What does it mean to age well with bipolar disorder?

Aaron Warner BSc (Hons), MSc

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Declaration by student

I declare that all of the work completed in this thesis is my own and has not been submitted in substantially the same form for the award of a higher degree elsewhere. The following sections of this thesis have been or will be submitted for publication:

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The subsequent statement of authorship outlines my contribution towards the writing and completion of the research in this thesis and confirms the contributions from other authors.

<u>**Statement of authorship**</u>

A statement of authorship is provided for each multi-authored manuscript in this thesis. This is accompanied by written certification from other authors of each chapter. The principal author for each chapter was the PhD candidate, Aaron Warner (AW). The PhD candidate's primary supervisor was Dr Jasper Palmier-Calus (JPC), and he was also supervised by Professor Fiona Lobban (FL), Professor Carol Holland (CH) and Dr Elizabeth Tyler (ET). Geoff Settle (GS), Verity Rhodes (VR), Daisy Harvey (DH), and Connie Newens (CN) also provided input in the research completed within this thesis. Author contributions for each chapter are outlined below.

Chapter 3: Physical health comorbidities in older adults with bipolar disorder: A systematic review

Supervisors JPC, CH, FL and ET contributed to the initial design of the study alongside AW. AW completed the protocol, database searches, data extraction, data analysis and write up of the article. DH supported AW with title/abstract and full text screening. CN completed quality assessment with AW. JPC, FL, CH and ET all provided feedback on each draft of the article and provided guidance throughout the completion of this paper.

Chapter 4: What does it mean to age well with bipolar disorder? A qualitative study using photo elicitation

AW, JPC, FL, CH and ET all contributed to the study design. AW completed interviews with participants, transcribing of the data and write up. Data analysis was completed by AW, JPC, FL, CH, ET, GS and VR. JPC, FL, CH and ET provided feedback on each draft of the paper.

Chapter 5: The changing care of older adults with bipolar disorder: A narrative analysis

The study was conceptualised by AW, JPC, FL, CH and ET. AW completed all interviews with participants, transcribing and write up of the data. AW, JPC, FL, CH, ET, VR and GS were involved in data analysis. JPC, FL, CH and ET all provided feedback on initial drafts of the paper.

Chapter 6: Quality of life in older adults with bipolar mood states: A secondary analysis of The English Longitudinal Study of Ageing data

AW, JPC, CH, FL and ET all contributed to the design of this study. AW completed the protocol and data cleaning. AW, JPC and CH competed data analysis. JPC and CH provided feedback on drafts of this paper.

Thesis abstract

Background: Bipolar disorder is characterised by episodes of mania and depression that cause significant impairment and disruptions to people's lives. This diagnosis has been linked to increased rates of suicide, reduced lifespan, and increased mortality, although there is limited research exploring the challenges faced by people with bipolar disorder as they age. It is possible that there is an important interaction effect between ageing and bipolar disorder that exacerbates the difficulties faced by this group, meaning further attention and support is required. This thesis investigated the challenges faced by older adults with bipolar disorder and explored their preferences, priorities, and needs in later life. Knowledge gathered from four studies helped to identify potential adaptations to care that can be used to improve quality of life in this population and enable them to age well with bipolar disorder.

Methods: A range of methods were used to complete this thesis. First, a systematic review and narrative synthesis of 23 papers reporting on 19 studies was completed to investigate the prevalence and predictors of physical health comorbidities in older adults with bipolar disorder. Second, a qualitative study consisting of photo elicitation interviews with 17 participants used reflexive thematic analysis to analyse data and explore what it means to age well for older adults with bipolar disorder. Third, 16 biographical narrative interviews were analysed using narrative analysis to understand the changing care and care needs of older adults with bipolar disorder. Finally, a multilevel analysis of seven waves from The English Longitudinal Study of Ageing data was completed to examine quality of life in older adults with bipolar mood states and assess the predictors of quality of life in this group.

Results: Ageing with bipolar disorder was associated with an increased prevalence of certain physical health comorbidities such as cardiovascular disease and some forms of cancer. To age well, participants highlighted the importance of lifelong learning to improve their understanding

and management of bipolar disorder and find balance in later life. This learning also helped participants to feel confident in taking an active role in treatment decisions which enabled them to regain agency. Finding a sense of belonging, feeling accepted and building upon strengths all supported older adults with bipolar disorder to age well. Furthermore, giving back to others, such as helping younger age groups with bipolar disorder, allowed participants to develop confidence and self-worth. Participants indicated that there was a disconnect between the care they desired and the care that they currently received from services. Older adults with bipolar disorder appeared to have unique and changing care needs that were often neglected. To improve support, services should attempt to offer care that is consistent and facilitates the development of trusting relationships with professionals. The range of issues faced by this population was found to result in poorer quality of life that appeared to be partly driven by loneliness.

Conclusions: Older adults with bipolar disorder face unique challenges and changing care needs that mean treatments require adaptation to improve outcomes in this group. At present, treatments appear to focus on symptom reduction, although participants indicated that treatments prioritising connection and consistency of care are desired. Further attention is required to understand the difficulties associated with ageing whilst experiencing bipolar disorder, to improve care and reduce the inequalities currently experienced by this population.

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List of abbreviations

BD: Bipolar disorder

OABD: Older adult bipolar disorder

NICE: National Institute for Health and Care Excellence

DSM: Diagnostic and Statistical Manual of Mental Disorders

ICD: International Classification of Diseases

WHO: World Health Organisation

NIHR: National Institute for Health and Care Research

ARC NWC: Applied Research Collaboration Northwest Coast

PPI: Patient and public involvement

CBT: Cognitive behavioural therapy

OR: Odds ratio

IRR: Incidence rate ratios

HR: Hazard ratio

MMAT: Mixed Methods Appraisal Tool

GRIPP2: Guidance for Reporting Involvement of Patients and Public

UK: United Kingdom

NHS: National Health Service

CPN: Community psychiatric nurse

HIAT: Health Inequalities Assessment Toolkit

Chapter 1: Introduction

1.1 Overview

Bipolar disorder is a chronic mood disorder characterised by fluctuations in affective states and disruption to thoughts and behaviour that significantly impair peoples' quality of life (Grande et al., 2016). A wealth of literature highlights the difficulties associated with living with a diagnosis of bipolar disorder (Müller-Oerlinghausen et al., 2002). Bipolar disorder is often linked to poor clinical outcomes and diminished wellbeing, and research suggests that 10-20% of people diagnosed with bipolar disorder take their own lives (Grande et al., 2016). Therefore, living with a diagnosis of bipolar disorder often has a significant impact on peoples' wellbeing (Miklowitz & Johnson, 2008).

Research suggests that living with bipolar disorder as an older adult can be complex and challenging to manage (Depp & Jeste, 2004). Older adults with bipolar disorder may experience the mental health difficulties associated with bipolar disorder alongside those related to ageing such as cognitive decline and frailty (Sajatovic et al., 2015). As highlighted in chapter three of this thesis, they often experience high levels of physical health comorbidity (Warner et al., 2023). This can contribute to reduced quality of life compared to younger age groups with bipolar disorder and the general population (Depp et al., 2006). Despite this, the literature surrounding the experiences and needs of older adults with bipolar disorder is limited. Therefore, more research is needed to understand how best to support this group and reduce the health inequalities they experience (Dols et al., 2016).

This thesis aimed to identify the challenges faced by older adults with bipolar disorder and understand what support enables them to age well. To do this, the researcher initially investigated the prevalence and predictors of physical health comorbidities among older adults with bipolar disorder (chapter 3). Following this, the researcher explored what it means to age well with bipolar disorder (Chapter 4) and investigated the changing care needs of this group

in later life (chapter 5) to gather a comprehensive understanding of the clinical needs and preferences of this population. Finally, quality of life among older adults with bipolar mood states and the potential predictors of quality of life in this group were examined to highlight the impact of living with bipolar disorder in later life (chapter 6). This research will therefore help to identify key problems faced by this group, determine their changing priorities and essential care needs and use this knowledge to illuminate potential adaptations to support that can help improve quality of life for older adults with bipolar disorder.

This chapter will provide background information and will acquaint the reader with the key issues experienced by people with bipolar disorder and the unique challenges faced by older adults with this diagnosis. As there is a lack of research surrounding this population, this chapter will begin by outlining issues pertaining to bipolar disorder more generally before focusing on bipolar disorder in later life and the context for the four papers included within this thesis.

1.2 Diagnostic criteria

According to most diagnostic manuals used in Western mental health systems, bipolar disorder is described as a chronic mood disorder involving episodes of elation (mania and hypomania) alongside periods of depressed mood and disruptions to behaviour and thought that substantially impair people's quality of life (American Psychiatric Association, 2013). Mania is a term that refers to euphoric or irritable mood experienced alongside a marked increase in energy that contrasts with a person's usual behaviour and presentation (Miklowitz & Johnson, 2008). Mania is diagnosed when this period of elation lasts for one week or more, and symptoms such as a decreased need for sleep, increased self-esteem or grandiosity, racing thoughts, distractibility or increased risk-taking or poor decision-making are common (Belmaker, 2004). These experiences must also significantly impact the individual's daily life and often result in hospitalisation, although this is not a requirement to meet the criteria for a

manic episode. Hypomania is categorised as experiences of elation that last for four days or more and consist of experiences such as hallucinations, delusions and high energy that may cause functional impairment but are not as severe as mania and do not result in hospitalisation (Grande et al., 2016). Whilst bipolar disorder is often defined by its manic episodes, depressive episodes are regularly reported to be the most debilitating aspect of bipolar disorder (Carvalho et al., 2020). Depressive episodes are characterised as a period of two weeks or longer where a person experiences significantly low mood resulting in a loss of interest in activities that usually provide pleasure (Carvalho et al., 2020). Overall, episodes of mania, hypomania and depression can cause a range of challenges for people diagnosed with bipolar disorder (Keck et al., 2001).

The criteria used by clinicians to diagnose bipolar disorder categorise it into four subgroups based on the course and severity of difficulties experienced (Anderson et al., 2012). These subgroups are bipolar disorder I, bipolar disorder II, cyclothymic disorder and bipolar disorder not otherwise specified. To meet the criteria for bipolar disorder I, people must have experienced one manic episode lasting for one week or longer (Anderson et al., 2012). Although experiences of depression are not required to meet the criteria for bipolar disorder I, people who receive this diagnosis commonly report depressive periods alongside episodes of mania (Grande et al., 2016). Bipolar disorder II requires individuals to have experienced at least one hypomanic episode and one major depressive episode (Müller-Oerlinghausen et al., 2002). Cyclothymic disorder is sometimes diagnosed when people experience both hypomanic and depressive episodes that do not meet the criteria for full episodes for two years or more (Mitchell et al., 2008). Finally, bipolar disorder not otherwise specified refers to experiences where people present with features of bipolar disorder that do not meet criteria for any of the categories described (Mitchell et al., 2008). Whilst cyclothymic and bipolar disorder not otherwise specified experiences do not meet the criteria for full episodes of mania or depression

these may still significantly impact the individual's quality of life and wellbeing (Bauer & Pfennig, 2005). Some people may also experience 'mixed episodes' in which aspects of both mania and depression are evident (Bauer & Pfennig, 2005). This can be particularly debilitating and challenging to cope with and these issues commonly result in one of the bipolar disorder diagnoses described above (McIntyre et al., 2020).

1.2.1 Debates surrounding the bipolar disorder diagnostic criteria

There has been significant debate surrounding the validity, reliability and efficacy of the diagnostic criteria used to label individuals as experiencing bipolar disorder. Whereas for some people receiving a diagnosis of bipolar disorder can offer relief, validation and improve access to treatment, for others, it can leave them feeling powerless and stigmatised and result in a loss of agency (Phillips & Kupfer, 2013). Some authors argue that a diagnosis of bipolar disorder is necessary as it helps to establish common language between professionals that can be used to understand the service user's difficulties and guide more effective treatment (Huda, 2019). In contrast, others suggest that these criteria are too simplistic and lack reliability and validity (Cooke et al., 2010). For example, arguments are made that for a diagnostic category to be deemed reliable, it should provide clear information about what symptoms someone should experience and what potential treatments can be used to alleviate those symptoms (Angst, 2007). However, with bipolar disorder, this is often not the case, as there is considerable overlap with other labels such as schizophrenia (Smith et al., 2017). 23-31% of people who receive a diagnosis of bipolar also experience auditory hallucinations and 82% experience delusional beliefs, both of which are symptoms synonymous with the schizophrenia diagnosis (Smith et al., 2017). Further overlap is reported in the literature, with 56% of people with bipolar disorder also meeting the criteria for substance misuse disorders, 21% for obsessive-compulsive disorder, up to 50% for personality disorders and 92% experiencing symptoms consistent with anxiety disorder criteria (Krishnan, 2005).

1.2.2 Dimensional and continuum approaches

A key issue for some people is that the use of medical terms such as 'diagnosis' and 'episodes' of mania and depression indicate that bipolar disorder is a discrete disorder that can be clearly distinguished from 'normal' aspects of human lives (Cooke et al., 2010). This also suggests that the different episodes (mania, hypomania, depressed, mixed) can be distinguished from 'normal' mood that people experience (Mansell et al., 2007). However, literature highlights that both depressive and hypomanic traits are commonly observed within the general population (Cooke et al., 2010). This has led some authors to question whether it is more helpful to view disruptions to people's mood on a continuum that ranges from healthy wellbeing to serious difficulties that significantly impair one's quality of life (Moller, 2003). This explanation of mood instability identifies that someone's affect may fluctuate along this continuum depending on environmental factors such as the individual's life circumstances, coping strategies and personality style and proposes that experiencing elevated or depressed mood is understandable following challenging events (Phillips & Kupfer, 2013).

According to Boyle & Johnstone (2014), experiences consistent with bipolar disorder should be viewed on a continuum as it allows for effective assessment and treatment that focuses on building a coherent understanding of people's difficulties in collaboration with the service user. Whilst this may still lead to a diagnosis of bipolar disorder which is valued by some, the continuum approach considers the psychological and environmental factors that contribute to symptoms and uses this knowledge to drive intervention (Jones & Bentall, 2007). The idea of viewing these experiences on a continuum rather than diagnosing someone as being completely unable to regulate their mood has been found to normalise mood instability, reduce stigma and facilitate person-centred, compassionate ways to formulate distress and provide effective treatment (Cooke et al., 2010). Despite this, the argument surrounding the best way to understand experiences of bipolar disorder is still ongoing within psychological and

psychiatric literature (Boyle & Johnstone, 2014). However, The National Institute of Health and Care Research (NICE, 2014) recommend that treatment decisions should always be based on the preferences and priorities of the service user to ensure that appropriate treatment is offered.

1.3 Aetiology and risk factors

There has been strong debate surrounding what causes the difficulties associated with bipolar disorder (Furnham & Anthony, 2010). Whilst no definitive aetiology has been established, there is a general consensus that a range of factors interact to cause the challenges observed among people with this diagnosis (Anderson et al., 2012). In particular, research has highlighted the influence of biological, psychological and social factors (Bender & Alloy, 2011).

1.3.1 Biological risk factors

For many years, biological explanations were used to understand the expression of bipolar disorder symptoms (Kujawa & Nemeroff, 2000). Research suggests that genetic components are more influential in the expression of bipolar disorder than any other mental health diagnosis (Craddock & Jones, 1999). To support this argument, authors refer to the wealth of family studies indicating that the risk of being diagnosed with bipolar disorder is 5-10% higher for those who have a family member with this diagnosis (Craddock & Sklar, 2013). Furthermore, twin studies highlight that bipolar disorder is more concordant in monozygotic twins, at around 40-70% (who are genetically identical) as opposed to 4.5%-5.6% of dizygotic twins (who share approximately half their genes). This suggests that genetic factors appear to play a role in increasing susceptibility to bipolar disorder (Barnett & Smoller, 2009). However, the fact that studies exploring monozygotic twins do not find 100% concordance rates implies that genetic components alone are insufficient to understand the causes of bipolar disorder (Marneros &

Angst, 2007). Bentall (2003) urges caution when interpreting twin studies, arguing that being a twin is already associated with slightly abnormal development and issues such as increased risk of congenital difficulties and delays in reaching developmental milestones are common. Bentall (2003) adds that it is unclear if such problems are linked to bipolar disorder specifically but findings such as this have the potential to skew the results of twin studies, meaning further research is required. This view is supported by researchers still being unable to establish a single gene that can account for the expression of bipolar disorder despite a wealth of research in this area (Barrett & Smoller, 2009). Consequently, it appears that other factors may also contribute to the development of bipolar disorder.

1.3.2 Psychological risk factors

There has been a growing interest in understanding psychological factors that can contribute to the risk of developing bipolar disorder (Alloy et al., 2005). A particular area of interest has been surrounding the association between cognitive styles and mood instability observed in bipolar disorder (Jones et al., 2005). Jones and colleagues (2005) found that individuals with bipolar disorder experienced lower self-esteem, more negative perceptions of themselves, greater need for achievement, and greater dependency on others compared to healthy matched controls. These findings are supported by Alloy and colleagues (2005) who reported that people with bipolar disorder often display high levels of perfectionism, striving, and self-criticism in comparison to individuals experiencing unipolar depression and healthy controls. These negative, self-critical cognitive styles are believed to be linked to maladaptive coping mechanisms such as rumination, which is thought to be associated to both depressive and manic mood states observed in bipolar disorder (McKinnon et al., 2013). Rumination is considered an unhelpful coping mechanism as it results in a passive fixation on negative or positive thoughts without taking necessary, positive actions that aim to resolve the issue (Gruber et al., 2011). Dodd and colleagues (2019) identified that rumination was elevated among those with

bipolar disorder in comparison to controls and found that this led to increased mood instability and poor outcomes in this group (Gruber et al., 2011). Furthermore, coping styles among individuals with bipolar disorder are found to be more passive and more avoidant than individuals from the general population or with other psychiatric diagnoses, which may explain this group's poor engagement with services and high rates of relapse (Goossens & van Achterberg, 2008). Whilst this research is important, a number of authors highlight that research surrounding coping styles is limited due to the heterogeneity of methods used and lack of valid and reliable emotional regulation assessments (Dodd et al., 2019).

Mansell and colleagues (2007) outline a cognitive model of mood swings that describes why mood instability is maintained for people with bipolar disorder. This model suggests that peoples attempts to manage extreme mood instability are disrupted by their conflicting and extreme personal appraisals that they give to their internal states. Mansell and colleagues state that this can then lead to exaggerated efforts to control internal states which increases stress and leads to further affective instability. This then maintains an unhelpful cycle that exacerbates symptoms and leads to prolonged affective difficulties. Furthermore, people's specific beliefs about affective states, the self and others lead to interactions that increase people's vulnerability to relapse (Mansell et al., 2007). Consequently, psychological treatments that aim to address unhelpful cognitive appraisals of how to regulate affect are recommended for people with bipolar disorder according to this model (Mansell et al., 2007).

1.3.3 Social and environmental risk factors

A range of social and environmental risk factors have been found to increase the likelihood of difficulties associated with bipolar disorder (Miklowitz & Johnson, 2009). For example, several studies have found significant associations between having a history of childhood maltreatment and abuse and the development of bipolar disorder symptoms as adults (Rowland & Marwaha, 2018). Childhood emotional abuse has been found to be the most common form

of maltreatment among individuals with bipolar disorder (Manoli et al., 2023; Palmier-Claus et al., 2016). However, experiences such as childhood sexual and physical abuse are up to four times more prevalent in people diagnosed with bipolar disorder in comparison to the general population (Rowland & Marwaha). Childhood maltreatment has also been linked to significantly poorer clinical outcomes, increased mood episodes and a higher risk of suicide and substance misuse, highlighting it as an important risk factor for bipolar disorder (Daruy-Filho et al., 2011). Despite this, research has failed to establish why childhood maltreatment puts people at such an increased risk of developing bipolar disorder (Agnew-Blais & Danese, 2016). Some authors have suggested that childhood maltreatment can result in disruptions in the hypothalamic pituitary adrenal (HPA) axis, dysregulated cortisol levels and hypothyroidism which all make it more challenging to regulate one's mood, thus increasing the risk of mood instability (Manoli et al., 2023). Other authors argue that increased childhood maltreatment may be a consequence of a higher prevalence of psychological difficulties in parental figures among people with bipolar disorder, suggesting an interaction between genetic and environmental factors (Fisher & Hosang, 2010). Consequently, further research is needed to clarify this association.

1.3.4 The biopsychosocial model of bipolar disorder

The failure to identify one causal factor that explains the aetiology of bipolar disorder has led to the development of models that attempt to highlight the importance of interactions between biological, psychological and social factors in bipolar disorder (Bombaci, 2015). The biopsychosocial model of bipolar disorder acknowledges that while certain biological factors contribute to an increased susceptibility to bipolar disorder, there is now compelling evidence that psychological factors (e.g., negative cognitive styles) and social factors (e.g., unsupportive interpersonal relationships and stressful life events) play a vital role in the expression of these genetic vulnerabilities (Mansell et al., 2008). This explanation has been reported to be

especially robust for the prediction of depressive symptoms but also appears to predict manic symptoms (Mansell et al., 2008). Therefore, research now highlights the complexity of bipolar disorder which has led to changes in the way many clinicians attempt to understand and treat people living with this diagnosis (Sagman & Tohen, 2012; Cooke et al., 2010).

1.4 Prevalence and impact bipolar disorder

Bipolar disorder is believed to affect approximately 1% of the world's population, although some studies estimate that features of bipolar disorder such as mania affect up to 7.5% of young adults (Grande et al., 2016; Jansen et al., 2011). However, there is variability in prevalence rates within different countries (McIntyre et al., 2020). For example, prevalence rates range from 0.1-1.8% in Nigeria and Ethiopia, up to 3-4% in South Africa, and 5% in the United States of America when subthreshold bipolar disorder diagnoses such as cyclothymic disorder are considered (McIntyre et al., 2020; Grant et al., 2005). Some authors suggest that this number could be substantially higher as certain subgroups of bipolar disorder, specifically bipolar II, are often underdiagnosed (Angst, 2006). Fagiolini and colleagues (2013) report that 30-40% of people presenting with difficulties associated with bipolar disorder are initially diagnosed with unipolar depression as symptoms of hypomania are often missed or underreported. This is further complicated by the overlap between bipolar disorder symptoms and symptoms of other psychiatric diagnoses as reported earlier (Angst et al., 2003). This is highlighted by Scott & Leboyer's (2011) research indicating that over 60% of people diagnosed with bipolar disorder experience 1-4 other diagnoses before being given a bipolar disorder diagnosis. Consequently, the prevalence of people living with bipolar disorder may be much higher than is currently estimated within existing literature (Ketter, 2010).

A prominent issue for people experiencing bipolar disorder is that challenges surrounding diagnosis can lead to them experiencing symptoms such as hypomania for up to 10 years before a diagnosis is reached and treatment can commence (Angst et al., 2003). This

can cause high levels of stress as well as inappropriate and ineffective treatments which contribute to the poor outcomes observed in those living with symptoms of bipolar disorder (Scott & Leboyer, 2011). There are a number of potential reasons for this delay, such as questionable reliability and validity of assessments and people's reluctance to seek help as some aspects of bipolar disorder (hypomania) can lead to increased productivity (Lobban et al., 2012). However, the inability to efficiently identify and treat bipolar disorder is thought to contribute to increased mood episodes, worse quality of life and an increased risk of suicide in this group (Grande et al., 2016). Additionally, failures to effectively support people with bipolar disorder is estimated to have a substantial cost to the economy, with some suggesting that it costs the British economy £340 million annually (Young et al., 2011) whereas Scott & Leboyer (2011) estimate that unrecognised bipolar disorder can cost the individual nearly $1700-2300 more each year than those who have a confirmed diagnosis of bipolar disorder. As a result, the impact of bipolar disorder is significant for the individual, society and the economy, meaning improved support is needed for this group (Sajatovic, 2005).

1.5 The course of bipolar disorder

Bipolar disorder is often considered a lifelong problem that affects people across the lifespan and into later life (Suppes et al., 2000). This assertion is supported by a 40-year follow up study reporting only 16% of people diagnosed with bipolar disorder were considered to have recovered (complete symptom remission for five years), whereas 50% of this cohort were still experiencing frequent mood episodes (Angst, 1980). In particular, depressive episodes appear to last for longer time periods, with the mean duration of depressive episodes believed to be around 11 weeks, whereas manic episodes last on average for 6 weeks (Saunders & Goodwin, 2010).

1.5.1 Factors influencing the course of bipolar disorder

Certain factors are believed to affect the course and severity of bipolar disorder symptoms (Ellicott et al., 2019). Age of bipolar disorder onset has been explored within the literature and several studies have suggested those with early onset bipolar disorder experience different challenges compared to those with late onset (Carter et al., 2003). Definitions of early and late onset differ within the literature (Carter et al., 2003). However, one study that defined early onset as before 18 years of age and late onset as after 40 years of age, found that those with early onset bipolar disorder experienced more severe symptoms, greater psychiatric comorbidity, more mixed episodes and poorer response to medication (Schurhoff et al., 2000). Other authors have supported this by reporting that earlier onset bipolar disorder is associated with poorer outcomes and prolonged course (Coryell et al., 2013). For example, Coryell and colleagues (2013) found that earlier onset was linked to significantly longer depressive episodes, whereas other studies have reported that early onset bipolar disorder results in greater cognitive impairment in later life (Tsai et al., 2007), increased substance abuse (Ernst & Goldberg, 2004) and longer delays to treatment that result in poorer outcomes (Leverich et al., 2007).

An essential factor believed to influence the course and severity of bipolar disorder is a history of trauma and negative life events (Ellicott et al., 2019). These have been linked to a greater risk of rapid cycling, a higher number of lifetime episodes, increased suicidal ideation and attempts as well as more psychotic features (Ellicott et al., 2019). Stressful life events have also been linked to an earlier age of onset and disruptions to sleep that may exacerbate mood instability (Aldinger & Schulze, 2017). Importantly, positive social support has been shown to influence the course of bipolar disorder and reduce the risk of relapse leading to a less severe course (Studart-Botto et al., 2022). This is highlighted by Johnson and colleagues' (2003) findings that having a supportive partner at bipolar onset reduces the course of illness and

specifically impacts remission between episodes. However, bipolar disorder has been found to result in lower levels of social support, increased isolation and stigma which all exacerbate the course and severity of symptoms for many (Aldinger & Schulze, 2017). Therefore, treating bipolar disorder is complex and a range of factors must be considered when working with this group (Goodwin, 2003).

<u>1.5.2 Recovery from bipolar disorder</u>

Recovery from bipolar disorder has generally been defined as relapse prevention and complete symptom reduction (Goldberg et al., 2005). Due to the complex and persistent nature of bipolar disorder, recovery based on this definition is difficult to achieve, leading many to believe that bipolar disorder is a lifelong illness where complete recovery is rare (Grande et al., 2016). More recently, authors have suggested that the way we define recovery needs to be considered (Jagfeld et al., 2021). The concept of recovery has been expanded and now considers definitions such as syndromal recovery, functional recovery and improved quality of life (Harvey, 2006). According to van der Voort and colleagues (2015) syndromal recovery means that the individual no longer meets the Diagnostic and Statistical Manual of Mental Disorders (DSM) or International Classification of Diseases (ICD) criteria for bipolar disorder for a period of 8-weeks or more. This definition does allow for some symptoms of mood instability but symptoms must not be above mild severity (van der Voort et al., 2015). Functional recovery is defined by the individual's ability to develop and maintain interpersonal relationships, maintain occupational functioning and actively engage in rehabilitation with services (Wingo et al., 2010). Finally, enhancing quality of life for people with bipolar disorder generally involves attempting to reduce residual symptoms such as depression which may reduce their engagement with interventions and impact outcomes (Harvey, 2006).

People with bipolar disorder often state that they are dissatisfied with pre-existing definitions and aims of recovery (Jones et al., 2013). Instead, many individuals with bipolar

disorder desire treatments that aim to meet their own personal recovery outcomes that prioritise their values and goals (Jones et al., 2012). According to Todd and colleagues (2012), this definition allows individuals with bipolar disorder to take control of their difficulties, guide their treatment and move towards their personal definition of recovery. This approach requires professionals to change their role from 'looking after people' to becoming 'holders of hope' where they allow people with bipolar disorder to guide the direction and pace of treatment, using their expert patient position to determine their goals for recovery (Todd et al., 2012). Using this self-management approach has been endorsed by service users with bipolar disorder and is suggested to be a beneficial way to enable people to move towards recovery, manage difficulties more effectively and remove barriers to seeking treatment (Todd et al., 2012). Consequently, the way recovery is defined is vital in providing hope for individuals with bipolar disorder and this should be carefully considered before deciding which treatments are offered to service users (Dodd et al., 2017).

1.6 Treatments for bipolar disorder

Most treatments for bipolar disorder have traditionally aimed to reduce mood instability and move individuals to euthymic (stable) mood (Geddes & Miklowitz, 2013). Following this, treatments then focus on reducing the risk of relapse, reducing subthreshold symptoms and improving the individual's occupational and social functioning (Geddes & Miklowitz, 2013). Generally, the most common treatments offered have been pharmacological such as mood-stabilising medication aiming to reduce episodes of mania, hypomania and depression (Sachs et al., 2000). More recently, the National Institute for Health and Care Excellence (NICE, 2014) recommend offering both pharmacological and psychological treatments to support individuals with bipolar disorder. This section will discuss treatment options for bipolar disorder in more depth.

1.6.1 Pharmacological treatments

Pharmacological treatments generally involve using medication that aims to target and reduce manic symptoms, depression and mixed episodes (Bowden, 2002). These treatments are used to move the service user towards stability when experiencing an acute episode, maintain stability and reduce the risk of relapse by minimising symptoms between episodes (Keck & McElroy, 1998). Mood stabilisers that aim to prevent mood instability without increasing the risk of episodes of the opposite polarity are the most common pharmacological treatment for bipolar disorder (López-Muñoz et al., 2018). Research indicates that effective mood stabilisers affect serotonin and dopamine levels and the pathways that send chemical signals from postsynaptic receptors to the cell nucleus, therefore reducing mood disturbances (López-Muñoz et al., 2018). Different medications are typically used to treat manic and depressive symptoms (Hirschowitz et al., 2010).

1.6.2 Treating mania

For several years, lithium has been viewed as the gold standard drug treatment for manic symptoms due to the extensive research and empirical evidence surrounding it (Geddes & Miklowitz, 2013). A number of studies indicate that lithium is an effective treatment for mania, with trials suggesting that up to 70% of lithium users experience recovery from mania (Geddes & Miklowitz, 2013). However, side effects such as weight gain and renal issues have led to the introduction of new medication (Carvalho et al., 2020). Anticonvulsants such as carbamazepine and divalproex sodium have been shown to be as effective as lithium in stabilising mania, although the use of carbamazepine is limited due to side effects such as neurotoxicity and the long-term efficacy of Divalproex is inconclusive (Miklowitz & Johnson, 2006). Antipsychotic medication is also commonly used to treat mania and has been found to show some promising results (Berk & Dodd, 2005). However, the majority of antipsychotic medications have also been linked to substantial weight gain and increased sedation, amongst other side effects,

meaning their use has to be considered carefully and in collaboration with the service user, carefully weighing up the pros and cons of the different choices (Derry & Moore, 2007).

1.6.3 Treating depression

To treat symptoms of depression, pharmacological treatments usually involve using antidepressant medications (Geddes & Miklowitz, 2013). Several studies indicate that antidepressants are effective in reducing the risk of depressive episodes, but suggest there is an increased risk of mood cycling when they are not used alongside other mood-stabilising medication (Fountoulakis et al., 2005). Consequently, most guidelines only recommend antidepressant medication for bipolar disorder when used alongside other mood-stabilising medications such as those listed above (McIntyre et al., 2020). Overall, whilst pharmacological treatments appear to be effective in reducing mood instability and the risk of relapse, they appear to present a number of risks and side effects that often result in low acceptability for service users (Belmaker, 2004). Research highlights that up to 60% of people with bipolar disorder are either partially or fully non-adherent with medication and this has been linked to poor clinical outcomes and high costs to the economy (Chakrabarti, 2016). As a result, alternative treatments are now commonly recommended to people experiencing bipolar disorder (Clatworthy et al., 2009).

1.6.4 Psychosocial interventions

1.6.5 Cognitive behavioural therapy

Cognitive behavioural therapy alongside pharmacological treatments is now recommended by the National Institute for Health and Care Excellence (NICE, 2014). Cognitive behavioural therapy works on the premise that mood instability is influenced by negative thinking styles caused by difficult life events and dysfunctional core beliefs (Scott et al., 2006). The aim of cognitive behavioural therapy is to support individuals to assess the evidence for these negative

beliefs and to enable them to develop more positive thinking styles and more effective coping strategies (Scott et al., 2006; Mansell et al., 2007).

A number of studies have assessed the efficacy of cognitive behavioural therapy as a treatment for bipolar disorder (Basco & Rush, 2005). For example, a randomised controlled trial found that receiving 12-14 sessions of cognitive behavioural therapy was associated with fewer depressive episodes and improved functioning in people with bipolar disorder (Kessing et al., 2013). Lam (2005) also reported that cognitive behavioural therapy alongside pharmacological treatment resulted in reduced relapse rates of 44% compared to 75% for people who received pharmacotherapy alone. A systematic review and meta-analysis by Oud and colleagues (2016) found that cognitive behavioural therapy reduced the risk of relapse for people with bipolar disorder but identified that much of the existing literature surrounding the efficacy of cognitive behavioural therapy for bipolar disorder was low in quality. A trial examining recovery focused cognitive behavioural therapy that aims to work towards the service user's personal recovery outcomes has also been found to be acceptable, feasible and clinically effective (Jones et al., 2015). However, whilst literature suggests cognitive behavioural therapy can be an essential and effective treatment for people with bipolar disorder, some studies do report no significant improvements (Scott et al., 2006), and others report that cognitive behavioural therapy is less cost-effective than other psychological treatments such as group psychoeducation (Parikh et al., 2012).

1.6.6 Psychoeducation

Psychoeducation is a core aspect of many psychosocial approaches to treating bipolar disorder (Smith et al., 2010). The main aim of psychoeducation is to support people with bipolar disorder to improve their understanding and awareness of their difficulties and use this to develop coping strategies that reduce the risk of relapse (Smith et al., 2010). Psychoeducation can also help improve resilience, improve medication adherence and reduce unhelpful coping

mechanisms such as drug abuse that result in substantially poorer outcomes (Rabelo et al., 2021). Psychoeducation is often delivered in several different formats, including individual and group psychoeducation and also psychoeducation with families (Rabelo et al., 2021).

Group psychoeducation is the most well-researched form of psychoeducation, and literature suggests that this approach can help to improve outcomes for people with bipolar disorder when used alongside pharmacotherapy (Colom & Vieta, 2006). A trial completed by Colom and colleagues (2003) randomly assigned service users with bipolar disorder to 21 sessions of structured group psychoeducation with adjunct pharmacotherapy or 21 sessions of an unstructured support group. After five years, those assigned to the psychoeducation group reported fewer relapses, less severe symptoms and less time in hospital. Individual psychoeducation has received less attention within existing literature (Colom et al., 2003). However, another randomised controlled trial by Morris and colleagues (2016) reported that group psychoeducation was not more clinically effective than an unstructured support group but it was found to improve outcomes for individuals who had experienced fewer bipolar disorder episodes. Additionally, one study has found that 7-12 sessions of individual psychoeducation alongside medication resulted in up to 30% fewer manic relapses and improved social functioning (Perry et al., 1999). Consequently, psychoeducation appears to be a valuable intervention for people experiencing bipolar disorder (Rabelo et al., 2021).

1.6.7 Family-focused therapy

Interventions that involve the family of people with bipolar disorder are essential as research indicates that familial stressors can exacerbate symptoms, whereas familial support is linked to improved outcomes (Miklowitz & Chung, 2016). Bipolar disorder has also been found to have a substantial effect on not only the service user but also relatives who often neglect their own needs to become the main caregiver (Geddes & Miklowitz, 2013). Family members also report living in fear of relapse, experiencing painful emotions and state that being thrust into the role

of carer for people with bipolar disorder can be distressing, exhausting and impact their own mental health (Speirs et al., 2023). Consequently, their ability to provide continuous support for family members living with bipolar disorder is reduced which results in worse clinical outcomes for the service user (Pompili et al., 2014). Despite this, family members often report not receiving enough information and advice about bipolar disorder (Miklowitz & Chung, 2016). Family-focused interventions attempt to provide psychoeducation to family members, communication skills training and problem-solving skills training (Rea et al., 2003). This has been found to enable family members to provide improved support to the individual with bipolar disorder which can enhance their ability to cope and maintain improved relationships (Rea et al., 2003).

Research indicates that family therapy can be an effective adjunctive treatment and highlights the importance of involving family and caregivers in the treatment of people with bipolar disorder (Miklowitz, 2007). Miklowitz and colleagues (2000) found that service users with bipolar disorder who received family-focused therapy alongside medication experienced reduced relapse, increased time between relapses, and improved medication adherence and these benefits were observed at two-year follow-up compared to those receiving crisis management. Educating caregivers has also been found to improve outcomes, even when the service user with bipolar disorder does not attend these educational sessions (Perlick et al., 2010). In a randomised controlled trial, 'recovered' service users with bipolar disorder whose relatives attended psychoeducation sessions showed reduced depressive symptoms and longer intervals between episodes (Reinares et al., 2008). However, whilst family therapy does appear to be an important and useful adjunctive treatment, some service users with bipolar disorder might be reluctant to engage depending on familial structure, cultural preferences and their relationships with family members (Geddes & Miklowitz, 2013). Furthermore, it is possible that families that engaged with these educational sessions may already be more supportive and

willing to engage in treatment (Rea et al., 2003). Research surrounding the efficacy of family-focused therapy also remains limited and randomised controlled trials that control for confounding variables are needed to determine its effectiveness for treating bipolar disorder (NICE, 2014).

1.6.8 Interpersonal and social rhythm therapy

A wealth of literature has suggested that mood episodes observed in bipolar disorder are influenced by changes to people's circadian rhythms and that mood instability is directly linked to sleep disturbances (Takaesu, 2018). As a result, interpersonal and social rhythm therapy was developed by Frank and colleagues (2000). This treatment aims to use a problem-solving approach to support people with bipolar disorder to manage stressors whilst encouraging them to consistently maintain routines that promote healthy sleep and wake rhythms (Steardo et al., 2020). A randomised controlled trial completed by Frank and colleagues (2005) assigned 175 people with bipolar disorder to interpersonal and social rhythm therapy each week or intensive clinical management and medication. After two-year follow-up, people who received interpersonal and social rhythm therapy showed longer times to relapse and improved vocational functioning compared to the control group (Frank et al., 2005). A second randomised controlled trial also reported positive outcomes for interpersonal and social rhythm therapy when combined with family-focused therapy (Miklowitz et al., 2003). Compared to service users who received medication, two sessions of family psychoeducation and crisis management, the group who received family-focused therapy alongside interpersonal and social rhythm therapy reported fewer depressive symptoms and increased time between episodes (Miklowitz et al., 2003). However, a recent systematic review reported that there was no high-quality evidence indicating that there are significantly improved outcomes as a result of interpersonal and social rhythm therapy for people with bipolar disorder (Oud et al., 2016). Consequently, further investigation is required to determine the efficacy of this treatment.

<u>1.6.9 Overview of treatment issues</u>

Overall, pharmacological approaches have been most commonly used for treating bipolar disorder, although evidence suggests that combining this approach with psychosocial treatments such as those discussed can be most beneficial (Geddes & Miklowitz, 2013). Whilst several authors indicate the efficacy of pharmacological interventions, there remain concerns about the potential side effects of using medication to treat bipolar disorder (Derry & Moore, 2007). Furthermore, research into the long-term impact of mood stabilising medication use is limited, meaning our understanding of how this affects people in later life is insufficient (Depp & Jeste, 2004). The next section explores the challenges faced when ageing with bipolar disorder and highlights why it is important to consider older adults, who are often neglected within existing literature (Sajatovic et al., 2015).

1.7 Ageing with bipolar disorder

The majority of the existing literature focuses on populations within the adult age range (18-60 years; Sajatovic et al., 2015). However, very little research explores the experiences and challenges faced by older adults with bipolar disorder (aged 60+; Depp & Jeste, 2004). This is important, as figures suggest that up to 25% of people diagnosed with bipolar disorder are older adults and this number could rise to approximately 50% as the population continues to live longer (Dols et al., 2016). Furthermore, research highlights that older adults with bipolar disorder experience different cognitive, clinical, and psychosocial challenges compared to young and middle-aged individuals (Sajatovic et al., 2015). These challenges are also believed to be associated with a high risk of suicide among older adults with bipolar disorder in comparison to older adults with other mental health diagnoses (O'Rourke et al., 2017). Consequently, more research is needed to identify what support is necessary to reduce the poor outcomes and life satisfaction observed in this group.

1.7.1 Clinical features of older age bipolar disorder

Older adults with bipolar disorder experience different challenges to younger age groups and this requires attention (Tyler et al., 2022). Research suggests that bipolar disorder in older adults is characterised by more prolonged periods of depression, but less frequent and intense manic episodes compared to younger age groups with bipolar disorder (Shobassy, 2021; Nivoli et al., 2014). Similar to younger adults, medication non-adherence and alcohol misuse are significant predictors of suicidal ideation among older adults with bipolar disorder (O'Rourke et al., 2017). However, self-perceived cognitive failures also predicted suicidal ideation among older adults with bipolar disorder, suggesting this group may experience different clinical features to younger age groups (O'Rourke et al., 2017). Finally, older adults with bipolar disorder are also found to experience poorer quality of life, reduced wellbeing and worse functioning than healthy older adult controls, even during clinical remission (Depp et al., 2006). Therefore, the unique clinical features experienced by older adults with bipolar disorder appear to warrant increased attention.

1.7.2 Cognitive decline and dementia

The potential association between bipolar disorder in later life and increased cognitive difficulties has been investigated by numerous studies (Gildengers et al., 2012). For example, Gildengers and colleagues (2009) found that older adults with bipolar disorder experienced significantly worse cognitive dysfunction and accelerated cognitive decline compared to healthy controls. These findings are supported by Silva and colleagues (2009) who compared cognitive functioning in older adults with bipolar disorder to service users with mild cognitive impairment. This study reported that the group of older adults with bipolar disorder had increased deficits in motor initiative, verbal abstraction, attention and calculation and suggested that bipolar disorder may be linked to unique cognitive impairments (Silva et al., 2009). The specific mechanisms leading to increased and accelerated cognitive decline in older adults with

bipolar disorder are not yet understood (Schouws et al., 2016). However, Gildengers and colleagues (2009) suggest that genetic abnormalities, combined with repeated mood episodes throughout the lifespan, factors associated with ageing, increased risk of substance abuse and physical health problems interact to accelerate cognitive decline in older adults with bipolar disorder.

Living with the challenges associated with bipolar disorder has been linked to a risk of reduced brain reserve and cognitive deterioration that increases the likelihood of older adults with bipolar disorder developing neurocognitive disorders such as dementia (Shobassy, 2021). A study completed by Nunes and colleagues (2007) highlighted this, reporting that 19% of older adults with bipolar disorder had dementia compared to 7% of age-matched controls. These findings have been replicated by Almeida and colleagues (2016) who found that older adults with bipolar disorder were at increased risk of developing dementia in later life compared to healthy controls. Kessing and Andersen (2004) also identified that each affective episode leading to an inpatient admission increases the risk of dementia in later life by 6% for people with bipolar disorder. Consequently, this highlights the cognitive impact of living with bipolar disorder throughout the lifespan and the challenges faced by older adults with this diagnosis.

1.7.3 Psychiatric and physical comorbidity

Living with bipolar disorder is linked to high levels of physical health and psychiatric comorbidity in adult populations, and research suggests that these issues may also be problematic in older adults with bipolar disorder (Lala & Sajatovic, 2012). In terms of psychiatric comorbidities, the research surrounding older adults with bipolar disorder is mixed (Sajatovic et al., 2006). Goldstein and colleagues (2006) completed a study indicating that older adults with bipolar disorder experience significantly higher rates of psychiatric comorbidities compared to age-matched controls without bipolar disorder. In particular, the prevalence rates of generalised anxiety disorder (20.5% vs 2.5%), alcohol use disorder (38.1% vs 14.4%) and

panic disorder (19% vs 2.5%) were elevated in older adults with bipolar disorder (Goldstein and colleagues, 2006). The most common psychiatric comorbidities observed in older adults with bipolar disorder are often reported to be anxiety disorders and substance misuse disorders (Lala & Sajatovic, 2012; Sajatovic et al., 2006; Dols et al., 2014). However, a common theme within the literature is that older adults with bipolar disorder experience less psychiatric comorbidity than younger age groups with bipolar disorder (Lala & Sajatovic, 2006). Consequently, findings suggest that psychiatric comorbidity is common among older adults with bipolar disorder but less severe than in younger age groups, again highlighting differences in clinical features between younger and older adults with this diagnosis.

Bipolar disorder has long been associated with increased physical health problems such as increased risk of cardiovascular disease, renal disease and obesity (Depp & Jeste, 2004). However, much of the research surrounding links between bipolar disorder and physical health comorbidities has been completed on younger populations (Forty et al., 2014). Authors have suggested that the side effects associated with the long-term use of mood-stabilising medication and chaotic lifestyles observed in bipolar disorder may increase the risk of physical health comorbidities in later life (Sajatovic et al., 2015). The limited available literature supports this; Lala and Sajatovic (2012) found that older adults with bipolar disorder experience a higher prevalence of cardiovascular disease, diabetes, and respiratory and endocrine conditions compared to younger populations with bipolar disorder. Older adults with bipolar disorder have also been found to experience high rates of hypertension (27.8%), arthrosis (29.1%) and peripheral atherosclerotic disease (18.8%), leading to increased medication use and polypharmacy (31.7% on six or more medications) (Dols et al., 2014). However, due to the lack of high-quality research that included healthy control groups and failures to control for key confounding variables, it is difficult to determine whether elevated physical health comorbidities in older adults with bipolar disorder are caused by disorder specific factors or

other confounding variables. Furthermore, very few reviews have summarised the prevalence of physical health comorbidities in this group. Consequently, this warrants further investigation and is the focus of Chapter 3 of this thesis.

1.7.4 Differences between older adults with early vs. late onset bipolar disorder

Literature suggests that age of bipolar onset may affect the course and severity of symptoms in adult populations (Depp et al., 2004). However, research surrounding the impact of age of bipolar disorder onset in older age groups is limited and findings are often mixed (Oostervink et al., 2009). For example, Oostervink and colleagues (2009) state that older adults (aged > 60 years) with early onset bipolar disorder (onset <50 years of age) are more at risk of experiencing rapid cycling but report experiencing fewer suicide attempts compared to those with late onset bipolar disorder (onset aged 50+). Oostervink and colleagues also found that older adults with late onset bipolar disorder recovered faster and were discharged from hospital earlier than early onset groups. One study reported that psychotic features were more prevalent in older adults with late onset bipolar disorder (Wylie et al., 1999), although Schürhoff and colleagues (2000) reported that early onset resulted in higher psychotic features, highlighting the mixed results from studies exploring this topic. Additionally, Chu and colleagues (2010) found that whilst older adults with early onset bipolar disorder (onset aged < 40 years) experienced a higher percentage of days depressed than those with late onset (onset aged 40+), these differences were minimal. Because of this, Chu and colleagues report that categorising older adults with bipolar disorder by early onset or late onset has very limited clinical use. Similar results were highlighted by Depp and colleagues (2004) who reported that there was no evidence that early onset or late onset bipolar disorder should be considered distinct syndromes, although their findings were limited by having a small sample size and cross-sectional design. Overall, literature surrounding the impact of age of onset on older adults with bipolar disorder is mixed

and sometimes contradictory. Further investigations using larger sample sizes and controlling for key covariates would help to understand this link.

1.8 Treatments for older adults with bipolar disorder

The unique challenges faced by older adults with bipolar disorder imply that the care they receive should be adapted to meet their changing needs (Sajatovic et al., 2015). However, Dols and colleagues (2016) highlight that there are currently no specific recommendations for this group and The National Institute for Care and Excellence (NICE, 2014) still recommends the same treatments as those offered to younger age groups with bipolar disorder. This can pose new challenges, as alongside the different clinical presentation, increased physical health comorbidities and accelerated cognitive decline, older adults with bipolar disorder also experience an increased risk of isolation as well as being less satisfied with the social support they receive (Beyer et al., 2003). Some studies have also identified that this group face additional stressors such as financial concerns following retirement and changes in housing and familial structures which can lead to an increased risk of mood instability (Sajatovic et al., 2012). Additionally, older adults with bipolar disorder have been found to have more passive coping styles and attempt to cope independently rather than attempting to engage with services (Tyler et al., 2021). Consequently, older adults with bipolar disorder are at risk of being neglected by services and potentially receive care that fails to meet their changing care needs in later life (Dautzenberg et al., 2016).

1.8.1 Pharmacological interventions

There are significant gaps in our knowledge surrounding treatments for older adults with bipolar disorder (Tyler et al., 2021). However, Sajatovic (2002) suggests that treating this group is complicated by factors such as increased physical health problems and side effects of medication that can exacerbate these issues. An example of this is lithium, which as mentioned

previously, is widely used among younger adults with bipolar disorder (Licht, 2012). However, lithium pharmacokinetics are drastically altered by ageing and renal clearance in older adults is reduced by up to 30-60% compared to younger individuals (Sajatovic, 2002). These issues are believed to result in side effects such as renal disease, weight gain, mental slowing, tremor, urinary frequency and ataxia in older adults who use lithium, potentially limiting its efficacy in this group (Janssen, 2000). Antipsychotics are also common when treating younger adults with bipolar disorder but are not recommended for older adults due to an increased risk of movement disorder among older individuals (Bhalerao et al., 2012). Consequently, due to the increased risk of adverse side effects and polypharmacy in older adults with bipolar disorder, caution must be taken when prescribing pharmacological therapies in this group (Vasudev et al., 2018).

1.8.2 Psychosocial interventions

While there is evidence highlighting the efficacy of psychosocial interventions for younger adults with bipolar disorder (aged < 60), there is only a very limited evidence base concerning older adults with bipolar disorder (Tyler et al., 2021). Furthermore, examining the effects of psychosocial interventions is made more complicated by the variation in cognitive ability, physical health challenges, and psychological processes observed in older adults with bipolar disorder (Sajatovic, 2002). Recent evidence suggests psychosocial interventions that support older adults with severe mental illnesses to accept the challenges they face, maintain physical and mental fitness and establish meaningful emotional connections may be valued over simply focusing on symptom eradication (Smart et al., 2021). A recent pilot randomised controlled trial found that psychosocial interventions that are recovery-focused and prioritise building strength and resilience alongside supporting older adults with bipolar disorder to maintain agency in their life are beneficial for this group (Tyler et al., 2021). Whilst larger scale trials are needed to support these findings, it appears that psychosocial interventions could help older

adults with bipolar disorder move towards personal recovery and maintain agency in later life. Overall, the different challenges faced by older adults with bipolar disorder mean treatments should be adapted to improve their effectiveness and reduce the health inequalities in this group. This may also enable older adults with bipolar disorder to age well and live meaningful lives as they age. What constitutes ageing well and the importance of considering what supports older adults with bipolar disorder to age well is discussed in the following section.

1.9 What does it mean to age well?

Whilst no literature prior to this thesis has explored what ageing well means to older adults with bipolar disorder, a wealth of literature has investigated what factors allow the general population to age well in later life. A selection of the theories used to understand the concept of ageing well will be discussed below and their application to older adults with bipolar disorder will be considered.

1.9.1 Selective Optimisation with Compensation

The selective optimisation with compensation model of ageing was proposed by Baltes & Baltes (1990). It suggests that older age is a process where individuals experience age-related gains and losses, meaning adaptations are required to achieve successful ageing. This framework offers a conceptualisation of ageing well that is not dependent on outcomes but instead focuses on the simultaneous maximisation of one's gains and minimisation of losses to age well (Baltes & Carstensen, 2003). It is proposed that ageing well depends upon three key processes of adaptation which in turn allow individuals to identify and achieve meaningful goals that align with their personal values; these three processes are selection, optimisation and compensation (Marsike et al., 1995). Selection refers to the process of selecting high-priority, attainable goals whilst considering one's biological capacity and skills and neglecting goals deemed less important as people age (Alonso et al., 2013). During optimisation, individuals

must attempt to acquire the means and functions acquired for goal attainment (Baltes & Dickson, 2001). Optimisation may involve learning new skills or reactivating previously unused goal-relevant internal or external resources that may promote growth and support goal attainment in old age (Bajor & Baltes, 2003). Finally, compensation becomes necessary when age-related losses result in an insufficient capacity to achieve one's goals in old age (Baltes & Carstensen, 2003). Consequently, individuals may have to compensate and pay less attention to areas not deemed important for goal attainment and attempt to delegate these activities to someone else in order to age well (Baltes & Freund, 2003).

This theory is used to explain what is important to age well within the general ageing population rather than with older adults with bipolar disorder. It appears that older adults with bipolar disorder experience unique losses as they age such as accelerated cognitive decline, more physical health challenges and mood instability (Sajatovic et al., 2015). As a result, this group may require different types of optimisation, compensation and support compared to the general population in order to age well in later life.

1.9.2 Socioemotional Selectivity Theory

Socioemotional Selectivity Theory was proposed by Carstensen and colleagues (2003). This theory suggests that reduced rates of interaction in later life result from lifelong selection processes where people strategically adapt their social networks in a way that maximises social and emotional gains and minimises social and emotional risks (Carstensen et al., 2003). Rather than viewing changes in social patterns among older adults as caused by decremental processes associated with ageing, it proposes that these changes reflect gradual choices made by the individual across the life course (Lansford et al., 1998). Although inconsistent with traditional models of social ageing, socioemotional selectivity theory is supported within the literature and builds upon life span models of adult change (Cartensen et al., 2003).

According to socioemotional selectivity theory, perceived limitations on time as we age can lead to the reconstruction of goal hierarchies (Carstensen, 2021). Consequently, goals that provide emotional meaning and connection in life are prioritised over goals that provide only future satisfaction (Lockenhoff & Carstensen, 2004). Research highlights that this focus on deriving emotional meaning from life can provide older adults within the general population with improved perceptions of social support and improved physical wellbeing (Lockenhoff & Carstensen, 2004). However, older adults with bipolar disorder are known to experience difficulties in maintaining supportive, emotionally meaningful relationships and report decreased perceptions of social support compared to healthy controls (Beyer et al., 2003). Consequently, it remains to be seen whether the socioemotional selectivity theory is applicable to older adults with bipolar disorder and whether this theory can be used to support this group to age well.

1.9.3 The Life Course Perspective

The life course perspective highlights that physical, societal and psychological aspects of individual ageing are shaped by several factors that cumulate over the lifespan rather than being influenced specifically by chronological age (Dannefer & Settersen, 2010). Importantly, this perspective marks a move away from viewing ageing as a distinct phase of life and instead moves towards viewing ageing as a continuously evolving interaction between one's psyche, body and the social world (Blane et al., 2004). This interactive process is explained within five key principles: 1) ageing and development are lifelong processes 2) individuals' lives are linked 3) individuals' life courses are embedded within context 4) the timing of transitions is important 5) individuals have agency (Bengtson et al., 2012). The first principle centres on the idea that events, relationships and behaviours during earlier life stages have consequences for later life relationships and wellbeing (Kuh et al., 2013). The principle that 'Individuals' lives are linked' emphasises the interconnectedness of lives, how lives are embedded in relationships

and influenced by them (Drobnic & Blossfeld, 2004). Principle 3 explains the importance of considering the historical time and place, large events (e.g., wars, economic decline) that may have taken place during this time and how this may shape individual psychology, family interactions and world views that potentially change the course of one's life (Bengston et al., 2012). Principle 4 highlights the impact of transitions and their timing within the social contexts in which people make important life choices that affect their life course (Hareven, 1994). The final principle, individuals have agency, concerns the idea that individuals can engage in effort and planning that affects their life outcomes and that people are active agents in the construction of their life course (Shanahan & Hood, 2000).

Overall, the life span perspective highlights that ageing is an interactive process that is constantly evolving and shaped by the experiences and inequalities within individuals' lives (Kuh et al., 2013). This is an important shift in our understanding of ageing and what is necessary to age well as past theories have sometimes viewed the ageing process as a distinct phase of one's life (Settersen, 2006). This theory may also be important to understand what is necessary to age well with bipolar disorder and to understand the impact of living with bipolar disorder across the lifespan. Individuals with bipolar disorder are known to experience several health inequalities that according to the life course perspective may impact their ability to age well and affect their ability to enjoy life satisfaction in later life (Sajatovic & Blow, 2007). This theory may help us to understand how challenges experienced throughout the lifespan affect people with bipolar disorder in older age and allow us to consider what adaptations are required to enhance support for this group and improve clinical outcomes in later life.

1.9.4 Cognitive Reserve Theory

Theories of cognitive reserve are vital within ageing literature, as they highlight that our lifestyle experiences, IQ, education, occupational attainment and leisure activity throughout the lifespan may influence our level of cognitive reserve which determines how efficient our

brains become and potentially reduces the rate of cognitive decline and dementia as we age (Stern, 2009). Authors believe that developing higher cognitive reserve may mean that some older adults do not have to compensate for factors associated with ageing for longer periods, which enables them to engage in meaningful activities associated with healthy ageing for longer (Stern, 2002). This has been linked to more sustained health and wellbeing as older adults (Scarmeas & Stern, 2003). Cognitive reserve theory offers support to the lifespan perspective of ageing which emphasises how our experiences, occupational attainment and active choices across the lifespan can significantly impact the ageing process (Bengston et al., 2012). This is potentially concerning for people ageing with bipolar disorder, as bipolar disorder has been found to damage employment prospects, increase unemployment throughout the lifespan (Murwaha et al., 2013) and is thought to cause neurocognitive impairments that result in reduced cognitive reserve (Anaya et al., 2016). Reduced cognitive reserve in older adults with bipolar disorder may therefore partially explain the higher mortality rates, accelerated ageing, increased risk of vascular diseases and cognitive deterioration observed in this group, although this requires further investigation (Sajatovic et al., 2015).

1.10 Thesis aims and objectives

This thesis aimed to consider what it means to age well with bipolar disorder. To explore this research question, four empirical studies were completed. The aims of these studies are summarised in more detail below.

1.10.1 Study one: Physical health comorbidities in older adults with bipolar disorder: A systematic review

Existing research suggests that older adults with bipolar disorder may experience increased physical health comorbidities as they age. However, the research examining physical health comorbidities in this group is currently limited. The aim of this paper was to investigate the

prevalence and predictors of physical health comorbidities in older adults with bipolar disorder. The physical health comorbidities examined within this systematic review were cardiovascular disease, cancer, diabetes, obesity, renal disease, oral health outcomes. This paper has been published in the Journal of Affective Disorders. Please see the reference below.

Warner, A., Holland, C., Lobban, F., Tyler, E., Harvey, D., Newens, C., & Palmier-Claus, J. (2023). Physical health comorbidities in older adults with bipolar disorder: A systematic review. *Journal of Affective Disorders*, 326 (232-242).

1.10.2 Study two: What does it mean to age well with bipolar disorder? A qualitative study using photo elicitation

Limited research has attempted to understand the preferences and priorities of older adults with bipolar disorder and what helps this group to age well in later life. This study used photo elicitation and semi-structured interviews to explore what is important to older adults with bipolar disorder as they age and what ageing well means to older adults with bipolar disorder. Data gathered from 17 interviews with older adults with bipolar disorder was analysed using reflexive thematic analysis. Findings from this study can help to identify how older adults with bipolar disorder can adjust to their changing circumstances to live meaningful lives as they age. This paper has been submitted to Psychology and Psychotherapy: Theory, Research and Practice and is currently under review.

1.10.3 Study three: The changing care and care needs of older adults with bipolar disorder: A narrative analysis

Study three was a separate qualitative study which used biographical narrative interviews to explore the experiences of care and support of older adults with bipolar disorder across their lifespan. It attempted to understand how and why the care needs of older adults with bipolar disorder change as they age. 16 older adults with bipolar disorder provided data which was

analysed using narrative analysis. Findings from this study identified the key care needs of older adults with bipolar disorder and considered how services could offer improved support. This paper has been submitted to Research on Aging.

1.10.4 Study four: Quality of life in older adults with bipolar mood states: A secondary analysis of English Longitudinal Study of Ageing (ELSA) data

The challenges faced by older adults with bipolar disorder contribute to a range of difficulties that may lead to poorer quality of life and diminished wellbeing (Depp et al., 2006). Despite this, limited research currently explores the impact of bipolar disorder on the quality of life of older adults with bipolar disorder. This study involved completing a multilevel analysis of the English Longitudinal Study of Ageing data (ELSA) to examine whether bipolar mood states predict poorer quality of life in older adults. The analysis also investigated predictors of quality of life among the older adults with bipolar mood states. Findings from this study contribute to existing literature by highlighting the consequences of experiencing bipolar mood states for older adults and illuminate factors that potentially contribute to poorer quality of life in this group. This knowledge can be used to identify key areas of support that can help to improve outcomes and the wellbeing of older adults with bipolar mood states.

1.11 Chapter summary

This chapter summarised literature surrounding the diagnosis, aetiology, and course of bipolar disorder in adult populations. Current treatment recommendations were also discussed, and limitations of existing research were considered. The unique challenges faced by older adults with bipolar disorder were outlined and the lack of treatments focusing specifically on this group's needs were identified. Finally, theories of ageing well and their application to the general ageing population were explored and the difficulties in ageing well for older adults with bipolar disorder were hypothesised. Overall, the background literature evaluated in this

chapter highlighted that more research is required to understand and support older adults with bipolar disorder to age well and live fulfilling lives as they age.

Alternative format

This thesis is presented in an alternative format and follows the Lancaster University manual of academic regulations and procedures (2022). Consequently, chapters consisting of original empirical research are related but are presented as individual research articles. Some repetition may be evident in the background and methods sections within these articles, although attempts have been made to reduce repetition throughout the thesis.

Chapter 2: Methodology

This chapter outlines the philosophical position of the researcher and justifies the chosen methodologies for this thesis. The researcher will discuss their ontological and epistemological positions and will explore arguments for using both qualitative and quantitative methods. The researcher will also identify steps taken to ensure reflexivity throughout the research process and enhance rigour within each of the studies. Finally, this chapter considers key ethical considerations and highlights the importance of patient and public involvement in the research project.

2.1 Ontological and epistemological considerations

2.1.1 Ontology

Ontology is the study of being and what represents reality (Goertz & Mahoney, 2012). Considering one's ontological perspective is an essential part of the research process as it encourages the researcher to assess their perceptions of what constitutes truth and how this is influenced by human nature and societal beliefs (Klakegg, 2016). For many years, the dominant ontological position within psychology and health research was that there was a real observable reality in which scientific methods such as experimentation could help us achieve concrete knowledge about the world (Fletcher, 2020). This approach is commonly called realism and is often adopted by researchers who use quantitative methods to systematically examine and measure phenomena with the aim of capturing what they perceive to be real, objective truth (Goertz & Mahoney, 2012). However, an alternative ontological position, known as relativism, suggests that reality is subjective and constructed by interactions between individuals and shaped by society, culture and personal experiences (Hugly & Sayward, 1987). This approach is predominantly suited to qualitative methods where the researcher uses techniques that aim to gather idiosyncratic and experiential knowledge (Harper, 2011). Relativism suggests that there are multiple realities and that it is not possible to objectively gather concrete knowledge

or truth (Gura, 1992). Therefore, the ontological assumptions of the researcher largely determine the methodological approach chosen, and researchers should consider their perceptions of reality, truth, and how best to capture this within their project (Guarino et al., 2009).

2.1.2 Epistemology

Epistemology typically refers to our beliefs about the nature of knowledge, how we acquire knowledge, and how we make sense of the world (Roots, 2007). The epistemological position of a researcher sets out what conditions they believe are necessary to acquire knowledge and also identifies a particular source that can be used to gather knowledge (Roots, 2007). The epistemological position of the researcher is a key factor in determining the methodology used to collect data in research studies (Al-Ababneh, 2020). The two main epistemological positions discussed within existing literature are positivism and interpretivism (Ryan, 2018). Positivism is typically associated with quantitative research studies and is characterised as focusing on objectivity, causality, replicability, and trying to find factual data that is not influenced by human bias (Alharahsheh & Pius, 2020). In contrast, an interpretivist epistemological perspective suggests that knowledge is gathered by exploring human experiences and accepts that reality is constructed by the individuals who experience it and shaped by their political views, culture, social norms, and personal experiences (Potrac et al., 2014). Therefore, the interpretivist position views knowledge as unique to each individual meaning that it is not measurable or generalisable (Williams, 2000). This position is suited to qualitative research in which the researcher adopts methods that aim to facilitate an in-depth exploration of people's individual experiences rather than searching for universal laws that can be applied to large groups of people (Thanh & Thanh, 2015).

<u>2.1.3 Philosophical position</u>

This thesis applies both quantitative and qualitative methodology to understand what it means to age well with bipolar disorder. As qualitative and quantitative methodologies have historically been linked to certain ontological and epistemological positions, theorists have traditionally believed that using both of these approaches to conduct research is inappropriate (Johnson & Onwuegbuzie, 2004). Following years of debate surrounding positivist and interpretivist paradigms, critical realism has emerged as a philosophical position that has gained popularity as a philosophical framework for completing quantitative and qualitative research (Archer et al., 2013). Critical realism appeals to researchers who complete both qualitative and quantitative studies as it combines ontological realism with epistemological relativism (Halcomb & Hickman, 2015). Consequently, authors have suggested that critical realism bridges the gap between positivist and interpretivist philosophical positions (Scott, 2005). Critical realism does this by acknowledging that there is an independent reality that does exist (realism) but understands that gaining absolute knowledge of reality and the way it works is impossible (interpretivism; Zachariadis & Barrett, 2013). This is because each person observes this reality through their own conceptual lens that is influenced by their own experiences, beliefs, and position within the world (Pilgrim, 2014). Therefore, some knowledge is perceived to be closer to reality than other knowledge (Gorski, 2013).

In critical realist ontology, Bhaskar (2020) states that reality is split into three separate levels; these are the empirical level, the actual level, and the real level (Fletcher, 2017). The empirical level refers to events as we experience them (Fletcher, 2017). At the empirical level, objects or events can be explained and measured, but these events are always influenced by the experience and interpretation of humans (Walsh and Evans, 2014). At the actual level, events occur regardless of whether we interpret or experience them, but these can regulate and influence the empirical level (Walsh and Evans, 2014). Finally, the real level underpins the

actual level and is explained as causal mechanisms and structures that contribute to the way we understand the actual level, but these mechanisms are not fully explanatory and are instead viewed as causative agents or tendencies (Bhaskar, 2016). These layers are what separate critical realism from other ontological perspectives as it views events that cannot be observed as real on the basis that their effects can be experienced by the individual (Koopmans & Schiller, 2022). The researcher completing this thesis agreed that there might be an observable reality but acknowledged that there may be multiple layers of this reality that require exploration to enhance our knowledge. Therefore, the researcher's philosophical position was aligned with the critical realist perspective, and this determined the decision to use both qualitative and quantitative research methods to understand what it means to age well with bipolar disorder.

2.2 Overview and justification of thesis methodology

2.2.1 Study one (chapter 3): Physical health comorbidities in older adults with bipolar disorder: A systematic review

Study one aimed to investigate the prevalence and predictors of physical health comorbidities in older adults with bipolar disorder. Specifically, the researcher examined six physical health comorbidities that were found to be problematic for adult populations diagnosed with bipolar disorder following a scoping review of existing research. These were: cardiovascular disease, diabetes, cancer, obesity, renal disease, and oral health outcomes.

A systematic review was selected for this study, as this approach is valuable for uncovering all of the available evidence and using this to answer a chosen research question (Aromataris & Pearson, 2014). Systematic reviews do this by using rigorous, systematic methods that reduce the risk of researcher bias and inaccuracies in the results, therefore providing a meaningful, comprehensive synthesis of relevant research (Wright et al., 2007). A systematic review was also appropriate for this study, as it was consistent with the researcher's critical

realist philosophical position which is methodologically pluralistic and suggests that methodological choices should be based on the nature of the object of study and what the researcher wants to learn about this (Vincent & O'Mahoney, 2018; Clegg, 2005). It had been suggested that older adults with bipolar disorder may be at risk of increased physical health comorbidities (Depp & Jeste, 2004). However, after completing a scoping review of the existing research, the researcher identified a gap in this area that required further investigation. Consequently, a systematic review design was deemed appropriate to enable the researcher to thoroughly investigate the prevalence and predictors of physical health comorbidities in older adults with bipolar disorder and contribute to the literature surrounding this population.

2.2.2 Data collection – systematic review databases

To identify relevant studies for the systematic review, systematic searches were completed on four databases (MEDLINE, CINAHL, PubMed and psychINFO). The decision to search these particular databases was informed by discussions with a university librarian and the index of journals they include in their database. MEDLINE was selected as its subject scope includes health and biomedicine and covers areas such as behavioural and life sciences. CINAHL indexes health and nursing literature; psychINFO includes literature surrounding behavioural and social sciences within the field of psychology, and finally, PubMed includes predominantly life sciences and biomedical literature. Alongside this, specific search terms used to identify appropriate research articles were also developed alongside a librarian based at Lancaster University. Due to the range of physical health comorbidities examined within the systematic review, search terms were kept deliberately broad and aimed to capture literature investigating older adults and bipolar disorder. Whilst other databases such as SCOPUS which covers areas such as life, health and social sciences could have been searched, it was decided that this was impractical due to the limited literature surrounding physical health comorbidities in older

adults with bipolar disorder. Consequently, the search remained restricted to the four databases described above.

As recommended by Sajatovic and colleagues (2015), the cut-off age for participants in studies was 50 and over. Sajatovic and colleagues recommend this cut-off, as older adults with bipolar disorder experience reduced lifespan and the authors believe that research should aim to capture variables that affect health outcomes in the second half of this group's life. Including studies with this cut-off also ensured that any studies defining older adults with bipolar disorder as aged 50 and over were not excluded from the systematic review. Only studies that confirmed participants had a diagnosis of bipolar disorder consistent with DSM or ICD criteria were included as this ensured that the sample being explored was as homogeneous as possible. Only peer-reviewed research articles were included as this meant that all research had been rigorously evaluated prior to its inclusion in the systematic review. However, whilst this attempted to increase the quality of the systematic review, some valuable research included in theses and other documents of interest may have been excluded. Finally, as there were no resources for translation, only studies written in English were included. Again, this may have led to some important resources being excluded, and this is a noted limitation of the systematic review search.

2.2.3 Data analysis – narrative synthesis

After completing all searches and double-screening articles to determine eligibility, it was decided that narrative synthesis was the most appropriate method of synthesising the available evidence. Although evidence was limited, it was heterogeneous in terms of methodology, and there was insufficient data to compute standardised effect estimates. Consequently, other synthesis methods such as meta-analysis that aim to use statistical methods to calculate an overall effect within studies were not appropriate for this systematic review (Popay et al., 2006). However, weighted averages of the prevalence of each physical health comorbidity were

calculated where possible. Completing a narrative synthesis of the available evidence allowed the researcher to summarise key findings, highlight relationships, explore similarities and differences and evaluate the quality of the evidence (Lisy & Porritt, 2016). Therefore, narrative synthesis was appropriate for answering the research question as it provided a comprehensive overview of the prevalence and predictors of physical health comorbidities in older adults with bipolar disorder. For more details of the research methods used in this systematic review, please see chapter 3.

2.2.4 Steps to ensure rigour

An essential component of systematic reviews is that they are conducted in a rigorous manner to ensure that the evidence synthesis is as accurate as possible (Pollock & Berge, 2018). In this study, it was decided that having a second researcher who could double rate potentially suitable articles at title/abstract level and full articles was an effective way to reduce researcher bias and improve the quality of the review (Fink, 2019). Quality assessment of all included articles is also a key stage of completing a systematic review (Pollock & Berge, 2018). Quality assessment allowed the researcher to be transparent about the strengths and limitations of included articles and the quality of the review overall (Batten & Brackett, 2021). This transparency provides the reader with the opportunity to determine whether the reviews findings are generalisable and scientifically robust (Pieper et al., 2012). In this systematic review, the researcher, alongside his supervisory team concluded that the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018) was an appropriate tool to assess quality across the heterogenous designs of included papers. Further attempts were made to enhance rigour throughout this process by incorporating reflexivity at all stages. Reflexivity encourages the researcher to be transparent and open about their decision making and attempts to identify potential biases that are common when completing systematic reviews (Finlay, 1998). To reduce the risk of bias, all key decisions such as determining article eligibility, synthesis

methods and the most appropriate way to report findings were made alongside the supervisory team and another PhD student. This led to a collaborative process where a range of perspectives and knowledge were available to the researcher to enhance the rigour and quality of this systematic review.

2.3 Qualitative Methods

2.3.1 Study two (chapter 4): - What does it mean to age well with bipolar disorder? A qualitative study using photo elicitation

2.3.2 Design

Chapter 4 used qualitative methodology to answer the experiential research question 'What does it mean to age well with bipolar disorder?'. It was hoped that understanding what enables older adults with bipolar disorder to age well could enhance our knowledge about what support is necessary to help this group to live meaningful, enjoyable lives as they age and improve their quality of life. Photo elicitation interviews were used to collect data for this study before data was analysed using reflexive thematic analysis.

2.3.3 Participants and recruitment

2.3.4 Purposive sampling

The strategy for recruiting participants should be consistent with the aims of the study and the chosen ontological and epistemological perspectives of the researchers (Campbell et al., 2020). To complete chapter 4, a purposive sample of older adults with bipolar disorder was recruited. Purposive sampling is used when individuals with specific characteristics are required to make sure that appropriate information is gathered to answer the research question being explored (Campbell et al., 2020). For chapter 4, a sample of older adults with bipolar disorder was required to meet the aims of the study, meaning a purposive approach was appropriate. Specifically, the research aimed to recruit people aged 60 and over who met criteria for bipolar

disorder based on the Structured Clinical Interview for DSM-5 (SCID-5-RV, 2015). Participants were recruited from a range of different services to try to ensure that individuals with contrasting and unique experiences of bipolar disorder were involved, therefore increasing the transferability of findings (Slevin & Sines, 1999). NHS ethical approval was granted which allowed the researcher to recruit from three community-based NHS services within the Northwest of England. Alongside this, the researcher recruited from charity organisations in the UK and online via social media. The researcher also recruited through Spectrum Connect, which is a confidential database of people who have agreed to be contacted about mental health research at Lancaster University.

2.3.5 Inclusion and Exclusion Criteria

To increase homogeneity in the sample, comprehensive inclusion and exclusion criteria were developed. These will be discussed in more detail below.

2.3.6 Inclusion Criteria

- Aged 60 and over.

- Must meet criteria for bipolar disorder according to the SCID-5.

- Capacity to provide informed consent.

- Adequate English language skills to participate in the study.

2.3.7 Exclusion Criteria

- Known moderate to severe learning disability as this may limit the individual's ability to participate in the study.

- Current immediate risk to self or others.

- Participants who have a cognitive impairment that may limit their ability to participate in the project.

- Individuals who are currently within inpatient services or are involved with home treatment teams or crisis teams.

The researcher decided to include participants aged 60 and over as this was consistent with the World Health Organisation's (World Health Organisation, 2021) chronological definition of older adults, elderly or aged. As mentioned, Sajatovic and colleagues (2015) state that studies should consider defining older adults with bipolar disorder as aged 50 and over rather than 60 due to research indicating that this group experiences increased medical comorbidity and a reduced lifespan. However, as this thesis aimed to understand what it means to age well with bipolar disorder and wanted to specifically understand the transitions and changes that occur in later life, a cut-off of 60 was deemed more appropriate for this study.

To determine whether participants met criteria for bipolar disorder the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders 5 research version (DSM-5-RV) was used. The SCID-5-RV has been used in several studies to characterise the population being researched in terms of psychiatric diagnosis (First et al., 2015). The aim of using the SCID-5-RV in this study was to make sure that participants had experienced similar challenges and symptoms that were consistent with bipolar disorder during their lifetime. However, it was not used to formally diagnose participants and was strictly used to confirm that participants met criteria for bipolar disorder for research purposes. Participants were informed of this prior to participating in the study, to reduce potential distress and confusion.

To confirm that participants had the capacity to consent to take part in the study, they were provided with a participant information sheet and asked to decide if they would like to take part. Participants were also given the opportunity to ask questions about the research and their participation prior to them completing either a written or verbally recorded consent form. If the researcher was recruiting from NHS services, they also contacted a clinician who worked with the individual to gather any important information surrounding capacity or risk to confirm that

the individual met the inclusion criteria. If the participant was able to read and understand the participant information sheet and communicate their decision to take part, they were deemed to have the capacity to consent and were included in the study. Participants also had to be able to speak adequate English to participate as the researcher did not have access to an interpreter. This may have limited the generalisability of the findings and restricted the inclusion of participants from different cultures who may have had unique experiences of ageing with bipolar disorder. Consequently, this should be considered in future research.

2.4 Data collection – Photo elicitation interviews

2.4.1 Rationale for photo elicitation interviews

For study two, the researcher used photo-elicitation interviews to collect data from 17 participants who were older adults with bipolar disorder. Photo elicitation is a research method that involves using photographs to generate verbal discussion within interviews (Glaw, 2007). The photographs used within the interview can be taken or brought to the encounter by the researcher or participant depending on the purpose and aims of including visual materials (Clark-Ibáñez, 2004). Photo elicitation is now more commonly used and interviews adopting this method generally consist of the interviewer asking participants to discuss and elaborate on the visual images brought to the interview (Glaw, et al., 2007). Harper (2002) suggests that areas of the brain that process visual content are evolutionarily older than brain areas that process verbal and written content. Consequently, using visual images within interviews can help to elicit unique content as these images activate deeper elements of human consciousness than words alone (Harper, 2002). Furthermore, using images within interviews has been reported to trigger emotions, memories and information that may not be accessible within conventional semi-structured interviews (Torre & Murphy, 2015). This is particularly important when completing interviews with older adult populations who may experience declining memory as a result of ageing (Coleman, 2016).

Literature suggests that a key advantage of using photo elicitation is that it provides participants with the opportunity to discuss images and content that is important to them and guide the interview encounter (Harper, 2002). This helps participants to feel more relaxed and communicate deeper, more meaningful content than observed in semi-structured interviews (Richard & Lahman, 2015). Copes and colleagues (2018) recommend photo-elicitation when interviewing vulnerable participants as it helps to facilitate engagement and ensure that the encounter feels safe. For these reasons, photo elicitation interviews were selected as an appropriate method of collecting data in this study. Furthermore, visual methods encouraged participants to embrace creativity which is reportedly a strength of many people living with bipolar disorder (Johnson et al., 2012). Participants were asked to take photographs of aspects of their lives that represented ageing well with bipolar disorder or content that had been important to them as they aged, before these were then used to prompt discussions within the interview encounter. This approach provided rich, in-depth experiential information that was consistent with critical realist ontology and was appropriate for answering the research question 'What does it mean to age well with bipolar disorder?'

2.4.2 Topic guide

A key focus of the interviews for this study was to explore participants' photographs in depth by asking questions such as 'Please could you tell me about the photographs you have selected and why you feel they represent ageing well with bipolar disorder to you? Alongside this, interviews aimed to cover other areas of interest that helped to provide a comprehensive understanding of what it meant to age well with bipolar disorder. A topic guide was developed alongside the research team that included three qualified clinical psychologists, a Professor in Ageing and two public advisors who were older adults with lived experiences of mental health difficulties. Feedback was also sought from the service user advisory panel at Lancaster University which consists of approximately ten people with lived experience of bipolar

disorder. Feedback from both the research team and advisory group ensured a range of perspectives were used to shape the topic guide and confirm that interviews included important topics that were focused on answering what it means to age well with bipolar disorder. For example, public advisors provided information about their experiences of ageing with mental health difficulties and advised on potentially important areas to consider within the interviews.

2.5 Data analysis - Reflexive thematic analysis

When considering ways to analyse the data gathered from photo elicitation interviews, the researcher considered which methods were consistent with critical realist methodology and the most effective way to analyse visual and experiential content from these interviews. After evaluating potentially suitable methods of analysis, it was decided that reflexive thematic analysis as outlined by Braun & Clarke (2006) was the most appropriate method of analysing data. Reflexive thematic analysis is a flexible approach that can be applied to a range of disciplines, populations and topics (Braun & Clarke, 2019). Furthermore, reflexive thematic analysis has been used to analyse data collected using various methods including photo elicitation interviews (Herrington et al., 2021). This approach is also in line with the critical realist approach as it does not require commitment to one philosophical position and whilst sitting within a qualitative paradigm, authors have used a realist approach to complete thematic analysis (Braun & Clarke, 2021).

The aim of reflexive thematic analysis is to identify broad themes that represent important patterns of meaning within the dataset (Braun & Clarke, 2006). Other pattern-based approaches such as interpretative phenomenological analysis were considered within this study. Interpretative phenomenological analysis is an idiographic approach that attempts to interpret and understand how individuals make sense of a specific phenomenon within the world (Smith, 2011). It differs from reflexive thematic analysis in that it is more idiographic and is specifically focused on the unique details of each participant interview (Braun & Clarke, 2021). Because

of this, interpretative phenomenological analysis is usually recommended with smaller sample sizes of less than 10 participants (Eatough & Smith, 2017). This approach is also best suited to studies where the data source consists of in-depth interviews alone (Braun & Clarke, 2021). Consequently, whilst interpretative phenomenological analysis is a useful and valid way of analysing qualitative data, this study's use of visual methods to collect data and larger sample size of 17 participants meant reflexive thematic analysis was selected over this approach. Please see chapter four for details on how the researcher used a six-step approach to reflexive thematic analysis to analyse data for this study.

2.6 Study three (chapter 5) - The changing care of older adults with bipolar disorder: A narrative analysis

Study three aimed to explore the experiences of care and changing care needs of older adults with bipolar disorder in later life. This research question felt important to explore as NICE (2014) still recommend that older adults with bipolar disorder receive the same treatments as younger age groups. However, older adults appear to have different needs, which can lead to them receiving inappropriate and ineffective treatments (Sajatovic et al., 2015). The research team concluded that improving our understanding of how and why the care needs of older adults with bipolar disorder change over time could highlight necessary adaptations to care for this group (Dautzenberg et al., 2016). As the research question for this study was experiential, qualitative methods were again deemed appropriate (Lewis, 2015). Data for this study was collected using biographical narrative interviews before narrative analysis was conducted.

2.6.1 Participants and recruitment

As with study two, a purposive sample was selected for this study, and participants were recruited from community-based NHS services within the Northwest of England, Spectrum Connect at Lancaster University, UK-based mental health charity organisations and via social media (Twitter). However, this study aimed to understand participants' experiences of care and

support across their lifespan and focused on capturing key transitions that illuminated how and why their care needs changed over time and specifically into later life. To ensure that participants had sufficient experience of living with bipolar disorder to make sense of how and why their care needs changed over time, participants were required to have lived with bipolar disorder for ten years or more. Participants in this study did not have to complete the SCID-5 assessment. Instead, participants were asked to confirm that they had received a diagnosis of bipolar disorder from a healthcare professional at some point in their lives. Given the stricter inclusion criteria (10 or more years with a diagnosis), it was also hoped that this would make recruitment easier. The researcher acknowledged that self-report diagnosis can be inaccurate and may lack credibility at times (Paulhus & Vazire, 2007). However, removing the SCID was deemed appropriate by the research team as it reduced the amount of time that participants were involved in the study. Furthermore, certain questions within the SCID-5 can be triggering for some participants and it was felt that removing this requirement reduced the likelihood of participant distress within this study.

2.6.2 Data collection

Rationale for biographical narrative interviews

As the research question for this study focused on exploring participants' experiences throughout the life course and aimed to highlight key changes in later life, biographical narrative interviews were determined to be the most effective data collection method. Narrative methods are often described as incompatible with realist methodology as their focus is to gather stories that are undeniably socially constructed and unique to each individual (Wiltshere, 2018). Consequently, some authors believe that searching for the 'truth' in narrative research is not possible (Earthy & Cronin, 2008). However, researchers have highlighted that critical realism's acknowledgement of the influence of society, language and culture on people's

experiences make it an ontological position that is compatible with experiential and social constructionist methods such as those employed in narrative research (Willig, 1999).

Biographical narrative interviews were selected as they encourage the participant to tell their story about a significant chapter of their lives and convey an account that consists of multiple events and actions along a timeline (Jovchelovitch & Bauer, 2000). Furthermore, biographical narrative interviews allow the researcher to uncover key transitions that occur over time for participants and the reasons for these transitions (Ziebland, 2013). Importantly, biographical narrative interviews are less structured than traditional semi-structured interviews and encourage the participant to tell their story with minimal interruptions from the interviewer (Anderson & Kirkpatrick, 2016). By reducing the influence of the interviewer, the participant is able to convey a more 'valid' and personal account of their lived experience and tell their story in a way that makes sense to them (Jovchelovitch & Bauer, 2000).

Narrative interviews typically consist of three key stages (Anderson & Kirkpatrick, 2016). After introducing the aim of the study to the participant the researcher then asks a pre-determined opening question that aims to elicit the participant's narrative account of the topic being explored (Muylaert et al., 2014). In this study, participants were asked the question 'Please could you tell me about your experiences of care and support since you first tried to get help for bipolar disorder or first came into contact with mental health services, up until now?' During the participants' telling of their story, the researcher should use predominantly non-verbal cues to encourage the individual to openly discuss their experiences and should not interrupt until the participant has clearly completed telling their story (Ziebland, 2013). In stage two of the interview, the interviewer can then ask narrative-based questions (e.g., what happened after that?) about the content already discussed by the participants (Rosenthal, 1993). Finally, in stage three of the interview, the researcher should ask questions about any areas of

interest that have not been covered so far before concluding the interview (Corbally & O'Neill, 2014).

2.6.3 Topic guide

Although narrative interviews are predominantly less structured than traditional semi-structured interviews, the researcher should pay particular attention to developing the opening question as this facilitates the telling of the participant's narrative (Rosenthal, 1993). In this study, the researcher developed the opening question 'Please could you tell me about your experiences of care and support since you first tried to get help for bipolar disorder or first came into contact with mental health services up until now?' alongside research supervisors and two public advisors who were older adults with experience of mental health difficulties. This range of perspectives ensured the question was constructed in a way that would facilitate engagement and meaningful content from participants. Stages two and three of the interviews were also constructed with the support of the research team and public advisors and were informed by important topics in existing research (Sajatovic et al., 2015). Overall, this ensured that the narrative interviews completed in this study were appropriate for collecting data that helped to understand the changing care and care needs of older adults with bipolar disorder.

2.6.4 Data analysis

2.6.5 Justification of narrative analysis

A number of studies highlight that there is no set way or method of analysing narrative data (Franzosi, 1998). This is highlighted by reviewing the literature, where some studies have used grounded theory to analyse narrative data (Hunter, 2010). The aim of grounded theory is to gather a deep, 'insider' perspective of people's experiences and generate a theory that is grounded within the narrative data, therefore going beyond description and towards a more theoretical explanation of the phenomenon being explored (Oktay, 2012). Other studies have

used thematic analysis (Hunter, 2010) to identify key patterns of meaning across the narrative dataset as discussed in the previous section of this chapter. Whilst these approaches are valid and appropriate for analysing narrative data, this study's focus on exploring participants' experiences over time and identifying important transitions experienced by older adults with bipolar disorder required a different approach. Consequently, narrative analysis was selected to analyse the data gathered from biographical narrative interviews.

Narrative analysis was selected as the most appropriate way to analyse data for a number of reasons. Firstly, narrative analysis focuses on participants' stories and considers the role that language, culture, and relationships have in the shaping of these stories (Earthy & Cronin, 2008). As opposed to other qualitative methods that focus on what is said in terms of content such as interpretative phenomenological analysis and grounded theory, narrative analysis is interested in how stories are told, why they are told in this way and what the individual felt and experienced whilst telling their story (Smith, 2016). Additionally, unlike other forms of qualitative analysis such as reflexive thematic analysis where the coding of data is intensive and breaks the story apart, narrative analysis is conscious of over-coding data and seeks to keep participants' stories intact and examine the wealth of unique content within them (Smith, 2016). By doing this, narrative analysis allows the researcher to make sense of important transitions and events that occur over time in the lives of participants and provide valuable insight into the individual's past actions and beliefs, their present behaviours, and their future desires and intentions (Herman & Veraeck, 2019). Overall, narrative analysis provides the researcher with the opportunity to uncover new meaning and make sense of human behaviour and movement over a period of time (Esin, 2011). Consequently, narrative analysis was found to be the most effective way to explore the changing care and care needs of older adults with bipolar disorder in later life and consider how and why this groups care needs change over time.

2.7 Data sufficiency in qualitative research

In qualitative research, the term data saturation is commonly used to determine and justify the sample size selected and is defined as the point where no novel information, codes or themes are evident during data collection (Fusch, 2015). Whilst some authors argue that establishing data saturation is an essential aspect of ensuring quality in qualitative research, there is increasing debate around its usefulness and validity as a concept (Braun & Clarke, 2019). Low (2019) argues that defining data saturation by stating that no new information is evident within the data is not possible, as there are always new insights and novel information available whilst data is being collected and analysed. Braun & Clarke (2019) state that the term data saturation is often more consistent with positivist orientation rather than the relativist philosophical position adopted by the researcher in this thesis, as it implies that meaning resides within the data rather than meaning being developed through interpretation by the researcher which is influenced by their theoretical and contextual practices. Consequently, data saturation defined as the point where no novel information is available is inconsistent with the philosophical position of the researcher, although steps were taken to determine that sufficient information had been gathered to end data collection in both qualitative studies.

As recommended by Malterud and colleagues (2016) the researcher in this thesis considered the aims of the studies, the richness of the data collected, and the analysis strategy used to make an informed decision about when it was appropriate to stop collecting data. This was completed alongside the research team and public advisors who provided feedback on the data and helped to determine that the findings were meaningful and sufficient to comprehensively answer the research questions. Although these decisions are inherently subjective and it is not possible to know whether more interviews may have resulted in new information, these considerations helped to make sure that the process of determining data sufficiency in these qualitative studies was as rigorous and reflexive as possible.

Table 1: Qualitative methods used in thesis

Study aims	Data collection	Method of analysis	Features of analytical method
Study 2 - To understand what it means to age well with bipolar disorder.	Photo elicitation interviews	Reflexive thematic analysis	• Structured analytical method. • Flexible method of analysing data that can be used to analyse data collected in various ways (including photo-elicitation). • Intensive coding process where participants' stories are often broken apart. • Aims to identify key themes or patterns across the data rather than making sense of the data as a whole.
Study 3 - To explore the changing care and care needs of older adults with bipolar disorder as they enter later life.	Biographical narrative interviews	Narrative analysis	• Analyses the structure, content and function of people's stories and how these develop across time. • Tries to keep the story intact throughout the analysis. • Themes aim to tell a coherent story between participants (similarities and differences). • Aims to capture key transitions and changes in the lives of participants over time (and why).

2.8 Methods to ensure rigour in qualitative research.

As studies two and three both used qualitative design, steps were taken to ensure that the methods used for these studies were rigorous at all stages of the research process. Whereas quantitative designs attempt to assess the quality of their studies using positivist criteria such as objectivity, validity, reliability and generalisability, criteria such as this are not appropriate in qualitative research, as this approach has different ontological and epistemological assumptions (Denzin & Lincoln, 2008). Lincoln & Guba (1986) suggest that qualitative researchers should instead aim to promote rigour in their studies by enhancing transferability, confirmability, credibility, and dependability. In line with the critical realist philosophical position of the researcher, steps were taken to incorporate these concepts into all stages of the research process within studies two and three.

2.8.1 Transferability

According to Lincoln and Guba (2000), transferability in qualitative research is comparable to external validity in studies that use quantitative research methods. In positivist studies that utilise quantitative methods, external validity refers to the extent that research findings can be applied to broader or diverse target populations (Findley et al., 2021). In qualitative studies, transferability refers to the extent to which the findings of the study can be applied to other settings, contexts, and populations (Slevin & Sines, 1999). The concept of transferability in qualitative research is often disputed (Kuper et al., 2008). Many researchers believe that the small sample sizes included in qualitative studies and its focus on exploring specific environments result in it being impossible for findings to be applicable to different populations and situations (Kuper et al., 2008). However, Rodon and Sese (2008) dispute this view and suggest that certain steps can be taken by qualitative researchers to improve the transferability of their research findings and enhance rigour within their studies.

To increase the transferability of the qualitative studies within this thesis, the researcher initially used purposive sampling to ensure that the research focused on key informants who had in-depth knowledge of the topic being explored as suggested by Mays & Pope (1995). By using this approach, the researcher was able to maximise the information gathered from participants and include 'thick' descriptions of the context in which the research was undertaken, the sample that was investigated, and the services from which this sample was recruited (Seale & Silverman, 1997). The researcher also attempted to enhance transferability by attempting to highlight how findings can be used to improve our theoretical knowledge of what it means to age well with bipolar disorder and how and why the care needs of older adults with bipolar disorder change over time and into later life. Furthermore, the researcher outlined the impact of these findings and their potential relevance to service provision within multiple healthcare services and contexts within the UK as recommended by Morse (2015). Consequently, it is hoped that the findings from these studies support transferability by being applicable to other populations and can be used to inform support for older adults who are experiencing other mental health difficulties.

2.8.2 Confirmability

Confirmability within qualitative research is comparable to the concern of objectivity for quantitative researchers (Anney, 2014). For quantitative researchers, objectivity is a key focus, although ensuring true objectivity is challenging when even questionnaires and surveys are designed by humans (Thomas & Magilvy, 2011). Despite numerous steps being taken, researcher bias within even quantitative studies is inevitable (Sandelowski, 1986). This is the same for qualitative research, although the steps taken to highlight potential researcher bias differs to quantitative studies (Shenton, 2004). In qualitative research, the researcher is inherently part of the analytical process as interpretation of findings is co-created by them and the participant during the interview (Drisko, 1997). Therefore, the aim is not to remove the

influence of the researcher but to involve other researchers who can provide feedback on interpretations of the data and corroborate that the findings are tangible (Shenton, 2004). Steps such as this are vital for enhancing confirmability in qualitative research and investigators should clearly outline the steps taken to ensure that findings are representative of participants' views as much as possible (Ghafouri & Ofoghi, 2016).

The researcher attempted to enhance the confirmability of qualitative studies in this thesis by taking the following steps. Throughout the research process, the researcher kept a reflexive journal to highlight both practical and personal reflections after contact with participants and noted initial interpretations during analysis (Anney, 2014). This reflexive journal allowed the researcher to reflect on their position within the research and to consider their influence on the research process (Holmes, 2020). By doing this, the researcher was able to better maintain a 'curious stance' by questioning their prior knowledge and acknowledging limitations in their understanding of the phenomena being explored (LeVasseur, 2003). The researcher also kept an audit trail consisting of raw data, observational notes from interviews, and initial reflections from interviews (Krefting, 1991). According to Johnson and colleagues (2020) keeping an audit trail enables the researcher to clearly examine and reflect on their decisions during data collection and analysis and validate their interpretation of the data.

2.8.3 Credibility

Credibility in qualitative research refers to the amount of confidence that researchers can have in the truth and authenticity of their findings (Anney, 2014). Credibility is essential as it determines whether interpretations of data are plausible and are consistent with the original views of participants (De Wet & Erasmus, 2005). Numerous approaches can be used to increase the credibility of qualitative studies (Cutliffe & McKenna, 1999). To improve the credibility of this thesis, data analysis was completed alongside the research team who all offered unique perspectives due to their contrasting backgrounds (Lincoln & Guba, 1986; Anney, 2014).

Feedback from the research team also helped the researcher to remain transparent about potential influences that may have changed the way that they collected and interpreted data. Overall, incorporating multiple perspectives into the analytical process aimed to ensure that interpretations were more consistent with the experiences of participants (Yardley, 2000). The researcher also used triangulation, which involved using more than one qualitative method to obtain corroborating evidence and multiple perspectives to enhance credibility (Patton, 1999). Photo elicitation, semi-structured interviews and narrative interviews were used to capture different aspects of the research question and comprehensively answer what does it mean to age well with bipolar disorder?

2.8.4 Dependability

Dependability in qualitative research is comparable to reliability in quantitative studies (De Wet & Erasmus, 2005). Dependability refers to the consistency of findings and has close ties to credibility according to Shenton (2004). To increase dependability in the qualitative studies completed within this thesis, the researcher attempted to describe the research design and processes in depth, alongside their strengths and limitations so that future researchers are aware of how repeatable the study is and how unique the situation being explored is (Stenfors et al., 2020; Kefting et al., 1991). For example, separate topic guides for each qualitative study were developed alongside the research team and public advisors. The corresponding topic guides were then used throughout the interview processes for each of the qualitative studies in this thesis. Using an audit trail, triangulation of methods and receiving feedback from numerous researchers also serve to increase the dependability of the studies whilst also enhancing credibility and confirmability as discussed (Shenton, 2004). Overall, by increasing dependability and being transparent about the processes used to conduct the qualitative studies in this thesis, the researcher allowed the reader to assess the quality of the research practices used, therefore, enhancing the standard of these studies (Thomas & Magilvy, 2011).

2.8.5 Reflexivity

Reflexivity has been described as one of the essential ways that qualitative researchers can improve the quality and rigour of their work (Dodgson, 2019). Reflexivity is important when completing qualitative work from a critical realist position, as critical realism acknowledges that the world is layered into different forms of knowledge that can be influenced by factors that are not immediately observable (Roberts, 2014). An influential factor that can affect the design, completion and analysis of qualitative research is the role of the researcher and the impact of their experiences and identity, which can inevitably inform the research process (Palaganas et al., 2017). Whilst some researcher subjectivity is inherent in qualitative approaches, the practice of reflexivity allows the researcher to identify their role in the creation of knowledge and increase the trustworthiness of their work (Macbeth, 2001). Reflexivity is therefore defined as an analytical focus on the role of the researcher in qualitative research (Dodgson, 2019). It involves developing self-awareness through the researcher being introspective and considering how their values, socioeconomic background, gender, race and assumptions impact their research (Haynes, 2012). Overall, the aim of reflexivity in qualitative research is to explicitly highlight the relationship between the researcher and participants and the researcher's influence on this (Berger, 2015).

The researcher in this PhD thesis used reflexive thematic analysis and narrative analysis to analyse data gathered from interviews with participants. These qualitative methods both required the researcher to outline their personal assumptions and consider how these impacted the completion of the research (Braun & Clarke, 2019; Riessman, 1993). Consequently, as reflexivity was an essential component of the researcher's philosophical position and the methods used, the researcher took several steps to increase reflexivity throughout the research process.

Prior to beginning data collection or analysis, the researcher completed a positionality statement that included a description of their underlying beliefs, their personal and career experiences, background, gender, social class, ethnicity, and age and considered the influence that these may have had on the research process, as recommended by Holmes (2020). Whilst this helped to illuminate potential researcher biases, the researcher acknowledged that their positionality was fluid and could change over the course of a long research project such as a PhD (Jootun et al., 2009). To capture these changes, the researcher also kept a reflexive diary which consisted of personal reflections following each encounter with participants and methodological challenges such as the limitations of the interview schedule (Jootun et al., 2009). This allowed the researcher to be transparent about their role in the research and make sense of how and why their positionality changed over time (Nadin & Cassell, 2006). The researcher also engaged in regular supervision with three qualified Clinical Psychologists and a Professor in Ageing. This supervision provided a safe space for the researcher to explore their experiences and personal feelings whilst completing the research (Elliott et al., 2012). This helped the researcher to develop their self-awareness and highlighted internal biases that may have impacted the research (Hellawell, 2006). Supervision also offered support in navigating the emotionally challenging nature of completing research with individuals experiencing mental health difficulties, whilst improving reflexivity and the quality of the qualitative studies within this thesis.

2.9 Quantitative methodology

2.9.1 Study four (chapter 6) - Quality of life in older adults with bipolar disorder: A secondary analysis of The English Longitudinal Study of Ageing (ELSA) data

2.9.2 Design

For study four, the researcher used quantitative design to investigate quality of life in older adults experiencing bipolar mood states and assessed predictors of quality of life in this

population. Whilst quantitative research is typically associated with a positivist philosophy, critical realists believe that positivism is limited as it fails to consider how knowledge is influenced by external mechanisms (Scott, 2007). However, critical realists argue that the choice of methods used should be determined by the research problem being investigated (Vincent & O'Mahoney, 2018). Whilst completing studies one, two and three, the researcher identified that quality of life among older adults with bipolar disorder appeared to be disrupted and this was an area that had only received limited attention within existing literature. Therefore, investigating the hypothesis that older adults with bipolar disorder experience poorer quality of life using quantitative methods was considered appropriate. Quantitative methods were consistent with the researcher's philosophical position and allowed the researcher to identify associations and accurate comparisons that were not possible using qualitative methods (McEvoy & Richards, 2006).

2.9.3 Measuring quality of life

To measure quality of life in this study, the researcher used the Control, Autonomy, Self-realisation, Pleasure-19 (CASP-19) that was recorded within ELSA. The CASP-19 was deemed appropriate as it has been validated ($a = 0.6$ and 0.8; $r = 0.6$, $p = 0.01$) and used in numerous studies involving older adults (Wiggins et al., 2008). However, the researcher also considered the limitations of using a self-report questionnaire to measure quality of life in this study. From a critical realist perspective, it is important to acknowledge that people's responses can be affected by numerous factors such as context, time, and their personal experiences (Bhaskar et al., 1998). Therefore, it is possible that these factors may have affected the way people completed the quality of life questionnaire and that this may have directly influenced the results. Although the researcher's position is not consistent with the belief that there is a single reality that can be accurately measured using questionnaires, it was felt that adopting quantitative methodology in this study would provide valuable data that could highlight the

consequences of living with bipolar disorder in later life. This decision is supported by Pring (2000) who suggests that compensation such as this is appropriate for critical realists where the aim of the study is to examine the generalisability of a problem within a chosen population. Consequently, quantitative methods were used to measure quality of life in older adults experiencing bipolar mood states and assess the predictors of quality of life in this group.

2.9.4 The use of secondary data

To complete this study, the researcher conducted a secondary analysis of existing data. Cheng and Phillips (2014) state that there are generally two approaches for analysing existing data: the research question-driven approach and the data-driven approach. Prior to completing this study, the researcher's previous findings and existing literature suggested that older adults with bipolar disorder experience a range of challenges that potentially lead to poorer quality of life than the general ageing population (Depp & Jeste, 2004; Sajatovic et al., 2015). However, very little research has directly examined quality of life in older adults with bipolar disorder. Consequently, the researcher identified a gap within the literature and wanted to examine the hypotheses that 1) bipolar mood states will be associated with poorer quality of life in older adults, and 2) Certain factors will predict quality of life in older adults with bipolar mood states. Therefore, a research question-driven approach was utilised, and a suitable dataset was sought to address this research question.

The researcher used data from The English Longitudinal Study of Ageing (ELSA; Banks et al., 2021), which is an ongoing prospective observational study of community-dwelling individuals in England, aged 50 and over. This gave the researcher access to a large dataset that included data from older adults who reported a diagnosis of bipolar disorder or experienced psychiatric mood swings. Using secondary data was also appropriate as it was cost-effective, convenient, and provided a larger, more representative sample of older adults with experiences consistent with bipolar disorder, therefore increasing the generalisability of the findings

(Johnston, 2014). Using secondary data has also been found to accelerate the pace of research and this was taken into consideration by the researcher as this thesis already consisted of three other studies. Whilst there are benefits to using secondary data, there are also limitations to this approach. For example, data was not collected with the researcher's specific hypothesis in mind and the researcher was not involved in data collection. Consequently, it was difficult to make sense of study-specific nuances or problems during data collection that might impact the interpretation of certain variables in the dataset (Cheng & Phillips, 2014). These limitations are noted in Chapter 6; however, the analysis of secondary data was deemed an appropriate method for investigating quality of life in older adults with bipolar mood states.

2.9.5 Secondary data analysis – multilevel modelling

After determining which variables of interest would be included in the analysis, the researcher and research supervisors concluded that multilevel modelling would be the most appropriate method of analysing data. Multilevel models are specifically aimed at analysing statistical data that has a clustered or hierarchical structure (Hox, 1998). In this study, seven waves of ELSA data ranging from 2006-2019 were combined to increase the sample size and representativeness of the sample. As repeated measurements were collected from participants across these waves, the data was nested within individuals (Peugh, 2010). Nested data structures can be problematic as they violate the assumption of independent observations that is required when completing more traditional analyses such as t-tests, multiple regression, or ANOVA (Peugh, 2010). Therefore, the researcher determined that multilevel modelling was the most effective method for analysing this nested data and reducing the risk of type I errors, where the researcher rejects the null hypothesis and also parameter estimate biases (Hox, 1998). Please see chapter six for further details on the variables examined using multilevel modelling in this thesis.

2.10 Ethical considerations

Appropriate ethical approval was received for each study prior to their completion to reduce the risk of harm to any participants. Lancaster University Ethics and the National Health Service (NHS) research ethics committee (REC reference: 21/LO/0405) approved the research protocol for both qualitative studies and three NHS Trusts granted permission for the researcher to recruit participants from their services. For study four, ethical approval was sought from Lancaster University ethics to complete a secondary analysis of the English Longitudinal Study of Ageing data. All data included in the English Longitudinal Study of Ageing had already received ethical approval from NHS Trusts, and participants were given unique ID numbers to maintain anonymity. Therefore, participants had given their consent for their information to be used for research purposes.

2.10.1 Ensuring the safety of participants and researchers.

An essential aspect of any research involving human participants is that no unnecessary harm is caused during any stage of the research process (Kavanaugh & Ayres, 1998). As participants who took part in this thesis were experiencing mental health difficulties and were potentially vulnerable, it was vital that steps were taken to reduce harm to themselves and also the researcher. It was important for the researcher to be aware that participants bring their own life experiences, some of which may be particularly traumatic, to the research encounter (Williamson & Burns, 2014). Whilst most participants were familiar with discussing these experiences with healthcare professionals, it was valuable to explain the differences between a research and clinical encounter and set clear boundaries with participants to mitigate the risk of participants under or overestimating the researcher's ability to use the information they provide to affect their care (Williamson & Burns, 2014). For this reason, the aims of the research were made clear using a participant information sheet and participants were informed about how their data would be used. Consent was recorded for all participants to ensure that they understood and agreed to the aims of the studies. Prior to completing the interviews,

feedback was sought from the research team and service user advisors to ensure that all content was sensitive and worded appropriately to reduce the risk of emotional harm to participants.

Keeping the researcher safe should be a priority when completing research (McCosker et al., 2001). Like participants, researchers also bring their own experiences that may be triggered through distressing content in interviews (McCosker et al., 2001). Consequently, having strategies in place to provide a supportive environment in which the researcher can express difficult feelings is essential (Williamson & Burns, 2014). This space for reflection can help the researcher to enhance their skills and resilience and maintain a safe level of emotional connection with the participants' experiences (Califf et al., 2003). Regular supervision with research supervisors who were clinical psychologists and a professor in ageing provided this space within this project. Other steps such as obtaining an up-to-date risk assessment from a clinician who worked with the participant and ensuring home visiting and clinical cover were available, all helped to keep the researcher and participants safe throughout this project.

2.10.2 Confidentiality and anonymity

An important ethical consideration for studies completed within this thesis was how to maintain participant confidentiality and anonymity. Confidentiality and anonymity are essential ethical components that protect the privacy of participants whilst completing all stages of the research process (Wiles et al., 2008). Confidentiality is often maintained by modifying participants' personal information (e.g., using a pseudonym) whereas anonymity refers to collecting data without using any personal information that can be used to identify the individuals (e.g., data used in ELSA study; Coffelt et al., 2017). Maintaining participant confidentiality and anonymity was also vital as it served to protect the privacy of participants which in turn reduced the risk of harm during the research (Wiles et al., 2008). Providing assurances that participants' personal details would not be shared also protected them from repercussions from employers,

stigma, and embarrassment therefore encouraging engagement with the research (Coffelt et al., 2017). The following steps were taken to protect anonymity and confidentiality in this thesis:

- All documents containing personal participant information were stored in locked filing cabinets and in the Lancaster University OneDrive which was password protected and encrypted.

- All other research data was stored in a separate locked filing cabinet at Lancaster University.

- All participants agreed that quotes from their interviews could be used in the final papers.

- The researcher ensured that any quotes used did not contain identifiable information and also gave participants a pseudonym to maintain their anonymity.

- The researcher informed participants prior to their participation that confidentiality would have to be broken and the relevant services contacted if they expressed a risk to themselves or others at any point.

2.11 Patient and public involvement

2.11.1 Rationale

Patient and public involvement is widely considered to be vital in improving the accessibility, quality and appropriateness of health research (Staniszewska & Denegri, 2013). The term patient and public involvement refers to research that is completed with patients or members of the public who work directly alongside the researcher to design, complete, analyse and disseminate the research study (Price et al., 2022). It is becoming increasingly common for institutions to mandate patient and public involvement and for research funders in the UK to ask applications to make clear how patient and public involvement will inform their research study (Boivin et al., 2018). Consequently, improving patient and public involvement in health research is a key priority for policymakers, academic journals, research funders and researchers

(Greenhalgh et al., 2019). The researcher therefore aimed to ensure public and patient involvement was incorporated throughout the research completed within this thesis. Two public advisors who were older adults with lived experience of mental health difficulties were recruited and met regularly with the researcher to advise on research design, data collection, data analysis and dissemination.

2.11.2 PhD design

Feedback from the two public advisors and members of the service user advisory panel at Lancaster University was incorporated and used to ensure that the research was conducted in a way that remained focused on understanding what it means to age well with bipolar disorder. By incorporating public and patient involvement, the researcher hoped that all studies were accessible to participants from a range of backgrounds and that findings could be used to make a real-world difference (Tomlinson et al., 2019). Furthermore, it was hoped that discussing the topic with public advisors who had lived experiences of the problems under investigation would help the researcher to more comprehensively understand the challenges faced by older adults with bipolar disorder. The PhD design was also reviewed alongside public advisors using the Health Inequalities Assessment Tool (HIAT). The HIAT assessment was used to consider how the project could remain focused on addressing health inequalities experienced by older adults with bipolar disorder. This informed how the research was designed and ensured that it illuminated how to improve support for this group in future.

2.11.3 Data collection

The researcher designed the topic guides for both qualitative studies alongside public advisors. The aim of this was to make sure that the topic guides were worded sensitively and appropriately for participants and that key topics surrounding older adults with bipolar disorder were covered. As reported by Tomlinson and colleagues (2019) seeking support from public

advisors when recruiting participants can also be helpful in considering where to find participants, how to approach them and what information to provide.

2.11.4 Data analysis

During qualitative data analysis, public advisors were involved in reviewing preliminary themes that had been identified during interviews. This process helped the researcher to consider whether the topic guide required adaptation and ensured that key topics of interest were being covered. Involving public advisors in the analytical process also offered the researcher a unique, lived experience perspective that enhanced the results (Gillard et al., 2012). Following the completion of data analysis, public advisors highlighted areas where findings could be disseminated to maximise the impact of the PhD project, such as through Bipolar UK, Bipolar Scotland, NHS services, and other charity organisations.

2.11.5 Ethics

Prior to the qualitative studies commencing, the researcher completed an application for HRA/REC ethical approval from the NHS. Public advisors were involved in reviewing all information sheets, consent forms and the topic guide and providing feedback. Gathering feedback from public advisors ensured that these information sheets were appropriate and clear for the target audience, that the topic guide was developed in a way that allowed for essential areas of interest to be explored and the research question answered comprehensively. All of these documents were also reviewed by a service user researcher from the Spectrum Centre for Mental Health Research at Lancaster University.

2.11.6 Limitations

Whilst there were a number of clear benefits to incorporating public and patient involvement in numerous aspects of this PhD project, there were areas where this support could have been better utilised. Firstly, the researcher did not involve public advisors in the design, or analysis

of the systematic review (chapter 3). Instead, the researcher completed initial screening and data extraction alongside another PhD student and their supervisors. Additionally, data analysis for the qualitative studies was completed in separate meetings with public advisors and research supervisors as one public advisor felt uncomfortable attending this meeting with all of the supervisors present. Meeting together with both public advisors and research supervisors would have made this process more collaborative and may have generated different interpretations of the data, although the wellbeing of the public advisor was prioritised. Finally, public advisors were unable to review transcripts of qualitative interviews due to ethical concerns and confidentiality. Consequently, whilst several steps were taken to ensure public and patient involvement throughout the project, there were certain missed opportunities that could have further enhanced collaboration within this thesis.

2.11.7 Funding for patient and public involvement

All patient and public advisors received payment for the activities described above from Applied Research Collaboration Northwest Coast (ARC NWC). Payments included £25 for short meetings (2 hours or less requiring no preparation), £50 for short meetings requiring preparation, £75 for long meetings (4 hours or more) that required preparation beforehand and £150 for whole day meetings with preparation.

2.12 Chapter summary

This chapter outlined the researcher's critical realist philosophical position and highlighted how this informed the methodology adopted in this thesis. The methods used to complete the four studies were justified and discussed in depth to highlight their strengths and consider why they were selected over other approaches. The researcher also explored the steps taken to enhance reflexivity and rigour throughout this thesis. Finally, key ethical considerations were explained and the importance of public and patient involvement within this PhD was evaluated.

Chapter 3 - Physical health comorbidities in older adults with bipolar disorder: A systematic review

<u>Introduction to systematic review paper</u>

As outlined in chapter 2, the researcher identified a gap in the literature surrounding physical health problems faced by people as they age with bipolar disorder. The following chapter of this thesis consists of a systematic review that aimed to address this gap and investigate the prevalence and predictors of physical health comorbidities in older adults with bipolar disorder. This systematic review has been published in The Journal of Affective Disorders. Please see the reference below.

Warner, A., Holland, C., Lobban, F., Harvey, D., Newens, C., & Palmier-Claus, J. (2023). Physical health comorbidities in older adults with bipolar disorder: A systematic review. *Journal of Affective Disorders*, 326 (232-242).

Chapter 3: Physical health comorbidities in older adults with bipolar disorder: A systematic review

Aaron Warner[1,2]*

Carol Holland[2]

Fiona Lobban[1,4]

Elizabeth Tyler[3]

Daisy Harvey[1]

Connie Newens[4]

Jasper Palmier-Claus[1,4]

[1]Spectrum Centre for Mental Health Research, Division of Health Research, Lancaster, UK

[2]Centre for Ageing Research, Division of Health Research, Lancaster, UK

[3]Division of Psychology & Mental Health, University of Manchester, Manchester, UK

[4]Lancashire & South Cumbria NHS Foundation Trust, Lancashire, UK.

*Email address of corresponding author: a.warner3@lancaster.ac.uk

Postal Address of corresponding author: Health Innovation One, Sir John Fisher Drive, Lancaster University, Lancaster, LA1 4YW

Keywords: Bipolar disorder – ageing – physical health - comorbidity

3.1 Abstract

Objective: To ascertain the prevalence and predictors of physical health comorbidities in older adults with bipolar disorder.

Methods: The authors conducted a systematic review and narrative synthesis of peer-reviewed journal articles reporting on physical health comorbidities in older adults (aged ≥50) with a diagnosis of bipolar disorder. The Mixed Methods Appraisal Tool (MMAT) assessed study quality.

Results: 23 papers reporting on 19 studies met the inclusion criteria. The literature on diabetes, obesity and renal disease was inconclusive. There was some tentative evidence to higher rates of cardiovascular disease and some forms of cancer in older adults with bipolar disorder in comparison to the general population, but this requires further investigation. We identified no studies looking at oral health.

Limitations: The quality ratings of the identified research were generally low. Very few studies included a comparison sample from the general population or controlled for key covariates in their analysis.

Conclusion: Existing literature provides tentative evidence that some physical health comorbidities are elevated in older adults with bipolar disorder. Clinicians should consider interventions that improve the physical health of this group, alongside the chronic mental health difficulties they experience.

3.2 Introduction

Bipolar disorder is characterised by extreme depressive and manic episodes, and disruption to thinking and behaviour that can significantly impair quality of life (Diagnostic and Statistical Manual of Mental Disorders - 5, 2013). People with a diagnosis of bipolar disorder experience high rates of suicidal thoughts, self-injury, and diminished wellbeing (Depp & Jeste, 2004). Although bipolar disorder is commonly diagnosed in young adulthood, symptoms and related difficulties often persist across the lifespan and into later life (Schurhoff et al., 2000). Older adults represent 25% of people diagnosed with bipolar disorder (Ljubic et al., 2021). This number could increase dramatically as the number of older adults continues to rise and our awareness and detection of bipolar disorder improves (Dols et al., 2014; Sajatovic et al., 2015). There is a major need to better understand the difficulties faced by older adults with bipolar disorder to ensure that they receive appropriate and effective care.

People with bipolar disorder are at increased risk of physical health problems (Depp & Jeste, 2004). Research highlights that adults living with bipolar disorder experience high levels of weight gain, diabetes, cardiovascular disease and hypertension (Young & Grunze, 2013; McIntyre et al., 2006). Mortality rates are estimated to be 2-3 times higher in bipolar disorder, and women and men with bipolar disorder die around 8.5 to 9 years younger when compared to the general population, which is largely due to a high prevalence of medical comorbidity (Crump et al., 2013). Whilst it is generally accepted that people with bipolar disorder are disproportionately affected by physical health conditions, our understanding about their causes, presentation and prevalence in older adults is very limited (Lala & Sajatovic, 2012; Dols et al., 2016).

Research demonstrates that the general ageing population are more likely to experience higher levels of physical health comorbidity than younger age groups (Firth et al., 2020). Alongside this, lifestyle factors associated with bipolar disorder such as high levels of substance misuse (Kemp et al., 2009), insomnia (Ng et al., 2015) and poor diet (Sylvia et al.,

2011) are thought to predict physical health problems, including diabetes and cardiovascular disease. These physical health problems may negatively impact the course of bipolar disorder, and are linked to increased mood episode recurrence, suicidality, and hospitalisations (Bauer et al., 2016). Consequently, it is possible that there is an interaction effect between bipolar disorder and ageing, which combine to produce worse physical health outcomes in older adults with bipolar disorder.

At present, there is a lack of expert-based advice aimed specifically at older adults with bipolar disorder (Dols et al., 2016), which may result in poorer outcomes and less effective treatments for this group (Kilbourne, 2005; Kilbourne et al., 2008). In 2004, Depp and Jeste reviewed medical morbidity in older adults with bipolar disorder, reporting that 20% of people had seven or more medical comorbidities, and that rates of diabetes are high. However, this review was conducted over a decade ago and now requires updating. Other reviews surrounding older adults with bipolar disorder appear to have predominantly focused on available treatments (Oshima & Higuchi, 1999; Sajatovic, 2002; Aziz et al., 2006) and cognitive impairment (Quraishi & Frangao, 2002; Young et al., 2006; Samame et al., 2013), or have not been systematic in their reviewing of the literature (Lala & Sajatovic,2012). To the best of our knowledge, there is no up to date systematic review that provides a comprehensive overview of the prevalence and predictors of physical health comorbidities experienced by older adults with bipolar disorder.

3.2.1 Aim of review

To review the prevalence and predictors of physical health comorbidities in older adults with bipolar disorder.

3.3 Methods

The review followed PRISMA guidelines (Page et al., 2021), with a protocol registered on a review protocol repository (PROSPERO ID: CRD42021241087). A systematic search of four databases (PsychINFO, MEDLINE, CINAHL and PubMed) identified peer reviewed journal articles published from 1980 to April 2022. This date range was selected as the term bipolar disorder was first included in DSM-III in 1980. Search terms related to bipolar disorder, ageing and older adults (see online Supplementary Material). This article concerns the findings of papers reporting on physical health comorbidities. A second article outlining the findings for psychiatric comorbidities in older adults with bipolar disorder will be published elsewhere.

3.3.1 Inclusion and exclusion criteria

The authors included articles published in the English language and in peer reviewed journals. Eligible research methods included cross sectional, cohort, experimental, epidemiological, case series and case control design studies. Eligible studies had to report on an apriori selected physical health comorbidity, namely diabetes, cancer, renal disease, cardiovascular disease, obesity, or oral health outcomes. These physical health comorbidities were identified as problematic for populations with bipolar disorder following a scoping review of existing literature and consideration of research in adult populations.

Studies were included if the sample had received a formal diagnosis or met criteria for bipolar disorder I or II according to the Diagnostic and Statistical Manual (DSM-III, DSM-IIIR, DSM-IV, DSM-IV-TR & DSM-V) or bipolar affective disorder in the International Classification of Diseases (ICD-9 or ICD-10). Eligible studies had to include a sample of participants aged 50 and over, a cut-off recommended by Sajatovic and colleagues (2015). Studies that included participants of any age and other diagnoses were included, but only if 75% of the sample had a diagnosis of bipolar disorder and results were separable for those aged ≥50 with bipolar disorder.

3.3.2 Screening and data extraction

The primary author screened all of the identified articles to assess eligibility. 19% (588 articles) of articles at title/abstract level were also double rated by a second researcher (D.H.), with good levels of agreement (kappa=0.72). D.H. also double screened 20% of full text articles (64 articles), again with high levels of agreement (97%). Any disagreements were resolved through discussion with the wider team. After completing full text screening, the first author extracted key information (authors, country, sample, age of sample, diagnostic system used, design, study aims, physical health comorbidities assessed and main findings) into a purpose-built database. The primary author also reviewed the reference lists and citing articles from the eligible research papers and relevant reviews and searched the past work of the first author of each manuscript included in this review.

3.3.3 Quality assessment

Methodological quality was assessed using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018), as it is a suitable tool for evaluating the quality of studies across heterogeneous designs. The lead author (AW) and sixth author (CN) quality assessed all papers independently with excellent levels of agreement (92% agreement). All conflicts were resolved during discussions between both reviewers (see Table 3).

3.3.4 Data synthesis

Narrative synthesis aims to adopt a textual approach that analyses the relationships within and between studies, whilst ensuring a robust assessment of the evidence (Popay et al., 2006). However, it is suggested that systematic reviews utilising this approach often fail to effectively report the synthesis methods, leading to doubts over the validity of their findings (Campbell et al., 2020). We addressed this limitation by using an approach that followed guidelines outlined by Campbell and colleagues (2020). This included reporting how the narrative synthesis had

been completed, explaining why the data had been reported and clearly outlining the findings and limitations of the synthesis. Where appropriate, the authors have reported weighted averages of the prevalence of physical health comorbidities in the study samples.

3.4 Results

The systematic search identified 3081 papers after the removal of duplicates. The lead author screened 321 full articles. In total, 23 papers reporting on 19 studies met the eligibility criteria and were included in this systematic review (see figure 1).

Figure 1 – PRISMA Flowchart of screening procedures.
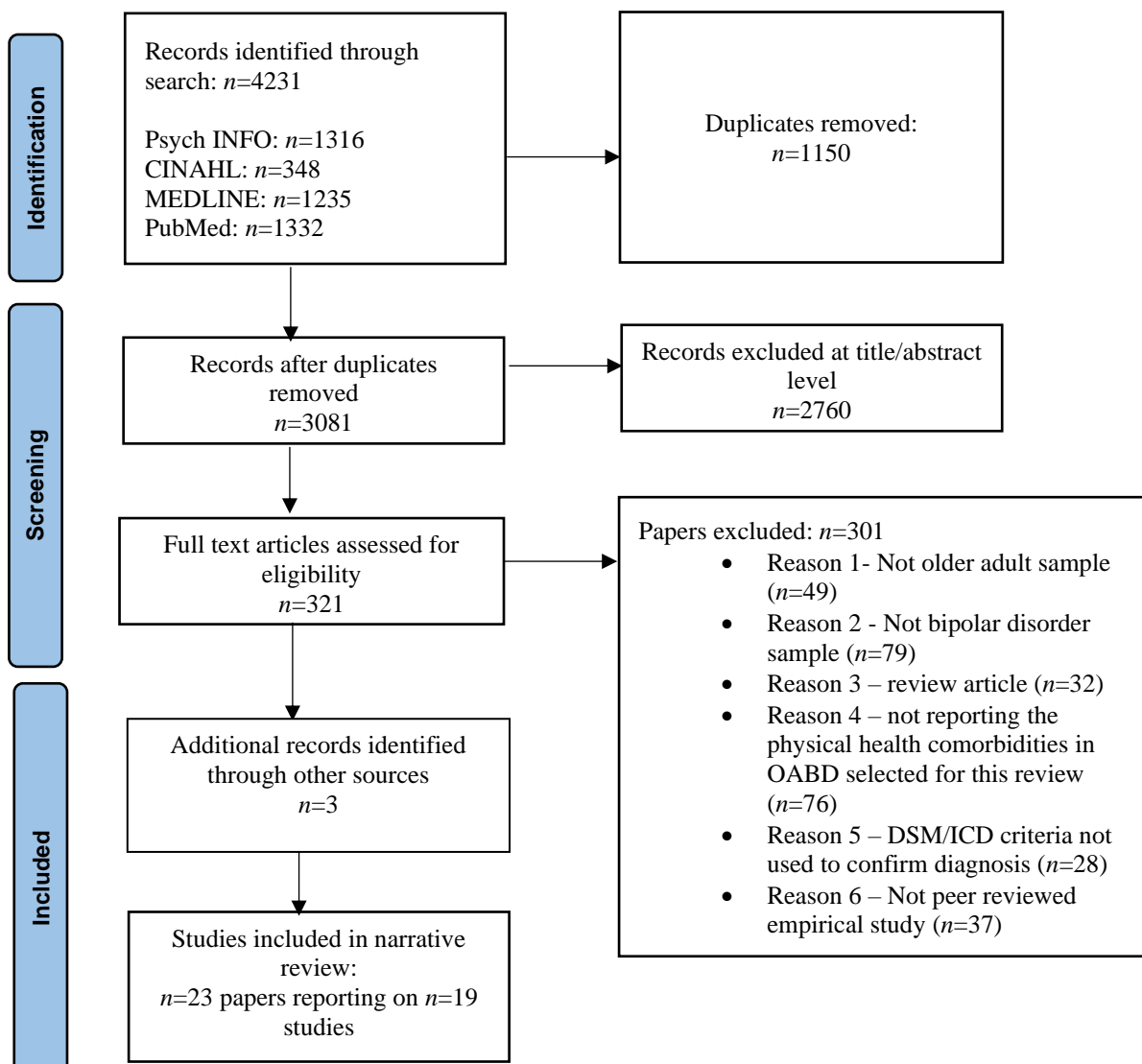
3.4.1 Study characteristics

Six studies were included from Taiwan, and the United States of America. Studies were also included from the Netherlands (*n*=3), Sweden (*n*=1), Spain (*n*=1) Australia (*n*=1), and Canada (*n*=1). Five papers from Australia (Almeida 2014; 2016; 2018; 2018b;2018c) used the same sample and were therefore counted as one study. Eight studies were cross-sectional, five were cohort studies, five were case-control and one was an epidemiological study. The total number of participants included across all studies was 99,241, ranging from 48 older adults with bipolar disorder (Sajatovic et al., 2005) to 46,490 older adults with bipolar disorder (Chen et al., 2020). The study characteristics are presented in Table 2 below. The literature reported on diabetes (*n*=13), cancer (*n*=5), renal disease (*n*=6), cardiovascular disease (*n*=13), and obesity (*n*=3) in older adults with bipolar disorder. We identified no studies reporting on oral health outcomes in older adults with bipolar disorder.

Table 2: Study characteristics

Authors	Country	Sample	Age of Sample	Diagnostic System	Design	Study Aims	Physical Health Comorbidity	Main Findings
Almeida et al.(2014;2016a;2018 a-c)	Australia	37892 older men (101 had BD) (Almeida et al. (2014). 37 768 men, 256 with BD (2016b) 37,173 older men, 250 males with BD a diagnosis of BD (2018;2018b;2018c) 38, 173 men, 250 with BD.	65-85	ICD 8, 9 and 10	Cross sectional (2018b) and Cohort study (2014;2016;2018;2018b;2018c)	Determine the following: the 14-year cause specific mortality of older men with and without severe mental disorders. Investigated the prevalence of common medical morbidities among older men with EO and LO diagnosis of BD.	Cancer, cardiovascular diseases, coronary heart disease, diabetes, renal disease	More people with BD were obese than schizophrenia spectrum controls and the prevalence of medical morbidities was greater among participants with BD than without BD.
Almeida et al. (2022)	USA	1519 men and women with BD. 622 age matched men without BD.	50+	DSM-IV or ICD-10	Cross-sectional	To compare physical health comorbidities among older males with BD and older females with BD and older adults without BD.	Cardiovascular disease, renal disease	Older men with BD had a higher prevalence of cardiovascular disease and renal disease in comparison to older adults without BD.
Beunders et al. (2021a)	The Netherlands	101 patients with OABD and 2545 older adults from general population.	60+	Mini-International Neuropsychiatric Interview Plus (based on ICD-10 and DSM-IV)	Cohort study	Investigate the accumulation of physical diseases in older adults with bipolar disorder and older adults from the general population over a three-year period.	Cancer, diabetes, heart disease	OABD accumulated chronic physical diseases faster than older adults from the general population over a three-year period.
Beunders et al. (2021b)	The Netherlands	227 older adults with bipolar disorder.	50+	DSM IV- TR	Cross-sectional	Explore a range of candidate determinants of cognitive performance in OABD.	Cardiovascular disease, diabetes, obesity	Cardiovascular risk is related to cognitive performance in OABD.

Chen et al. (2015)	Taiwan	80 individuals with Bipolar I who had at least 1 psychiatric admission.	60+	DSM-IV	Case Control	Examine the relationship between Coronary Heart Diseases and clinical characteristics in BD patients.	Cardiovascular diseases	About 1/4 of old bipolar patients have Coronary Heart Diseases (CHD's) in both Asian and Western populations.
Chen et al. (2017)	Taiwan	124 patients with BD-I who had at least one psychiatric admission and cardiologist-confirmed Cardiovascular disease (CVD) diagnosis. 124 age, sex matched controls with BD but without CVD.	50+	DSM-IV and ICD-9	Cross-sectional	Examine the relationship between Cardiovascular Diseases and traditional risk factors in association with BD in older age.	Cardiovascular disease, diabetes mellitus	Traditional risk factors (e.g., diabetes mellitus) and non-traditional risk factors associated with BD (e.g., first episode mania) significantly increased the risk of Cardiovascular Diseases.
Chen et al. (2020)	Taiwan	46,490 patients with BD, 467 of whom experienced sudden cardiac death	50+ and <50	ICD-9-CM	Cohort study	Estimate the incidence and standardized mortality ratio (SMR) of sudden cardiac death in patients with BD across the lifespan.	Cardiac failure, congestive heart illness, renal disease	The risk of sudden cardiac death is remarkably high in BD patients across the lifespan.
Dols et al. (2014)	The Netherlands	101 BD patients.	60+	DSM-IV-TR	Cross-sectional	Analyse psychiatric and medical comorbidity in a Dutch BD elderly cohort.	Diabetes	OABD patients had on average two comorbid medical conditions and relatively high medication use.
Fenn et al. (2005)	USA	330 older adults hospitalised for bipolar disorder	Across age span including 50+	DSM-IV	Cross-sectional	Assess if the prevalence of medical morbidity increases with age in bipolar disorder patients.	Diabetes, cardiovascular disease	Medical morbidities increase with age in bipolar disorder patients and negatively impacts health related quality of life.
Gildengers et al. (2008)	USA	54 patients with BD I (N=39) or II (N=15), 108 participants with Major Depressive Disorder (MDD).	60+	DSM-IV	Case-control	Compare medical burden in elderly patients with BD with that in those with major depressive disorder.	Diabetes	Compared with patients with major depressive disorder, patients with BD had similar levels of general medical comorbidity and number of systems affected.
	Taiwan		>50	DSM-IV			Cardiovascular disease	

Lee et al. (2019)		62 patients with BD with illness onset <40 years of age.			Case-control	Investigate morbidity and related factors in for stroke in OABD.		High morbidity of stroke, could be found in older bipolar patients with typical-onset age.
Liao et al. (2020)	Taiwan	113 patients with BD and 104 patients with schizophrenia	>50	DSM-IV	Case-control	Evaluate differences in outcomes related to physical health between older community-dwelling adults with BD and early onset schizophrenia.	Cardiovascular disease, diabetes, obesity	OABD remain at higher risk for obesity and medical morbidity than schizophrenia patients.
Martinsso n et al. (2016)	Sweden	5,442 patients with BD with and without lithium treatment compared to the general population.	50-84	ICD	Epidemiol ogical	Investigate if there is an increased risk of cancer associated with lithium treatment	Cancer	BD was not associated with increased cancer incidence and neither was lithium treatment in these patients.
Nivoli et al. (2014)	Spain	593 BD outpatients.	>65 and <65	DSM-IV-TR	Cohort study	Analyse differences in clinical and socio-demographic characteristics between older and younger BD outpatients.	Cancer, coronary heart disease, diabetes, obesity, renal failure	OABD experienced more medical comorbidities when compared to younger people with BD.
Regenold et al. (2002)	USA	243 inpatients with diagnoses of major depression, BD I, schizoaffective disorder, schizophrenia, and dementia.	50-74	DSM-IV	Cross-sectional	Determine if there is an increased prevalence of diabetes among patients with particular psychiatric disorders.	Diabetes mellitus	Rates of type 2 diabetes mellitus were: schizoaffective (50%), bipolar I (26%), major depression (18%) dementia (18%), schizophrenia (13%).
Rej et al. (2015)	Canada	1388 BD patients discharged from a psychiatric hospitalization in Ontario, Canada, between 2006 and 2012.	66+	DSM-IV	Cohort study	Explore whether lithium use would be associated with higher rates of medical hospitalization.	Cancer, renal disease, congestive heart failure, diabetes	There were high rates of health service use for medical conditions among older adults with BD, but this did not appear to be associated with lithium use.

Sajatovic et al. (2005)	USA	48 older adults with BD, and compared groups with early-onset (EOS) versus late-onset (LOS) BD.	50+	DSM-IV	Cohort study	Evaluate clinical characteristics among 48 older adults with BD, and compared groups with EOBD versus LOBD.	Diabetes	Both groups had extensive medical comorbidity (mean of 3.7 comorbid medical conditions).
Sajatovic et al. (2022)	USA	1377 older adults with BD. 301 healthy volunteers.	50+	DSM-IV or ICD-10	Cross sectional	Assess symptoms, physical health comorbidity and functioning in OABD.	Cardiovascular disease, renal disease	Older age was associated with greater somatic comorbidity, specifically for BD.
Tsai et al. (2009)	Taiwan	82 euthymic outpatients with BD I, 59 were matched with healthy controls based on age and years of education.	60+	DSM-IV	Case-control	Investigate the differences in medical burden between older adult community-dwelling bipolar patients and age-matched healthy controls.	Diabetes mellitus	Older adult bipolar patients were found to be more likely than the comparison group to have diabetes mellitus (27.1%).

3.4.2 Diabetes

Thirteen studies reported on diabetes in older adults with bipolar disorder (Almeida et al., 2014; 2018a-c; Beunders et al., 2021a,b; Chen et al., 2017; Dols et al., 2014; Fenn et al., 2005; Liao et al., 2020; Nivoli et al., 2014; Regenold et al., 2002; Rej et al., 2015; Sajatovic et al., 2005; Tsai et al., 2009; Gildengers et al., 2008; Beunders et al., 2021b). Ten of these studies (Almeida et al., 2014; Chen et al., 2017; Dols et al., 2014; Liao et al., 2020; Regenold et al., 2002; Sajatovic et al., 2005; Tsai et al., 2009, Fenn et al., 2005; Beunders et al., 2021a,b) reported the prevalence of diabetes with a weighted average of 20.2%. Prevalence rates ranged from 10.1% (Fenn et al., 2005) to 43.5% (Chen et al., 2017). The majority of studies failed to distinguish between type I and type II diabetes and reported its presence as a single variable.

Tsai and colleagues (2009) reported that their sample of older adults with bipolar disorder were more likely to have diabetes (n=59; 27.1%) than age matched controls from the general population (n=59; 13.6%), although these results were not statistically significant (x^2=2.50; p=0.113). Almeida and colleagues (2018b) observed that diabetes was more prevalent in a sample of older adult men with both early onset (aged < 60 years; n=175; 12.6%) and late onset (aged 60+ years; n=75; 14.7%) bipolar disorder, when compared to older men without bipolar disorder (n=37,923; 7.7%). However, no significant differences were noted in rates of diabetes between older adults with early onset or late onset bipolar disorder.

Regenold and colleagues (2002) found significant differences in rates of diabetes among age, race and gender matched older adults with bipolar disorder, schizophrenia, schizoaffective disorder, and dementia. The sample of older adults with bipolar disorder had higher rates of diabetes (n=243; 26% prevalence of diabetes) when compared to older adults with a diagnosis of schizophrenia (13% prevalence) or dementia (18% prevalence), but lower rates than people diagnosed with schizoaffective disorder (50% prevalence) (x^2=14.5, df=4, p=0.006). This study attempted to control for the confounding effects of age, gender, race, medication use, and body mass in their group comparison. The authors suggested that the

increased prevalence of diabetes in older adults with bipolar disorder and schizoaffective disorder was potentially linked to specific physiopathology common to both diagnoses. We failed to identify any studies investigating predictors of diabetes in this population, suggesting a lack of evidence in this area.

3.4.3 Cancer

Five studies (Almeida et al., 2014, 2018b, 2018c; Beunders et al., 2021a; Martinsson et al., 2016; Nivoli et al., 2014; Rej et al., 2015) investigated the prevalence of cancer diagnoses in older adults with bipolar disorder. Four of these included the prevalence of cancer in their samples (Almeida et al., 2014; Beunders et al., 2021a; Nivoli et al., 2014; Martinsson et al., 2016) with a weighted average of 6.5%. The prevalence of cancer ranged from 6% (Martinsson et al., 2016) to 19.6% (Nivoli et al., 2014) in these studies.

Martinsson and colleagues (2016) investigated lithium treatment as a predictor of cancer incidence in a sample of 5442 people aged 50-84 years with bipolar disorder taken from a Swedish nationwide register. They found that overall cancer risk was not increased in bipolar disorder patients with (IRR = 1.04, 95% confidence interval (CI): 0.89–1.23) or without (IRR = 1.03, 95% CI: 0.89–1.19) lithium treatment, when compared to the general population. However, when exploring specific types of cancer, cancer risk was significantly increased in bipolar disorder patients who were not receiving lithium treatment in the respiratory system and intrathoracic organs (IRR = 1.72, 95% CI: 1.11–2.66), digestive organs (IRR = 1.47, 95% CI: 1.12–1.93), as well as in the endocrine glands (IRR = 2.60, 95% CI: 1.24–5.47). Finally, no significant increase in cancer risk was observed in older bipolar disorder patients receiving lithium treatment in comparison to the general population.

Cohort studies involving 38,173 men aged 65-85 years (*n*=250 with bipolar disorder diagnosis) by Almeida and colleagues (2018b; 2018c) reported the prevalence of a number of medical comorbidities and found that the prevalence of cancer in older adults with bipolar

disorder (*n*=101; 10.9%) was similar to that of older adults without bipolar disorder (*n*=35,691; 16.7%). Another analysis of the same dataset by Almeida and colleagues (2014) also reported that older adults with bipolar disorder (*n*=101) had lower rates of mortality due to cancer (10.9%) in comparison to patients with schizophrenia (*n*=444; 13.7%), depression (*n*=958; 19.3%), alcohol misuse (*n*=698; 20.5%) and no severe mental disorder (*n*=35,691; 16.7%).

3.4.4 Renal disease

Six studies (Almeida et al., 2016, 2018b, 2018c; Almeida et al., 2022; Chen et al., 2020; Nivoli et al., 2014; Rej et al., 2015; Sajatovic et al., 2022) considered renal disease in older adults with bipolar disorder. Four studies (Nivoli et al., 2014; Almeida et al., 2016; Chen et al., 2020; Sajatovic et al., 2022) reported the prevalence of renal disease in their sample, recording a weighted average of 1.4%. Prevalence rates ranged from 1.3% (Chen et al., 2020) to 8.6% (Nivoli et al., 2014).

Almeida and colleagues (2018b) found no statistically significant difference in the prevalence of renal disease in older adults with both early onset (*n*=175; 3.4%) and late onset (*n*=75; 4%) bipolar disorder, compared to older adults without bipolar disorder (*n*=37,923; 2.1%). They did report an increased risk of hospital contacts caused by renal disease in those with both early onset (onset aged < 60 years; Hazard Ratio (HR) 1.46; 95% Confidence Intervals (CI): 1.20, 1.78) and late onset bipolar disorder (onset aged 60+ years; HR = 1.60, CI:1.20, 2.13) in comparison to older men without bipolar disorder. However, Almeida and colleagues reported no significant differences in the prevalence of renal disease or risk of hospital contact among participants in the early onset and late onset bipolar disorder groups.

In a cohort study investigating the predictors of renal disease in older adults with bipolar disorder, Rej and colleagues (2015) analysed data from 1388 bipolar disorder patients aged > 66 years. The authors reported that older adults with bipolar disorder using lithium (n=279; 11.5% renal disease prevalence) did not have a statistically significantly higher prevalence of

renal disease than older adults with bipolar disorder who were being treated with valproate (n=452; 15.9% prevalence) and non-lithium/non-valproate users (n=657; 12% prevalence). However, as a note of caution, Rej and colleagues did suggest that the findings may have been influenced by clinicians' not prescribing lithium to those who had pre-existing renal conditions.

3.4.5 Cardiovascular disease

Thirteen studies reported on cardiovascular disease in older adults with bipolar disorder (Almeida et al., 2014, 2016, 2018b, 2018c; Almeida et al., 2022; Beunders et al., 2021a,b; Chen et al., 2015; Chen et al., 2017; Chen et al., 2020; Fenn et al., 2005; Lee et al., 2019; Liao et al., 2020; Nivoli et al., 2014; Rej et al., 2015; Sajatovic et al., 2022; Beunders et al., 2021b). Seven of these (Almeida et al., 2014; Beunders et al., 2021a,b; Fenn et al., 2005; Nivoli et al., 2014; Liao et al., 2020; Sajatovic et al., 2022; Beunders et al., 2021b) stated the prevalence of cardiovascular disease in their sample of older adults with bipolar disorder, with a weighted average of 32.6% across studies. Prevalence rates ranged greatly from 10.2% (Nivoli et al., 2014) to 54.9% (Liao et al., 2020).

Almeida and colleagues (2018b; 2018c) found that cardiovascular diseases were more prevalent in older adults with both early (onset < 50 years of age; n=80; 56.2% average) and late onset (onset 50+; n=170) bipolar disorder (49.4% average), compared to older adults without bipolar disorder from a community representative sample in Western Australia (n=37,183; 37.3% average). The data also showed that cardiovascular disease was more prevalent among older adults with early onset (onset aged <50 years) than those with late onset (onset aged 50+) bipolar disorder in this sample.

When investigating the link between cardiovascular risk factors (hypertension and diabetes) and diseases (stroke and ischaemic heart disease), Almeida and Colleagues (2018b; 2018c) found that both early onset (52.6%; OR=1.50, 95% CI=1.11, 2.03) and late onset bipolar disorder groups (62.7%; OR=1.86, 95% CI=1.16, 2.99) had greater age adjusted odds of

developing cardiovascular disease when compared to older adults without bipolar disorder (44.6%). However, differences in the prevalence or risk of developing cardiovascular disease among participants with early onset or late onset bipolar disorder were negligible. Although these findings are noteworthy, it is important to consider that the number of older people with bipolar disorder in Almeida's (2018b; 2018c) studies were relatively small (*n*=250), which may have contributed to some imprecision in the results.

A case control study by Chen and Colleagues (2015), included a sample of older adults with bipolar disorder with cardiovascular disease (*n*=20) and a control group of older adults with bipolar disorder but without cardiovascular disease (*n*=60). This study concluded that high serum sodium levels during an acute affective episode may be a predictor of an increased risk of cardiovascular disease in older adults with bipolar disorder. Chen and colleagues hypothesised that the high serum sodium levels observed in this group may be caused by unhealthy lifestyles and salt consumption during affective episodes, as well as the long-term use of lithium that has been linked to nephrogenic diabetes insipidus and water-loss hypernatremia. Additionally, a separate cross-sectional study by Chen and colleagues (2017) investigated predictors of cardiovascular disease in older adults with bipolar disorder. Chen and colleagues found that first episode mania was identified as a key risk factor in developing cardiovascular disease in this group after adjusting for factors such as smoking, obesity, alcohol use and dyslipidemia. The authors suggested that this highlights that older adults with bipolar disorder may have unique risk factors for developing cardiovascular disease due to specific features of bipolar disorder (e.g., first episode mania), in comparison to the general population. However, this study did not include a healthy comparison group from the general population, making it difficult to confirm the reliability of these findings.

Chen and colleagues (2020) completed a cohort study including 46,4690 patients with bipolar disorder and found that older adult males with bipolar disorder carry an increased risk of sudden cardiac death in comparison to older adult females with bipolar disorder (0.54, 95%

CI: 0.45–0.66, p < 0.001). This highlights that there may be unique sex differences in cardiovascular risk among older adults with bipolar disorder. This study also reported that older adults with bipolar disorder had a higher cumulative incidence of sudden cardiac death when compared to younger adults with bipolar disorder. These findings suggest that older adults with bipolar disorder may experience increased cardiovascular risk in comparison to younger age groups with bipolar disorder. Finally, this study found that dementia is linked to an increased risk of sudden cardiac death in older adults with bipolar disorder (1.75, 95% CI: 1.30–2.35).

3.4.6 Obesity

Three studies (Liao et al., 2020; Nivoli et al., 2014; Beunders et al., 2021b) reported on obesity in their sample of older adult outpatients with bipolar disorder. Liao and colleagues (2020) recruited a sample of community dwelling older adults with early onset bipolar disorder (onset < 40 years of age; *n*=113) and early onset schizophrenia (*n*=104). 39.8% of the bipolar group were obese, compared to 32.4% of the schizophrenia group, although this difference was not statistically significant. However, the bipolar group did have a significantly higher body mass index (Adjusted OR) = 1.11, 95% CI 1.02–1.21) than the schizophrenia group.

A cohort study by Nivoli and colleagues (2014) reported a modest prevalence of obesity (0.8%) in community dwelling adults with bipolar disorder (aged <65; *n*=470) and 5.2% of community dwelling older adults with bipolar disorder aged over 65 in Spain (*n*=123), although these findings were not statistically significant. Finally, Beunders and colleagues (2021b) stated that the prevalence rate of obesity among their sample of 227 older adults with bipolar disorder was 17.2%. After analysing findings from these three studies, it is unclear why there are such large discrepancies in the prevalence rates reported in the samples. No studies reported on the predictors of obesity in older adults with bipolar disorder.

3.4.7 Oral health

We identified no studies reporting on oral health outcomes in older adults with bipolar disorder.

3.4.8 Quality assessment

Just six studies included samples that were representative of older adults with bipolar disorder according to the quality assessment tool (Almeida et al. 2014; 2016; 2018a-c; Almeida et al., 2022; Beunders et al., 2021a; Dols et al., 2014; Rej et al., 2015; Sajatovic et al., 2015). However, all included studies confirmed use of DSM or ICD criteria for bipolar disorder allowing for more homogeneous samples. Many studies had small samples of older adults with bipolar disorder, or only included community dwelling samples often referred to as 'survivor samples' that may have been subjected to better care and outcomes. Because of this, bipolar disorder patients who were most unwell may have died prematurely or might have been living within inpatient services, meaning that the experiences of these individuals were not captured within these studies. Consequently, findings may not be generalizable to a large proportion of people experiencing bipolar disorder, and results may be skewed.

Only seven studies (Almeida et al. 2014; 2016; 2018a-c; Almeida et al., 2022; Beunders et al., 2021a; Regenold et al., 2002; Tsai et al., 2009; Martinsson et al., 2016; Sajatovic et al., 2022) included a 'healthy' comparison group without mental health difficulties from the general population. Just four studies (Fenn et al., 2005; Beunders et al., 2021a; Chen et al., 2015; Tsai et al., 2009) controlled for confounding variables such as medication use, and social and lifestyle factors (e.g., smoking, alcohol use, medication use). This makes it difficult to determine whether high prevalence rates reported were due to factors specific to bipolar disorder or other confounding variables. Finally, despite these limitations, the majority of studies (n=16; Almeida et al. 2014; 2016; 2018; 2018b; 2018c; Almeida et al., 2022; Chen et al., 2015; Chen et al., 2020; Dols et al., 2014; Fenn et al., 2005; Lee et al., 2019; Liao et al., 2020; Martinsson et al., 2016; Nivoli et al., 2014; Regenold et al., 2002; Rej et al., 2015;

Sajatovic et al., 2005; Tsai et al., 2009; Sajatovic et al., 2022; Beunders et al., 2021b) were

rated as having used appropriate measures that were clearly defined and valid and reliable for

answering the study's research question (table 3).

Table 3: MMAT quality assessment table

Author(s)	Ratings from Mixed Methods Appraisal Tool (MMAT)						
	S1	S2	3.1	3.2	3.3	3.4	3.5
Almeida et al. (2014; 2016; 2018a-c)	1	1	1	1	1	0	1
Almeida et al. (2022)	1	1	1	1	1	0	1
Beunders et al. (2021a)	1	1	1	0	1	1	1
Beunders et al. (2021b)	1	1	0	1	0	0	1
Chen et al. (2015)	1	1	0	1	1	0	1
Chen et al. (2017)	1	1	0	0	1	1	1
Chen et al. (2020)	1	1	0	1	1	0	1
Dols et al. (2014)	1	1	1	1	1	0	1
Fenn et al. (2005)	1	1	0	1	1	1	1
Gildengers et al. (2008)	1	1	0	0	1	0	1
Lee et al. (2019)	1	1	0	1	1	0	1
Liao et al. (2020)	1	1	0	1	1	0	1
Martinsson et al. (2016)	1	1	0	1	1	0	1
Nivoli et al. (2014)	1	1	0	1	1	0	1
Regenold et al. (2002)	1	1	0	1	1	0	1
Rej et al. (2015)	1	1	1	1	1	0	0
Sajatovic et al. (2005)	1	1	1	1	1	0	1
Sajatovic et al. (2022)	1	1	0	1	1	0	1
Tsai et al. (2009)	1	1	0	1	0	1	1

MMAT Questions
- S1. Are there clear research questions?
- S2. Do the collected data allow to address the research questions?
- 3.1. Are the participant's representative of the target population?

- 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)?
- 3.3. Are there complete outcome data?
- 3.4. Are the confounders accounted for in the design and analysis?
- 3.5. During the study period, is the intervention administered (or exposure occurred) as intended?

<u>Key</u>

- 0=No
- 1=Yes
- 2=Don't know

3.5 Discussion

This systematic review systematically identified literature reporting on the prevalence and predictors of physical health problems in older adults with bipolar disorder. The authors identified 23 papers reporting on 19 studies that investigated five key physical health comorbidities, using a variety of study designs across seven countries. Overall, the evidence was limited, with few studies for each outcome and little use of matched samples, controlling for covariates in analyses, or longitudinal analysis. Nevertheless, there was some tentative indication of higher rates of cardiovascular disease in older adults with bipolar disorder in comparison to the general population, although this needs to be investigated further. Findings highlighted that the prevalence of cardiovascular disease was 32.6% among older adults with bipolar disorder on average.

Quality assessment highlighted a number of limitations within the identified literature. Very few studies (n=7) included a 'healthy' comparison group, making it difficult to draw conclusions on the severity of the problems in older adults with bipolar disorder in comparison to the general population. Papers that did include a comparison group found no statistically significant differences in the prevalence of diabetes or renal disease in older adults with bipolar disorder when compared to the general population. There was some tentative evidence to suggest higher rates of cardiovascular disease and some forms of cancer in older adults with bipolar disorder, but this requires further investigation. There was insufficient evidence to determine whether this group experience higher levels of obesity, and no studies were found that explored oral health outcomes in older adults with bipolar disorder, which has been identified as a problem in adult samples (Kang et al., 2022).

The majority of studies in this review (n=15) failed control for social, environmental and lifestyle factors that may confound findings in bipolar disorder populations. Consequently, it is not possible to conclude which specific factors associated with bipolar disorder predict physical health problems in older adults. Studies did speculate that dietary choices during

affective episodes and first episode mania may be a predictor of increased physical health comorbidity in this group. Furthermore, in contrast to previous studies exploring cancer risk (Lin et al., 2013; BarChana et al., 2008) and renal disease (Close et al., 2014) in adult samples, papers in this review did not highlight lithium medication as a predictor of these comorbidities. Whilst these findings potentially have important clinical implications, a failure to control for key confounding variables means it is not possible to verify whether these effects are an artefact of common risk factors. Further research that controls for social, lifestyle and environmental factors is vital in allowing us to identify key predictors of physical health comorbidities in older adult bipolar disorder populations. This could help to highlight and implement prevention measures that reduce the risk of older adults with bipolar disorder developing physical health problems in later life.

Existing research in adult populations proposes that the causes of physical health problems in bipolar disorder are likely multifactorial. A systematic review completed by Di Florio and colleagues (2014) reports that one in three adults with bipolar disorder have an alcohol use disorder, whereas Jackson and colleagues (2015) found that many smoke cigarettes. Furthermore, adults with bipolar disorder are often sedentary for over 10 hours a day (Vancampfort et al., 2017) and consume 200 more calories each day than the general population (Teasdale et al., 2019), putting them at greater risk of developing physical health problems such as cardiovascular disease and diabetes. To date, these findings have not been replicated in older adult samples but may provide hypotheses as to why people with bipolar disorder experience poor physical health in later life.

3.5.1 Strengths and limitations

This paper systematically summarises the available literature on six physical health comorbidities in older adults with bipolar disorder. The search terms for this systematic review were kept deliberately broad to capture all key articles investigating older adults with bipolar

disorder, and key physical health comorbidities in this group. However, there are also some limitations to this systematic review. Firstly, the authors only included published papers written in English increasing the chances of a file drawer effect (Rosenthal, 1979). Many of the eligible studies included only a small sample of older adults with bipolar disorder and they did not include age matched control groups or comparison groups of older adults from the general population without mental health difficulties. Large-scale studies that include matched healthy control groups are needed to determine whether the observed prevalence rates and group differences are caused by specific factors associated with bipolar disorder itself or other confounding variables. This review also only covers six key physical health comorbidities in older adults with bipolar disorder, and other comorbidities reported in existing literature (e.g., strokes, hypertension, body mass index, dementia, gastrointestinal diseases, chronic respiratory diseases, musculoskeletal diseases, liver disease, and endocrine and metabolic diseases) may warrant further attention.

3.5.2 Clinical implications

This review provides tentative evidence that clinicians should pay specific attention to physical health comorbidities when treating older adults with bipolar disorder. Despite literature highlighting that comorbid physical health problems lead to worse clinical outcomes, increased health care use and greater cost to the economy in older adults with bipolar disorder (Sajatovic et al., 2006; Lala & Sajatovic, 2006), there remains a lack of age specific treatments for this group (Clifton et al., 2013). It is important that clinicians consider treatments that aim to improve the physical health of people with bipolar disorder, as this could potentially reduce their risk of developing physical health problems in later life (Jackson et al., 2015). This includes supporting them to develop more healthy lifestyles and diets, as dietary choices during affective episodes, lack of sleep, excessive smoking and sedentary lifestyles are believed to contribute to the development of the physical health comorbidities as discussed in this review.

It could also be beneficial to tailor treatments that focus on enabling this group to maintain independence and enhance their ability to engage in activities that are meaningful to them despite the physical health difficulties they may experience in later life. These findings are in line with a recovery approach (Leamy et al., 2011), which argues that treatments should focus on supporting people with bipolar disorder to live meaningful lives despite the challenges they face, rather than simply removing the symptoms of bipolar disorder. Consequently, these steps may have a significant impact on clinical outcomes and the quality of life of older adults with bipolar disorder.

3.5.3 Future research directions

Future research should aim to address some of the limitations identified within this review. In particular, studies should aim to include healthy control groups from the general population, and control for key confounding variables. This would enable us to conclude whether elevated rates of physical health comorbidities among older adults with bipolar disorder are due to factors specific to bipolar disorder, or other covariates. Future research should also include larger numbers of older adults with bipolar disorder from a range of backgrounds including both community and inpatient services, to ensure representative samples. This review shows that the majority of studies exploring physical health comorbidities in older adults with bipolar disorder, included 'survivor cohorts' living in the community, who may experience more positive outcomes, and relative stability. Consequently, the experiences of many older adults with bipolar disorder are not represented within existing literature.

We found mixed findings regarding sex differences in physical health comorbidities among older adult men and women with bipolar disorder. Our findings highlighted that older adult women with bipolar disorder may be at greater risk of sudden cardiac death when compared to older adult men with bipolar disorder. (Chen et al., 2020). Almeida and colleagues (2022) did not find any significant sex differences in the physical health comorbidities assessed

within this review, although they did report that diseases of the gastrointestinal, respiratory, musculoskeletal and endocrinological systems, appear to affect more women than men with older adult bipolar disorder. These findings may have important clinical implications when supporting older adults with bipolar disorder, although more research is needed to confirm these results. This review also identified a lack of research surrounding obesity in older adults with bipolar disorder. A recent study by Lengvenyte and colleagues (2022) found that violent suicide attempts were linked to higher levels of abdominal obesity in older adults with bipolar disorder, but the reason for this association remains unclear. Future research could therefore explore the potential association between physical health comorbidities such as this, and psychological functioning in older adults with bipolar disorder.

The authors identified that there is no current literature exploring oral health outcomes in older adults with bipolar disorder. Oral health outcomes in this group may warrant investigations, as a recent report completed by Kang and colleagues (2022) found that individuals with severe mental illness generally experience poorer oral health outcomes in comparison to the general population, and a key risk factor for poor oral health is older age. Future research should also investigate other comorbidities that may affect older adults with bipolar disorder, such as gastrointestinal disease, dementia, respiratory diseases, musculoskeletal diseases, strokes, endocrine and metabolic diseases, hypertension, and body mass index, as these are not covered in the current review. Current literature investigating their prevalence among older adults with bipolar disorder is limited, although these comorbidities could be problematic for this group and may have important clinical implications.

3.6 Conclusion

To conclude, this review provides tentative evidence that some physical health comorbidities may be elevated in older adults with bipolar disorder. However, research surrounding the

prevalence and predictors of physical health comorbidities in this group remains limited. Very few studies included healthy control groups or controlled for key covariates, meaning it is difficult to make any strong conclusions. Further research in older adults with bipolar disorder is needed to understand physical health comorbidities in this population and improve prevention and intervention strategies.

Chapter 4 - What does it mean to age well with bipolar disorder: A qualitative study using photo elicitation

Introduction to photo elicitation paper

Chapter 4 presents a qualitative study that used photo elicitation interviews and reflexive thematic analysis to explore what it means to age well for older adults with bipolar disorder. This study aimed to identify what was important to people as they aged with bipolar disorder and what enabled this population to live meaningful, fulfilling lives in later life. This paper contributes to existing literature by highlighting the preferences and priorities of this group and suggesting areas of adaptation when aiming to treat older adults with bipolar disorder. The chapter below has been submitted for publication to Psychology and Psychotherapy: Theory, Research and Practice and is currently under review. The researcher has received feedback from reviewers and the subsequent paper has been resubmitted for publication.

Chapter 4: What does it mean to age well with bipolar disorder? A qualitative study using photo elicitation

Aaron Warner[1,2,4]*

Fiona Lobban[1,5]

Carol Holland[2]

Elizabeth Tyler[3]

Geoff Settle[4]

Verity Rhodes[4]

Jasper Palmier-Claus[1,5]

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[1]Spectrum Centre for Mental Health Research, Division of Health Research, Lancaster, UK

[2]Centre for Ageing Research, Division of Health Research, Lancaster, UK

[3]Division of Psychology & Mental Health, University of Manchester, Manchester, UK

[4] NIHR Applied Research Collaboration North West Coast, UK

[5]Lancashire & South Cumbria Care NHS Foundation Trust, Lancashire, UK

*Email address of the corresponding author: a.warner3@lancaster.ac.uk

Postal Address of the corresponding author: Health Innovation One, Sir John Fisher Drive, Lancaster University, Lancaster, LA1 4YW

4.1 Abstract

Objectives: To explore what ageing well means to older adults with bipolar disorder.

Methods: Older adults with bipolar disorder took photographs of aspects of their lives that they felt represented ageing well. They then completed audio-recorded photo elicitation interviews to explore what it meant to age well with bipolar disorder in detail. Data was analysed using reflexive thematic analysis.

Results: 17 participants met criteria for bipolar disorder I or II. The analysis resulted in four key themes to ageing well with bipolar disorder: 1) *Lifelong learning* – referring to how participants accumulated a wealth of knowledge about bipolar disorder and used this to maintain stability in later life 2) *Finding where you belong* – relating to how participants prioritised finding new communities, utilised family support and refined their support networks over time to age well 3) *Recognising your value and worth* – which involved participants using their strengths and experiences to support others 4) *Continuity of support* – highlighting the importance of continuous support that prioritises meaningful relationships with professionals and encourages participants to play an active role in their treatment.

Conclusions: Participants ageing with bipolar disorder identified unique challenges indicating that services require adaptation to meet their needs and support them to age well. Findings suggested that services should provide continuous care that allows this group to actively engage with their treatment, build upon their strengths, and develop meaningful connections with professionals. This approach may enhance the support offered to older adults with bipolar disorder and reduce the inequalities they experience.

<u>Practitioner points</u>

- Older adults with bipolar disorder may experience unique challenges in later life that require support to be adapted to be appropriate and effective.

- Older adults with bipolar disorder potentially benefit from continuous care that enables them to develop meaningful relationships with professionals and take an active role in their treatment.

- Support that encourages older adults with bipolar disorder to identify and build upon their strengths may be beneficial in helping them to develop self-worth and provide meaning in their lives.

4.2 Introduction

Bipolar disorder is characterised by marked episodes of elation (mania and hypomania) and depression, alongside disruptions to behaviour and thought that significantly impair people's quality of life (American Psychiatric Association, 2013). Bipolar disorder affects more than 1% of the world (Grande et al., 2016). It is typically diagnosed in younger adults, but its challenges often persist throughout the lifespan and into later life (Depp & Jeste, 2004). Older adults are thought to represent around 25% of people diagnosed with bipolar disorder (Ljubic et al., 2021) and this number could increase dramatically as the population ages and identification of bipolar disorder improves (Dols et al., 2014; Sajatovic et al., 2015). Older adults with bipolar disorder may also experience accelerated cognitive decline (Gildengers et al., 2009) and increased physical health comorbidities (Warner et al., 2023) compared to the general population meaning that increased attention and support is required to enable this group to age well (Sajatovic et al., 2015).

There are multiple theories of what it means to age well (Franklin & Tate, 2009). Selective Optimisation with Compensation theory (Baltes & Baltes, 1990) suggests that people must respond to age-related gains and losses by maximising their strengths and minimising losses to experience successful ageing. (Freund, 2008). Socioemotional Selectivity Theory (Carstensen, 1992) proposes that ageing well involves motivational shifts where people focus on emotionally meaningful activities and minimise their engagement with social relationships that lead to emotional risks (Carstensen et al., 2003). Although these theories help to understand ageing well in the general population (Baltes & Carstensen, 1996), there is a lack of understanding of what is required to age well whilst experiencing severe mental health difficulties (Westerhof & Keyes, 2010).

Although there is no empirical research on ageing well with bipolar disorder, studies indicate that ageing with severe mental health difficulties may present different challenges

to those ageing in the general population. For example, in a qualitative study of 22 people from the general population, Reichstadt and colleagues (2010) highlighted that finding a balance between self-acceptance and self-contentedness and engaging with life in a way that promotes self-growth is vital to ageing well. However, Smart and colleagues' (2021) qualitative study of 16 people with psychosis-related disorders found that managing stigma, coping with mental health difficulties, and developing positive relationships with professionals were essential aspects of ageing well for this group. Importantly, older adults diagnosed with bipolar disorder often experience increased levels of physical health conditions (Warner et al., 2023), reduced lifespan, and poorer quality of life than the general population (Sajatovic et al., 2015). Therefore, research exploring what helps older adults with bipolar disorder to age well and live fulfilling lives as they age could be highly beneficial.

The positive psychology literature highlights that focusing on what helps people and makes them happy, rather than symptom reduction alone, is vital to improving engagement and clinical outcomes for people experiencing mental health difficulties such as bipolar disorder (Duckworth et al., 2005). For example, a pilot trial completed by Celano and colleagues (2020) found that people experiencing bipolar depression showed greater improvements in optimism and positive affect when they received a positive psychology intervention focusing on strengths and gratitude in comparison to treatment as usual. Another recent pilot trial study also found promising outcomes when delivering a recovery-focused intervention building upon the strengths of older adults with bipolar disorder and developing their resilience (Tyler et al., 2022). Consequently, positive psychology may be particularly important to older adults with bipolar disorder as emphasis is often placed on their limitations rather than what enables them to build upon age-related gains and optimise areas of growth in later life (Ranzijin, 2002).

There is currently a lack of research qualitatively exploring the experiences and needs of older adults with bipolar disorder. Consequently, our knowledge of what is essential to this group as they age and how best to support them is limited and needs to be addressed (Sajatovic et al., 2015; Kilbourne et al., 2008). This study aims to qualitatively explore what ageing well means to older adults with bipolar disorder and considers what factors are important to enable them to live meaningful lives as they age. The study uses the novel approach of photo elicitation to generate verbal discussion during qualitative interviews (Glaw et al., 2017). Photo elicitation has been found to evoke deeper layers of meaning and elicit emotional content that is more difficult to access in traditional semi-structured interviews (Harper, 2002). This approach also gives participants the opportunity to guide the interview encounter by discussing images that are personal and important to them (Harper, 2002). This has been found to help participants feel more comfortable which is beneficial when completing interviews with potentially vulnerable individuals such as older adults with bipolar disorder (Copes et al., 2018). Finally, this method encourages participants to use creativity, which is often reported to be a key strength of individuals with bipolar disorder (Johnson et al., 2012), therefore making this a valuable approach for the current study.

4.3 Methods

4.3.1 Design

This study used qualitative interviews supported by a one-week period of photo elicitation. Interviews were analysed using reflexive thematic analysis, as outlined by Braun & Clarke (2006).

4.3.2 Participants and recruitment

Participants were recruited through: i) community-based older adult mental health services within three NHS Trusts in England; ii) a confidential participant database consisting of people diagnosed with bipolar disorder who previously consented to be contacted about future research opportunities; iii) advertising on social media; and iv) UK based charity organisations.

The inclusion criteria were: i) age $\geq$ 60, as this was consistent with the World Health Organisations (2021) chronological definition of elderly, older adults or aged ii) a diagnosis of bipolar disorder I or II based on the Structured Clinical Interview for DSM-5 Disorders, research version (SCID-5-RV, 2015); iii) capacity to provide informed consent; and iv) adequate English skills to communicate during the interview. The exclusion criteria were: i) a moderate to severe learning disability; ii) current immediate risk to the self or others; or iii) currently receiving care from an inpatient or crisis service.

4.3.3 Data collection

A purposive sample of participants aged 60 and over was collected. Participants were assessed using the SCID-5-RV to determine whether they met bipolar disorder I or II criteria. They also provided demographic information.

Eligible participants were briefed about photo elicitation. They were given cameras and at least one week to take photographs of aspects of their lives they felt represented them ageing well with bipolar disorder. Participants could also use their mobile phones to take photographs or use existing photographs if preferred (black and white or colour photographs were permitted). Participants were not required to print these photographs and could instead show them to the researcher on their phones, computer or online. During this one-week period, the researcher called participants to answer any questions, encourage engagement and provide support where necessary. The researcher encouraged participants

not to take photographs of other people due to issues around confidentiality, although participants were able to discuss people or places of importance within the interviews.

Following the period of photo elicitation, the lead author met with participants to complete one-to-one interviews either face-to-face, online or via telephone. These followed a topic guide that incorporated questions about the photographs of ageing well (see supplementary material). For example, 'please could you tell me about the photographs you have selected' and 'why do these represent ageing well with bipolar disorder to you?'. Each photograph was discussed individually and in depth. Two older adults with lived experience of mental health difficulties supported the development of the topic guide to ensure that it was appropriately worded and covered key areas of importance.

4.3.4 Data analysis

The authors used reflexive thematic analysis (Braun & Clarke, 2006) to analyse data. Reflexive thematic analysis is a flexible approach that can be adapted and employed across various study designs, populations, and disciplines (Terry & Hayfield, 2020), including photo elicitation studies (Herrington et al., 2021). It allows researchers to systematically identify and make sense of broad patterns of meaning within and across the data and highlight participants' lived experiences, perspectives, and views at both the latent (surface level, obvious) and semantic (hidden, implicit) levels (Terry et al., 2017). This enables the researcher to develop an in-depth understanding of what participants think and feel about a specific topic (Braun & Clarke, 2019). Consequently, reflexive thematic analysis was appropriate to illuminate participants' experiences of what it means to age well with bipolar disorder in this study.

The authors followed the six-step approach developed by Braun & Clarke (2006). Initially, the first author (AW) familiarised himself with the data by transcribing interviews

and reading the data several times while noting initial ideas. AW then generated initial codes across the dataset that were reviewed by all authors (JPC, FL, ET, CH, VR, and GS), who offered feedback and a range of perspectives on the data. Next, meaningful codes were collated into potential themes that reflected patterns of meaning at a more abstract and broad level than initial codes (Braun & Clarke, 2006). The authors then reviewed and refined these themes to ensure they were grounded in the data (Braun & Clarke, 2006). All data was managed using NVIVO software.

Samples sizes required for studies completing reflexive thematic analysis are variable and subjective (Braun & Clarke, 2019). For the current study, the authors determined that sufficient data had been collected by considering the aims of the research, the richness of the data and the analytical method used whilst also considering whether the research question had been answered comprehensively (Shaheen & Pradhan, 2019). These considerations were then used to inform the decision to stop collecting data as advised by Fusch & Ness (2015).

4.3.5 Reflexivity

A key aspect of completing reflexive thematic analysis is acknowledging that the researcher is central to the analysis (Terry & Hayfield, 2020). Therefore, rather than aiming for objectivity, this approach values the subjective and active involvement of the researcher (Terry & Hayfield, 2020). It is important however, that the researcher reflects on the impact of their experiences, values and social position on the analysis being completed (Braun & Clarke, 2019).

The first author (AW) in this study, was a PhD student at a university with experience working within NHS mental health services in England. AW previously supported older adults diagnosed with bipolar disorder, which may have influenced how he collected and

analysed the data. However, several actions were taken to enhance rigour throughout the research process and minimise researcher bias. Initially, AW completed a positionality statement highlighting his underlying personal beliefs, experiences, social class, and gender and considered how these may impact their role in the research process, as suggested by Holmes (2020). AW also kept a reflexive diary to identify personal and methodological challenges that may have influenced the research, ensuring that decision-making was as transparent as possible (Nadin & Cassell, 2006). These challenges were discussed with the research team, consisting of three qualified clinical psychologists (JPC, FL, and ET), a Professor in Ageing (CH), and two older adult public advisors with lived experience of mental health difficulties (GS & VR) during regular supervision. This supervision ensured that a range of perspectives were available to the lead author which helped them to consider and highlight internal biases that may have influenced their interpretations of the data. Overall, these steps taken to enhance reflexivity encouraged a more rigorous approach to study design, data collection, and the interpretation of findings (Yardley, 2000).

4.3.6 Ethics

This project was approved by the NHS Health Research Authority (REC reference: 21/LO/0405), and three NHS Trusts agreed to recruit their service users to the study. All participants provided written or audio-recorded consent to take part.

4.4 Results

Eighteen participants were recruited for the study. Seventeen older adults met criteria for bipolar disorder I or II following the SCID-5-RV assessment and subsequently completed interviews with the lead author (AW) (see Table 4 for participant characteristics). One participant did not meet bipolar disorder I or II criteria and was excluded from the study. Interviews ranged from 40-90 minutes. There was no limit to the minimum or maximum number of photographs that participants could take to the qualitative interviews. The mean number of photographs participants brought to prompt discussion during the interviews was 3.5 (range 1-6; SD 1.38). 53% (n=9) of participants took new photographs, 29% (n=5) brought existing photographs, and 18% (n=3) brought both new and existing photographs to the interview. These photographs captured images representing supportive others, locations that reduced stress (e.g., seaside, rural areas), places of community (e.g., church, peer support groups), expressions of creativity (e.g., artwork), and activities that provided them with satisfaction (e.g., gardening, cooking) and helped maintain stability. If participants' discussed people or places during the interviews, interviews were anonymised and deidentified during transcription to maintain confidentiality. All interviews were transcribed verbatim, and pseudonyms were used.

Key themes and subthemes were identified by synthesising important patterns of meaning from participants' interviews. Four main themes captured ageing well with bipolar disorder: 1) Lifelong learning 2) Finding where you belong 3) Recognising your value and worth 4) Continuity of support. Each theme contained subthemes and are discussed individually below.

Table 4: Participant characteristics

Demographics (n = 17)	Total
Age, *mean* (range, SD)	65.0 (60-74, 4.2)
Gender (n, %)	
Female	12 (79%)
Male	5 (21%)
Ethnicity (n, %)	
White British	11 (64%)
Black British	1 (6%)
White Other	4 (24%)
Indian	1 (6%)
Diagnosis (n, %)	
Bipolar disorder I	16 (94%)
Bipolar disorder II	1 (6%)
Employment status (n, %)	
Retired	6 (35%)
Unemployed	7 (41%)
Employed	4 (24%)
Living status (n, %)	
Alone	6 (35%)
With spouse	9 (53%)
With children	1 (6%)
With parent(s)	1 (6%)
Marital status	
Married	9 (53%)
Single	7 (41%)
Widowed	1 (6%)
Education (highest level) (n, %)	
No qualifications	1 (6%)
Secondary	3 (17%)
A/O level	4 (24%)
Undergraduate degree	5 (29%)
Postgraduate degree	4 (24%)
Number of hospitalisations, *mean* (range, SD)	2.8 (1-11, 3.0)
Age when diagnosed, *mean* (range, SD)	36.2 (16-61, 14.0)
Place recruited from (n, %)	
NHS service	6 (35%)
Research participant database	9 (53%)
Social media	1 (6%)
Charity organisation	1 (6%)

Theme 1: Lifelong learning

Table 5 provides more quotes from the data. This theme explains how participants learnt about themselves and bipolar disorder over time and used this knowledge to find a healthy balance in later life, despite still facing challenges in managing their mood. Through a process of trial and error, participants developed insight into what helped them to cope and build the confidence to establish and maintain their interpersonal boundaries. This was often reported to be a painful journey, but accumulating a wealth of knowledge about bipolar disorder over time empowered them to actively engage with treatment decisions and fight to maintain agency as they aged.

Table 5: Additional supporting extracts for all themes

Theme	Example quotes	Source
1.1: **Tuning your bandwidth as you age**	*I wake up in the mornings and look at the diary. I veer towards things that must be done, and the rest of it I let go of.*	Lisa
	It's about learning to understand what bipolar is, its effect on you, and how to manage its worst parts. It takes time.	Steven
	It's by trial and error, failing and picking yourself up over time. Then, noticing that was the turning point and not doing it again as you age.	Claire
1.2: **Recognising your lived experience**	*Over time, it's not just with your diagnosis. You know yourself more, your body, what works, what makes you feel better, and what doesn't. That can help you to maintain independence.*	Rachel
	I now understand my triggers. That's what I've learned during the ageing process. It's allowed me to be more in control and tell people what I need.	Steven
	You must develop the confidence and skills to express yourself, not be intimidated by the medical folk, and say I know me; I have had this for a long time. I know this works.	Jayne
	I think it's important to make sure you learn after each incident or episode and hopefully that learning helps you to cope better in the future. And also, by dealing with the painful side of things, hopefully it stops you from going to such a painful place as you get older.	Gail
2.1: **Discovering new communities**	There are *people with whom I can share that I have had problems in the past, and it doesn't seem to be a burden.*	Dan
	If you haven't got a family, find another one. Find a community and be part of it because there is nothing to live for otherwise.	Claire
	From diagnosis to recovery, I've had so much support from the church. Having that faith and community has helped me a lot.	Sharon

2.2: **Family as an anchor**	*My husband said I'm not going anywhere. That is something nobody has ever said to me before. When someone tells you they're not leaving you, it's the best thing ever.*	Angela
	I find it very hard to think about people who do not have relatives. Who can they hook onto to see meaning in this life?	Emma
	Family visit me in hospital, remind me to take my medication, and ask how I feel. They're quick to pick up on anything wrong and suggest a solution.	Karen
	The most important thing I've found is the support of my wife that she gives me. Because I understand and know that it cannot be easy to live with and understand someone who has got bipolar. So, the most important person is the person who is close to the person that's got bipolar.	Steven
2.3: **Refining your network as you age**	*Strategic thinking is important. People with bipolar are good at that. If we're who we are meant to be, then the people we're meant to be around will still love us.*	Angela
	Surround yourself with sympathetic people and not people who are against people with mental illnesses.	Karen
	Some people love you when you're manic and abandon you when you're depressed. We can't accept that and should stick with people who love us unconditionally.	John
3.1: **Desire to give back**	*I don't want people to feel as bad as me and blame themselves. I try to do bits and bobs, so hopefully, I can help people somehow.*	Rachel
	It was really rewarding to be part of something where my experience of real difficulty and tough times has been used to create something wonderful for people.	Claire
	If I were giving back to society, it would make me feel more valued. Now I'm not doing anything, so I'm not valued. I'm not valuing myself, either.	Gail
	I get involved in support groups ran by the church. It makes me feel that I'm doing something good and that I'm getting somewhere. I'm helping somebody, I feel useful.	Jack
3.2: **Focus on what you can do**	*It's good to feel of use, especially when it's a charity, knitting hats for the homeless, or just doing what I can to help.*	Karen
	The fact that I'm here and there's something good I can do that expresses who I am and gives pleasure to others is amazing.	Angela
	I can still offer something which gives me some validation that I haven't destroyed my capacity to be a useful human being.	Claire
	Gardening is another kind of way of developing therapy. Now, I'm not a gardener, but my wife is a gardener, and I can see similar things between gardening and creative therapy. Both of them involve planting some idea down, whether it's in a journal or whether it's in a garden and allowing it to flourish. And learning about when the episodes might come along also takes time. It has helped me to cope as I've got older.	Steven
4.1: **A lifetime of repetition**	*The worst thing when you are feeling up or down is having to go through your whole life history.*	Janice
	It brings back painful memories; I want to move on, not dwell on the past, which I'd have to because the new person doesn't know anything.	Dave
	It was too difficult to start again with someone new. I hate it when the consultant changes and they change with alarming frequency.	Karen

4.2: Knowing that support is coming	*I'm not sure if depression would get picked up if people didn't come to see me, they might think she's just old and lonely.*	Shirley
	People checking in on you is very important. If you're struggling, it must be highlighted that you're not coping.	Dave
	Someone checking in shows you're not alone. I'm under mental health services, but I never see anybody. People need to know that they are not alone.	Linda

1.1: Tuning your bandwidth as you age

This subtheme identifies how participants learnt to manage bipolar disorder and integrated it into their lives. Although they still experienced challenges related to bipolar disorder, participants learnt to accept certain limitations and set boundaries to prevent themselves from experiencing mood episodes.

> **Shirley:** *"I find for myself with mental health illnesses and physical illnesses, you have to delete some things, just do what you can do and make sure that you're not putting too much pressure on your brain".*

This process was described as a trade-off where participants sometimes felt it was necessary to avoid enjoyable activities due to the fear of becoming overstimulated and experiencing mania. Whilst this reduced the risk of participants becoming unwell, it made life more restricted for some. However, this was a price that some participants were willing to pay to maintain stability as they aged.

> **Emma:** *"Other people don't have to think; they just live. If we want to live well, we must constantly think and control ourselves. So, I'm trying to keep myself flat, which is not nice, but that's the price I pay for trying to stay well".*

Many participants had lived with bipolar disorder for numerous years and had accumulated a wealth of knowledge. They had often experienced numerous treatments and medications and developed a strong understanding of what worked for them and what did not. This allowed participants to manage their bipolar disorder experiences more effectively as they aged.

> **Lisa:** *"I have learnt enough about my condition to avoid the things that are bad for me, to diminish them and to lessen them. Some of them can't be completely avoided, but I have a better handle on stress".*

Participants felt that over time they had developed the confidence to actively guide their treatment and communicate directly with professionals about their preferences. This empowered participants by helping them to maintain agency as older adults as highlighted by Claire.

> **Claire:** "*So, not ageing well for me is not learning. It means abdicating agency, just saying you're in charge, you know more than me, and I'm just going to leave it up to you, doctor. That's not ageing well for me; I want to be part of things".*

Theme 2: Finding where you belong

This theme highlights how participants' priorities changed over time as they aged with bipolar disorder. When younger, participants often focused their energy on pursuing their careers but now described feeling that bipolar disorder had taken this away from them. As they aged, participants focused more on establishing meaningful, emotional connections

with others and prioritised what they felt could not be taken from them. This provided meaning and security that many participants had never experienced.

2.1: Discovering new communities

As they focused on establishing meaningful connections, participants discussed seeking communities where they felt accepted, valued, and understood. For example, some participants' photographs highlighted the importance of attending church or arts and crafts clubs. This sense of community was a powerful experience, as highlighted by Lisa, who stated that finding community allowed her to establish an identity and finally feel "part of the human race" after feeling outcast whilst living with bipolar disorder.

> **Lisa:** *"The community makes me feel human and part of the human race. The community makes me feel comfortable with myself, they give me company and they give me activity. The most important thing it gives me is a strong sense of identity".*

Additionally, becoming part of a new community gave participants a safe space to discuss difficulties. Some participants reported feeling like a burden when discussing concerns with family and were cautious about speaking to professionals due to fear of being hospitalised. Finding a space to discuss their experiences openly was described as therapeutic by participants. The quote below shows the value of sharing experiences within a peer support group.

> **John:** *"The support group was a really good experience because I knew I could talk about the past or present, and other people could comment but not judge me, which was extremely healing".*

However, some participants suggested that peer support groups focused too much on people's difficulties rather than their strengths, which was frustrating.

Angela: "*When I used to go to a bipolar support group, it was very frustrating because it was all focused around what we couldn't do. We could've gone out and done something creative, anything really. We could've all gone home feeling better about ourselves, but it didn't happen*".

2.2: Family as an anchor

Participants' photographs often displayed the importance of family when ageing with bipolar disorder. Participants reported experiencing challenges with family members when they were younger and first diagnosed with bipolar disorder. They described feeling outcast and marginalised by their family in the past. Often mental health was not discussed or accepted, and some participants still felt frustrated by this lack of support.

Gail: "*Sometimes I blame my parents. I think they could have been more helpful, but in that generation, mental health wasn't a thing*".

However, over time, many participants felt that changing attitudes towards mental health led to them being better understood and supported by family. Participants also felt inspired to maintain their wellbeing by their children and grandchildren whom they wanted to see grow up. This meant risk-taking was no longer attractive, as they could not jeopardise their remaining time with family.

Karen: *"I think to myself, I want to see these grandchildren grow up. Therefore, I need to keep myself as well as possible. I don't want to spend time in mental hospitals when I could be babysitting or taking them out, so that's a big spur to keep well".*

Finally, participants learnt to trust the opinions of family members who had proven their support over time by staying with them when many other people had left. This meant family could now act as a "sounding board" and provide insights into whether their mental health was declining or support from services was required. This made participants feel anchored, supported, and protected by family.

Sharon: *"Make sure that you have at least one family member who understands you, knows what bipolar is, and knows that you are not acting up. Then when you are having a bad day, this person is there to hold the fortress for you; that is very important".*

2.3: Refining your network as you age

This subtheme displays how participants refined their networks as their priorities and values changed in later life. This was a challenging process for participants as it often meant distancing themselves from long-time friends whose values and lifestyles no longer resonated with them. Participants discussed the importance of focusing on supportive relationships whilst reducing contact with unhelpful ones.

Dan: *"It's important to have shared expectations with friends. I have changed some of my old friendship groups. Part of it is that certain people do things I can't afford*

to participate in, and it's no longer helpful for me".

This refining of networks also included healthcare; participants avoided services where they felt dismissed and sought services that were empathic and understanding. Participants reported feeling safer and less vulnerable to experiencing a mood episode when they were surrounded by more secure support as they aged.

Jayne: *"when I rang 111, I thought, this is why people are committing suicide; they're not getting the support. I didn't want to call them again, but then I tried another service and got a lovely lady on the call. She made me feel better, and I felt like I was in good hands, which made the difference"*.

Theme 3: Recognising your value and worth

This theme highlights participants' desire to still be viewed as contributing to society and to be more than their diagnosis. Participants wanted to use their experiences of bipolar disorder to help others as it gave meaning to what they had overcome, rather than bipolar disorder being viewed as only a traumatic influence on their lives. Participants highlighted the importance of focusing on strengths rather than limitations as this helped to find new ways to contribute to society, community or family and build confidence as they aged.

3.1: Desire to give back

Participants felt that although their experience of bipolar disorder had been challenging, their accumulated knowledge whilst overcoming these difficulties allowed them to give back and positively change others' lives. This included supporting new generations of people diagnosed with bipolar disorder by offering advice or showing that there can be

hope of living a meaningful life.

> **Sharon:** "*It makes me feel like I'm able to make changes and let people know they are not alone; this is where I was, and this is where I am now. It makes me feel that I can contribute to society and help people who are struggling*".

Participants also felt it was important to express gratitude and give back to their family or community who had supported them during difficulties. Helping others gave participants a sense of purpose and highlighted their ability to contribute whilst ageing with bipolar disorder.

> ***John:*** "*Coming out of that depression made me grateful for the people around me, full of gratitude, and I could express that gratitude by being of help in any way*".

3.2: Focus on what you can do

This subtheme relates to how participants adapted and identified new ways to contribute as they aged. For example, participants' photographs often highlighted the importance of embracing their creativity to provide for others.

> **Angela:** "*I feel sorry for anyone that hasn't discovered their creative side. Because, even when you're stuck in a chair, which I sometimes am because of arthritis, you can still be creative and create something beautiful that you can give to somebody else and give them pleasure*".

Focusing on activities they could still complete allowed participants to build

confidence and self-worth, which were both seen as crucial aspects in ageing well with bipolar disorder.

>**Claire:** *"I'd encourage people of any age to still take part in activities outside of themselves, whatever you can do. Be active, be engaged because then you gain confidence to be your best advocate".*

Theme 4: Continuity of support

Participants outlined how the support they desired had changed as they aged, as they now prioritised consistent care and meaningful relationships with professionals. Participants expressed frustration when they could not see the same professional consistently. This meant they had to frequently repeat their experiences of bipolar disorder, which was exhausting and traumatic. Many participants felt that continuity of care could help them to establish meaningful connections with professionals and combat loneliness, which was a significant concern as they aged.

4.1: A lifetime of repetition

Participants stated that repeatedly discussing their life stories with new professionals was frustrating and potentially re-traumatising. This led to participants feeling unable to maximise their contact with services.

>**Karen:** *"I absolutely hate it; it sets me back. I don't want to talk about myself to somebody new. I want everybody to know where I'm at so we can move on instead of dwelling on the past, which you must if it's someone new because they don't know you".*

Participants argued that continuity of care was vital as it allowed professionals to understand their key needs better. Building a relationship with one professional helped them feel safe and understood, providing a sense of security as they aged.

Claire: *"The good thing is when you have a GP who knows you, they know you not only when you are ill, so they can offer effective support. When you have someone you only see in crisis, they don't know your baseline, and it's very hard for them to offer support".*

However, one participant highlighted the consequences of feeling stuck with a professional not offering appropriate support.

Dave: *"Getting stuck with a bad psychiatrist is suicide, simple as that".*

4.2 Knowing that support is coming

This subtheme shows the importance of knowing a professional would visit and check participants' wellbeing. This provided connection, companionship, safety, and reduced loneliness. This was vital, as participants felt that loneliness could be more dangerous than mood instability as they aged. Loneliness compounded their difficulties, and participants stated that combatting loneliness should be considered a key focus of interventions.

Lisa: *"loneliness is awful. It is the worst enemy of ageing, not just the illness itself".*

Participants stated that regular professional visits reduced loneliness and meant that changes in mania and depression were better detected. However, some participants lived

alone and reported that a critical reason for recent relapses was that no one was available to identify early warning signs and offer support. Consequently, they suggested regular check-ins with professionals would provide connection and reduce their risk of relapse.

> **Gail:** *"living by myself, I think I'd been poorly for a while before I was put in hospital, and I could have avoided it. Having someone come and visit every couple of weeks for a chat and coffee would make me feel safer and more supported"*.

4.5 Discussion

This qualitative study used photo elicitation interviews to facilitate in-depth, meaningful discussions about what ageing well means to older adults with bipolar disorder. Our analysis highlighted the importance of lifelong learning, finding belonging, recognising value and worth, and consistent support as crucial aspects of ageing well in this population. Participants developed a wealth of knowledge over their lifespans and used this to learn about their mental health issues, identify key triggers, and find a balance between a fulfilling life and avoiding activities that may trigger mood instability. Establishing a sense of belonging and prioritising connection with others was an essential aspect of ageing well. Additionally, identifying and using strengths to support others gave participants a sense of meaning and purpose that enhanced their quality of life. Finally, interventions prioritising continuity of care were considered necessary as these enabled participants to develop meaningful relationships with professionals that made them feel safe and supported and reduced loneliness.

Previous research in the general ageing population highlights the importance of maintaining positive social support systems to age well (Rechstadt et al., 2010). Smart and colleagues (2021) also observed that developing positive relationships with professionals was a key factor in enabling older adults with psychotic disorders to age well. However, a review completed by Smart and colleagues (2020) indicates that there is currently a lack of interventions aimed at improving the social functioning of older adults with mental illness, which may increase loneliness and social isolation. This is important, as Socioemotional Selectivity Theory (Carstensen, 1992) suggests that due to an awareness that life is time-limited, people must focus on meaningful emotional activities and reduce contact with emotional endeavours that are unstable or damaging in order to age well. One way of encouraging older adults with bipolar disorder to find meaningful emotional connections

and belonging might be through social prescribing and peer support groups, where people can openly discuss their mental health challenges with people with similar experiences. Indeed, these interventions have been found to reduce loneliness, increase social support, and provide a social comparison function that can improve the quality of life for people experiencing severe mental illness (Aggar et al., 2021). However, a small number of participants in this study felt frustrated that peer support groups often focused too much on their difficulties rather than identifying and building upon their strengths. Ensuring that peer support groups focus on highlighting the strengths of older adults with bipolar disorder may help to develop confidence and improve their wellbeing.

Participants identified the importance of lifelong learning as this enabled them to make necessary adaptations and maintain stability as they aged. This is supported by Bowling & Dieppe (2005), who highlighted that learning from past mistakes is an integral part of ageing well, and Von Faber and colleagues (2021), who found that the ability to adjust to one's changing circumstances is vital. However, participants suggested that some adaptations can be painful when ageing with bipolar disorder as they may have to avoid enjoyable activities in fear of triggering a mood episode. This process was described as a trade-off between enjoyment and stability, which contrasts with studies involving the general population, where engaging in enjoyable activities is reported only to be beneficial (Rechstadt et al., 2010). An essential intervention in helping older adults with bipolar disorder to manage this trade-off may be psychoeducation, where people can learn to understand bipolar disorder, its triggers, and how to manage their life whilst allowing for enjoyment and fulfilment (Smith et al., 2010). Recovery focused interventions that support older adults with bipolar disorder to identify their personal goals and actively guide the intervention in collaboration with professionals have also been found to increase agency and enable people to live well alongside their bipolar disorder experiences (Tyler et al.,

2022).

The Selective Optimisation with Compensation Theory (Baltes & Baltes, 1990) suggests that a critical factor in ageing well is identifying realistic, attainable goals and maximising strengths whilst minimising age-related losses. In this study, participants identified their lived experience of bipolar disorder as a key strength that they could use to support others. This is consistent with Tyler and colleagues' (2021) findings, who also found that supporting others was important to older adults with bipolar disorder. In our study, supporting younger generations with bipolar disorder gave participants a sense of purpose and the belief that they could contribute despite their age and mental health diagnosis. Consequently, older adults with bipolar disorder may benefit from delivering and receiving peer support worker interventions, which have been found to provide hope, validation, and connection to people experiencing mental health difficulties (Barr et al., 2020).

Our findings suggested that current treatments should prioritise continuity of care that enables older adults with bipolar disorder to develop meaningful relationships with professionals (Geddes & Milowitz, 2013; Goodwin et al., 2016). In addition, continuity of support may help professionals to develop an improved understanding of the difficulties faced by older adults with bipolar disorder, improve communication regarding treatment decisions, and lead to more efficient and effective support (Biringer et al., 2017). This may also improve outcomes and satisfaction rates for people experiencing mental health difficulties, such as the older adults with bipolar disorder in this study (Adair et al., 2005).

4.5.1 Strengths and limitations

There are several strengths in this study. Firstly, the authors used photo elicitation to prompt discussion in the interviews. This method has been found to elicit more profound, personal

information than standard semi-structured interviews (Harper, 2002). However, it also encourages participants to be creative, which is often identified as a strength for people with bipolar disorder (Johnson et al., 2012). The research also had strong patient and public involvement, which enhanced reflexivity and ensured a range of perspectives were available at all stages of the research process, therefore improving rigour (Yardley, 2000).

Regarding limitations, only few participants (35%) were actively receiving care from NHS services, and all were living in the community. Therefore, this sample may represent a 'survivor cohort' who experience relatively positive outcomes and stability whilst living with bipolar disorder (Sajatovic et al., 2015). The experiences of individuals within inpatient services who potentially experience the most severe difficulties were not captured within this study, which may have influenced the findings (Nivoli et al., 2014). Also, although no upper age limit was included, most of the sample were aged 60-65, meaning that the experiences of the oldest age groups may have been missed (Gwozdz & Sousa-Posa, 2010). Indeed, over 75-year-olds potentially experience a range of comorbidities and unique challenges that were not captured within this study (Vargas et al., 2017). Most participants were also predominately White British, and this has been highlighted as a key problem in bipolar disorder research, as individuals from African ancestry are found to experience higher levels of misdiagnosis and different challenges that would have potentially led to different findings (Akinhanmi et al. 2018). Additionally, most participants identified as female, were well-educated, and had or were retired from professional working backgrounds. The majority of participants were also diagnosed with bipolar disorder I which potentially resulted in different experiences and challenges to individuals diagnosed with bipolar disorder II. Due to these limitations, these findings may not be representative of a number of older adults with bipolar disorder II or those from different cultures or backgrounds.

4.6 Conclusion

This study elucidates what ageing well means to older adults with bipolar disorder. Participants identified lifelong learning, finding belonging, recognising their value and worth, and continuity of care as essential factors in ageing well with bipolar disorder. Additionally, participants emphasised the importance of using their accumulated knowledge of bipolar disorder to find balance in later life. Our findings also highlighted the value of helping others with bipolar disorder, as this enabled participants to establish meaning within their lives. Finally, our study suggested that services should provide empathic, continuous care in which older adults with bipolar disorder take an active role in their treatment, supported by professionals who understand their fluctuating needs over time. This approach may enhance care for older adults with bipolar disorder.

Chapter 5 – The changing care of older adults with bipolar disorder: A narrative analysis

Introduction to biographical narrative interviewing paper

Chapter 5 built upon chapters 3 and 4 by attempting to understand how care had changed throughout the lifespan for older adults with bipolar disorder and explored how and why this groups care needs changed over time. This chapter aimed to illuminate what kind of support older adults with bipolar disorder required to improve their wellbeing and live well as they aged. This study had important clinical implications and identified ways to improve care and outcomes for this population which was lacking within existing literature. This chapter has been submitted for publication to Research on Aging.

Chapter 5: The changing care of older adults with bipolar disorder: A narrative analysis

Aaron Warner[1,2,4]*

Jasper Palmier-Claus[1,5]

Carol Holland[2]

Elizabeth Tyler[3]

Verity Rhodes[4]

Geoff Settle[4]

Fiona Lobban[1,5]

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[1]Spectrum Centre for Mental Health Research, Division of Health Research, Lancaster, UK

[2]Centre for Aging Research, Division of Health Research, Lancaster, UK

[3]Division of Psychology & Mental Health, University of Manchester, Manchester, UK

[4] NIHR Applied Research Collaboration North West Coast, UK

[5]Lancashire & South Cumbria NHS Foundation Trust, Lancashire, UK

5.1 Abstract

Objectives: To explore experiences of care and changing care needs in older adults with bipolar disorder. **Methods:** People with bipolar disorder (aged ≥60) were recruited through three NHS Trusts in the Northwest of England, charity organisations, a confidential university participant database and social media. Participants completed single time-point biographical narrative interviews, analysed using narrative analysis. **Results:** 16 participants' accounts led to the creation of four themes: 1) *Navigating the disruption caused by diagnosis* 2) *The removal of services that provided hope* 3) *Later life: We are on our own now* 4) *Changing care needs in later life: We still need support.* **Discussion:** The care needs of older adults with bipolar disorder appear to change over time and services often fail to offer adequate, tailored care for this group at present. Current support requires adaptation to be effective and appropriate and to enable this group to age well in later life.

5.2 Introduction

Bipolar disorder is characterised by recurrent episodes of elevated mood (mania and hypomania), alongside periods of depression and disruptions to thought and behaviour that can affect quality of life (American Psychiatric Association, 2013). Bipolar disorder is believed to affect up to 1% of the population worldwide, and, at present, approximately 10-25% of all individuals diagnosed with bipolar disorder are aged 60 or over (Dautzenberg et al., 2016). These numbers are expected to increase dramatically by 2030 due to the ageing of the total population and improved awareness of bipolar disorder (Depp & Jeste, 2004). Research highlights that bipolar disorder in older adults is potentially more complex to treat due to an increased number of physical health comorbidities (Warner et al., 2023; Lala & Sajatovic, 2012), accelerated cognitive decline (Shouws et al., 2010) and less social support when compared to younger age groups with bipolar disorder (Beyer et al., 2003). Consequently, more research is needed to explore the changing care needs of older adults with bipolar disorder to enable us to improve the care and support available for this group.

Existing literature suggests that older adults with bipolar disorder experience distinct psychological and emotional challenges compared to younger age groups with bipolar disorder (Depp & Jeste, 2004; Clifton et al., 2013). Nivoli and colleagues (2014) found that bipolar disorder in older adults is associated with longer manic and depressive episodes and shorter inter-episode intervals compared to younger populations. Research also indicates that people with late-onset bipolar disorder experience more manic episodes and more severe cognitive impairment than those with early onset (Schouws et al., 2009). Additionally, Goldstein and colleagues (2006) determined that older adults with bipolar disorder experience a significantly higher prevalence of psychiatric comorbidities such as alcohol use disorder (38.1% vs 14.4%), panic disorder (19% vs 2.5%), and generalised anxiety disorder (20.5% vs 2.5%), compared to age-matched controls without bipolar

disorder. Consequently, older adults with bipolar disorder potentially face different challenges to younger age groups with bipolar disorder and the general ageing population meaning they require adaptations to the care they receive (Sajatovic et al., 2015).

The National Institute for Health and Care Excellence (NICE, 2014) recommend the same treatments to older adults with bipolar disorder as those for younger age groups. At present, the long-term use of mood-stabilising medication remains the most common treatment (Morlet et al., 2019). Whilst some literature suggests that the long-term use of some medications, such as lithium, can improve outcomes and also decrease the risk of Alzheimer's disease (Nunes et al., 2007), there is also an indication that the long-term use of mood-stabilising medication can increase the risk of cognitive difficulties (Pachet & Wisniewski, 2003) and physical health difficulties such as diabetes, weight gain, and renal failure (Sajatovic et al., 2022; Lala & Sajatovic, 2012) in later life. Some authors have argued that mood-stabilising medications have concerning side effects in the long term and are insufficient to address the changing physical, psychological and social care needs of older adults with bipolar disorder (Morlet et al., 2019). Additionally, older adults with bipolar disorder may have more passive coping styles than the general population and are more accepting of their difficulties (Schouws et al., 2015). Whilst this appears to enable older adults with bipolar disorder to adapt and complete new activities, it also suggests that this group may become more resigned to their challenges and attempt to cope independently rather than seeking support from services (Schows et al., 2015). When older adults with bipolar disorder do seek help, they often receive inadequate treatments that fail to meet their changing care needs or disengage from services completely, which may leave their needs unmet and potentially contribute to reduced quality of life and poor clinical outcomes (Dautzenberg et al., 2016).

There is insufficient qualitative research exploring the changing care needs of people

with bipolar disorder as they enter later life. Consequently, our knowledge about how best to support this group as they age is limited and may lead to insufficient and ineffective care (Sajatovic et al., 2015). This study aims to qualitatively explore the changing care and care needs of older adults with bipolar disorder in later life. This could identify necessary adaptations that might improve the support offered to this group and enhance their quality of life as they age. The study uses biographical narrative interviews (Wengraf, 2001) to capture the experiences of older adults with bipolar disorder since they first tried to seek help for bipolar disorder or first came into contact with mental health services, until the time of the interview in later life. This approach provides the opportunity to identify how and why peoples' care needs change over time and considers how services might adapt and tailor support, with the ultimate goal of improving wellbeing and tackling health inequalities.

5.3 Methods

5.3.1 Design

The research question for this study was experiential and therefore qualitative methods were appropriate (Hammarberg et al., 2016). The lead author completed single time-point biographical narrative interviews (Wengraf, 2001) with participants, which were analysed using narrative analysis.

5.3.2 Participants and recruitment

Participants were purposively sampled through 1) community-based mental health services within three NHS Trusts in the Northwest of England, 2) a confidential university-based participant database consisting of people living with mental health difficulties who

previously consented to be contacted about research projects, 3) advertising on social media, 4) UK based mental health charity organisations, such as Bipolar Scotland. The inclusion criteria for the study were: 1) aged ≥60; 2) a confirmed diagnosis of bipolar disorder from a healthcare professional during their lifespan; and 3) reporting experiences consistent with bipolar disorder for ten or more years to ensure that the researcher could understand how and why their care and care needs changed over time. Capacity to provide informed consent was assessed by the interviewer or by a clinician who worked directly with the participant if they were recruited from NHS services. All participants were required to have adequate English language skills to complete the interview. Exclusion criteria included a known moderate to severe cognitive impairment or learning disability, any imminent current risk to the self or others, and current inpatient or crisis service input.

5.3.3 Data collection

Participants provided informed written or audio consent to take part. They then completed single time-point biographical narrative interviews (Wengraf, 2001) with the lead author (AW). These interviews were comprised of three stages. In stage one, the interviewer aimed to capture participants' experiences of care and their changing care needs over time by asking the question, 'Please could you tell me about your experiences of care and support since you first tried to get help for bipolar disorder, or first came into contact with mental health services, up until now?'. During this stage, the interviewer took the role of an interested listener and allowed participants to tell their stories without interruption and used mainly non-verbal cues to offer encouragement, as recommended by Rosenthal (1993). In stage two, the interviewer waited for the participant to voluntarily break off from telling their story before asking narrative-informed questions about the biographical content that the participant covered during the initial telling of their story (e.g., what happened after

that, what care did you receive following that?). Following stages one and two, the interviewer offered participants the opportunity to have a break before asking questions about areas that were not covered during stages one or two but seemed to be important in answering the research question comprehensively (e.g., can you tell me what you feel your key care needs are at present and why?). Questions for stage three of the interview were developed by the research team alongside older adult public advisors with experience of mental health difficulties. Finally, the interviewer asked whether participants wanted to add anything before concluding the interview. Participants provided demographic information for descriptive purposes.

5.3.4 Data analysis

The authors analysed the interview transcripts using narrative analysis. This approach allows researchers to make sense of participants' stories and highlight key events and transitions within participants' lives, whilst considering the influence of society and culture on individuals' stories (Wertz, 2011). Leading figures in narrative analysis stress that there is no one way to complete a narrative analysis (Frost, 2009; Esin, 2011). Researchers are encouraged to be imaginative and innovative while remaining reflexive and ensuring rigour in the analytical process (Frost, 2009).

The analysis comprised of the following steps. The lead author (AW) transcribed all interviews verbatim before reading and re-reading participants' interviews to immerse himself in the data (Crossley, 2000). Narrative concepts, such as the tone in which each participant's story was told, were noted during this initial process (Crossley, 2000). This helped highlight the participant's feelings towards the topic (Smith, 2006). The lead author then worked with one interview at a time to generate initial codes and identify recurrent topics and stories within participants' narratives (Anderson & Kirkpatrick, 2016). During

this process, a one-page summary of each participant's narrative was developed to highlight key events within their interview (Jovchelovitch & Bauer, 2000). They then worked to develop key themes that highlighted similarities and differences in the telling of participants' stories (Esin, 2011). The themes aimed to identify broader patterns of meaning across the dataset and portray key events, transitions and changes in the care and care needs of older adults with bipolar disorder. Finally, the themes were outlined in a way that told a coherent story of the experiences of care and support (Anderson & Kirkpatrick, 2016).

Throughout the analytical process, participant narratives were explored on the personal, interpersonal, positional, and ideological levels outlined by Murray (2000). On the personal level, the researchers examined how participants' stories portrayed how they viewed the world and their sense of self and considered what function the telling of their stories had for participants (Murray, 2000). On the interpersonal level, the researchers assessed their role in shaping the participants' narrative accounts. On the positional level, the researchers considered the differences in social position which existed before the interaction between participant and interviewer (Murray, 2000), such as social power and how this may have influenced the interview process and subsequent narrative. Finally, at the ideological level, the role that societal beliefs, systems, and ideologies might have had in developing the narrative told by the participant were considered (Doise, 1986). This included issues such as stigma surrounding mental health and ageing and the impact of seeking support from the National Health Service (NHS) or other relevant services. These levels were considered throughout the analytical process and used to provide an in-depth narrative account of participants' experiences of care and their changing care needs as they aged with bipolar disorder.

5.3.5 Reflexivity

The lead author for this study was a PhD student at a UK university who also had experience working alongside older adults experiencing mental health difficulties within the NHS. These experiences potentially influenced how the study was designed, conducted, and analysed. The research team took several steps to ensure transparency and rigour at all stages of the research process (Jootun et al., 2009). Before data collection, AW completed a positionality statement that identified their philosophical position, gender, class, and personal experiences and considered how these might influence their perceptions of the data (Holmes, 2020). AW also engaged in regular supervision, which offered the opportunity to discuss any challenges and receive feedback on the study design, data collection and analysis at all stages. Three members of the research team were qualified clinical psychologists (FL, JPC and ET), one was a Professor in Ageing (CH), and two were older adult public advisors with lived experiences of mental health difficulties (VR and GS). AW kept a reflexive diary throughout the research process, highlighting any methodological or personal challenges that may have influenced how the research was conducted to ensure transparency in decision-making (Watanabe, 2017).

5.3.6 Ethics

This study received NHS Health Research Authority approval (REC reference: 21/LO/0405). It also received approval from three NHS Trusts that allowed the research team to recruit participants from their services. All participants had to provide written or audio-recorded verbal consent before participating in the study.

5.4 Results

Eighteen older adults with bipolar disorder were invited to take part in the study. Two declined, resulting in sixteen biographical narrative interviews. Seven participants were recruited from a confidential university research database, four participants were from NHS services, four were from mental health charities, and one was from social media. The mean age of participants was 66.1 (60-75; SD 4.9), the majority were female (69% vs 31% males), and most participants reported a diagnosis of Bipolar Disorder I (88%). The sample was also predominantly White British (50%), with 5% identifying as White Other, 6% Black British, 6% Indian and 6% Asian British (see Table 6 for participant characteristics). All participants were given pseudonyms to maintain their confidentiality and anonymity.

Table 6: Participant characteristics

Demographics (n = 16)	Total
Age, *mean* (range, SD)	66.1 (60-75, 4.9)
Gender (n, %)	
Female	11 (69%)
Male	5 (31%)
Ethnicity (n, %)	
White British	8 (50%)
Black British	1 (6%)
White Other	5 (32%)
Indian	1 (6%)
Asian British	1 (6%)
Diagnosis (n, %)	
Bipolar disorder I	14 (88%)
Bipolar disorder II	2 (12%)
Employment status (n, %)	
Retired	6 (37.5%)
Unemployed	6 (37.5%)
Employed	4 (25%)
Living status (n, %)	
Alone	9 (56%)
With spouse	5 (32%)

With children	1 (6%)
Prefer not to say	1 (6%)
Education (highest level) (n, %)	
No qualifications	2 (12%)
Secondary	3 (19%)
A/O level	1 (6%)
Undergraduate degree	7 (44%)
Postgraduate degree	3 (19%)
Number of hospitalisations, *mean* (range, SD)	2.4 (0-10, 2.6)
Age when diagnosed, *mean* (range, SD)	33.3 (18-54, 13.5)
Place recruited from (n, %)	
NHS service	4 (25%)
Research participant database	7 (44%)
Social media	1 (6%)
Charity organisation	4 (25%)

Participants' stories highlighted four key phases that provided insight into the changing care and care needs of older adults with bipolar disorder over their lifetime, which has been split into parts as recommended by Wilson and colleagues (2015). Part one focused on participants' initial confusion and fear after being diagnosed with bipolar disorder and their subsequent attempts to access support. Part two highlighted how community care and peer support provided brief hope and safety following a diagnosis before this disappeared, leaving participants disappointed. Part three illuminated participants' frustrations at being unable to access previously beneficial support in later life. This led to some feeling as though they were managing bipolar disorder alone, whilst others disengaged with services completely to avoid iatrogenic stress as they got older. Finally, in part four, participants described how they felt that their care needs had changed in later life and suggested that their support required adaptation to remain effective as they aged. Overall, participants' narratives portrayed a story that displayed a disconnect between the care they received in later life and the care required to meet their changing needs. Each part of the narrative is explored in more detail below (see figure 2 and table 7).

Figure 2: parts of participants' narratives

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┌─────────────────────────────────┐
│     Part one: Navigating the    │
│  disruption caused by diagnosis │
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                 │
                 ▼
┌─────────────────────────────────┐
│  Part two: The removal of       │
│   services that provided hope   │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│  Part three:  Later life – we   │
│      are on our own now         │
└─────────────────────────────────┘
                 │
                 ▼
┌─────────────────────────────────┐
│  Part four: Changing care needs │
│  in later life – we still need  │
│           support               │
└─────────────────────────────────┘
```
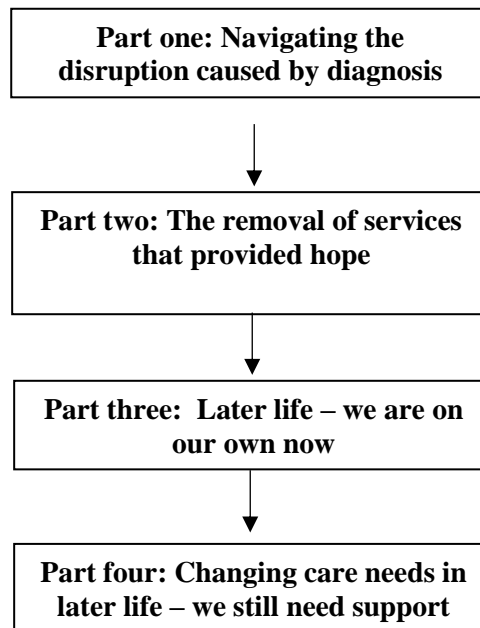
Part one: Navigating the disruption caused by diagnosis

Many participants experienced difficulties with their mental health for many years before being diagnosed with bipolar disorder. Often, they were diagnosed with bipolar disorder as younger adults, but identified receiving this diagnosis as a critical event in their lives that led to confusion and fear. Some participants also felt that a lack of support and information at this time exacerbated their concerns. This is apparent in Claire's story, where she described questioning her identity and what the future held following diagnosis.

> **Claire:** "*When I was told I had bipolar disorder, I visualised a woman who was unkempt, unwashed, uncared for, alone, and homeless. I thought, is that me? So, it was horror in many ways. I needed more information, but it wasn't given*".

Following the initial challenges of diagnosis, participants discussed their experiences of seeking support from services. This was sometimes a particularly difficult time for participants who described feeling that their agency and control over their lives had been taken away from them. Angela's story highlighted a loss of agency following her diagnosis of bipolar disorder.

Angela: *"When I first got the diagnosis, they said you're going to have to start taking these sodium valproate tablets. I said how long for, and they just said, well, forever probably. I do have a memory of just taking the first one and thinking God, I'm going to be on this forever, and this is me now".*

For some participants, their narratives portrayed feelings of hopelessness as they felt their care needs were not considered, their voices were not heard, and that care was 'done to them' rather than alongside or in collaboration with them. Karen's narrative exemplified this, as she discussed her difficult experiences in a psychiatric hospital after receiving a diagnosis of bipolar disorder.

Karen: "*After I was diagnosed and put in the hospital, my needs weren't addressed at all. Things were just done to me, and I had to put up with it".*

Other participants revealed contrasting experiences of being diagnosed with bipolar disorder. Susan stated that this was an important event that provided her with access to psychological support, which helped her to make sense of traumatic experiences leading up to diagnosis. For Susan, this support helped her to improve her understanding of bipolar

disorder and develop self-awareness that still helps her to manage mood instability to this day.

> **Susan:** *"The psychologist was understanding, she was respectful, she was humane, kind, patient and also very knowledgeable; she was absolutely superb. She took her time with me listening and letting me cry and eventually said this goes back to early childhood, so we need to go right back to the beginning. It helped me so much and helped me to realise that it wasn't all my fault. That still helps me today".*

However, the majority of participants expressed feeling stigma and rejection at this time. Amy's story highlighted the pain of feeling judged by family, friends and society following diagnosis.

> **Amy:** *"Being diagnosed brings pretty awful discrimination and it's hard to undo it once you have any kind of label attached to you".*

Linda described how her friends questioned her after she stopped working due to bipolar disorder. For Linda, this was a difficult experience that left her feeling isolated and misunderstood.

> **Linda:** "*My friends did not understand because none of them have bipolar disorder. When I stopped working, they used to question me and say well you're not ill now so why are you not going to work? The stigma was appalling, and I just received more and more abuse from everyone".*

Part two: The removal of services that provided hope

After being diagnosed with bipolar disorder many participants felt isolated and worried about their future, especially after being discharged from services, such as inpatient psychiatric hospitals. A key theme within participants' narratives was the importance of community care being introduced in the early 1990s. This meant that following discharge from hospital, participants had an allocated community psychiatric nurse (CPN) who visited consistently and provided emotional and practical support. Participants described the importance of developing consistent, trusting relationships with professionals who understood their care needs, offered compassion, and initiated quick access to support when necessary. Claire describes how her CPN was a reliable point of contact during crisis, which provided her with a sense of safety and security whilst living with bipolar disorder that benefitted her wellbeing.

> **Claire: "***My CPN didn't come across in any way that he was judging our situation. He was amazing and made me feel safe. They almost became part of the family. It was so helpful and validating for me."*.

Finding peer support groups was also a powerful moment in participants' journeys post diagnosis. Being able to share their experiences with people who understood and accepted them despite experiencing bipolar disorder was described as an important area of support for most participants. This point is demonstrated by David's narrative, that outlined the importance of being welcomed into a bipolar peer support group following many years of feeling outcast and marginalised.

David: *"I joined a bipolar support group when I moved towns and it was run by someone with bipolar. It was an astonishing feeling to be accepted, it was brilliant"*.

However, participants' narratives often changed to a more pessimistic tone as they began to age. Susan described the devastating impact of learning that resource scarcity would leave her without CPNs or community care.

Susan: *"When my CPN retired, I was bereft; I was so sad. I didn't know what I was going to do if something went wrong. Since then, I've had nothing; I have been on my own and unable to get any help outside of care when I'm in crisis"*.

Participants' narratives highlighted a sense of loss as they felt isolated and abandoned by services and without access to care that would meet their needs. This change in narrative tone was portrayed in Mandy's story where she highlighted the sense of loss when her CPN was taken away.

Mandy: **"***It was great, but then they started saying you're only getting a CPN if you're in services, and the minute you're out of services, you've got to go through the whole process again, and there's no guarantee you'll get the same one. It was much less organised, and the service cuts hit me hardest when I lost the CPN who kept me going between crises. After that, there was nothing"*.

These difficulties were often compounded when a number of participants reported that the peer support groups were shut down without consultation with themselves or other

group members. For many participants, peer support groups were a safe, supportive space, and their removal was frustrating and isolating.

> **Emma:** *"It was so helpful to see how other people with bipolar disorder live, and somehow the group I went to closed down; we don't know why, and no one ever explained why, which is very bad; it is patronising. It is so frustrating because it leaves us very isolated".*

Whilst the majority of participants' narratives portrayed a sense of loss and frustration as they aged, one participant had maintained contact with a long-term psychiatric nurse. Karen highlighted how this continuity of care had enabled her to maintain stability in later life by helping her to reduce isolation and increasing her motivation to stay well. This support also provided security as she entered later life with bipolar disorder, showing the power of this relationship and the value of consistent care for older adults with bipolar disorder.

> **Karen:** "*Having a psychiatric nurse whom I've known for years is like a friend visiting. It provides so much security, and I'd be lost without her".*

Part three: Later life – we are on our own now

As participants' narratives moved into later life, a common theme was that there was a substantial gap where they had no contact or support from services. Many felt all essential support was now inaccessible or had been removed, leaving them frustrated and increasingly

alienated from services. Mike's narrative highlighted his disappointment at the support offered from services within the UK at present.

Mike: *"Britain has the problem that the medical fraternity seems to have dropped the idea of care. There is no care anymore. It's just about medication delivery now. It is so frustrating and unhelpful".*

Participants stated that they had learnt to adapt and manage bipolar disorder alone or alongside family as they aged. They explained that learning to cope in this way made them highly self-reliant in later life. However, Emma described how her experiences of learning to cope with bipolar disorder and her frustration at being unable to access services led to her rejecting services altogether as she aged.

Emma: "*No, I don't want support from services now. I managed to sort everything myself. Basically, everything that I needed was not given. So eventually, you become very self-reliant, and you just cope with the help of family".*

Other participants described frustration and confusion as they sought support as older adults. For example, some participants still desired help from services to provide reassurance but were left exasperated by their inability to access appropriate care in later life. This was a common experience, and Linda's narrative outlined how she only realised that she had been discharged from services when trying to access urgent support during crisis. This left her feeling that a vital safety net had been taken away without her knowledge, leaving her feeling isolated and alone.

Linda: **"***I rang and said I'm stressed and need to speak to somebody. They said your case isn't active anymore, so why are you ringing us? It was only two years ago that I rang when I needed help, and now I can't access help"*.

Whilst these issues were observed in most participants in later life, some had contrasting experiences. For Mike, although he had experienced challenges with services throughout his life, he reported that his recent experiences of accessing support from the older adult community mental health team were resoundingly positive. Mike outlined the benefits of this support as an older adult, as it provided a safety net that was missing for other participants such as Linda. However, Mike's narrative highlighted how he had to fight to get support from services for many years before he finally received adequate care and support as an older adult.

Mike: *"I was recently referred to an older adult mental health team, which was very positive as they responded quickly and supported me. I couldn't have expected more. It was just that reassurance that the safety net was there. It was such a relief, but I've had to fight for years to get this, and it's been exhausting"*.

Part four: Changing care needs in later life – we still need support

Part four of participants' narratives highlighted how they felt their care needs had changed as they aged and that despite disengaging with services to avoid stress and frustration, they would still like support if it was more readily accessible. In particular, participants felt worried that they now had to manage the physical side effects caused by living with bipolar

disorder for many years and wanted support. For example, Claire voiced concerns over her physical health after using medication to manage mood instability for several years.

> **Claire:** *"Antipsychotics are known to have cardiac impacts. I've been on antipsychotics for a very long time, and I'm worried about what that could do. So, I worry more about the physical side of things now rather than being carried off by a wave of emotions like in the past".*

Angela's story further highlighted participants' concerns over the long-term physical health impact of taking mood stabilising medication for bipolar disorder. Angela's narrative illuminated how she had accepted medication as part of her life but suggested that she would like more information about its potential consequences in later life. However, this information was still difficult to access from professionals.

> **Angela:** *"I've had to accept that taking a mood stabiliser is part of my life. For years, I have asked what sodium valproate does to your body over the long-term, but nobody has ever given me much of an answer to that one. From doing my own research, it seems like it does have various physical health side effects which is concerning. I would like more information, but it is not available".*

Participants displayed how becoming older had brought additional financial stressors. When younger, participants placed emphasis on achieving success within their careers; however, many felt that this had contributed to significant stress and multiple mood episodes throughout their lives. As older adults, several participants wanted to retire or

reduce their workload to reduce the risk of relapse. Susan's story showed the challenges of managing the trade-off between retiring to reduce stress, surviving financially, and engaging in activities that brought her fulfilment and helped her to maintain stability as she aged.

Susan: "*How much do I give in? Our lives have had to shrink and will continue to shrink because of finances. Next year there will be a big drop in income, and I could be migrated to universal credit, which would be horrible. At the moment, I can afford to do things I enjoy, but I'm worried about what the future holds if I can't do that*".

Finally, many participants suggested that a key care need in later life was to be able to develop meaningful connections with professionals as this made them feel safe, supported, and understood. This was apparent in Geoff's narrative, where developing a meaningful relationship with a psychiatrist helped him to feel understood, safe, and supported which benefitted his wellbeing and ability to cope with challenges in later life.

Geoff: "*I have been really blessed to have a great psychiatrist in my life. We got on from the moment I walked into the room. Having that relationship with him where I feel comfortable with him has helped me massively. It helps me to cope when things get difficult*".

However, participants were frustrated that many services now operate via remote methods, such as using the telephone or online appointments. The use of technology was not only daunting for some participants but also limited their ability to engage in human

contact which seemed beneficial. For Linda, her inability to access face-to-face support and establish meaningful connections with professionals had a negative impact on her wellbeing.

Linda: "*You need to be able to talk to a human. I need a person I can talk to when the moment hits. I've found that as I've got older, there isn't any human to contact anymore. It's a complete nightmare*".

Whilst many participants reported difficulties in accessing care that met their changing care needs in later life, one participant's narrative highlighted the personal impact of accessing effective care as she aged with bipolar disorder. Shirley's account demonstrated the value of accessing support for her physical and mental health needs from services and family. She described how feeling supported, respected, and valued in later life made life worth living again, despite the challenges posed by ageing with bipolar disorder. Prior to receiving this support, Shirley discussed how she often felt unable to cope and contemplated suicide due to physical pain caused by arthritis and mental health challenges associated with bipolar disorder.

Shirley: "*I can't argue with the care I've had in terms of psychology and help with physical health. It's been fantastic as I've got older. Having the right support in place from services and family who understand can make life worth living again*".

Table 7: Additional supporting extracts for all themes

Theme	Example quotes	Source
1: Navigating the disruption caused by diagnosis	*When I was diagnosed, I was excited to tell people that someone had told me what was wrong. After that, I noticed that people started to withdraw because they thought I was odd and I had a mental label. I became very lonely after that.*	David
	When I was first diagnosed I wasn't offered any care or support, just medication, no care at all. It was scary.	Linda
	I was terrified to tell anyone that I had a diagnosis of bipolar disorder. They'd think of me differently and they wouldn't understand. I didn't feel like I could talk to anyone about it.	Debbie
2: The removal of services that provided hope	*Things were alright while there was support for people in the community but then they started discharging people into the community without support or a CPN. After that there wasn't any support and it fell apart.*	Mandy
	When I was back in the community, I was given a CPN who would help me figure out how to spend my time. It was helpful and I think it's quite astonishing that it doesn't happen anymore. This is the trouble.	Amy
	Respite services were so helpful and then they just removed them. Nothing like that is offered in my area anymore.	Debbie
3: Later life – We are on our own now	*I was discharged after a fairly lengthy period in hospital. I was amazed that there was hardly any follow-up. I've just been left alone.*	Geoff
	The only way that I have been able to access care is to find a private doctor. I am lucky because I have the money. Accessing a private doctor means I don't have to relive my traumatic experiences to every doctor in the NHS.	Emma
	There's just been nothing there, nothing to do, no care at all. The care is just so poor at the moment.	Debbie
4: Changing care needs in later life – We still need support	*I'm at some sort of crossroads now where I've got to decide whether I let my husband buy me a mobility scooter because he gets upset when I'm in pain. Or do I keep taking co-codamol and struggling to try to keep active?*	Susan
	I've really had enough of medication. The side effects of medication for me had been headaches and incontinence and I haven't enjoyed either obviously. So, I didn't want to go back to headaches and incontinence. I wanted to come off them.	Derek
	Now I'm older, the stress of becoming unwell with bipolar has a huge effect on the physical pain I suffer with. People don't understand that when you are struggling with bipolar and pain it leads to thoughts of suicide.	Shirley
	I am starting to experience some forgetfulness, mistakes and so on. It's beginning to worry me that maybe there's a connection between bipolar and memory. I want to find out more about it.	John

5.5 Discussion

This study contributes to existing literature by capturing the changing care and care needs of older adults with bipolar disorder in later life. Participants initially described their confusion and fear after being diagnosed with bipolar disorder and their attempts to navigate through this period whilst experiencing stigma and judgement from others. Narratives then highlighted a brief period of hope where community care and peer support groups were readily accessible, before the removal of these services caused stress and frustration for participants. As participants transitioned into later life, many felt that they were 'on their own' and unable to access appropriate services. For some, this led to them disengaging with services completely to avoid iatrogenic stress and attempting to cope alone or alongside family. Finally, older adults with bipolar disorder in this study expressed how their care needs had now changed due to concerns over their physical health, managing finances as they retire and difficulties in accessing face to face care where they can develop meaningful relationships with professionals. Whilst some participants were still able to access care and described the benefits of this, this study generally illuminated a disconnect between the care this group currently received and the care they desired. It is possible that this contributes to the range of challenges and poor outcomes commonly observed in older adults with bipolar disorder.

Older adults with bipolar disorder experience unique care needs, including concerns surrounding the physical health consequences of using mood-stabilising medication over several years. Existing literature suggests that older adults with bipolar disorder may be at increased risk of physical health comorbidities such as cardiovascular disease and some forms of cancer (Warner et al., 2023). Consequently, services should attempt to address the potential side effects of long-term medication use and other physical health challenges associated with ageing with bipolar disorder (Dols et al., 2013). Alongside this, some

participants felt that retirement would help to reduce stress and protect their mental health but were apprehensive about the associated financial challenges. Literature from the general population suggests that retirement can increase the risk of mental health challenges and mobility issues for some individuals (Dave et al., 2008). Our results indicate that treatments for older adults with bipolar disorder should also prioritise practical advice surrounding the transition into retirement and financial support that enables this group to live well as they age. Despite this, NICE guidelines still recommend similar treatments to younger age groups with bipolar disorder, meaning the care older adults with bipolar disorder receive may continue to be insufficient to meet their different needs (NICE, 2014).

Participants spoke openly about the benefits of receiving community care in the past and their disappointment at no longer being able to access this support. The Community Care Act was introduced within the NHS in 1990 with the aim of offering practical and high-quality care that supports people to live within their own homes wherever sensible and feasible (Thornicroft, 1994). However, cuts within NHS services, lack of staffing and reduced funding, alongside increased demand for services as people continue to live longer, has led to severe challenges in accessing community care (Howse, 2008). Furthermore, older adults who often require the most support from services as they experience complex comorbidities are at risk of becoming isolated and neglected (Howse, 2008). Our findings suggest that older adults with bipolar disorder now often attempt to manage difficulties alone or with support from family as they struggle to access care that meets their changing needs. These findings are in contrast with the NHS Long Term Plan and NHS Mental Health Implementation Plan (NHS England, 2019) which outlines that a key aim is to increase access to community care for older adults with mental illness and ensure that no underlying need is missed. Additionally, participants highlighted their frustration at being unable to access face-to-face appointments with professionals and

emphasised that the stress caused by this led to disengagement for some. These findings contradict those of a recent review demonstrating that using technology for mental healthcare delivery leads to improved health outcomes, improved cognitive function and reduced symptoms in older adults experiencing depression (Harerimana et al., 2019).

Peer support has been found to be beneficial for people experiencing mental health difficulties and has been linked to reduced admission rates, improved clinical outcomes, and reduced stigma (Repper & Carter, 2011; Mahlke et al., 2014). Our analysis suggests that peer support can be particularly important for older adults with mental health difficulties as they often experience a dual stigma that results in disengagement from services and poor quality of life (Depla et al., 2005). Participants' narratives supported this and demonstrated the benefits of acceptance from peers after experiencing continued stigma and rejection as they aged. Narratives highlighted that peer support groups were often closed without consulting participants or other group members, leaving older adults with bipolar disorder unable to access peer support. This contributed to isolation and loneliness which have been found to be the strongest predictors of mental health outcomes in older adults (Donizzetti & Legace, 2022). To avoid the removal of services that appear to benefit older adults with bipolar disorder, services should actively collaborate with this group to ensure that the support offered is tailored to their needs. Research and policy have identified the importance of service user involvement when designing care (Wright et al., 2015) and using the views of older adults with bipolar disorder to inform service adaptations can help to improve care and reduce the challenges discussed within this study.

5.5.1 Strengths and limitations

There are several strengths in this study. First, the authors utilised biographical narrative interviewing methods that allowed them to capture in-depth stories of participants'

experiences of care throughout their lifespan and identified their changing care needs as they transition into later life (Crossley, 2000). This helps to build upon the findings of existing literature (Sajatovic et al., 2015) and make sense of why older adults with bipolar disorder experience unique challenges requiring treatments to be adapted to reduce the difficulties they experience. Additionally, the authors ensured that patient and public involvement was incorporated at all stages of the research study, therefore enhancing reflexivity, improving rigour, and highlighting researcher bias which is essential when completing qualitative research (Morse, 2015).

Limitations include a small convenience sample, which included few participants currently receiving care from NHS services. Many had been discharged or struggled to access NHS or other services, which may have led to more negative accounts of services. However, the failure to recruit more participants actively receiving NHS care may also reflect current conditions within the NHS, where staff shortages result in staff having to prioritise high-risk cases and clinical care, rather than supporting research participation (Clarkson et al., 2023). Participants in this study were predominantly educated, White British and retired professionals. Consequently, the experiences of care and support and the care needs of this group may not be representative of all older adults living with bipolar disorder.

5.6 Conclusion

This study highlighted that the care needs of older adults with bipolar disorder change significantly over time and particularly in later life. Key concerns include the side effects of long-term medication use, barriers to accessing care and frustration at the removal of potentially beneficial services as they age. Services should develop an ongoing collaborative partnership with older adults with bipolar disorder and work with them to

adapt services to meet their changing individual care needs. This collaborative and person-centred approach will improve the support available to older adults with bipolar disorder, increase engagement and enhance their wellbeing, enabling them to live fulfilling lives as they age.

Chapter 6 – Quality of life in older adults with bipolar mood states: A secondary analysis of The English Longitudinal Study of Ageing (ELSA) data

<u>Introduction to secondary analysis of ELSA data study</u>

The previous chapters in this thesis highlighted that older adults with bipolar disorder experience a range of challenges that appeared to affect their wellbeing and quality of life. Despite this, the existing literature investigating quality of life among older adults with bipolar disorder was very limited and this warranted further attention. Because of this, the researcher aimed to address this gap in chapter 6 by examining whether bipolar mood states were associated with poorer quality of life among older adults. This chapter also attempted to identify predictors of quality of life in older adults with bipolar mood states. This emphasised the consequences of living with bipolar mood states in later life and highlighted factors that might contribute to poorer quality of life in this population. Chapter 6 will be submitted for publication to the British Journal of Clinical Psychology and is presented below.

Chapter 6: Quality of life in older adults with bipolar mood states: A secondary analysis of The English Longitudinal Study of Ageing data

Aaron Warner[1,2]*

Carol Holland[2]

Fiona Lobban[1,4]

Lee Bentley[5]

Elizabeth Tyler[3]

Jasper Palmier-Claus[1,4]

[1]Spectrum Centre for Mental Health Research, Division of Health Research, Lancaster, UK

[2]Centre for Ageing Research, Division of Health Research, Lancaster, UK

[3]Division of Psychology & Mental Health, University of Manchester, Manchester, UK

[4]Lancashire & South Cumbria Care NHS Foundation Trust, Lancashire, UK

[5]Manchester Metropolitan University, Manchester, UK

*Email address of the corresponding author: a.warner3@lancaster.ac.uk

Postal Address of the corresponding author: Health Innovation One, Sir John Fisher Drive, Lancaster University, Lancaster, LA1 4YW

6.1 Abstract

Objectives: To investigate: i) whether bipolar mood states are associated with poorer quality of life in older adults, and ii) what are some of the predictors of quality of life in older adults with bipolar mood states.

Methods: The authors completed a cross-sectional multilevel analysis on panel data from seven waves of The English Longitudinal Study of Ageing dataset. The main analysis included 567 participants who reported experiencing bipolar mood states. Some participants reported this in more than one wave, resulting in 835 observations of bipolar mood states across the seven waves. Quality of life was assessed using the Control, Autonomy, Self-realisation, and Pleasure-19 (CASP-19) measure.

Results: The presence of bipolar mood states was significantly associated with poorer quality of life, even after controlling for multiple covariates (age, sex, social isolation, loneliness, alcohol use, education level and socioeconomic status). Loneliness significantly predicted poorer quality of life in older adults with bipolar mood states. In contrast, higher educational attainment and being female predicted better quality of life in this group.

Conclusions: Older adults with bipolar mood states potentially have worse quality of life compared to the general population, which may be partly driven by loneliness. This has ramifications for the support offered to this population and suggests that treatments should focus on reducing loneliness to improve outcomes.

6.2 Introduction

The World Health Organisation (2023) defines quality of life as "an individual's perception 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". Quality of life encompasses physical, occupational, social, and spiritual wellbeing, and can fluctuate over time due to people's changing circumstances, making it challenging to measure accurately (Michalak et al., 2005). Michalak and colleagues (2006) suggest that quality of life may be a key indicator of people's wellbeing and important to consider when completing health related research. Assessing quality of life can enable researchers to identify the main difficulties that lead to diminished wellbeing in marginalised populations, such as older adults and those experiencing mental health difficulties (Sachs & Rush, 2003; Sahin et al., 2019). Improving our understanding of what affects quality of life in these groups can help us to consider necessary adaptations to care that can enhance the support offered (Depp et al., 2006).

A wealth of research highlights that old age can bring several challenges and losses that potentially contribute to decreased quality of life (Baernholdt et al., 2012). For example, Hawton and colleagues (2011) suggest that social isolation caused by reduced social contact in later life has a profound impact on quality of life as people age. Indeed, 11-17% of people aged 65 and over in the United Kingdom report feeling socially isolated and 13% of older adults living alone feel detached from society (Barnes et al., 2006). A longitudinal study by Victor & Bowling (2012) reported that changes in social networks, living arrangements, and poor physical health resulted in 9% of older adults feeling severely lonely and a further 30% feeling lonely at times (Victor & Bowling, 2012). Older age is also commonly associated with reduced physical functioning, and this has been found to be a predictor of the onset and persistence of mental health difficulties in older adults (Geerlings et al., 2000).

Living with mental health difficulties such as bipolar disorder can drastically affect

people's wellbeing (IsHak et al., 2012). Bipolar disorder is defined as a chronic mood disorder characterised by extreme fluctuations in mood that significantly impact functioning (Carvalho et al., 2020). It is present in approximately 1% of the population worldwide making it one of the leading causes of disability among adult populations (Grande et al., 2016). Due to the significant mental and physical health challenges associated with bipolar disorder, many people report that living with these experiences has a profoundly negative impact on their quality of life (Michalak et al., 2006). For example, this diagnosis has been linked to reduced social support, increased stigma, increased physical health comorbidities, poorer socioeconomic status, and higher levels of substance misuse, which all lead to poorer wellbeing, marginalisation and worse clinical outcomes compared to the general population (Gutiérrez-Rojas et al., 2008; Hawke et al., 2013; Carvalho et al., 2020). There is also evidence that people without a formal diagnosis, but experiencing extreme mood states (e.g., mania), are at risk of diminished functioning that is difficult to treat effectively (Evans et al., 1995).

Older adults experiencing bipolar disorder reportedly face both general difficulties associated with ageing and disorder specific difficulties (Depp and Jeste, 2004). This group have been found to experience increased physical health comorbidity, worse cognitive function and accelerated cognitive decline compared to the general ageing population (Warner et al., 2023; Schouws et al., 2016; Gildengers et al., 2009). Consequently, there is potentially an important interaction effect between ageing and bipolar disorder that leads to poorer outcomes (Sajatovic et al., 2015).

To date, there is little research exploring quality of life outcomes in older adults with bipolar disorder. Depp and colleagues (2006) completed a study reporting that older adults with bipolar disorder (n=54) experienced worse functioning, and poorer wellbeing in comparison to non-clinical controls (n=38), even when they were deemed to be in remission. These results did not change after controlling for covariates such as education, age, and occupational

attainment. Further, largescale research using representative samples from the general population is needed to better understand whether older adults with bipolar disorder experience lower quality of life. Knowledge of the factors contributing to poor quality of life would also help to identify important targets for intervention in older adults experiencing bipolar mood states.

This study analyses data from The English Longitudinal Study of Ageing (ELSA), a large epidemiological dataset of older adults in England, to examine whether bipolar mood states are associated with quality of life in older adults. It also investigates predictors of quality of life (loneliness, social isolation, socioeconomic status, education level, alcohol use, age, and sex) in older adults experiencing bipolar mood states. These predictors were selected based on existing literature surrounding older adults and individuals with bipolar disorder. For example, people with bipolar disorder are reported to experience increased loneliness, social isolation and increased alcohol use compared to the general population (Nilsson, 2016; Lee et al., 2022; Farren et al., 2012), whilst a link between socioeconomic status and quality of life has been found in research exploring older adults with mental health difficulties (Achdut & Sarid, 2020). Consequently, these factors potentially impact quality of life in older adults with bipolar mood states and this will be examined within this study.

The hypotheses are:

1. The presence of bipolar mood states will predict poorer quality of life in an older adult sample.

2. Demographic and lifestyle factors (loneliness, social isolation, socioeconomic status, education level, alcohol use, age, and sex) will predict quality of life in older adults with bipolar mood states.

6.3 Methods

6.3.1 Design

The authors completed a cross-sectional multilevel analysis on panel data from across seven waves of The English Longitudinal Study of Ageing data (ELSA; Steptoe et al., 2013). Two waves (1 & 2) were omitted from the analysis as they did not record data for the variables being assessed within this study.

6.3.2 Sample

The ELSA is an ongoing prospective observational study of community-dwelling individuals in England, aged 50 and over (Steptoe et al., 2013). The original sample was taken from households that had taken part in the Health Survey for England (HSE) between 1998 and 2001. The main fieldwork for ELSA began in 2002 and the same group of respondents have completed two-yearly interviews, known as waves, to assess key factors related to ageing. For this study, the researchers used data from waves 3-9 (2006-2019), based on the availability of key variables to examine quality of life in older adults with bipolar mood states.

6.3.3 Variables

Dependent variable

Control, Autonomy, Self-realisation, and Pleasure-19 (CASP-19; Hyde et al., 2003)

The ELSA includes the CASP-19 as a measure of quality of life. The CASP-19 consists of 19 items covering four domains that were initially developed to assess quality of life in old age: control, autonomy, self-realisation, and pleasure (Wiggins et al., 2004). The control domain comprises of four items, whereas the autonomy, self-realisation and pleasure domains all consist of five items. Each item included in this measure was scored on a four-point Likert scale that ranged from 0-3 with responses ranging from 'this applies to me: never; not often;

sometimes; often'. Scores ranged from 0-57 with higher scores indicating better quality of life. A study completed by Hyde and colleagues (2003) found the CASP-19 to be a useful, valid, and reliable scale for measuring quality of life in older adults. The authors reported that all domains on the CASP-19 have Cronbach's alphas between 0.6 and 0.8 and concurrent validity was strong ($r = 0.63$, $p = 0.010$) when assessed alongside the Life Satisfaction Index (Liang, 1984).

Independent variable

Bipolar mood states: The authors identified individuals with extreme mood swings consistent with bipolar disorder mood states based on participants' responses to the following question: What type of emotional, nervous, or psychiatric problems [^do (did) you /does (did) [^name]] │ have? There were then the options: 'mood swings' and 'manic depression'. Endorsement of either item was coded as a scoring position for bipolar mood states. Due to the low frequency of participants scoring positive for manic depression/bipolar disorder ($n = 100$) and mood swings ($n = 577$) across the seven waves, the authors decided to combine the variables to ensure adequate power for the analyses. This decision was deemed sensible through consultation with public advisors with bipolar disorder.

Other variables / covariates

Loneliness: Loneliness was assessed using the short form of the University of California, Los Angeles (UCLA) Loneliness scale (Russell et al., 1978). This measure has been frequently used in studies assessing loneliness using ELSA data (Bu et al., 2020; Victor & Pikhartova, 2020) and was found to have an acceptable level of internal consistency ($\alpha = 0.84$) and satisfactory psychometric properties (Neto, 2014; Shankar et al., 2011). The measure contains items that ask participants to respond to how often they felt 'isolated from others', how often 'they felt

lonely' and how often they 'felt left out. Responses to these items were rated from 1-3 then summed to produce a loneliness score that ranged from 3-9, with higher scores representing higher levels of loneliness among participants.

Social Isolation: Social isolation was measured using the validated index developed by Shankar and colleagues (2011). This index was based on participants being given a score of 1 for each of the following: having less than monthly contact (including on the telephone, face-to-face, using email, or text messaging) with family members, friends, or children. Participants were also given a score of 1 for not belonging to any clubs or social organisations and for living alone. Scores ranged from 0-5 with higher scores indicating increased isolation among participants in the study.

Socioeconomic status: Total non-pension net wealth was used to measure socioeconomic status as recommended by Shankur and colleagues (2010). Total non-pension net wealth was an estimation of the value of all financial assets of participants, minus any debt they had.

Education (categorical variable): Education was measured by classifying participants into three separate groups depending on their highest qualification achieved. Education level was collapsed into three categories as suggested by Shankar and colleagues (2010). Participants were categorised as having 'no qualifications', highlighting that the individual had left education without gaining any qualifications. The second category was 'intermediate qualifications', indicating that the individual had high school qualifications below degree level (e.g., o-level, a-level, National Vocational Qualifications (NVQ) at levels 1-3); and category three was defined as higher education, identifying participants who had degree level qualifications, NVQ at levels 4 or 5, or higher degrees.

Alcohol use (categorical variable): The authors controlled for alcohol use with a measure detailing how frequently participants consumed alcohol over the past 12 months. This measure was categorised into three groups: Group one consisted of participants who 'do not drink' or had not had an alcoholic drink in the past 12 months (Holdsworth et al., 2016). Category two was defined as 'irregular drinkers' consisting of participants who reported drinking monthly or less (Mazzaglia et al., 2001); category three identified participants who drank alcohol above this threshold (weekly or more) and were defined as 'regular drinkers'.

Other

Data was also available for the age (collapsed at aged 90) and sex (male or female) of participants. These were included as covariates in the analysis.

6.3.4 Missing data

Missing values are a problem that is frequently encountered by researchers who analyse large datasets. Missing data can arise due to issues such as dropout or non-responses from study participants and can lead to smaller sample sizes that can compromise the validity and reliability of findings (Kwak & Kim, 2017). A number of methods can be used to account for missing data and reduce the risks of producing biased results or incorrect inferences about the population being examined (White & Carlin, 2010). In the present study, the researchers utilised complete case analysis. This method involves only including complete data whilst excluding all cases with missing data from the analysis (Little et al., 2022). Its simplicity and efficiency present an advantage, although critics argue that this method can lead to smaller sample sizes and reduced statistical power, which can cause imprecision in the results (Little et al., 2022). However, complete case analysis is the most commonly used method of managing missing values within big data research (Ross et al., 2020) and was determined to be an

appropriate method for accounting for missing data within this study. It is noted that in the current dataset, missingness due to the severity of bipolar disorder, would underestimate the size of the effects (type II error, rather than type I error).

6.3.5 Statistical analysis

All analysis was completed in Stata 16.0. Multilevel modelling ('xtreg') was used to assess whether the presence of bipolar mood states (independent variable) predicted poorer quality of life (dependent variable) in older adults. Participants' unique ID number was entered as the random effect to account for the nested data structure. Multilevel modelling is a well-established method for analysing data that includes hierarchical structure where there are repeated measures of the same variables within individuals over time (Greenland, 2000). Consequently, this approach was appropriate for the present study where data was collected in seven waves ranging 2006-2019. A multilevel approach allowed the authors to model for random error and reduce the possibility of estimation error (Lara et al., 2014).

The analysis was run in multiple stages. In Model 1A, the authors ran an unadjusted model where the presence of bipolar mood states (independent variable) was entered as a predictor of quality of life (dependent variable), without any covariates. In Model 1B, the authors ran an adjusted model whereby bipolar mood states was entered as a predictor of quality of life, whilst adjusting for key covariates (age, sex, loneliness, social isolation, education level, socioeconomic status and alcohol use). A separate model (model 2) was used to explore predictors of quality of life in people with bipolar mood states only, to test Hypothesis 2.

Bootstrapping (10,000 reps) was used to account for parametric assumptions not being met in the data. Bootstrapping is a non-parametric method of hypothesis testing and effect size estimation that is used to navigate problems around nonnormalities in the sample distribution by accounting for biases caused by the central tendencies of the estimate (Preacher & Hayes,

2004). The authors also tested for multicollinearity to assess whether there was a linear relationship between the variables selected (Alin, 2010). All variables were only moderately correlated; multicollinearity was not at a problematic level to increase the standard error of the coefficients included in the analysis (Daoud, 2017).

6.4 Results

Sample characteristics and clinical information

In total, 54,565 cases across 14,819 participants from seven waves of ELSA data were included in the analysis (Table 8). Within this, there were 567 participants who reported experiencing bipolar mood states. Some of these individuals reported this in more than one wave, resulting in 835 observations of bipolar mood states across the seven waves. The average number of observations for each participant was 3.6 (range 1-7). The majority of participants were female for both those who experienced bipolar mood states (54.9%) and those who did not (55.0%). Participants who experienced bipolar mood states were less likely to have completed higher education (15.3% vs 18.4%) and were more likely to be categorised as a regular drinker (52.3% vs 49.1%). The bipolar mood states group also reported a lower mean net wealth (£226,783 vs £383,330), scored higher for loneliness (mean 5.56 vs 4.08) and social isolation (mean 2.50 vs 2.34), and scored lower on average for the CASP-19 quality of life measure (mean 33.5 vs 37.1).

Table 8: Demographic and clinical information

Characteristics	Bipolar mood states (*n=567*)	No bipolar mood states (*n=14,252*)
Mean age, years (range; SD)	62.4 (50-89; 9.04)	66.8 (50-90; 10.15)
Gender, *n*		
Male	256 (45.1%)	6412 (45.0%)
Female	311 (54.9%)	7844 (55.0%)
CASP-19, *mean* **(range, SD)**	*33.5* (0-53, 6.72)	37.1 (0-57, 4.72)
Loneliness, *mean* **(range, SD)**	*5.56* (3-9, 2.03)	*4.08* (3-9, 1.40)
Social isolation, *mean* **(range, SD)**	*2.50* (0-5, 1.18)	*2.34* (0-5, 1.05)
Education level, *n* **(%)**		
No qualifications	150 (28.7%)	3187 (24.1%)
Intermediate qualifications	292 (55.9%)	7604 (57.5%)
Higher education	80 (15.3%)	2437(18.4%)
Alcohol use, *n* **(%)**		
Does not drink	89 (17.1%)	2512 (18.7%)
Irregular drinker	159 (30.6%)	4332 (32.2%)
Regular drinker	271 (52.3%)	6602 (49.1%)
Total (non-pension) net wealth, mean £	£226,783	£383,330

<u>Quality of life in older adults with bipolar mood states</u>

Model 1A: Model 1A examined whether bipolar mood states predicted quality of life in older adults, without covariates. This model showed that bipolar mood states significantly, negatively predicted quality of life (*B*: -1.70; SE 0.21; CI -2.11 to -1.28; $p<0.001$). Therefore, those who endorsed bipolar mood states scored on average 1.7 points lower on the CASP-19 quality of life scales than those without bipolar mood states.

Model 1B: Model 1B was adjusted and covariates were entered alongside bipolar mood states as predictors of quality of life in older adults. The negative effects of bipolar mood states remained significant (*B*: -1.37; SE 0.20; CI -1.78 to -0.97; $p<0.001$) after controlling for age, sex, loneliness, social isolation, socioeconomic status, alcohol use and education level and did not greatly reduce. Older adults reporting bipolar mood states scored on average, 1.4 points lower on the quality of life scale compared to those without bipolar mood states.

All covariates included in the analysis were shown to be significant predictors of quality

of life in the sample of older adults. Higher loneliness (*B*: -0.79; SE 0.02; CI -0.82 to -0.75; *p*<0.001) and social isolation (*B*: -0.211; SE 0.02; CI -0.25 to -0.17; *p*<0.001) were associated with poorer quality of life. Higher education level (*B*: 1.10; SE 0.08; CI 0.94 to 1.25; *p*<0.001) and greater socioeconomic status (*B*: 1.73E-07; SE 4.00E-08; CI 9.41E-08 to 2.51E-07; *p*<0.001) positively predicted increased quality of life. Older age (*B*: 0.011; SE 0.02; CI 0.01 to 0.02; *p*<0.001), being female (*B*: 0.471; SE 0.04; CI 0.39 to 0.55; *p*<0.001) and being a regular drinker (B: 0.742; SE 0.09; CI 0.56 to 0.92; p<0.001) also resulted in positive effects in predicting quality of life in older adults (Table 9). Notably, the effects of covariates on quality of life were smaller than that for bipolar mood states.

Table 9: Quality of life in older adults with bipolar mood states

Model 1A: (*n* = 54,565 observations, 14,819 participants, 567 with bipolar mood states)

Model 1B: (*n* = 47,149 observations, 13,265 participants, 485 with bipolar mood states)

Model	DV	IV	*B*	BS SE	*p*	CI lower	CI upper
Model 1A	QoL (CASP-19)	**Bipolar mood states**	-1.70	0.21	<0.001	-2.11	-1.28
Model 1B	QoL (CASP-19)	**Bipolar mood states**	-1.37	0.20	<0.001	-1.78	-0.97
		Loneliness	-0.79	0.02	<0.001	-0.82	-0.75
		Social isolation	-0.21	0.02	<0.001	-0.25	-0.17
		Education level					
		Intermediate	0.62	0.06	<0.001	0.49	0.75
		Higher education	1.10	0.08	<0.001	0.94	1.25
		Alcohol use					
		Irregular drinker	0.43	0.09	<0.001	0.25	0.62
		Regular drinker	0.74	0.09	<0.001	0.56	0.92
		Total (non-pension) net wealth	1.73E-07	4.00E-08	<0.001	9.41E-08	2.51E-07
		Age	0.01	0.02	<0.001	0.01	0.02
		Sex (female)	0.47	0.04	<0.001	0.39	0.55
		Wave number					
		2	0.06	0.06	0.356	-0.07	0.18
		3	0.06	0.06	0.374	-0.07	0.18
		4	-0.03	0.06	0.694	-0.15	0.09

5		-0.25	0.07	<0.001	-0.38	-0.13
6		-0.38	0.07	<0.001	-0.52	-0.24
7		-0.39	0.07	<0.001	-0.52	-0.25

Key : QoL, quality of life ; DV, dependent variable ; IV independent variable; *B*, Beta; BS SE, bootstrapped standard error; CI, confidence interval.

Predictors of quality of life among older adults with bipolar mood states

Model 2: For Model 2, the authors ran a separate adjusted model that only included participants who reported experiencing bipolar mood states with the above covariates used to examine what predicts poorer quality of life in this group. Increased loneliness was found to significantly predict poorer quality of life (*B*: -1.25; SE 0.17; CI -1.57 to -0.92; *p*<0.001). Having completed intermediate (*B*: 1.30; SE 0.17; CI 0.10 to 2.51; *p*=0.033) or higher education compared to no education (*B*: 1.89; SE 0.70; CI 0.52 to 3.25; *p*=0.007) and being female (*B*: 1.02; SE 0.40; CI 0.24 to 1.80; *p*=0.011) significantly predicted better quality of life in this group. Older age also significantly predicted better quality of life in older adults with bipolar mood states, although the effect was relatively weak (*B*: 0.09; SE 0.03; CI 0.02 to 0.15; *p*=0.008) (Table 10).

Table 10: Predictors of quality of life in older adults with bipolar mood states

Model 2: (*n* = 711 observations, 485 with bipolar mood states)

Model	DV	IV	*B*	BS SE	*p*	CI lower	CI upper
Model 2 (bipolar mood states only)	**QoL (CAS P-19)**	**Loneliness**	-1.25	0.17	<0.001	-1.57	-0.92
		Social isolation	-0.33	0.22	0.879	-0.46	0.39
		Education level					
		Intermediate	1.30	0.61	0.033	0.10	2.51
		Higher education	1.89	0.70	0.007	0.52	3.25
		Alcohol use					
		Irregular drinker	0.38	0.74	0.607	-1.07	1.83
		Regular drinker	1.41	0.88	0.108	-0.31	3.12
		Total (non-pension) net wealth	1.04e-06	6.43e-07	0.107	-2.23e-07	2.30e-06

Age	0.09	0.03	0.008	0.02	0.15
Sex (female)	1.02	0.40	0.011	0.24	1.80
Wave number					
2	-0.80	0.76	0.296	-2.30	0.70
3	-0.34	0.73	0.639	-1.76	1.08
4	-0.66	0.79	0.405	-2.21	0.90
5	-0.79	0.78	0.319	-2.32	0.80
6	-0.34	1.41	0.807	-3.11	2.42
7	-2.04	1.54	0.184	-5.05	0.97

Key : QoL, quality of life ; DV, dependent variable ; IV independent variable; *B*, Beta; BS SE, bootstrapped standard error; CI, confidence interval.

6.5 Discussion

The primary objective of this study was to test the hypothesis that experiencing bipolar mood states would predict poorer quality of life in older adults. A secondary aim was to assess which factors predicted quality of life in participants experiencing bipolar mood states. In support of the primary hypothesis, bipolar mood states significantly predicted poorer quality of life, even when controlling for multiple covariates (age, sex, social isolation, loneliness, socioeconomic status, education level, alcohol use). This effect was relatively small; older adults indicating that they experienced bipolar mood states scored 1.7 points lower on the CASP-19 compared to older adults without bipolar mood states. In response to Hypothesis 2, loneliness significantly predicted poorer quality of life in older adults with bipolar mood states. Being female and having a high level of education predicted better quality of life in this group. Older age also had a very weak effect but was a statistically significant predictor of better quality of life in older adults with bipolar mood states.

As far as the authors are aware, this is the first study to examine an epidemiological sample to demonstrate that bipolar mood states significantly predict poorer quality of life in older adults, whilst controlling for multiple relevant covariates. Our findings appear consistent with the work of Depp and colleagues (2006) who reported that older adults with bipolar disorder experienced poorer wellbeing than healthy controls. This adds evidence that the poorer quality of life observed in younger age groups with bipolar disorder (Michalak et al., 2006) persists into later life and requires attention.

As observed in older adults in the general population (Ong et al., 2016) and younger adults with bipolar disorder (Giacco, 2023), loneliness appears to be problematic for older adults experiencing bipolar mood states. Loneliness is defined as a lack of desired companionship by Bekhet and colleagues (2008). It is not possible to determine the causes of loneliness in the current analysis, although it is plausible that factors such as lower perceived

social support among older adults with bipolar mood states could contribute to this finding (Beyer et al., 2003). Bipolar mood states are also thought to cause significant disruption to relationships and are linked to higher rates of divorce, which may leave people experiencing increased loneliness in later life (Granek et al., 2016). In contrast, social isolation was not found to be a predictor of poorer quality of life in older adults with bipolar mood states. Social isolation is a related but distinct concept to loneliness, defined as the objective lack of social contacts with the community, family, and friends (Fakoya et al., 2020). The literature investigating social isolation among older adults with bipolar disorder is limited. However, the finding that social isolation does not predict poorer quality of life in this study could potentially be linked to Blixen and colleagues' (2016) paper reporting that individuals with bipolar disorder often attempt to cope with challenges by socialising with others. This may limit social isolation in this group, although further research is needed to examine the causes and consequences of loneliness and social isolation among older adults with bipolar mood states.

Higher educational attainment was positively associated with better quality of life in individuals with bipolar mood states. People with bipolar disorder have been found to commonly experience oppression and stigma that creates barriers to them achieving higher educational attainment (Kruse & Oswal, 2018). Consequently, attempting to remove these barriers may be an important intervention that enables individuals with bipolar disorder to maintain improved wellbeing. Being female also significantly predicted increased quality of life in older adults with bipolar mood states. These findings are opposed to the limited available literature examining sex differences in bipolar disorder. Existing research suggests that females with bipolar disorder experience poorer functioning due to issues such as severe postpartum episodes, increased obesity, and greater risk of rapid cycling (Diflorio & Jones, 2010; Baskaran et al., 2014; Erol et al., 2015). Finally, older age was found to significantly predict increased quality of life in older adults experiencing bipolar mood states, although the effect was very

weak. At present, literature examining the experiences of the 'oldest old' with bipolar disorder (aged 75 and over; Gwozdz & Sousa-Posa, 2010) is sparse, potentially due to the increased mortality and reduced lifespan associated with this diagnosis (Sajatovic et al., 2015). Further research that explores sex differences and the experiences of the 'oldest old' may identify important clinical implications in these groups.

6.5.1 Clinical implications

The current study illuminates the consequences of ageing whilst experiencing bipolar mood states and suggests that this group require increased support to improve their quality of life. Despite this, literature surrounding older adults with bipolar disorder is insufficient; there is inadequate focus on how to adapt care to meet the needs of this population (Dols et al., 2016). Services should be aware that older adults with bipolar disorder potentially experience different challenges to younger age groups with bipolar disorder, meaning individualised, person-centred care is required (Ljubic et al., 2021). In particular, loneliness was found to be a highly significant predictor of poorer quality of life in this group and interventions should attempt to address this to improve outcomes.

6.5.2 Strengths and limitations

There are several limitations to this research. First, although ELSA is a large epidemiological sample, the number of individuals reporting bipolar mood states was relatively small, but sufficient to complete multilevel modelling. Second, the analysis was cross-sectional meaning it was not possible to draw inferences around causality. Third, we did not control for some potentially key covariates (e.g., substance misuse, medication use, history of psychological therapy) as the data was not available within ELSA. Finally, due to low response rates for people with bipolar disorder, we combined this variable with those who experienced

psychiatric mood swings. It is possible that this variable may not be representative of the experiences of people with bipolar disorder. However, this decision was driven by the available data and consultation with patient and public advisors and allowed for greater statistical power in the analysis.

6.5.3 Future research directions

Future research should aim to build upon the findings of this study and attempt to identify the causal factors associated with bipolar disorder that contribute to poorer quality of life through large-scale longitudinal research. Further research that explores the relationship between ageing with bipolar mood states and loneliness may help to illuminate why this appeared to be problematic in the current study. Improving our knowledge of the causes and predictors of poor quality of life could help us to better understand the key care needs of older adults with bipolar mood states, highlight necessary adaptations to care, enhance support and potentially improve quality of life for this population moving forward.

6.6 Conclusion

In conclusion, this analysis suggests that bipolar mood states significantly predict poorer quality of life in older adults, supporting our initial hypothesis. Loneliness is a predictor of poorer quality of life in older adults experiencing bipolar mood states. Being female and having higher educational attainment may support older adults with bipolar mood states to maintain better quality of life as they age. However, the specific factors that contribute to these findings require further investigation. Improving our understanding of the mechanisms that lead to poorer quality of life among older adults with bipolar disorder may enable us to provide more tailored, appropriate, and effective support to this group. At present, older adults with bipolar disorder appear to experience significant challenges that require increased attention within

clinical services to support this group to age well and improve their wellbeing in later life.

Chapter 7: Thesis discussion

7.1 Chapter overview

This chapter will discuss key findings from the four studies completed within this thesis (chapters 3-6) and their contribution to existing literature and theory surrounding older adults with bipolar disorder will be considered. The researcher will also evaluate the strengths and limitations of these studies, identify their potential clinical implications, and suggest future research directions to build upon this work. Finally, the researcher will reflect upon their experiences of patient and public involvement and their experiences whilst completing the thesis over the past three years.

7.2 Review of key findings

The overall aim of the four studies completed within this thesis was to explore what it means to age well with bipolar disorder. The aims and key findings from each study are summarised below.

7.2.1 Study one: Physical health comorbidities in older adults with bipolar disorder: A systematic review

Chapter 3 was a systematic review that investigated the prevalence and predictors of physical health comorbidities in older adults with bipolar disorder. Findings from 23 papers reporting on 19 studies highlighted that older adults with bipolar disorder experience an elevated prevalence of cardiovascular disease and some forms of cancer compared to older adults from the general population. The quality of the studies included within this review were inadequate to determine whether factors associated with bipolar disorder or other confounding variables

were responsible for these elevated prevalence rates meaning further research is required to support these results. However, findings suggested that physical health problems should be a focus of interventions for older adults with bipolar disorder.

7.2.2 Study two: What does it mean to age well with bipolar disorder? A qualitative study using photo elicitation

Chapter 4 was a qualitative study that used photo elicitation to explore what it means to age well for older adults with bipolar disorder. 17 participants were recruited, and findings highlighted the importance of lifelong learning, finding a sense of belonging, recognising value and worth and continuity of care. Participants discussed the importance of finding balance between enjoyment and stability, establishing meaningful connections, feeling accepted and giving back to others as key factors that enabled them to age well with bipolar disorder. This indicates that older adults with bipolar disorder prioritise connection and meaning within their lives rather than focusing on symptom reduction alone. Consequently, current treatments may require adaptation to support this group to age well.

7.2.3 Study three: The changing care of older adults with bipolar disorder: A narrative analysis

Chapter 5 used qualitative methods to investigate the changing care and care needs of older adults with bipolar disorder in later life. Biographical narrative interviews were completed with 16 older adults with bipolar disorder. Narrative analysis displayed the initial disruption caused after receiving a diagnosis of bipolar disorder and the stigma associated with this. Participants' narratives then highlighted the temporary benefits of care in the community and peer support groups before these services were removed for many. Part three of the analysis illuminated participants frustrations at being unable to access appropriate care in later life. Part four showed

that older adults with bipolar disorder now have different needs that they require support for. Overall, this study highlighted that older adults with bipolar disorder have unique and changing care needs but often struggle to access appropriate and effective care in later life.

7.2.4 Study four: Quality of life in older adults with bipolar disorder: A secondary analysis of the English Longitudinal Study of Ageing data

Chapter 6 used quantitative methods to investigate whether bipolar mood states predict poorer quality of life among older adults and assessed the predictors of quality of life for older adults with bipolar mood states. Multilevel modelling was completed on seven waves of data from the English Longitudinal Study of Ageing. Results showed that bipolar mood states significantly predict poorer quality of life in older adults. Furthermore, loneliness was a significant predictor of poorer quality of life in the group experiencing bipolar mood states. Higher educational attainment, being female and being older were all significantly associated with better quality of life in this population. Consequently, findings suggest that living with bipolar disorder may lead to specific challenges that impact the wellbeing and quality of life of older adults. This study also indicates that reducing loneliness may be an important focus of interventions to improve treatment outcomes.

7.3 Integration of findings within existing literature

The following sections explore these findings and their applicability to existing literature surrounding ageing with bipolar disorder.

7.3.1 The physical impact of ageing with bipolar disorder

Prior to completing the systematic review in this thesis, existing literature indicated that bipolar disorder is associated with increased physical health challenges that may be caused by factors

such as long-term medication use, chaotic lifestyles and poor nutrition often observed in those who receive this diagnosis (Sajatovic et al., 2015). For example, Lala & Sajatovic (2012) reported that 21-63% of individuals with bipolar disorder experience metabolic syndrome which contributes to rates of diabetes being 2-3 times higher in this group compared to the general population. Using mood stabilising medication was also reported to result in higher levels of obesity in people with bipolar disorder leading to poor outcomes (Gentile, 2006). Despite these concerns, very few studies considered how physical health comorbidities progress over time in this population, and whether these issues become more problematic in later life.

The main findings from the systematic review in this thesis were that cardiovascular disease and some forms of cancer were elevated in older adults with bipolar disorder compared to the general ageing population. These findings corroborate those from younger age groups with bipolar disorder (Swartz & Fagiolini, 2012; Barchana et al. 2008). However, the authors advised caution when interpreting these findings as the review also highlighted that literature surrounding this topic was sparse and lacking in quality (Warner et al., 2023). A particular concern was that most studies investigating physical health problems in older adults with bipolar disorder failed to control for potential confounding variables and did not include comparison groups from the general ageing population or younger adults with bipolar disorder. Because of this, it was not possible to establish whether elevated physical health comorbidities in older adults were linked to factors specific to bipolar disorder or other variables not accounted for in these studies. Furthermore, the evidence exploring potential links between bipolar disorder and the prevalence and predictors of diabetes, obesity and renal disease was inconclusive, and no studies investigated the prevalence of oral health outcomes in this group.

Chapter 5 in this thesis explored the changing care and care needs of older adults with bipolar disorder in later life. Participants within this study expressed concern about the impact

of living with bipolar disorder throughout their lifespan and were worried about the potential physical health consequences of long-term medication use. This is shown by a quote from Claire: *"Antipsychotics are known to have cardiac impacts. I've been on antipsychotics for a very long time, and I'm worried about what that could do. So, I worry more about the physical side of things now rather than being carried off by a wave of emotions like in the past".* Literature investigating the long-term side effects of medication used to treat individuals with bipolar disorder is mixed (Gitlin, 2016). Commonly prescribed medications such as lithium and anti-psychotics have been linked to an increased risk of renal disease and obesity (Close et al., 2014; Rummel-Kluge, 2010), although evidence is insufficient to determine whether long-term use of these predicted increased physical health comorbidities for older adults with bipolar disorder. However, this thesis shows that physical health problems in later life are of concern for service users and warrant further attention from clinicians and researchers.

7.3.2 Ageing well with bipolar disorder

Chapter 4 explored what it means to age well with bipolar disorder. Participants within this study identified that lifelong learning was an essential factor supporting them to age well with bipolar disorder. Numerous authors have identified the importance of lifelong learning for older adults in the general population (Sloane-Seale & Kops, 2008; Formosa, 2019). Duay & Bryan's (2006) qualitative study found that older adults from the general population described learning as a vital component in the process of ageing well and suggested that learning acts as a coping mechanism and a way to have fun. Narushima and colleagues (2013) reported that older adults who engage in lifelong learning experience increased wellbeing, improved social and physical health and also exhibit healthier lifestyles. However, for older adults with bipolar disorder, lifelong learning was focused on learning from their difficult experiences of bipolar disorder and using this accumulation of experience and knowledge to find balance in later life.

Participants described lifelong learning as a long process of trial and error where they learnt to understand and accept their boundaries to 'tune their bandwidth' as they aged with bipolar disorder. This is similar to Von Faber's (2021) finding suggesting that older adults view adaptation as a necessary and essential aspect of ageing well. Participants also described how they developed knowledge about which treatments were effective for them and used this information to communicate more effectively with professionals, allowing them to take an active role in their care. By engaging in lifelong learning, participants developed confidence and were empowered to regain agency in later life, which has been found to be a key indicator of ageing well in the general population (Bowling & Dieppe, 2005). Overall, our findings were consistent with studies exploring ageing well within the general population, although the function of lifelong learning for older adults with bipolar disorder is unique and focused on developing self-awareness and knowledge that enables them to manage the mood instability associated with bipolar disorder to age well.

Older adults with bipolar disorder who took part in this project described the importance of feeling useful and able to contribute to society despite the challenges they continued to experience. In particular, participants highlighted the value of feeling able to give back and use their accumulated experience and knowledge of living with bipolar disorder to support younger generations with this diagnosis. These findings are consistent with research surrounding older adults from the general population, where generativity and supporting younger generations has been shown to contribute to ageing well by acting as a personal growth function and providing meaning and purpose in the lives of older adults (Fisher, 1995; Hofer et al., 2014). For older adults with bipolar disorder, it was important that they could use their experiences to provide hope to younger age groups with bipolar disorder as this gave meaning to the challenges they had faced. One participant described how they wanted to show that there is 'an alternative endgame' for those living with bipolar disorder where they could live a long and enjoyable life,

contrary to many people's views surrounding bipolar disorder. Consequently, it appeared that becoming role models and providers of hope was essential to ageing well with bipolar disorder as this enabled them to give back and provided a sense of reciprocation. Jopp and colleagues (2017) suggest that having a successful ageing role model can reduce harmful stereotypes and change negative attitudes towards ageing. Therefore, older adults with bipolar disorder may personally benefit from engaging in roles such as peer support workers but may also act as positive role models that can help to reduce stigma and change perceptions of bipolar disorder and ageing therefore encouraging increased support for this population.

7.3.3 The importance of social connection

To age well with bipolar disorder, participants indicated that establishing a sense of belonging, feeling understood and accepted were all important components. This helped one participant to finally feel "part of the human race" after a lifetime of feeling outcast and marginalised. Similar findings were reported by Smart and colleagues (2021) who investigated what it means to age well with psychosis. In this study, sixteen older adults with psychosis related disorders highlighted that positive personal and professional social relationships played an essential role in ageing well. To achieve a sense of belonging, older adults with bipolar disorder in this study described having to narrow and refine their networks and focus specifically on those who offer unconditional support. This was challenging for many participants and meant moving away from long-term friendship groups who no longer have the same priorities and values. Whilst this was a painful experience for some, this helped participants to create an environment that offered them consistent support, therefore reducing loneliness and social isolation which have been found to be key risk factors for diminished wellbeing among older populations (Blazer, 2020; Shankar et al., 2015). Consequently, our findings indicated that older adults with bipolar disorder require support that helps to build connections and feel accepted to reduce the risk of

loneliness and enable them to age well. This thesis also displayed the impact for participants when they felt let down my friends, family, or professionals. This appeared to have negative consequences on their wellbeing, self-esteem, and their ability to age well in later life.

7.3.4 The need to adapt care for older adults with bipolar disorder

Chapter 5 highlighted that older adults with bipolar disorder may have unique care needs that change as they age. However, findings from this study demonstrated a clear disconnect between the care that this group desired and the care they currently received. Participants discussed their concerns about the long-term impact of mood stabilising medication and wanted more information about the potential physical effects of these treatments. This is important, as the National Institute for Health and Care Excellence (NICE, 2014) still recommend the same treatments as those offered to younger age groups with bipolar disorder. These treatments typically consist of providing mood-stabilising medications (NICE, 2014), although this appears to be at odds with the needs and wishes of older age groups and may in fact exacerbate their concerns. In contrast to younger people with bipolar disorder, older adults also reported that a key care need is to have financial advice and support when they retire. Susan highlighted concerns around retirement by stating "*How much do I give in? Our lives have had to shrink and will continue to shrink because of finances*". Heller-Sahlegren (2017) suggests that retirement can have a negative long-term impact on the mental health of older adults and Dave and colleagues (2008) found increased physical health difficulties among retirees. These issues may be even more problematic for individuals with bipolar disorder, who often have to retire at a younger age as they struggle to manage the impact of their mental health challenges (Ekman et al., 2013).

Participants in this thesis spoke about their desire to receive care in the community that was consistent and enabled them to develop positive relationships with professionals. In reality,

older adults with bipolar disorder described struggling to access care such as this. This had a negative impact on many participants, which led to some disengaging with services to avoid iatrogenic stress. A qualitative study by Biringer and colleagues (2017) highlighted the benefits of continuity of care for people experiencing mental health difficulties. Biringer and colleagues found that service users perceived continuity of care to be associated with increased safety, improved collaboration with professionals, more efficient and timely care and more choices about treatment decisions. Participants in this study echoed these findings and highlighted that inconsistent care led to them having to repeat their experiences of living with bipolar disorder to new clinicians. This felt re-traumatising, exhausting, and frustrating for participants and strengthened their beliefs that consistent support was necessary to enhance their care. Older adults with bipolar disorder also reported that cuts to community care had left them feeling neglected in many cases. The experiences of participants within chapter 5 appear to contrast with existing NHS England policy suggesting that a key aim of their NHS Long Term Plan is to increase community care for all older adults experiencing mental health difficulties (NHS England, 2019). As a result, our findings demonstrate that older adults with bipolar disorder are often marginalised and unable to access care that is effective and appropriate. This potentially leaves them experiencing a range of unique and changing care needs in later life which require increased attention.

7.3.5 Quality of life in older adults with bipolar disorder

Bipolar mood states were found to significantly predict poorer quality of life among older adults in study 4. These results are consistent with research from younger populations with bipolar disorder, where the challenges associated with this diagnosis have devastating consequences on individuals' life quality (Michalak et al., 2006). This study also builds upon the work of Depp and colleagues (2006) who reported that older adults with bipolar disorder

experience substantial disability that results in poorer wellbeing than the general population. Additionally, to the researchers' knowledge, no study had explored what predicts poorer quality of life in older adults experiencing bipolar mood states. Therefore, the results in chapter 6 indicating that loneliness is a highly significant predictor of poorer quality of life in older adults with bipolar mood states add valuable insight into the experiences of this group. These findings are consistent with chapter 4 in this thesis and a recent qualitative study by Tyler and colleagues (2021) where older adults with bipolar disorder outlined the consequences of loneliness whilst ageing. Loneliness is commonly reported to be problematic for older adult populations within existing literature (Cohen-Mansfield et al., 2016). However, loneliness among older adults with bipolar disorder may have different implications. Tyler and colleagues (2021) suggest that loneliness can lead to increased rumination in older adults with bipolar disorder. Rumination is defined as repetitive and consistent thoughts about emotionally relevant experiences (Kovács et al., 2020) and can have a negative impact on executive and cognitive functioning, leading to poorer outcomes for individuals for bipolar disorder (Silveira Jr et al., 2015). Consequently, this finding may have important clinical implications for older adults with bipolar disorder and indicates that reducing loneliness should be a focus of interventions.

High levels of educational attainment was associated with better quality of life in older adults experiencing bipolar mood states chapter 6. This is important, as research has demonstrated that bipolar disorder can disrupt and reduce educational attainment (Glahn et al. 2006). Karanti and colleagues (2021) also reported that level of educational attainment can have an impact on the treatment and management of bipolar disorder and potentially result in unequal treatment for those with lower educational levels. Whilst Karanti and colleagues (2021) were unable to determine the reasons behind this finding, our results corroborate that educational attainment potentially has important consequences for individuals with bipolar disorder and may contribute to quality of life as they age (Glahn, 2006). Results from chapter

6 also indicated that being female and being older were associated with better quality of life in older adults with bipolar mood states. The available literature suggests that being female with bipolar disorder is linked to increased obesity (Baskaran et al., 2014; Henry, 2001) and significantly higher risk of rapid cycling (Erol et al., 2015) suggesting poorer outcomes. Therefore, our findings contrast with these studies, although literature examining sex differences in older adults with bipolar disorder is sparse and requires increased investigation to build upon chapter 6 in this thesis. A very weak effect suggesting that older age predicts better quality of life in older adults with bipolar mood states was also found in this study. However, the experiences of the 'oldest old' (aged 75+) are rarely captured in bipolar disorder research. This is potentially due to shortened lifespan and increased mortality associated with bipolar disorder (Sajatovic et al., 2015; Depp & Jeste, 2004), although these findings suggest that investigating this population may have important clinical implications.

7.4 Theoretical implications

7.4.1 Theories of ageing well

This thesis builds upon theories of ageing well and demonstrates that some aspects of these theories require adaptation to be applicable to older adults with bipolar disorder. The following section integrates these findings into selected theories of ageing well from existing literature.

7.4.2 Selective optimisation with compensation

As discussed in chapter 1, the selective optimisation with compensation theory suggests that older adults must minimise ageing related losses and maximise ageing related gains to age well (Baltes & Baltes, 1990). This is achieved through processes of selecting high priority goals, optimising new or previously available skills, and compensating for areas that are not necessary

for goal attainment in order to age well (Baltes & Carstensen, 2003). Participants in this project described similar processes that helped them to age well with bipolar disorder. For example, participants often discussed the importance of accepting that full time employment and career related goals were no longer beneficial to their wellbeing as they aged. They adjusted and selected goals that were attainable with the difficulties associated with bipolar disorder. For some, these new goals centred around helping others through learning new skills or using pre-existing skills such as embracing their creativity and using their accumulated knowledge to support others. Compensation was necessary for many, as living with bipolar disorder for several years had led to a range of difficulties and limitations, which required them to adapt to remain well. Unique to older adults with bipolar disorder, however, may be that the process of compensation is potentially required at an earlier stage due to issues such as accelerated cognitive decline (Gildengers et al., 2009), increased physical health comorbidities (Warner et al., 2023) and challenges in maintaining employment (Murwaha et al., 2013). Due to the different challenges faced whilst ageing with bipolar disorder compared to the general population, the processes of selection, optimisation and compensation may be very different for this group, and increased support may be needed to help older adults with bipolar disorder to adapt and age well in later life.

7.4.3 Socioemotional selectivity theory

Another well-established theory describing the processes involved in ageing well within the general population is socioemotional selectivity theory (Carstensen et al., 2003). This theory suggests that older adults engage in lifelong selection processes where they prioritise social networks that provide emotional meaning due to the perception that their life is now time limited (Carstensen et al., 2003). This theory appears to be relevant to older adults with bipolar disorder who also described how refining their network as they age was essential to ageing

well. For older adults with bipolar disorder, this involved prioritising relationships with friends and family who consistently supported them despite their mental health challenges and at times unpredictable behaviour. Research highlights how bipolar disorder is often associated with disruptive behaviour during episodes that can place strain on not only the individual but family members, friends, spouses, and employers who attempt to support them (Granek et al., 2016). This is linked with high rates of divorce, decreased social support and difficulties in developing and maintaining positive relationships across the lifespan (Beyer et al., 2003). The social cost of bipolar disorder is often considerable and contributes to many with this diagnosis living alone in later life (Greenberg et al., 2014). Consequently, the process of network refining described in socioemotional selectivity theory may be different for older adults with bipolar disorder. Whereas older adults from the general population can engage in lifelong refining of their networks informed by their selections, older adults with bipolar disorder may not have the opportunity to choose their networks as they age but may be restricted to people who have remained consistent in their support despite the challenging and unpredictable behaviour of the individual. Alongside this, older adults with bipolar disorder may have to work to repair emotionally meaningful relationships that broke down due to their past behaviour during episode to develop a network of support that can help them to age well in later life.

7.4.4 The life course perspective

The life course perspective is a theory that describes ageing as an interactive and developmental process that is influenced throughout the lifespan by environmental, societal, and experiential factors (Dannefer & Settersen, 2010). These factors are believed to accumulate over time and shape the ageing process rather than ageing being viewed as distinct phase of life determined by chronology (Dannefer & Settersen, 2010). This theory may therefore be particularly important and relevant to ageing with bipolar disorder. Bipolar disorder is associated with

several challenges across the lifespan such as increased risk of childhood emotional and sexual abuse (Palmier-Claus et al., 2016; Maniglio et al. 2013), challenges during adulthood such as divorce (Granek et al., 2016), loss of employment and substance misuse and a range of difficulties in later life including high rates of physical health comorbidity and cognitive decline (Warner et al., 2023; Gildengers et al., 2009). As a result of this, it is possible that older adults with bipolar disorder experience accelerated ageing and reduced cognitive reserve in comparison to the general ageing population, as suggested by Sajatovic and colleagues (2015). This may explain figures indicating that this group experience increased mortality and reduced lifespan (Depp & Jeste, 2004). Therefore, the life course perspective and findings from this thesis show that individuals with bipolar disorder required increased attention and support throughout their life course. This may help to reduce the impact of challenges associated with bipolar disorder over this groups life course and enable them to age well. This may also enhance cognitive reserve and reduce the increased cognitive impairment observed in older adults with bipolar disorder.

Overall, this project builds upon existing theories of ageing and suggests that to age well, individuals with bipolar disorder may have to engage in earlier compensation and adaptation to losses due to the accelerated ageing processes associated with this diagnosis. Furthermore, whereas older adults from the general population are able to engage in lifelong selection processes where they can develop their support network based on those who provide emotional support, this may be more complicated for those with bipolar disorder. It is possible that emotionally meaningful and supportive relationships with family members, spouses and friends may become disrupted during affective episodes. Therefore, older adults may have to attempt to repair these relationships before they can develop an appropriate support network that facilitates ageing well. Finally, due to several negative consequences associated with bipolar disorder throughout the lifespan, increased awareness and earlier support is necessary

to reduce the impact of living with this diagnosis in later life, enhance the wellbeing of older adults with bipolar disorder and encourage this population to live meaningful lives as they age.

7.5 Clinical implications

The four studies included in this thesis highlighted several challenges faced by older adults with bipolar disorder and also identified potential adaptations to care that may benefit this group. Therefore, this thesis has important clinical implications, and these will be discussed in the following section.

7.5.1 Mental health services

A tentative finding within this thesis was that older adults with bipolar disorder appear to experience increased prevalence rates of certain physical health comorbidities (cardiovascular disease and some forms of cancer) compared to the general ageing population (Warner et al., 2023). These issues have been linked to poorer functioning and earlier mortality in older adults with severe mental illness (Bartels, 2004). These comorbidities suggest integrated services are needed to monitor and treat both the physical and mental health challenges experienced by older adults with bipolar disorder. However, participants in this project often felt unable to access services that addressed their complex and changing needs despite the NHS long-term plan (NHS England, 2019) outlining plans to ensure that services can deliver care that addresses these concerns in older adults. These findings are consistent with Tucker and colleagues (2009) paper, reporting that services within the UK struggle to cope with the complex needs presented by older adults with mental health difficulties. One study highlighted the potential benefits of introducing integrated care for this population. Mueser and colleagues (2010) completed a randomised trial in the United States of America examining an integrated intervention that aimed to reduce physical health burden and psychological symptoms in older adults with severe mental illness ($n = 183$). This trial reported high retention rates, significant improvements in

psychosocial functioning and self-efficacy among older adults with severe mental illness compared to those who received treatment as usual. Considerations should therefore be made to adapt and develop integrated services that address both the physical and mental health needs of older adults with bipolar disorder in the United Kingdom.

A key principle of the NHS long-term plan (NHS England, 2019) is to ensure improved access to community-based services for older people with mental health difficulties. This is important, as Tucker and colleagues (2009) report that the majority of older adults with severe mental illness would prefer to be supported in their own homes rather than travel to services as this can be challenging for them to access on a regular basis. However, participants in chapter 5 suggested that accessing community-based care was extremely challenging. For example, participants expressed frustration at no longer having the option of receiving support from a Community Psychiatric Nurse (CPN) that once benefitted them. Having a CPN helped participants to feel safe and supported, as they felt able to develop a long-term trusting relationship with a professional who visited regularly and understood their situation. This also provided them with quick access to support when necessary. However, due to cuts to community care (Robertson et al., 2017), support such as this has largely been removed, leaving participants concerned about how to access care outside of crisis, which potentially contributes significant stress that can lead to relapse in bipolar disorder (Cohen et al., 2004). Consequently, it is essential that community-based support such as this is considered and reintroduced wherever possible to support older adults with bipolar disorder.

As reported within the literature surrounding older adults with severe mental health difficulties (Crabb & Hunsley, 2006), older adults with bipolar disorder identified multiple barriers that reduced their motivation to engage with mental health services. For example, some participants in this project expressed feeling let down by services in the past and this led to them attempting to manage their difficulties alone or alongside family rather than risk

iatrogenic stress. Others felt discouraged as they were unable to access face-to-face appointments that allowed them to develop relationships with staff, as appointments were predominantly held over the phone or online during and following the COVID-19 pandemic. These findings contrast with other studies that have reported using remote methods increases engagement among older adults with mental health difficulties (Bartels et al., 2018). Whilst this increased accessibility may be beneficial, it is important that older adults with bipolar disorder still have the option to attend appointments in person, as participants felt this reduced stress and allowed them to communicate their needs to professionals more effectively. This may help to increase engagement in this group and remove a barrier to treatment that is sometimes problematic.

7.5.2 Interventions for older adults with bipolar disorder

At present, older adults with bipolar disorder are recommended the same treatments as younger age groups with bipolar disorder by the National Institute for Health and Care Excellence (NICE, 2014). Treatments typically consist of mood stabilising medication alongside psychological interventions such as cognitive behavioural therapy, with the aim of reducing mood instability and developing ways of identifying and coping with potential triggers (NICE, 2014). However, the findings within this thesis showed that the challenges faced by older adults with bipolar disorder are often complex and adaptations to care are required to meet the changing needs of this population. To manage the physical health comorbidities that were identified as problematic, a beneficial intervention may be to support older adults with bipolar disorder to develop healthier lifestyle choices surrounding diet and exercise. Bipolar disorder is often associated with increased calorie intake, sedentary lifestyles and cigarette smoking which may lead to increased physical health issues in later life (Jackson et al., 2015). These issues can become even more prevalent when the individual is experiencing a mood episode

(Chen et al., 2015). Consequently, interventions that help to educate and support older adults with bipolar disorder to improve their physical health should be a focus of intervention for older adults with bipolar disorder alongside managing psychological challenges.

Loneliness was identified as a key concern that could lead to diminished quality of life and increased risk of relapse as participants aged with bipolar disorder. These findings are consistent with research surrounding younger populations with bipolar disorder, where increased loneliness is linked to poorer social functioning (Lee et al., 2022). For older adults with bipolar disorder, it appeared that several difficult relationships and feeling let down or abandoned by others resulted in cognitive biases related to social threat that led to some participants withdrawing from others to reduce their risk of emotional harm. Whilst this protected participants emotionally, it potentially increased feelings of loneliness that reduced their ability to age well with bipolar disorder. Interventions such as individual and group Cognitive Behavioural Therapy (CBT) that aims to reframe these cognitive biases and develop helpful ways of coping with perceived social threat have been found to reduce feelings of loneliness in adult and older adult populations (Hickin et al., 2021; Smith et al., 2021). Consequently, CBT may be a beneficial intervention for supporting older adults with bipolar disorder to develop and maintain meaningful connections with others and reduce feelings of loneliness in later life. Social recovery focused CBT which attempts to support service users to engage in social activities that provide meaning and are aligned with the individuals' personal goals (Fowler et al., 2019) may also be beneficial in helping older adults with bipolar disorder to integrate into the community, increase hopefulness and self-agency and support this group to age well.

This thesis suggested that older adults with bipolar disorder valued interventions such as peer support groups but sometimes found these difficult to access. Peer support groups have been found to provide understanding, connection, and acceptance (Proudfoot et al., 2012) that

was deemed to be a core component of ageing well with bipolar disorder in chapter 4. However, some participants felt that peer support groups were often too focused on negative aspects of bipolar disorder and could be improved. To enhance the benefits of peer support groups, participants felt that these spaces could be used to collaboratively identify their strengths and find activities that enable the expression of these alongside other group members. Furthermore, participants felt that a key strength was their experience and knowledge of bipolar disorder and how to manage its challenges. Several participants highlighted their desire to use this accumulation of knowledge to support younger generations living with bipolar disorder. Therefore, it may be beneficial for peer support groups to consist of both younger and older adults with bipolar disorder, allowing older age groups to engage in generativity which has been found to support ageing well (Villar, 2012). Another potential intervention to facilitate older adults with bipolar disorder supporting younger generations could be to support this group to engage in peer support worker roles where they can offer support to younger people living with bipolar disorder. This intervention may provide older adults with meaning, purpose, and motivation, but also allow younger age groups with bipolar disorder to benefit from the wealth of knowledge this group possess (Barr et al., 2020; Proudfoot et al., 2012).

Chapter 4 identified maintaining agency and feeling actively involved in treatment decisions as an important aspect of ageing well for older adults with bipolar disorder. This suggests that this group may value treatment consistent with the personal recovery approach (Leamy et al., 2011). The personal recovery approach emphasises that treatments for individuals with mental health difficulties should be guided by service users' personal goals and values rather than focusing on symptom reduction only (Jones et al., 2013). This approach has been found to increase hope, meaning, and purpose within people's lives whilst also increasing engagement by encouraging service users to guide the treatment process in collaboration with professionals (Leamy et al., 2011). A recent pilot trial assessed the feasibility

of recovery focused therapy for older adults with bipolar disorder and found that this approach was acceptable, feasible and has the potential to improve outcomes in this group (Tyler et al., 2022). However, the recovery approach to treatment relies heavily on collaboration between professionals and the service user (Jones et al., 2013). Participants in this project stated that collaboration with professionals is currently challenging to establish as consistency and continuity of care is rare. To enhance recovery approaches which appear to benefit this client group, where possible, consistent and continuous care from the same professional should be facilitated. In combination, continuous care that adopts a recovery focused approach may help to reduce the challenges faced by this group, provide hope and improve quality of life which is currently diminished.

7.6 Strengths and limitations

The studies completed in this thesis have a number of methodological strengths and limitations. These will be discussed in the following sections.

7.6.1 Design

As outlined in the methodology chapter (chapter 2), the researcher adopted a critical realist philosophical position to complete both qualitative and quantitative studies that explored what it means to age well with bipolar disorder. Investigating this research question from a critical realist lens was beneficial as it provided the opportunity to use different methods to gather a novel understanding of the experiences, needs and preferences of older adults with bipolar disorder that was missing within existing literature. Using visual and biographical approaches to complete qualitative studies enabled the researcher to gather in depth data that illuminated participants idiosyncratic and unique experiences. The quantitative design used to complete chapter 6 afforded the examination of a large dataset that produced more generalisable,

objective findings that highlighted the consequences of living with bipolar disorder in later life. As there is very limited research exploring the experiences of older adults with bipolar disorder, the overarching research question was kept intentionally broad which encouraged flexibility and reflection throughout the research process. This enabled the researcher to explore separate aspects of ageing with bipolar disorder in each study and this meant that the studies were not necessarily informed by the findings of each other. This meant that studies could be completed at the same time and pragmatic decisions could be made based on the time constraints, methodological challenges, and difficulties when completing research during the COVID-19 pandemic. This was beneficial, although a sequential design where the findings of each study inform the design of the next study, may have led to more in-depth considerations of key issues discussed by participants.

7.6.2 Sampling

2.6.2.1 Systematic review (paper 1)

To complete the systematic review (chapter 3), a number of decisions were made to ensure that physical health comorbidities were investigated in a sample that represents older adults with bipolar disorder. First, the decision was made to only include papers where participants where aged 50 and over. Our decision to include people aged 50 and above was based on Sajatovic and Colleagues (2015) task force paper indicating that many studies use this cut-off for samples of older adults with bipolar disorder. Consequently, this reduced the possibility of suitable papers being excluded from the systematic review. Papers were also only included if participants had a confirmed diagnosis of bipolar disorder based on the Diagnostic and Statistical Manual of Mental Disorders (DSM) or International Classification of Diseases (ICD) criteria. These diagnostic manuals are widely used by clinicians to diagnose bipolar disorder and are based on comprehensive inclusion criteria. By doing this, it was hoped that

the findings surrounding physical health comorbidities in older adults with bipolar disorder were based upon a homogenous group of individuals that were representative of this population. However, only studies written in English were included in the systematic review, meaning the experiences of older adults with bipolar disorder from other cultures and backgrounds were potentially missed. This may have led to some important, novel findings being excluded from this paper.

7.6.2.2 Qualitative studies (papers 2 and 3)

The inclusion criteria for both qualitative studies were relatively broad as it was thought that the high rates of early mortality (Sajatovic et al., 2015) associated with bipolar disorder may make it challenging to locate and recruit older adults living with this diagnosis. However, in the first qualitative study (chapter 4), the decision was made to ask participants to complete the Structured Clinical Interview for Diagnostic and Statistical Manual 5 (SCID-5). The SCID-5 is a commonly used standardised assessment that aims to determine if individuals meet criteria for bipolar disorder based on their experiences. This aimed to make the sample for this study more homogenous and representative of people with bipolar disorder. However, our inclusion criteria did not require people to be actively experiencing a mood episode that would result in them receiving a current diagnosis of bipolar disorder for either qualitative study. It is possible that the data gathered from this sample did not concur with the experiences of some older adults with bipolar disorder who may be experiencing significant distress and considerable difficulties in managing their mood. For the second qualitative study (chapter 5), the researcher opted against asking participants to complete the SCID-5 assessment. This decision was made following consultation with the supervisory team and public advisors, after it was concluded that reducing the amount of burden on participants and NHS staff who were supporting them may help recruitment and ensure that the research was supportive of their needs. Participants

from the previous qualitative study were also able to take part which meant that some participants (*n* = 8) had already completed the SCID assessment and met criteria for bipolar disorder. For this study, participants also had to report experiencing challenges consistent with bipolar disorder for 10 years or more. This decision helped the researcher to capture changes in participants' care and care needs over time, which was the focus of this paper.

Participants for both qualitative studies were recruited from a range of services including through the NHS, charity organisations, via a confidential university-based participant database, by snowball sampling and through social media (Twitter). The aim of recruiting in this way, was to attempt to include a sample that although homogenous in terms of diagnosis, also had a range of unique experiences and backgrounds. However, for both qualitative studies, the author recruited several participants through Spectrum connect, which is a database of individuals who have agreed to be contacted about mental health research based at Lancaster University. The researcher only recruited small numbers through the NHS, which is a notable limitation of these studies, as individuals receiving NHS care may experience more severe challenges and poorer outcomes than many of those involved in this thesis. The difficulties in recruiting participants from NHS services may be due to the current conditions within the NHS where cuts and staff shortages lead to staff prioritising clinical care over research participation (Clarkson et al., 2023). Attempting to recruit from these services during the COVID-19 pandemic, where face-to-face contact with professionals was limited may have also been a contributing factor. The sample recruited may instead represent a 'survivor cohort' who experience better outcomes, are able to cope with bipolar disorder more effectively, are actively interested in partaking in research and who have disengaged with services to avoid iatrogenic stress. This may have influenced the data captured within these studies, although findings still build upon existing literature and illuminate key experiences of some older adults with bipolar disorder despite these limitations.

<u>7.6.2.3 Quantitative study (paper 4)</u>

The quantitative study in this thesis was the first to examine whether bipolar mood states predicted poorer quality of life among older adults using a large epidemiological database. Therefore, this paper addressed a gap within the literature and contributed valuable findings that highlight the substantial challenges faced by older adults with bipolar disorder. To complete the study, the researcher used data from the English Longitudinal Study of Ageing (ELSA). Whilst this is a large dataset of older adults aged 50 and over, the response rates for people reporting bipolar disorder was relatively low. There was no precedent on how to investigate bipolar disorder using ELSA data, as this study was the first to do so. Consequently, the researcher decided in consultation with his supervisors that combining the bipolar disorder variable with another variable indicating psychiatric mood swings was appropriate to produce a sample size of individuals with bipolar mood states with sufficient power to do the analysis. Feedback was also sought from an older adult public advisor with lived experience of bipolar disorder that this was a sensible way to categorise people as having experiences consistent with bipolar disorder. However, despite taking these steps, it was not possible to confirm that the ELSA participants had received a formal diagnosis of bipolar disorder from a healthcare professional or experienced mood instability that was consistent with bipolar disorder which may have limited the generalisability of the findings.

7.6.3 Data collection and analysis

An important strength of this thesis is that the critical realist position taken by the researcher encouraged the use of a range of data collection and analysis approaches. By using a number of different approaches to collect and analyse data the researcher was able to generate a comprehensive understanding of what it means to age well with bipolar disorder. Initially, completing a systematic review helped to provide a broad overview of the physical health

challenges faced by older adults with bipolar disorder that may lead to diminished wellbeing in this group according to the literature (Depp & Jeste, 2004).

Using photo elicitation interviews in chapter 4 potentially helped participants to feel more comfortable during interviews by allowing them to select topics that were important to them and guide the interview encounter (Bates et al., 2017). Glaw and colleagues (2017) suggest that this can lead to deeper, more meaningful information than using standard semi structured interviews, and using visual methods also taps into participants creativity, which is commonly believed to be a strength of individuals diagnosed with bipolar disorder (Johnson et al., 2012).

Study 3 (chapter 5) used biographical narrative interviews allowing the researcher to gather data that highlighted key changes in the care and care needs of older adults with bipolar disorder and provided the opportunity to capture how and why vital transitions occur in this group (Wengraf, 2001). This triangulation of qualitative methods led to the collection of unique knowledge that helped to understand the key preferences, priorities, and care needs of older adults with bipolar disorder and highlighted necessary adaptations that can be used to improve support in this group.

The use of quantitative methods (chapter 6) complimented the qualitative studies by providing objective findings suggesting that bipolar mood states significantly predict quality of life in older adults. This study also offered novel indications that loneliness significantly predicted poorer quality of life in older adults experiencing bipolar mood states, although the effects were relatively small. However, as the analysis was cross-sectional, it was not possible to establish causality in this study which is a limitation. The researcher did consider longitudinal analytical methods such as linear growth curve modelling which may have accounted for this, but it was concluded that there was limited power to run this analysis. Finally, the researcher used unstandardised betas because it is complex to calculate

standardised betas in multilevel modelling. This would need to be completed manually due to the XTREG command not allowing this function and this was deemed inappropriate for the current analysis. Despite these limitations, by using a variety of methodological approaches, this thesis helped to provide a significant contribution to the limited available literature surrounding older adults with bipolar disorder.

7.7 Patient and public involvement

Reflections on patient and public involvement within this project are outlined using the Guidance for Reporting Involvement of Patients and the Public 2 (GRIPP2) measure (Staniszewska et al., 2017). The GRIPP2 is a form that aims to increase transparency by researchers who have incorporated public and patient involvement within their research. Table 11 below presents the researchers experiences of collaborating with public advisors during this thesis in a format consistent with the GRIPP2.

Table 11 – GRIPP2 form

GRIPP2 Short form	
Section and topic	**Item**
1. **Aim of public and patient involvement in this project**	In this thesis, the aim of involving public advisors was to ensure that all studies were designed and completed in a way that was appropriate for participants and remained focused on exploring what it means to age well for older adults with bipolar disorder.
2. **Methods of public and patient involvement**	Public advisors who were older adults with experience of mental health difficulties were involved in the following aspects of this thesis: • Prior to completing this thesis, service user researchers from Lancaster University were consulted about the PhD protocol. • Public advisors provided feedback on all information sheets that were given to participants and referrers. • Advice was sought from public advisors on where to recruit from, how to approach participants and what information to provide prior to their participation. • Public advisors were involved in developing the topic guides for both qualitative studies. • Public advisors worked in collaboration with the researcher and the supervisory team to provide feedback on preliminary themes during the analysis of interview data. • Provided feedback on where to disseminate findings to maximise their impact.
3. **Results of public and patient involvement** & 4. **Discussion and conclusions**	• Collaborating with public advisors ensured that the research was developed in a way that remained focused on highlighting ways to address the significant health inequalities experienced by older adults with bipolar disorder. • Feedback from public advisors was beneficial in making sure that all information sheets were worded sensitively and appropriately for participants and referrers. This potentially helped to increase engagement in the research studies and encouraged participants to ask any questions they were unsure of. An example of this is when public advisors recommended providing a guide on what kind of objects/places etc., may be appropriate to take photos of in study 2.

		• Working alongside public advisors who had lived experience of being older adults with mental health difficulties helped to develop the topic guides for qualitative studies. Their feedback was important, as it meant the researcher was aware of key topics that needed to be covered during interviews.
		• Public advisors provided valuable insight into the experiences of participants whilst involved in research and identified what support participants may value from the researcher. This helped the researcher to adapt their approach and ensure that participants felt respected, valued, and safe within the research study.
5. Reflections/critical perspective on incorporating public and patient involvement		Overall, I feel that working alongside public advisors was helpful for me when completing this thesis. Their feedback on many aspects of the studies such as the design, recruitment and data analysis were invaluable. In particular, having feedback on the preliminary themes during qualitative data analysis helped me to reflect and consider new ways of interpreting the data. Their lived experience offered a unique perspective, and their feedback encouraged me to reflect on my own biases that may have influenced the way I understood this data. I felt that there were missed opportunities where the research could have benefitted from public advisor involvement. I did not include public advisors in the systematic review screening process or secondary analysis of ELSA data. Due to time restrictions, I did not feel it was possible to train public advisors to support with these studies, although in hindsight, I acknowledge that given the opportunity they could have provided valuable input that could have enhanced the studies. Because of ethical concerns, I was also unable to allow public advisors to view transcripts from interviews. This may have allowed them to highlight new perspectives and interpretations that could have improved the analysis of this data. In conclusion, I feel that involving public advisors in the project was highly beneficial in improving the quality of the thesis. However, there were missed opportunities that I would like to address in future research.

7.8 Future research directions

To date, there is very little research exploring what supports older adults with bipolar disorder to age well. This thesis therefore presents several novel findings and highlights areas requiring further investigation.

The findings of the systematic review in this thesis suggested that older adults with bipolar disorder appear to experience elevated prevalence rates of cardiovascular disease and some forms of cancer compared to the general ageing population. The results for studies investigating other physical health comorbidities such diabetes, obesity and renal disease were inconclusive and there was no research examining oral health outcomes in older adults with bipolar disorder. A key conclusion of this systematic review was that much of the available literature examining physical health comorbidities in older adults with bipolar disorder was low quality. There were only few studies that included a control group of individuals from the general population or controlled for key covariates in their analysis. Because of this, it was not possible to determine whether higher prevalence rates of physical health problems were due to factors specific to bipolar disorder or other confounding variables. Another issue was that many of the samples included in the available literature were 'survivor cohorts' living in the community and were not representative of a large number of individuals living with bipolar disorder who are based within inpatient services for example. Consequently, future research should aim to include large representative samples from a range of backgrounds, include comparison groups consisting of older adults from the general population and attempt to control for key covariates such as social, environmental and lifestyle factors that may influence findings. By doing this, it will be possible to assess which specific factors associated with bipolar disorder lead to the development of physical health comorbidities and compare these findings with individuals from the general population.

Study 2 (chapter 4) highlighted the importance of older adults with bipolar disorder

finding a sense of belonging and acceptance. One way that participants found this, was through attending peer support groups and it was suggested that interventions such as social prescribing may be beneficial. Future research that examines this groups experiences of attending peer support groups and considers the benefits of social prescribing interventions would add valuable insight into how these interventions enable older adults with bipolar disorder to age well. Results also showed the importance of lifelong learning and how having an improved understanding of bipolar disorder helped participants to manage their difficulties. Psychoeducation is an intervention that may help older adults with bipolar disorder to develop this understanding. This intervention has been found to be beneficial for younger age groups with bipolar disorder, but there is currently a lack of research exploring its efficacy in older adults. Future research could investigate this to determine whether this would be an effective way of supporting older adults with bipolar disorder to age well in later life. Interventions that help this group to maintain agency such as recovery focused interventions should also be investigated further to build upon the work of Tyler and colleagues (2022). Finally, study 2 also identified that older adults with bipolar disorder value being able to use their vast experiences of living with bipolar disorder to support younger people with this diagnosis. This suggests that older adults with bipolar disorder may be well placed to engage in peer support worker roles. No research has considered the impact of placing this group in such roles. Future research that considers the benefits of this on both younger people with bipolar disorder and the older adults in these roles would be beneficial.

Chapter 5 indicated that older adults with bipolar disorder have concerns around potential physical health side effects of being on mood stabilising medications for many years. At present, there is insufficient research to determine the long-term consequences of using mood stabilising medication or other medications commonly given to individuals with bipolar disorder. Future research should explore this link, as this may have important implications for

the care of older adults with bipolar disorder. A number of participants in this study also communicated that they felt unable to access care in later life or had disengaged with services to avoid iatrogenic stress. It would be helpful to learn more about why these barriers exist, the impact of these on older adults with bipolar disorder and how services can remove these barriers moving forward. Research such as this could help to increase access to care and provide hope to this group. This study also suggested that older adults with bipolar disorder often want to retire to reduce work related stress that has led to mood instability in the past. However, this led to significant financial worries that left participants unsure about what the future held. Research that aimed to uncover ways to improve support for older adults with bipolar disorder as they transition into retirement could potentially provide valuable insight into how services can support this group during this time.

Chapter 6 identified that experiencing bipolar mood states significantly predicts poorer quality of life in older adults. Another important finding was that loneliness was a highly significant predictor of poorer quality of life in this group and this requires further investigation. Our results also suggested that education level, being female and older age may predict better quality of life in this group. However, the number of individuals reporting bipolar mood states in this analysis was limited. Furthermore, the analysis was cross-sectional, meaning it was not possible to determine what caused poor quality of life in this group. Future research could build upon the findings of this study by attempting to examine what the key predictors of poor quality of life in older adults with bipolar disorder are in a large scale, longitudinal analysis. Improving our understanding of which factors lead to poorer quality of life in this population could help services to adapt care and reduce the impact of these causal factors. Doing this may help to improve the wellbeing and quality of life of older adults with bipolar disorder.

7.9 Reflexivity

This section provides an example of the researcher outlining their positionality and considering their influence on the research process whilst competing this thesis. The aim of this is to provide a first-person account that highlights the researcher's position and beliefs coming into the research study and how these changed over time following interactions with participants.

Prior to completing the research, I was aware that I was a 27-year-old white male from a working-class background in the Northwest of England and potentially had a contrasting position to the older adults with bipolar disorder that I would be interviewing and researching. Consequently, I initially approached the research from an outsider's perspective with limited knowledge about the lives of older adults with bipolar disorder. However, upon reflection, I realised that I held experiences that clearly influenced the way I designed and carried out the research. For example, before starting my PhD, I worked as an assistant psychologist within an NHS-based older adults inpatient mental health service. Within this role, I worked with older adults who were diagnosed with bipolar disorder and was aware of the challenges this group faced. I had also experienced mental health difficulties myself in the past, and my experiences of this may have led to some preconceived ideas about what participants within the project may find important to discuss. These experiences provided an insider perspective that potentially influenced my work in a number of ways.

My experiences of working within an older adult inpatient service within the NHS which was often a volatile and highly stressful environment led me to believe that participants would hold negative views of services and would be frustrated at the care they receive. This potentially shaped the questions I asked during the initial interviews and influenced the focus of these encounters. After reflecting on my experiences of growing up in a working-class environment and working within inpatient and forensic services, I felt that I had become hypersensitive to human distress and had learnt that people often communicate feelings of

distress through behaviour that is perceived as challenging or disruptive. I was aware that this may have led to me hesitating during the interviews and not pursuing certain lines of questioning if the participant appeared to become uncomfortable. This potentially led to some important information being missed during the interviews as I prioritised participant safety and well-being over the research data. However, reflecting on my interviewing skills with supervisors and public advisors helped me to become more confident when interviewing participants and helped to find a balance between ensuring participant safety and gaining rich, in-depth data.

As the research progressed, I became more confident in explaining my role during qualitative interviews, the purpose of the study and my interest in learning more about participants' experiences. I realised that participants were keen to share their experiences with someone who wanted to listen, and participant feedback suggested that the research process was enjoyable and therapeutic for many. I also learnt that my experiences of working with vulnerable individuals and my own experiences of mental health improved my ability to empathise with participants and build rapport. Whilst this was a positive, I learnt the value of reflexivity and ensuring that multiple perspectives are available when completing the research. Having feedback from research supervisors and public advisors who had experiences of ageing and mental health difficulties helped me to understand my influence on the research and identify blind spots and important areas of exploration that benefitted the qualitative research studies in particular.

I approached this PhD as someone who was more comfortable completing qualitative research studies as this approach felt more consistent with my philosophical position. I had little experience of quantitative research and was concerned about my ability to complete the secondary analysis of ELSA data. However, with the support of supervisors, I am pleased to have been able to complete this study. I feel that developing my knowledge and ability to

complete both qualitative and quantitative research has enhanced my skills as a researcher and will benefit me in my future career. Furthermore, it has helped me to appreciate the strengths and limitations of both quantitative and qualitative approaches and broaden my knowledge of research methods. Overall, completing this PhD and engaging in reflexivity throughout this process has enhanced the quality of my work and developed my confidence as a researcher and individual. Alongside this, I am hopeful that this thesis has illuminated the experiences and challenges faced by older adults with bipolar disorder in ways that can be used to improve the support for this population moving forward.

7.10 Thesis conclusion

This thesis aimed to improve our understanding of what it means to age well with bipolar disorder. Findings illuminated the physical health comorbidities associated with bipolar disorder in later life and identified this as an important area to consider when treating this population. Older adults with bipolar disorder stressed the importance of lifelong learning and using accumulated knowledge to manage mood instability more effectively and also support younger generations living with bipolar disorder. Alongside this, feeling accepted, finding a sense of belonging and recognising and building upon strengths also supported the process of ageing well by reducing loneliness and increasing confidence. The care needs of older adults with bipolar disorder were unique and changed in later life. A clear disconnect between care this group desired and the support they currently receive was highlighted. Community interventions that enable this group to develop meaningful, trusting relationships with professionals were beneficial but difficult to access. Issues such as this potentially contributed to the finding that bipolar mood states were significantly associated with poorer quality of life in this group. Overall, this PhD project argues that older adults with bipolar disorder require increased attention from clinical services and academia to identify ways to improve the care

currently offered and reduce the inequalities they experience.

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Appendices

Appendix 1: Systematic review search strategy (chapter 3)

	Search Terms
Search 1:	(DE "Bipolar Disorder" OR DE "Bipolar I Disorder" OR DE "Bipolar II Disorder" OR DE "Cyclothymic Disorder" OR DE "Mania" OR DE "Bipolar I Disorder" OR DE "Bipolar II Disorder" OR DE "Cyclothymic Disorder" OR DE "Mania" OR DE "Hypomania") OR TI (bipolar OR bi-polar OR "bi polar" OR "manic depress*" OR cyclothym* OR hypomani*) OR AB (bipolar OR bi-polar OR "bi polar" OR "manic depress*" OR cyclothym* OR hypomani*)
Search 2:	(DE "Geriatric Assessment" OR DE "Gerontological Counseling" OR DE "Geriatric Psychiatry" OR DE "Geriatric Psychotherapy" OR DE "Geropsychology" OR DE "Gerontological Counseling" OR DE "Geriatric Patients" OR DE "Geriatrics" OR DE "Geriatric Assessment" OR DE "Geriatric Psychiatry" OR DE "Gerontology" OR DE "Older Adulthood") OR (geriatric* OR elderly OR pensioner* OR ((older OR aged) N3 (patient* OR adult* OR resident* OR person* OR people))) OR (geriatric* OR elderly OR pensioner* OR ((older OR aged) N3 (patient* OR adult* OR resident* OR person* OR people)))(DE "Geriatric Assessment" OR DE "Gerontological Counseling" OR DE "Geriatric Psychiatry" OR DE "Geriatric Psychotherapy" OR DE "Geropsychology" OR DE "Gerontological Counseling" OR DE "Geriatric Patients" OR DE "Geriatrics" OR DE "Geriatric Assessment" OR DE "Geriatric Psychiatry" OR DE "Gerontology" OR DE "Older Adulthood") OR (geriatric* OR elderly OR pensioner* OR ((older OR aged) N3 (patient* OR adult* OR resident* OR person* OR people))) OR (geriatric* OR elderly OR pensioner*)
Search 3:	Search 1 and Search 2 combined

Dr Jasper Palmier-Claus
Health Innovation One
Bailrigg
Lancaster
LA1 4YW

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

30 July 2021

Dear Dr Palmier-Claus

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**What does it mean to age well with bipolar disorder?**
IRAS project ID:	**293564**
Protocol number:	**N/A**
REC reference:	**21/LO/0405**
Sponsor	**Lancaster University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation.

The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:
- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **293564**. Please quote this on all correspondence. Yours

sincerely,

Natalie Wilson

Approvals Manager

Email: camberwellstgiles.rec@hra.nhs.uk

Copy to: *Ms Claire O'Donnell, Lancaster University, Sponsor contact*

Appendix 3: Study advertisement for Chapter 4

NHS Lancashire & South Cumbria NHS Foundation Trust | **NHS** Pennine Care NHS Foundation Trust | **NHS** Greater Manchester Mental Health NHS Foundation Trust | **NIHR** Applied Research Collaboration North West Coast | Health Research | Lancaster University

Research Opportunity

Study title: What does ageing well mean to older adults with bipolar disorder?

- Are you aged 60 or over?
- Do you identify as experiencing bipolar disorder at present or have a formal diagnosis of bipolar disorder?

If so, you may be interested in participating in a study being carried out by Aaron Warner, a PhD student at Lancaster University. This study will aim to understand what is important to older adults as they age with bipolar disorder and why, and what may help them to age well.

Participants who are involved in the study will be asked to be part of photo elicitation (in which they will take photographs of what aspects of their lives help them to age well) and an individual interview in which they will discuss their photographs with the researcher.

If you would like to find out more about the study, please contact Aaron Warner:

Email: a.warner3@lancaster.ac.uk

Phone : 07495 729079

Participant Information Sheet

Title of Study: What does ageing well mean to older adults with bipolar disorder?

My name is Aaron Warner and I am conducting this research *as part of my PhD project* at Lancaster University. I would like to invite you to take part in a research study that will aim to explore what ageing well means to older adults with bipolar disorder. This information sheet will help you to understand the study in more detail should you be interested in participating. Please take time to read through it carefully as it is important that you understand why the research is being completed and what you will be asked to do should you participate. Thank you for taking the time to read this.

What is the study about?
The purpose of this study is to better understand what is important to older adults as they age with bipolar disorder, what their preferences and priorities are as they age and to explore what they believe helps them to age well with bipolar disorder.

Why have I been approached?
You have been invited to participate in this study as you are someone who has received a diagnosis of bipolar disorder or currently have experiences of bipolar disorder, and you are aged 60 or over.

Do I have to take part?
No, it is completely up to you whether you decide to take part in this study. If you do decide to take part, you will be asked to provide your written or verbal consent, although you can withdraw from the study at any time, without providing any reasons should you wish to do so. If you do withdraw more than one week after your participation, any data collected with your consent may be retained and used within the study if it has already been analysed by the researcher and included in the write up of the report. Your rights will not be affected in any way.

What will I be asked to do if I take part?
Initial Assessment (60-90 minutes)

Before you can take part in the study, you will have a brief phone call with the researcher to discuss the study and you will be asked some brief questions about whether you meet the inclusion criteria. This will last around 15 minutes. Following this, you will then be asked to meet with the researcher and answer some more detailed questions about your experiences of bipolar disorder. This will take around one hour and will be used to understand if you are eligible to take part in the study. To be eligible for the study, you will be required to meet the

criteria for bipolar disorder using an assessment called the Structured Clinical Interview for DSM-5. This assessment will not be used to provide a diagnosis and will only be used for research purposes. After this assessment has been completed, the researcher will let you know if you are eligible for the study. If you are deemed eligible, you will complete the steps outlined below.

Photo elicitation and individual interview (60-75 minutes)

This study will involve two stages. For the first stage, you will be asked to take photographs of aspects of your life that you believe represent you ageing well and aspects of your life that are important to you as you age with bipolar disorder (photo elicitation). The researcher will provide you with a digital camera to take photographs with, or you can use your own mobile phone if you prefer. You will be given instructions about what may be helpful to take photographs of, and you will be given one week to complete this stage. During this stage it will be recommended that you do not take photographs of yourself or other people to maintain the anonymity of yourself and others. you provide remain anonymous and confidential. The researcher will also call you during this week to provide any support or answer any questions you make have about taking your photographs.

After you have done this you will meet with the researcher again to complete an interview. During this interview, you will be asked to speak to the researcher about your photographs, why these photographs are important to you, and the researcher will also ask some questions about this. However, if there are any questions that you feel uncomfortable answering, you will be able to move on from these questions without answering. These interviews will be completed in person (if possible and dependent on covid-19 restrictions), online or by phone depending on your preference.

If you do decide to take part, the researcher will inform your GP or another healthcare professional who is involved in your care that you are participating in the study.

Will my data be Identifiable?
The information you provide will be made anonymous using pseudonyms (a different name) and people who do not need to know who you are will not be able to see your name or contact details. However, whilst the researcher will aim to ensure confidentiality, the only exception to this is if you tell me that there is a risk to yourself or others. In this case, we will need to inform somebody to keep you safe. If possible, I will tell you that I have to do this. Before you participate in the research project, the researcher may ask for your consent to request information from your clinical/social care team to determine your eligibility for the study and to ensure that there is no risk to anybody.

The research data collected from you for this study will be stored securely using a university approved secure cloud storage and only the researchers conducting this study and auditors will have access to these data. All files stored on a computer will be encrypted, the computer will be password protected and only the researcher will have access to them. Personal

information will be destroyed at the end of the study and you will be informed about the progress and results of the study before the study ends if you request. All of your personal data will be confidential and will be stored separately from your interview responses. The researcher will ensure that the typed version of your interview will be made anonymous by removing all information that could identify you, including your name. Some quotations from your interview may be used when the researcher completes the final report or tries to publish the study, although a pseudonym will be used and your name will not be included in the final report. After the study has been completed, research data will be kept for up to ten years. At the end of this period, it will be destroyed.

You can find out more about how your information is used:

- At www.hra.nhs.uk/information-about-patients/
- By asking the researcher Aaron Warner
- By emailing the researcher at a.warner3@lancaster.ac.uk

What will happen to the results?
The results will be used to complete a study that will be part of the researchers PhD project. This study may also be submitted for publication. If you are interested receiving a copy of a paper should the final report be published within an academic journal, please inform the researcher who will provide this.

What will happen to my data?

Only the researcher, and his academic supervisors will have access to your data or will be able to use data that has been collected from you in the study. Lancaster University will be the data controller for any personal information that is collected from you in the study and will be responsible for handling your data and managing it properly. Under General Data Protection Regulation (GDPR) you have certain rights when personal data is collected about you, however, your rights to access, move or change information are limited as the researcher will need to use your data in specific ways to ensure the findings of the study are reliable and accurate. If you would like to know more about your rights in relation to your personal data, please ask the researcher for more information.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

Are there any risks?
There are no serious risks anticipated with participating in this study, although there may be some burden when completing the initial assessment and interviews as these may be time consuming and include some sensitive questions. However, these assessments are unlikely to last over 1 hour. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?
You will be provided with £20 voucher for completing the baseline assessment and another £20 voucher for completing the follow up interview. You may also find it interesting to discuss your experiences and take part in the research.

Who has reviewed the project?
This study has been reviewed and approved by an Ethics Committee at Lancaster University as well as an NHS ethics committee.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact the main researcher:

Aaron Warner
Email: a.warner@lancaster.ac.uk
Phone: 07495 729079

Or you can also contact his project supervisors:

- **Dr Jasper Palmier-Claus**
  Email : j.palmier-claus@lancaster.ac.uk
- **Prof Fiona Lobban**
  Email : f.lobban@lancaster.ac.uk
- **Prof Carol Holland**
  Email : c.a.holland@lancaster.ac.uk
- **Dr Elizabeth Tyler**
  Email : e.tyler@lancaster.ac.uk

Complaints
If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM
REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future**, please contact your care team if you have one.** The following resources may also be of assistance if you feel distressed:

<u>**NHS 111**</u>

Call 111 for free on a mobile or landline number

Or alternatively, go online to 111.nhs.uk

(Available 24 hours a day, 7 days a week)

<u>**Mind InfoLine**</u>

Phone: 0300 123 3393

Email: info@mind.org.uk

Or via text: 86463

<u>**Samaritans**</u>

Email: jo@samaritans.org

Phone: 116 123 (available 24 hours a day, 365 days a year)

<u>**SANEline**</u>

Phone: 0300 304 7000 (available 4.30pm–10.30pm every day).

Any emergencies should be directed to the emergency services

Study Title: What does ageing well mean to older adults with bipolar disorder?

We are asking if you would like to take part in a research project that aim to understand what ageing well means to older adults with bipolar disorder, what is important for this group as they age and what this groups preferences, priorities and presenting needs are as they age. This can help to improve the support available to this group and reduce the difficulties they currently face.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the researcher, Aaron Warner.

Note: Please provide one copy of this form to the participant and one copy for the research team

Please put initials in these boxes

1. I confirm that I have read the information sheet, fully understand what is expected of me within this study and have had the opportunity to ask any questions and to have them answered ☐

2. I understand that the photographs that I take belong to me and that I can decide who sees them, how they are used in the research and that they will only be used if I give my permission to the researcher. ☐

3. I understand that the photographs I take will be used to prompt discussions in an interview with the researcher and that discussions within this interview will be audio recorded and then made into an anonymised written transcript. I also understand that these audio recordings will be kept until the research project has been examined. ☐

4. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

5. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication. ☐

6. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; I consent to information and quotations from my interview being used in reports, conferences and training events. ☐

7. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher will need to share this information with their research supervisor. ☐

8. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished. ☐

9. I consent to my GP being contacted and informed that I am taking part in this study ☐

10. I consent to my clinical/social care team being contacted by the researcher to obtain relevant clinical information about me for the study. I consent to clinical information being obtained from my medical records for the purpose of the research. ☐

11. I consent to take part in the above study ☐

12. I am happy to be contacted about future research projects ☐

13. Optional – I am happy to share the findings of the SCID assessment that I complete with the researcher with my mental health team/social care team

Name of Participant_____ **Signature**_____ **Date** _____

Name of Researcher _____**Signature** _____**Date** _____

Appendix 6: Example of SCID-5-RV used in chapter 4

A. MOOD EPISODES

NOTE: This module is for evaluating Current and Past Mood Episodes, Cyclothymic Disorder, Persistent Depressive Disorder (Dysthymia), AND Premenstrual Dysphoric Disorder. Bipolar I Disorder, Bipolar II Disorder, Other Specified Bipolar Disorder, Major Depressive Disorder, and Other Specified Depressive Disorder are diagnosed in Module D.

CURRENT MAJOR DEPRESSIVE EPISODE	MAJOR DEPRESSIVE EPISODE CRITERIA					
Now I am going to ask you some more questions about your mood.	A. Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood, or (2) loss of interest or pleasure.					
Since (1 MONTH AGO), **has there been a period of time when you were feeling depressed or down <u>most of the day nearly every day</u>? (Has anyone said that you look sad, down, or depressed?)** *IF NO*: **What about feeling empty or hopeless most of the day nearly every day?** *IF YES TO EITHER OF ABOVE*: **What has that been like? How long has it lasted? (As long as 2 weeks?)**	1. Depressed mood most of the day, nearly every day, as indicated either by subjective report (e.g., feels sad, empty, hopeless) or observation made by others (e.g., appears tearful). NOTE: in children or adolescents, can be irritable mood.	?	1	2	3	A1
➤ *IF PREVIOUS ITEM CODED "3:"* **During that time, did you lose interest or pleasure in things you usually enjoyed? (What has that been like? Give me some examples.)** ➤ *IF PREVIOUS ITEM NOT CODED "3:"* **What about a time since** (1 MONTH AGO) **when you lost interest or pleasure in things you usually enjoyed? (What has that been like? Give me some examples.)** *IF YES*: **Has it been nearly every day? How long has it lasted? (As long as 2 weeks?)**	2. Markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated either by subjective account or observation).	?	1	2	3	A2
		IF BOTH ITEM A.1 AND A.2 ARE CODED "1," GO TO ***PAST MAJOR DEPRESSIVE EPISODE*** A.5				
FOR THE FOLLOWING QUESTIONS, FOCUS ON THE WORST 2 WEEKS IN THE PAST MONTH (OR ELSE THE PAST 2 WEEKS IF EQUALLY DEPRESSED FOR ENTIRE MONTH). *IF UNKNOWN:* **Since** (1 MONTH AGO), **during which 2-week period would you say you have been doing the worst?**	NOTE: When rating the following items, code "1" if the symptoms are clearly due to a general medical condition (e.g., insomnia due to severe back pain).					

Topic Guide: What does it mean to age well with bipolar disorder?

1. **The purpose of this research study is to try to understand what ageing well means to older adults with bipolar disorder. Please could you tell me, in your own words, what you think it means to age well?**

   Prompts

   What do you think is involved in ageing well?

   Could you tell me why you feel this is important?

2. **What impact does bipolar have as you age? (Are there things that it makes harder/easier)**

   Prompts

   Could you explain why that is?

   Please could you say a bit more about that?

3. **Please could you tell me about the photographs you have selected and why you feel they represent ageing well bipolar disorder to you?**

   Prompts

   Could you tell me why you feel this is important?

4. **Why did you feel it was important to include these particular photographs?**

   Prompts

   Please could you tell me more about that?

   That's great, thank you, that's just what I'm looking for.

5. **How do you feel this has helped you to age well?**

   Prompts:

Why do you think that has been important for you?

Is there any way in particular you feel that this has helped you to age well with bipolar?

What impact do you think this has had on you?

6. What do you think it means to not age well?

Prompts:

Why do you think that?

Why do you feel that is an important aspect of not ageing well?

7. What would make you feel that you were not ageing well?

Prompts:

Why would that represent you not ageing well?

8. What do you think you would do about this if you felt you were not ageing well?

Prompts:

Why do you think that would help you to age well?

9. What support have you found most helpful as you have aged with bipolar disorder and why? (support from family, friends, services)

Prompts:

Could you tell me why you feel this has been most helpful?

Why do you think this has been so important to you?

How do you feel your life may have been different without this support as you age?

10. What do you believe would be the most helpful way to support older adults with bipolar disorder in later life?

Prompts:

Why do you feel this would be most important?

How do you feel this would change the lives of older adults with bipolar disorder as they age?

11. **Please could you summarise your experiences of ageing with bipolar disorder in three words? What would these three words be and why?**

Prompts:

Please could you expand upon that point?

Please note: The questions in this topic guide are examples of the topics that may be covered and may change as the project progresses and after feedback from service users who will be supporting with the development of the project.

Appendix 8: Advert for chapter 5

Research Opportunity

Study title: The changing care of older adults with bipolar disorder in later life? A narrative analysis

- Are you aged 60 or over?
- Have you received a diagnosis of bipolar disorder from a healthcare professional?
- Have you experienced living with bipolar disorder for 10 years or more?

If so, you may be interested in participating in a study being carried out by Aaron Warner, a PhD student at Lancaster University. The aim of this study is to better understand the changing care needs of older adults with bipolar disorder in later life. It is hoped that learning more about this can improve our understanding of how best to support older adults with bipolar disorder and provide more effective care.

People who participate in this study will be asked to complete an interview with the researcher in which they discuss their experiences of care and support, since they first tried first tried to get help for bipolar disorder, or first tried to access mental health services, up until now.

If you would like to find out more about the study, please contact Aaron Warner by email: a.warner3@lancaster.ac.uk

Appendix 9: Participant information sheet for chapter 5

Participant Information Sheet

Title of Study: What are the changing care needs of older with bipolar disorder in later life?

My name is Aaron Warner and I am conducting this research as part of my PhD project at Lancaster University. I would like to invite you to take part in a study that aims to understand the changing care need of older adults with bipolar disorder in later life. This information sheet aims to help you understand the study in more detail and also will also explain your role should you be interested in participating. Please take time to read through this information as it is important that you understand why the research is being completed and what you will be asked to do should you participate. Thank you for taking the time to read this.

What is the study about?
The aim of this study is to better understand the changing care needs of older adults with bipolar disorder in later life. It is hoped that learning more about this can improve our understanding of how best to support older adults with bipolar disorder and provide more effective care.

Why have I been approached?
You have been invited to participate in this study as you are aged 60 or over, you have received a formal diagnosis of bipolar disorder from a healthcare professional and have had experiences of bipolar disorder for 10 years or more.

Do I have to take part?
No, it is completely up to you whether you decide to take part in this study. If you do decide to take part, you will be asked to provide your written or verbal consent, although you can withdraw from the study at any time, without providing any reasons should you wish to do so. If you do withdraw more than one week after your participation, any data collected with your consent may be retained and used within the study if it has already been analysed by the researcher and included in the write up of the report. Your rights will not be affected in any way.

What will I be asked to do if I take part?
Before you can take part in the study, you will have a brief phone call with the researcher to discuss the study and you will be asked some brief questions about whether you meet the inclusion criteria (e.g., have you received a diagnosis of bipolar disorder from a healthcare professional?). This will last around 5-10 minutes. Following this, you will then be asked to meet with the researcher (either face-to-face, online or over the phone) where you will be asked some brief demographic questions (your age, gender, ethnicity, length of diagnosis, medication use, number of inpatient admissions, have they received psychological therapy,

occupation and current living status) and provide your informed consent. This will take around 10 minutes in total. After these steps have been completed, the researcher will let you know if you are eligible for the study. If you are deemed eligible, you will complete the steps outlined below.

Interview (60-75 minutes)

If you decide to take part in the study, you will be asked to complete an interview with the researcher. This interview is called a biographical narrative interview, and you will be asked to discuss your experiences of living with bipolar disorder from the time you first started experiencing symptoms or received a formal diagnosis to now. The aim of the interview will be to learn about your experiences of living with bipolar disorder and understand how your care needs have changed over time and why this may be. However, if there are any questions that you feel uncomfortable answering, you will be able to move on from these questions without answering. These interviews will be completed in person (if possible and dependent on covid-19 restrictions), online or by phone depending on your preference.

If you do decide to take part, the researcher will inform your GP or another healthcare professional who is involved in your care that you are participating in the study.

Will my data be Identifiable?
The information you provide will be made anonymous using pseudonyms (a different name) and people who do not need to know who you are will not be able to see your name or contact details. However, whilst the researcher will aim to ensure confidentiality, the only exception to this is if you tell me that there is a risk to yourself or others. In this case, we will need to inform somebody to keep you safe. If possible, I will tell you that I have to do this. Before you participate in the research project, the researcher may ask for your consent to request information from your clinical/social care team to determine your eligibility for the study and to ensure that there is no risk to anybody.

Research data collected for this study will be stored securely using a university approved secure cloud storage and only the researchers conducting this study and auditors will have access to these data. All files stored on a computer will be encrypted, the computer will be password protected and only the researcher will have access to them. Personal information will be destroyed at the end of the study and you will be informed about the progress and results of the study before the study ends if you request. All of your personal data will be confidential and will be stored separately from your interview responses. The researcher will ensure that the typed version of your interview will be made anonymous by removing all information that could identify you, including your name. Some quotations from your interview may be used when the researcher completes the final report or tries to publish the study, although a pseudonym will be used and your name will not be included in the final report. After the study has been completed, research data will be kept for up to ten years. At the end of this period, it will be destroyed.

You can find out more about how your information is used:

- At www.hra.nhs.uk/information-about-patients/
- By asking the researcher Aaron Warner
- By emailing the researcher at a.warner3@lancaster.ac.uk

What will happen to the results?
The results will be used to complete a study that will be part of the researchers PhD project. This study may also be submitted for publication. If you are interested receiving a copy of a paper should the final report be published within an academic journal, please inform the researcher who will provide this.

What will happen to my data?

Only the researcher and his academic supervisors will have access to your data or will be able to use data that has been collected from you in the study. Lancaster University will be the data controller for any personal information that is collected from you in the study and will be responsible for handling your data and managing it properly. Under General Data Protection Regulation (GDPR) you have certain rights when personal data is collected about you, however, your rights to access, move or change information are limited as the researcher will need to use your data in specific ways to ensure the findings of the study are reliable and accurate. If you would like to know more about your rights in relation to your personal data, please ask the researcher for more information.

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

Are there any risks?
There are no risks anticipated with participating in this study, although there may be some burden when completing the initial assessment and interviews as these may be time consuming and include some sensitive questions. However, these assessments are unlikely to last over 1 hour. However, if you experience any distress following participation you are encouraged to inform the researcher and contact the resources provided at the end of this sheet.

Are there any benefits to taking part?
You will be provided with £20 voucher for completing the interview with the researcher. You may also find it interesting to discuss your experiences and take part in the research.

Who has reviewed the project?
This study has been reviewed and approved by an Ethics Committee at Lancaster University as well as an NHS ethics committee.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact the main researcher:

Aaron Warner

Email: a.warner3@lancaster.ac.uk

Or you can also contact his project supervisors:

- **Dr Jasper Palmier-Claus**
  Email : j.palmier-claus@lancaster.ac.uk
- **Prof Fiona Lobban**
  Email : f.lobban@lancaster.ac.uk
- **Prof Carol Holland**
  Email : c.a.holland@lancaster.ac.uk
- **Dr Elizabeth Tyler**
  Email : e.tyler@lancaster.ac.uk

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Dr Laura Machin Tel: +44 (0)1524 594973
Chair of FHM
REC Email: l.machin@lancaster.ac.uk
Faculty of Health and Medicine
(Lancaster Medical School)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, **please contact your care team if you have one.** The following resources may also be of assistance if you feel distressed:

NHS 111

Call 111 for free on a mobile or landline number

Or alternatively, go online to 111.nhs.uk

(Available 24 hours a day, 7 days a week)

Mind InfoLine

Phone: 0300 123 3393

Email: info@mind.org.uk

Or via text: 86463

Samaritans

Email: jo@samaritans.org

Phone: 116 123 (available 24 hours a day, 365 days a year)

SANEline

Phone: 0300 304 7000 (available 4.30pm–10.30pm every day).

Any emergencies should be directed to the emergency services

Appendix 10: Consent form for chapter 5

Consent Form

Study Title: What are the changing care needs of older adults with bipolar disorder in later life?

We are asking if you would like to take part in a research project that aims to better understand the changing care needs of older adults with bipolar disorder in later life. It is hoped that learning more about this can improve our understanding of how best to support older adults with bipolar disorder and provide more effective care.

Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, Aaron Warner (email: a.warner3@lancaster.ac.uk)

Note: Please provide one copy of this form to the participant and one copy for the research team

Please put initials in these boxes

1. I confirm that I have read the information sheet, fully understand what is expected of me within this study and have had the opportunity to ask any questions and have them answered.

2. I understand that my interview will be audio recorded and then made into an anonymised written transcript. I also understand that audio recordings will be kept until the research project has been examined.

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

4. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.

5. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project.

6. I consent to information and quotations from my interview being used in reports, conferences and training events. I also understand that the researcher will discuss data with their supervisor as needed.

7. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator will need to share this information with their research supervisor.

8. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.

9. I consent to my GP being contacted and informed that I am taking part in this study ☐

10. I consent to my clinical/social care team being contacted by the researcher to obtain relevant clinical information about me for the study. I consent to clinical information being obtained from my medical records for the purpose of the research. ☐

11. I consent to take part in the above study. ☐

12. I am happy to be contacted about future research projects ☐

Name of Participant_____ Signature_____ Date _____

Name of Researcher _____Signature _____Date _____

298

Appendix 11: Demographic sheet for chapter 5

Demographics Sheet

Participant ID:

Age:

Gender:

Ethnicity:

Diagnosis (BD I or BD II):

Age when diagnosed:

Employment status:

Living status:

Education level:

Number of hospitalisations:

Place recruited from:

Topic Guide –Biographical Narrative Interviews

Introduce the research and explain the interview process

This study aims to explore your experiences of care whilst living with bipolar disorder, and tries to understand if/how your care needs have change in later life, and why?

Stage 1 – The Narrative

1. **Please could you tell me about your experiences of care and support, since you first tried to get help for bipolar disorder, or first came into contact with mental health services, up until now?**

Note: At this stage the interviewer should use non-verbal prompts and should encourage the participant to continue telling their story. The interviewer should avoid speaking or interrupting until it is clear that the participant has finished telling their story.

Stage 2 – follow up questions

- Follow up questions based on what has already been said in the narrative:
- Examples:
- What kind of care did you receive there?
- How was that helpful?
- What happened after that?
- How did your care change when you came into this service?
- What was that like?

TWO. Follow-up CUE-QUIN Questions on Mentioned Topics in order

- only topics raised in sub stage ONE
- only in the order of their raising

<u>Stage 3</u> – Questioning phase (Areas of interest not already covered)

At this stage the interviewer may ask questions to find out more information about a topic of interest that was discussed in study 1 or has been missed within stage 2 of the interview.

Questions such as those below are valuable at this stage:

> **Please could you tell me about your experiences of living with bipolar disorder at present and the impact it has on your life? What do you feel your key needs are at present, are the being met and why?**

Optional questions during stage 3 (depending on content of interview so far)

1. At what point in your life did you notice it became a problem for you?
2. Could you tell me about what was going on in your life at that point/who was around you/what support did you have?
3. **What treatment/support did you receive initially**? **Was this helpful for you?**
4. **What support do you think would have been helpful at that time?**
5. **How do you feel the support/treatment you receive has changed over time?**
6. Could you tell me about a time when you felt your bipolar disorder was being managed well? What about a time when it wasn't being managed well?
7. What support helped you? What support was unhelpful for you?
8. **Could you tell me about a time when you felt your needs were being met?**
9. **Could you tell me about what you feel your key needs are at present? Are they being met and why?**
10. **How do you feel your care needs have changed over time and why?**
11. **What support have you found most helpful as you have aged? What support has been unhelpful as you have aged?**
12. What support do you feel would be key for older adults with bipolar disorder?
13. What advice would you give to older adults living with bipolar disorder?
14. **Overall, how would you summarise your experiences of care whilst living with bipolar disorder over time? And in later life?**
15. Is there anything else you would like to add that has not been covered so far?

- **<u>Prompts</u>**
- What happened at this point?
- What happened before this?
- What happened after this?
- Please can you say more about this?
- Ask about specific dates and years of key events

Stage 4 – Conclude the interview and inform the participant of the next steps (e.g., transcribing, ask whether they would like to be informed of the results).

Note: The questions in this topic may change as the project progresses and after feedback from service users who will be supporting with the development of the project.

Appendix 13: Ethical approval for chapter

Name: Aaron Warner

Supervisor: Jasper Palmier-Claus

Department: Health Research

FHM **REC Reference:** FHM-2023-3372-RECR-1

Title: Quality of life in older adults with bipolar disorder: A secondary analysis

Dear Mr Aaron Warner,

Thank you for submitting your ethics application in REAMS, Lancaster University's online ethics review system for research. The application was recommended for approval by the FHM Research Ethics Committee, and on behalf of the Committee, I can confirm that approval has been granted for this application.

As Principal Investigator/Co-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 licences 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 any changes to your application, including in your participant facing materials (see attached amendment guidance).

Please keep a copy of this email for your records. Please contact me if you have any queries or require further information.

Yours sincerely,

Dr Laura Machin
Chair of the Faculty of Health and Medicine Research Ethics Committee
fhmresearchsupport@lancaster.ac.uk

Appendix 14: Example of coding from chapter 4 analysis (What does it mean to age well with bipolar disorder?)

Handwritten annotations (left margin, top to bottom):
- Having Choices is important
- Want to feel trusted and believed when unable to work
- Important to be helpful.
- Able to use knowledge and experience
- Need to have interesting things to do

Handwritten annotations (right margin, top to bottom):
- feeling useful
- achievement
- Respected and Valued by others
- Still able to help family and younger generations
- useful, part of the community
- important to help others
- Able to offer something useful.
- people have power over us. Scary.
- Knowledge / experience
- Able to find positives
- staying in contact, maintaining relationships
- Able to support loved ones.

Handwritten annotation (bottom): importance of not feeling stuck, left behind.

1. **Int:** The purpose of this study is to try and understand what it means to age well with
2. Bipolar disorder and what is important to people as they age. To begin, please could
3. you tell me what you think it means to age well?
4. **Angela:** erm… ok… I think it means to still feel useful… to still feel that you are
5. achieving something and that you are respected and valued by others and that you
6. have choices. Erm, yeah… you have choices.
7. **Int:** ok, thank you. You mentioned feeling useful, please could you tell me more about
8. that and why that is important to you?
9. **Angela:** yeah, you know, that you can help your family and younger generations.
10. Erm… that you are useful within your community.
11. **Int:** yeah…
12. **Angela:** erm… so for example, when we are at the allotment and someone needs a
13. hand with something, we have something to offer them. Erm… I think the other side
14. of it is that you are not bullied or undervalued by the government. So people who are
15. on state benefits for example need to be trusted and believed… erm… that's really
16. important. The brown envelopes keep coming and coming and you're still reporting
17. on things that you've been telling them for years and years, the same things. And…
18. erm… its terrifying the amount of power that people have over you and I don't think
19. anyone feels totally powerful or totally safe, but I think we need a measure of that.
20. **Int:** Great, thank you. You also mentioned about feeling useful to your family, please
21. could you tell me more about that and why it feels important to you?
22. **Angela:** Yes, there are things that we know about life and how life works. Erm… I've
23. got four children and they all ask me about my opinion and that's really important that
24. I can help them, give them advice and tell them that things are going to be ok. It might
25. not be, but it's important that I can tell them that things are going to be ok as they get
26. older. Its important to let them know that getting older isn't all terrible… you can't
27. run half marathons anymore but its not all terrible (laughs). Yeah… being able to
28. make things for them, give them gifts for birthdays and Christmas, things that they
29. value and to have a really good conversation with them when you can't physically see
30. them that makes them feel better.
31. **Int:** brilliant… you also mentioned about being able to make choices and that it is
32. Really important to you. Please could you tell me more about that?
33. **Angela:** Yeah, there needs to be things to do that are interesting. You know, I often
34. think about elderly Syrians that have been left behind and they have let their families
35. go to seek refuge elsewhere and now they are just sitting in bombed out dusty
36. buildings and they're stuck, they've got nothing. The kind of old age that they
37. envisage where they are surrounded by family and loved is not an option for them. So
38. I'm not just thinking of me, there's people ageing all over the world in different
39. situations. I worked in West Africa for a while and you'd have these courtyards and

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Appendix 15: Coding summary from narrative analysis (Chapter 5)

Narrative analysis coding (key events and transitions in participants' story)

Before bipolar disorder diagnosis

- Upheaval and uncertainty - early life trauma
- Outcast and misunderstood – feeling isolated and alone
- People noticed I was different.
- Felt punished unnecessarily because I was different.

Initial contact with services

- Confusion and fear when given bipolar disorder diagnosis – no information provided.
- No support was offered – I was on my own.
- I was told take lithium and we'll leave you alone.
- I didn't want help when I was first diagnosed – I didn't believe them and rejected the diagnosis.
- I felt isolated - I was a community of one with bipolar disorder.
- Reading about bipolar helped me – it made me realise there was some hope of a normal life.

Experiences in mental health hospital

- the support workers were very helpful – they would talk to me about things other than my mental health which was helpful
- being locked up and not being able to go out was frustrating.
- Being released from hospital can be daunting if there is no support following it.

CPN's introduced

- CPN's were generally "wonderful".
- CPN's were part of the family – they didn't judge me.
- They provided me with quick access to support.
- A safe person to talk to
- I felt safe and supported knowing they were there.
- However, people coming into your home can be invasive and frustrating, services need to be aware of that.
- Good communication is key, and it wasn't there from some people.

CPN's removed

- A massive blow – Unable to access the help I needed.

- There was no longer any care between crises – only when I had periods of hopelessness and mania which could have been too late.
- It has remained this way for many years now.

Support as you get older.

- There is less support now I am older – the quality of care has deteriorated.
- Who do I contact? I need to know where to go if I become unwell.
- I am responsible for all of my care needs now (taking medication etc)
- I want consistency – I need one person who knows me well and is my go to contact (CPN in the past)
- Family support is more important than ever in old age – they know me well and spot warning signs – no one checks in on me so they are my safety net
- Bipolar support groups are frustrating – bipolar doesn't need to be in the title, just send us to groups where anyone can attend (normalise bipolar)

Changing care needs as you age

- My care needs have changed because they have had to – the services are not there to meet my needs so I have had to adapt
- I have learnt how to live with bipolar disorder over many years – I have a better understanding of how to keep myself well and stay out of hospital
- It is up to me to remain mentally and physically active (be engaged) – I want to feel part of something now.
- I have to be true to myself now I am older – I have to fight to maintain agency.
- I don't feel like bipolar will get me now – I don't worry about that like I did in my 20's.
- I worry about physical health problems now – does medication cause cardiovascular disease? What are the long-term effects of medication?
- I need to know exactly what is happening and when now I am older – I don't want any surprises (with medication for example)
- Having a GP who knows you well makes a massive difference.
- Talking therapy is hard to access and it always has been – I would like it though.

Levels of narrative analysis

Personal level – Telling her story potentially may have had some therapeutic benefit for the participant. The participant's story highlights how she initially experienced biographical disruption (Bury, 1982) when diagnosed with bipolar disorder. Following this, she portrayed a time where she questioned her identity, however, her story shows how she fought back from rejection and marginalisation to living a meaningful and fulfilling life in older age. This telling of her story may highlight what she has overcome and could potentially be an empowering experience for the participant.

Interpersonal level – as I have worked with older adults with a diagnosis of bipolar disorder in my previous roles, I may have internal biases that shape the way the interview was constructed. I was also focused on making sure that the participant offered information that could answer the research question, and it is possible that they were not able to tell their story of their experiences of care exactly how they wanted at certain points.

Positional level – I am a 29-year-old, white, male, PhD student which may have influenced the way the participant told her story to me. It is possible that the participant omitted certain aspects of the story as she felt uncomfortable discussing periods where she was vulnerable to a younger individual or wanted to portray herself as coping well. As a mother, the participant could potentially have constructed the story in a way that omits traumatic content to protect me from becoming overwhelmed as a younger individual. Conversely, the participant may have felt more comfortable discussing her story with me as I am not in a clinical role and may not be seen as a threat that could lead to hospitalisation as in the past.

Societal level – the participant felt outcast by society from an early age. She described feeling marginalised and bullied from an early age after moving to the UK. The participant's story was also shaped by her experiences of being a woman and mother. The participant was concerned that her challenges with mental health difficulties may had led to her being viewed as being unable to care for her children. These societal views influenced the way the participant sought help from services and loved ones due to fears that she would be punished if she openly discussed her difficulties. Therefore, her experiences of care, her care needs and her views surrounding services were directly shaped on a societal level.

Narrative tone – the beginning of the participants story is pessimistic and is characterised by abuse, neglect, and discrimination. However, the tone becomes more uplifted when she discusses her experiences with the CPN who was seen as part of her family and a secure figure in her life. The tone then becomes more optimistic as she discusses how she rebuilt her life over time and achieved relative stability, before this moves to frustration at the lack of appropriate support available for older adults with bipolar disorder.