framework. Table 1 shows the full eligibility criteria.

Screening process

Retrieved abstracts were deduplicated with Mendeley Desktop⁶ 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.

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., 2007, 2006; 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.

Table 1 Screening criteria to select abstracts and full texts

[INSERT Table 1 Screening criteria about here]

Table 2 CHIME personal recovery domains (dark blue) with subdomains (light blue) ordered according to number of studies identifying the subdomain (adapted from Leamy et. al (2011, p. 448)); see online Appendix B for lower-level subdomains

[INSERT Table 2 CHIME personal recovery domains about here]

⁵ https://www.crd.york.ac.uk/PROSPEROFILES/136978_STRATEGY_20191111.pdf

⁶ <https://www.mendeley.com/download-desktop>

Data synthesis

“Best fit” framework synthesis guidelines (Carroll et al., 2013, 2011) 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 2 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 online Appendix B were added from publications on the framework (Bird, 2015; Bird et al., 2014) in discussion with Mike Slade, leader of the research group that developed CHIME.

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, 2019, 2006). Two other reviewers (SJ & 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 SJ 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 bipolar disorder (see Section ‘Feedback from people with lived experience of bipolar disorder’).

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

Results

Database searches returned 2,713 unique abstracts, which were all screened (Figure 1). 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 personal recovery focus. Although abstracts in any

language were eligible, only twelve non-English full texts were assessed, which were all excluded⁷. 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 (Durgu and Dulgerler, 2020; Echezarraga et al., 2019; Tse et al., 2019). 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.

Figure 1 PRISMA diagram for study identification

[INSERT Figure 1 PRISMA diagram for study identification about here]

Study and participant characteristics

Twelve articles published between 2010 and 2020 met eligibility criteria. Online Appendix A 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 bipolar disorder 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/subjective recovery experiences in bipolar disorder 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 et al., 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 bipolar disorder.

Study quality

Table 3 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 concern was whether the articles adequately discussed the relationship between researchers and participants. Also, there was doubt for three articles (Borg et al., 2013; Durgu and Dulgerler, 2020; Todd et al., 2012) 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 3 Study quality appraisal using CASP criteria: 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?

[INSERT Table 3 Study quality appraisal using CASP criteria about here]

⁷ 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.

Synthesis

Figure 2 summarises the synthesis. The left part shows the domains of the proposed conceptual framework for personal recovery in bipolar disorder, 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 2 for comparison), and themes in the new inductive Tensions domain (green), ordered from left to right according to their relative importance. Online Appendices B and C contain the codebook and number of articles coded in each (sub-)domain/theme. Online Appendix D provides additional quotes, also for less rich and lower-level subdomains.

Figure 2 Proposed conceptual framework for personal recovery in bipolar disorder: POETIC; deductive CHIME domains (dark blue) with retained second-level (light blue) and promoted (yellow) subdomains; inductive new domain and themes in green

[INSERT Figure 2 Proposed conceptual framework for personal recovery about here]

The findings can be summarised as follows: First, deductive coding revealed that the CHIME domains covered most of the personal recovery processes in bipolar disorder, 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 bipolar disorder than in transdiagnostic CHIME. Third, inductive analysis revealed tensions between personal recovery 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 bipolar disorder.

Purpose and meaning

Purpose and meaning unified two important personal recovery 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 personal recovery. “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.

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).

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 et al., 2019b).

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 personal recovery: "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 et al., 2019b). In their considerations around coming off medication, participants traded negative side effects off against their fear of relapse.

Tensions

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

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 really under doctors' orders, not to ... try to do everything I was doing prior to being hospitalized" (Warwick et al., 2019b). 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).

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 mental health 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 et al., 2014) when they felt their behaviour was monitored disproportionately as a result of their disclosure.

Ambiguity also arose in response to receiving a bipolar disorder 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 personal recovery 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 et al., 2012).

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., 2016), and “adventurous” (Fernandez et al., 2014) elated mood as well as the “dangerous” (Veseth et al., 2012) downside of becoming “uncontrollable” (Tse et al., 2019), “destructive”, and “scary” (Fernandez et al., 2014). Especially at the beginning of their personal recovery 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 suppressing “seductive” (Morrison et al., 2016) rises in energy to stabilise mood and “whether there could ever be a place” for manic experiences in their lives (Mansell et al., 2010).

Identity

Rebuilding a positive sense of self was an important personal recovery process because societal and self-stigma associated with a bipolar disorder 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 et al., 2019b). Importantly, challenges to the sense of self could also arise later in the personal recovery 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 et al., 2014).

Connectedness

The Connectedness domain highlighted the importance of feeling connected with different groups of people, including family, friends, peers with lived experience of bipolar disorder, 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, mental health 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).

Feedback from people with lived experience of bipolar disorder

service user researcher and a volunteer with lived experience of bipolar disorder 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 mental health 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.

Discussion

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

Specific aspects and challenges of personal recovery in bipolar disorder

Finding "something in your life you really love doing" (Warwick et al., 2019b) surfaced as a core driver for personal recovery in bipolar disorder. 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 bipolar disorder 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 (Carmona et al., 2017; Marwaha et al., 2013).

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 bipolar disorder symptoms (Alloy et al., 2012; Dempsey et al., 2017; Depue and Iacono, 1989). This could explain why identifying and overcoming unrealistic expectations appeared as a personal recovery challenge for some individuals with a bipolar disorder 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 bipolar disorder in the UK did not receive any advice 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 personal recovery 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 personal recovery challenge in bipolar disorder, 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 mental health symptoms, although there is also evidence for positive aspects of psychosis (Chadwick, 1997; National Hearing Voices Network, 2020; Richards, 2008; Romme and Escher, 1993). The presence of symptoms experienced as positive may be particularly strong in bipolar disorder compared to other SMHs. Rusner et al. (2009) characterise the intensity of living with bipolar disorder as "both a gift and a challenge" (see also Taylor et al., 2015).

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 bipolar disorder diagnosis (Identity), and loss of relationships and credibility by their friends or colleagues (Connectedness). Not adopting a separate Difficulties domain (Stuart et al., 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 et al., 2014) intermitting with stable periods appears as particular challenge in bipolar disorder. A recent metasynthesis (Warwick et al., 2019a) also identified this as one of the main causes of distress in bipolar disorder. 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" (Anthony, 1993; Deegan, 1988) maintains negative thoughts, emotions, and experiences as key features of personal recovery (Recovery in the Bin et al., 2019). Thus, the POETIC framework could help to rectify the impression of personal recovery as mainly positive endeavour with a more nuanced account of the experiences of people who live with bipolar disorder.

Facing tensions, difficulties, and mood swings with mindful acceptance

Beyond the established CHIME domains, Tensions characterises personal recovery in bipolar disorder as a complex process. The two new themes 'Balancing acceptance with ambitions' and 'Openness enables support, but also stigmatisation' highlight conflicts between personal recovery domains. They underline that personal recovery cannot be attained by targeting personal recovery 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 et al., 2012). Other tensions and difficulties in personal recovery in bipolar disorder 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 mental health 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., 2019a) 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 et al., 2019b).

Implications for research

Finding a balance between acceptance and ambitions and dealing with recurrent experiences of loss seem to pose particular challenges in bipolar disorder. Mindful acceptance appears as promising approach to cope with the difficulties and tensions involved in personal recovery 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 et al., 2009), mindfulness-based cognitive therapy (Segal et al., 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 bipolar disorder 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 bipolar disorder 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 bipolar disorder 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 personal recovery (Jones et al., 2013). Finally, research still needs to evaluate whether structured therapeutic approaches more reliably or faster improve quality of life or personal recovery in bipolar disorder, as some individuals also benefit from other experiences such as spirituality.

Implications for practice

This review also has implications for recovery-oriented psychotherapy and general care for people with bipolar disorder. Foremost, it highlights that professionals should take caution not to introduce personal recovery 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 bipolar disorder 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 bipolar disorder 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 bipolar disorder (cf., Warwick et al., 2019a). This draws further attention to the potential benefits of family interventions. They have an evidence base

for bipolar disorder in addition to pharmacotherapy (Chatterton et al., 2017; Justo et al., 2007; Mansfield et al., 2012; Reinares et al., 2016) but are often difficult to access (Miklowitz and Chung, 2016; Reinares et al., 2016).

Although many aspects of personal recovery in bipolar disorder appear individual, continued efforts for social change to increase awareness and decrease stigma of SMHIs are likely to benefit everyone (Warwick et al., 2019a). This review found that disclosure of mental health 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.

Strengths and limitations

To our knowledge this is the first systematic review of personal recovery experiences in bipolar disorder 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 personal recovery experiences in bipolar disorder to other SMHIs 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 personal recovery 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., 2006), staying well (Crowe and Inder, 2018; Russell and Brown, 2005), and self-management (Morton et al., 2018b; Murray et al., 2011). Third, diversity among study participants was limited. Onset of bipolar disorder symptoms is most frequently in late adolescence and early adulthood (Merikangas et al., 2011; Pini et al., 2005) with equal prevalence in men and women (American Psychiatric Association, 2013; Pini et al., 2005). 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 personal recovery. Thus, despite consolidating experiences from 163 participants from seven countries, generalisation of the findings requires caution.

Conclusions

This systematic review synthesised qualitative research to answer the question “What do we know about the experience of personal recovery of individuals diagnosed with bipolar disorder?”. The transdiagnostic CHIME personal recovery processes (Leamy et al., 2011) capture a large part of recovery experiences in bipolar disorder, 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 personal recovery processes in

bipolar disorder. Self-management, medication, taking on socially valued roles and ambivalence around related mood states, emerged as areas deserving particular attention for people living with bipolar disorder. Mindful acceptance may be a promising way to cope with mood changes and some of the tensions in personal recovery in bipolar disorder. Extending on CHIME, this review argues that personal recovery in bipolar disorder is POETIC.

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Table 1 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)
3	Qualitative data	Contains direct quotes of participants	
4	Participants	At least three participants	
5	Participant age	Average age of participants at least 16 years	
6	Diagnosis	6.A) All participants have bipolar disorder as primary diagnosis OR 6.B) Results for participants with bipolar disorder diagnosis reported separately for all research questions and/or themes (if some participants have different diagnoses or no diagnosis such as caregivers, professionals)	6.1) If participants have dual/multiple diagnoses, exclude if remission criteria or recovery are defined for these instead of bipolar disorder (e.g. from other mental health problems, substance abuse, addiction, eating disorders) 6.2) Diagnosis of quoted participants is not provided.
7	Personal recovery	Title and abstract screening	
		Experiences of personal recovery, 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 personal recovery (i.e. have only symptom-focused outcomes)
		Full text screening	
		At least two out of the following must hold: 7.A) Research question/aims refer to personal or subjective recovery experiences 7.B) Personal recovery definition is provided 7.C) Stated relevance to personal recovery elsewhere in the article	7.1) Only focuses on clinical or functional recovery (e.g. symptoms remission, relapse prevention, resuming employment etc.) OR 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 does not refer to any definition or literature of personal recovery

Table 2 CHIME personal recovery domains (dark blue) with subdomains (light blue) ordered according to number of studies

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	Over-coming 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			

Table 3 Study quality appraisal using CASP criteria: 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?

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

Figure 1 PRISMA diagram for study identification

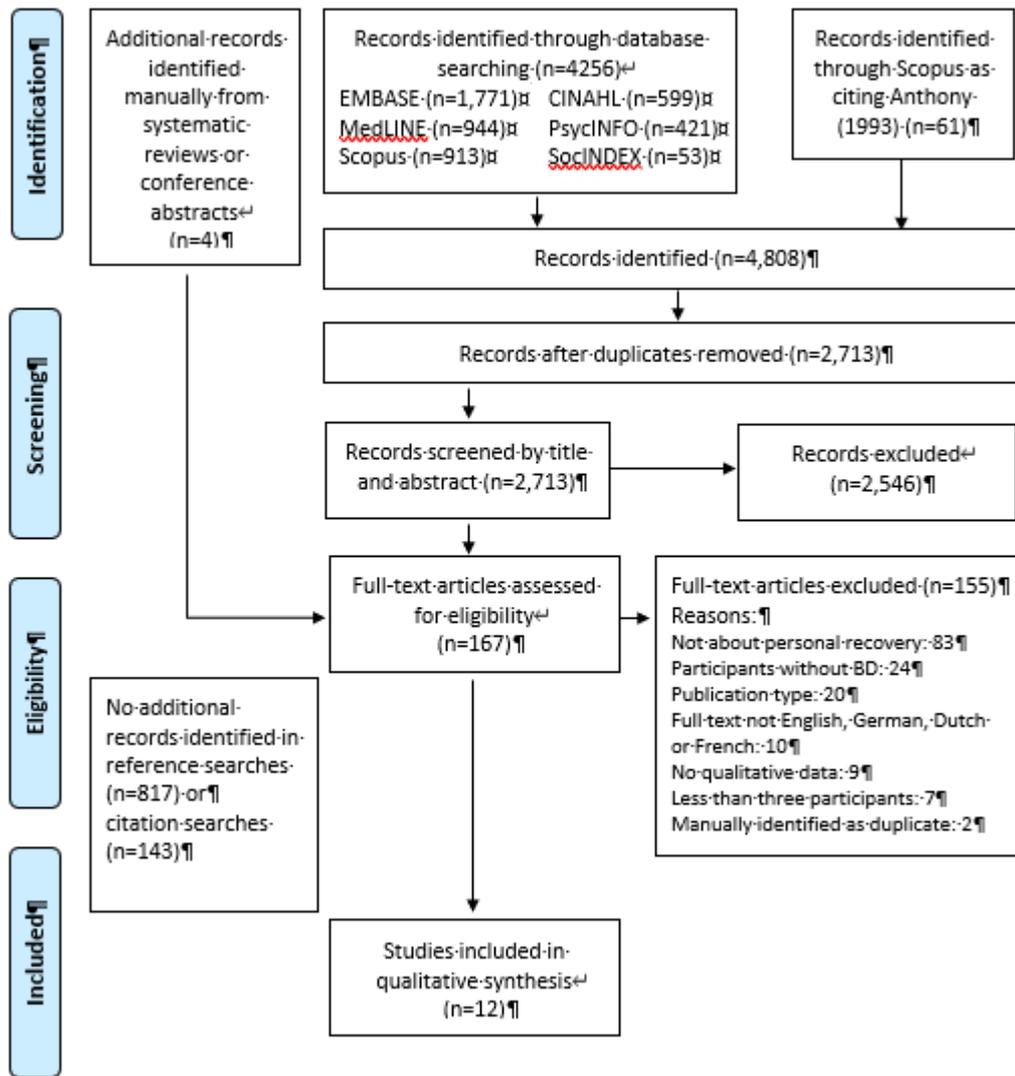


Figure 2 Proposed conceptual framework for personal recovery in bipolar disorder: POETIC; deductive CHIME domains (dark blue) with retained second-level (light blue) and promoted (yellow) subdomains; inductive new domain and themes in green

POETIC: Lived experience of personal recovery in bipolar disorder					
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	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