Advancing the study of quality of life in bipolar disorder: A multimethod approach

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A thesis submitted in partial fulfilment of the requirements for the degree of Doctor of Philosophy (Clinical Psychology)

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Abstract

Bipolar disorder (BD) is a chronic, severe mental illness characterised by the experience of alternating pathological mood states interspersed with periods of relative euthymia. While symptom reduction has been the primary goal of treatment in BD, there is increasing recognition that attention to quality of life (QoL; broadly, outcomes other than symptom including environmental, social, physical and psychological context) is important given BD’s chronicity and breadth of impacts, as well as the construct’s potential for representing consumer goals and benefits of psychosocial therapies. However, the field is challenged by conceptual and measurement tensions, lack of clarity regarding the relationship between mood and QoL, and lack of attention towards the lived experience of QoL and QoL-focused interventions. This project aims to advance the study of QoL in BD through a multimodal investigation of these unaddressed questions. Firstly, a systematic review of the definition, usage and measurement of QoL in the empirical BD literature was conducted to clarify conceptual approaches to QoL in BD: while the definition of QoL was frequently left unspecified, four distinct constructs were identified as relevant to the understanding of QoL in BD. Secondly, a longitudinal quantitative analysis of change in QoL suggests current guideline-driven practice improves mental, but not physical QoL for people with BD. Bidirectional relationships between mood and QoL were highlighted in an investigation of the dynamic relationship between these phenomena. Thirdly, a qualitative investigation of salient aspects of QoL from the perspective of individuals with BD suggests that self-appraisals were made relative to reference points, use of which could be flexible and adaptive. Finally, a qualitative investigation of the experience of a QoL-focused self-management intervention highlights a range of potential benefits of this therapeutic approach that may not be adequately integrated in current clinical practice. Taken together, these four studies serve the function of answering the question of what questions need to be answered about QoL in BD. A provisional, heuristic framework organising QoL concepts is generated from a critical, integrative discussion, and suggests a research agenda to further clarify QoL theory and measurement. Perhaps most importantly, a range of clinical applications are highlighted by the project, with potential to improve the QoL of individuals with BD.
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A heartfelt thanks to the family and friends who have alternately supported me, put up with me, and endured being abandoned by me during this time. Thank you especially to Georgia for always being there with wine, Netflix and a shoulder to cry on.

Finally, to my husband Morgan: I could not have completed this journey without you. Thank you for always believing in me and loving me. I love you.
General Declaration

In accordance with the Swinburne University Higher Degree’s by Research Committee regulations, I hereby declare that this thesis:

i. Contains no material which has been accepted for the award of any other degree or diploma at any university or equivalent institution,

ii. To the best of my knowledge contains no material previously published or written by another person except where due reference is made in the text of this thesis,

iii. Where work is based on joint research or publications, full disclosure of the contributions of the relative authors are made (see p. iv-x). The ideas, development, and writing of all chapters in the thesis were the principal responsibility of me, the candidate, working under the supervision of Professor Greg Murray, Dr Simone Buzwell and Professor Erin Michalak.

This thesis includes four published papers (a summary on the journals in which the papers have been published and citations to date is presented in Appendix A). In order to maintain a consistent style of presentation published articles are included in the relevant chapters of this thesis. I declare that I have obtained, where necessary, permission from the copyright owners to use any third-party copyright material reproduced in the thesis (such as artwork, images, unpublished documents), or to use any of my own published work (such as journal articles) in which the copyright is held by another party (such as publisher, co-author). Documents confirming permission to reproduce such work have been presented in Appendix B of this thesis.

Emma Morton

August 2018
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We hereby declare our contribution to the publication of the ‘paper’ entitled: What does ‘quality of life’ refer to in bipolar disorders research? A systematic review of the construct’s definition, usage and measurement.

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DECLARATION

We hereby declare our contribution to the publication of the ‘paper’ entitled:
The ‘new normal’ – relativity of quality of life judgments in individuals with bipolar disorder: A qualitative study

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DECLARATION

We hereby declare our contribution to the publication of the ‘paper’ entitled: ‘Taking back the reins’ – A qualitative study of the meaning and experience of self-management in bipolar disorder

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Oral Presentations


Poster Presentations


Awards

2016  Recipient of the Schizophrenia Fellowship of NSW Consumer Research Poster Award: Society for Mental Health Research

2015  Society of Mental Health Research Travel Award
CHAPTER 1. PROJECT OVERVIEW: BIPOLAR DISORDER AND THE IMPORTANCE OF QUALITY OF LIFE
1.1 Introduction

The study of quality of life (QoL) in bipolar disorder (BD) has grown exponentially since 1990 (Murray & Michalak, 2012). However, relative to the study of QoL in the broader medical literature and the parallel field of schizophrenia research, the understanding of QoL in BD is nascent and a number of important issues of conceptualisation, measurement, and practical application of QoL have not been addressed. The current project seeks to incrementally advance this field by investigating various aspects of the construct of QoL in BD.

There are a number of ongoing areas of debate regarding QoL, both generally and specific to the experience of mental health conditions. Firstly, the optimal conceptualisation and measurement of QoL is hotly debated, limiting the ability to interpret and generalise the results of empirical investigations in this area. In particular, the boundaries between QoL and symptoms of illness are poorly understood, leading some to challenge the utility of the construct and benefits of investigating this on top of symptoms (e.g., Katschnig, 2006a). In mental health conditions such as BD, the issue of validity of self-reported QoL is of specific concern (Atkinson, Zibin, & Chuang, 1997; Katschnig, 2006b), given questions regarding the impact of symptoms and the unknown cognitive processes, such as adaptation to illness, which may result in self-reports that diverge from clinician perspectives. Finally, while QoL emerged in the mental health literature as part of a paradigm shift championing broader psychosocial outcomes, there is limited understanding of how interventions developed according to these perspectives will be received by individuals with BD themselves.

This chapter first presents an overview of the project, including research aims and a summary of the following chapters. The phenomenology and prevalence of BD spectrum disorders is summarised, followed by a review of shifting treatment priorities in mental health generally, and an argument for the relevance and importance of QoL in BD.

1.2 Overview of the Project

There was one overarching aim of the present project: to advance the understanding of the construct of QoL in BD. This was addressed through a series of four empirical studies investigating different aspects of the QoL construct, followed by an integrative critical discussion drawing out insights across studies. Study 1 aimed to investigate current definitions, usage and measurement of the QoL construct in the BD literature in order to create clarity regarding top-down conceptualisations of QoL and propose pragmatic solutions...
for empirical research in the context of definitional and measurement ambiguities. Study 2 aimed to clarify boundaries between the QoL construct and symptoms of BD by investigating, using multilevel modelling, the time-varying relationship between QoL and depressive/manic symptoms in a large community sample. The aim of Study 3 was to investigate implicit cognitive processes involved in QoL self-report by using qualitative analysis techniques to identify themes characterising how people with BD spoke about their QoL. The fourth and final study had the dual aims of a) investigating the acceptability of a BD-specific model of QoL by investigating service user’s experiences of a self-management intervention developed according to these principles, and b) furthering knowledge of practical applications of QoL in BD by generating suggestions for researchers and clinicians seeking to use QoL-targeted therapies. While each individual study moves the field forward in its own terms, a number of cross-study findings will be leveraged into a general integration.

All of the chapters were researched and written during the course of candidature. Permission to analyse data pertaining to Chapter 6 was granted by Dr Lakshmi Yatham (University of British Columbia; see Appendix C). Research pertaining to chapters 8 and 9 was carried out in accordance with the University of British Columbia and Swinburne University of Technology Human Ethics Review Boards and abided by the Declaration of Helsinki (see Appendix D). Annual and final reports have been submitted (10/6/2016 and 2/6/2017).

It is important to note that the thesis is presented in the style of a series of published papers as per Swinburne University of Technology’s Higher Degree by Research requirements. Chapters 5, 6, 8 and 9 therefore present the articles (in a style consistent with the overall thesis) that summarise the background, aims, methods, results, and discussion (including limitations and future areas of research) for the four studies outlined above. As such, there is a degree of unavoidable repetition across chapters, for example there is repetition of background information in each article, and, given that they drew data from the same overarching mixed-methods study, Study 3 and 4 share the same methods section. However, each chapter presents a unique study or analysis. Each chapter will be introduced with a guide in order to provide contextual information and linkage to the overall project.

This thesis is organised in nine chapters. Reviews of relevant literature are presented in the first three chapters. The remainder of the present chapter (Chapter 1) summarises the paradigm shift in mental health from traditional treatment targets to broader psychosocial
outcomes and the specific relevance of QoL to BD. Chapter 2 introduces the history of QoL as a construct in the broader sociological, medical and mental health literatures. Various philosophical approaches to defining QoL and current debates regarding its optimal measurement are presented to contextualise the relatively immature study of QoL in BD. Chapter 3 briefly reviews the current state of the literature on QoL in BD and measurement instruments used in this area. The review of past literature emphasises topics that are the background for the four empirical studies, namely: a) QoL in BD as compared to the general population, b) QoL in BD as compared to the related mental illnesses of unipolar depression and schizophrenia, c) QoL in BD-I as compared to BD-II, d) the impact of mood symptoms on QoL in BD, e) the relationship between QoL and the related construct of functioning, f) the impact of psychoeducation interventions on QoL in BD, and g) qualitative investigations into QoL in BD. Chapter 4 contrasts the relatively immature study of QoL in BD with the parallel literature in schizophrenia. This chapter highlights the fact that poor understanding of the QoL construct as it applies to schizophrenia has led to a dearth of practical impacts in that field, and leverages the limitations faced by that literature to number of research questions crucial for advancing the study of QoL in BD. The research program of the current project is briefly summarised in the broader context of gaps in conceptual understanding.

Chapter 5 contains the background, aims, design, results and discussion for Study 1, a systematic review of the definition, usage and measurement of QoL in the BD literature. The article is presented as published in the Journal of Affective Disorders (Morton, Michalak, & Murray, 2017).

Chapter 6 presents the background, aims, design, results and discussion for Study 2, a longitudinal naturalistic investigation of the dynamic relationship between QoL and symptoms of BD. The article is presented as published in Psychological Medicine (Morton, Murray, et al., 2017).

Chapter 7 contains the background, aims, methods, results and discussion for Study 3, a qualitative investigation of implicit processes involved in subjective appraisals of QoL in BD. The article is presented as published in Quality of Life Research (Morton, Michalak, Hole, Buzwell, & Murray, 2018).

Chapter 8 presents the background, aims, design, results and discussion for Study 4, a qualitative investigation of the experience of a QoL-focused self-management intervention.
Finally, Chapter 9 presents an integrative discussion of the project as a whole. An extended discussion of QoL concepts identified in Study 1 is presented as an initial step in creating a framework for understanding QoL as it applies to BD. Findings across the four studies are then leveraged to develop insights about each QoL construct, as well as potential interrelations between these, generating implications for theory, measurement and clinical practice. Limitations of the overarching multimethod design are reviewed, followed by a summary of the status and future direction of the study of QoL in BD in light of the present project’s impact.

1.3 Bipolar Disorder: Phenomenology and Prevalence

BD is a chronic, severe mental disorder characterised by the experience of episodes of pathologically depressed, elevated or mixed mood states. According to the DSM-5 (American Psychiatric Association, 2013), bipolar spectrum disorders are diagnosed according to varying severity of manic symptoms; that is, distinct periods of abnormally elevated, irritable, or expansive moods. There are a number of recognised BD subtypes: BD I involves at least one lifetime episode of mania that lasted for at least one week and significantly impacted functioning. A diagnosis of BD II requires a history of at least one episode of both hypomania (at least four days of less severe manic symptoms that may disturb functioning, but are not disabling) and depression (the experience of a depressed mood or loss of interest in usual activities for at least one week). Mixed episodes are common in both BD-I and BD-II, and involve the experience of symptoms of mania and depression within the same episode. Although BD-I and II are thought of as episodic disorders, cyclothymic disorder, in which the individual experiences recurrent, near-continuous episodes of subthreshold hypomania or depression, also falls under the diagnostic umbrella of BD. The lifetime prevalence of bipolar spectrum disorders is estimated to be 2.4% globally (BD-I: 0.6%, BD-II: 0.4%; Merikangas et al., 2011).

BD is associated with significant distress, disability, and mortality, and has been ranked by the World Health Organization as the fifth leading cause of disease burden among mental disorders (Ferrari et al., 2016). Tragically, suicide is a substantial risk in BD: it is estimated that 25-50% of individuals with BD will attempt suicide at least once, and that 8-
19% will die from suicide (Latalova, Kamaradova, & Prasko, 2014). Given these major impacts, QoL has emerged as an outcome of interest in BD (Murray & Michalak, 2012).

1.4 Quality of Life in Bipolar Disorder: A New Outcome of Interest

QoL is increasingly an outcome of interest in the BD literature (Michalak, Yatham, & Lam, 2005), paralleling the paradigm shift from a narrow, biomedical focus to a broader, psychosocial approach in mental health care and research generally (MacQueen, Young, & Joffe, 2001; Sachs & Rush, 2003). Traditional treatment targets in mental illness are clinical outcomes (e.g. mortality rates, symptoms, biomarkers) or service utilisation (e.g., hospitalisation; Thornicroft & Slade, 2014). However, in mental health (as in medical fields more generally), dissatisfaction arose with the restricted scope of traditional clinical outcomes, and attention turned to broader assessments of an individual’s social and personal context such as QoL (Basu, 2004; Frisch, 2012; Higginson & Carr, 2001).

Broadly conceptualised, QoL is a holistic, comprehensive concept referring to the ‘goodness’ of one’s life (Zautra & Goodhart, 1979). The term ‘QoL’ is thus easily understood and imbued with personal meaning, contributing to its intuitive appeal to consumers, carers, governments, researchers and clinicians (Oliver, Huxley, Bridges, & Mohamad, 1996). Although a broad and fuzzy concept, the term typically acts as shorthand for a collection of outcomes not traditionally assessed in healthcare (Orley, Saxena, & Herrman, 1998), such as an individual’s social, occupational, and environmental context (Ware, 1995). Most frequently, QoL is a patient-reported outcome, meaning its inclusion as an outcome in clinical trials for the evaluation of novel medications is recommended or mandated in Australia (Pharmaceutical Benefits Advisory Committee, 1995), America ("Patient Outcomes Research Act of 1989," 1989; US Department of Health and Human Services (USDHHS) 2009), the UK (Fayers et al., 1997), and the European Union (European Medicines Agency (Committee for Medicinal Products for Human Use), 2005). QoL has been highlighted as a means to direct attention to improving consumer valued areas, assess the broad impacts of complex psychosocial interventions, holistically evaluate the impacts of pharmacological treatments, and improve routine clinical care by enhancing therapeutic alliance and empowering consumers (Bigelow, Brodsky, Stewart, & Olson, 1982; Higginson & Carr, 2001).

The evolution of outcomes in BD reflects this general shift in mental health from an exclusive focus on illness factors to an interest in the individual’s broader context and unique
perspectives. It has been noted that historically, research in BD was largely conducted from a biomedical perspective (Michalak et al., 2012), with outcomes of clinical trials typically consisting of clinician rated measures of mania and depression, adverse effects of medication, biomarkers, functioning, time to relapse or medical intervention, and rates of hospitalisation or service use (Martinez-Arán et al., 2008; Nolen, 2002). Clinical focus broadened from this primarily biomedical approach following increased recognition of the diverse impacts of BD on functioning and QoL and the beneficial role of complementary psychosocial therapies on such outcomes (MacQueen et al., 2001; Sachs & Rush, 2003). Proponents of this paradigm shift argued that recovery more broadly should take precedence as the fundamental goal of treatment, rather than be treated as an optional ‘secondary’ outcome (Colom & Vieta, 2004; Michalak, Murray, Young, & Lam, 2007). Accordingly, interest in QoL developed rapidly towards the end of the 20th century, with publications on bipolar disorders referencing this outcome increasing exponentially between 1990 and 2010 (Murray & Michalak, 2012). QoL is viewed as an outcome of particular importance in bipolar disorder given the disorder’s chronic, severe course, the noxious impacts of some interventions, and the breadth of life domains impacted by the illness (Gitlin & Miklowitz, 2017; Murray & Michalak, 2012; Sachs et al., 2003). As an outcome measure, QoL directs attention to existing targets of psychosocial interventions in BD, and may consequently provide a better measure of treatment response (Bigelow et al., 1982; Gigantesco & Giuliani, 2011; Keck, 2004). QoL is particularly valued from a consumer perspective due to its holistic, patient-centered premise, and its congruence with the assumptions of the consumer-driven recovery movement. Attention to QoL has potential benefits for clinical practice: incorporating personally valued QoL in treatment may enhance engagement and adherence. Finally, as well as being a treatment goal of interest, QoL may play a uniquely predictive role in mental health. The present chapter will review these reasons for focusing on QoL in the treatment of BD and current gaps in need of attention.

1.4.1 The Chronic Course of Bipolar Disorder

QoL is increasingly prioritised in the treatment of chronic illnesses generally, where the goal of care is not cure but instead improving life circumstances and patient-valued outcomes (Guyatt, Feeny, & Patrick, 1993). The chronic, relapsing course of BD thus demands attention be directed towards QoL improvement: although pharmacological management of BD leads to faster remission from acute mood episodes, less frequent hospitalisations and a longer time to relapse (Goodwin & Consensus Group of the British
Association for Psychopharmacology, 2009; National Collaborative Centre for Mental Health, 2014; Yatham et al., 2013), complete remission of BD remains rare. Even with prophylactic pharmacotherapy, 37% of individuals with BD experience a mood episode within the first year of treatment, 60% within two years, and 73% in five years (Gitlin, Swendsen, Heller, & Hammen, 1995). High rates of relapse have been confirmed in a number of other longitudinal studies (e.g., Coryell et al., 1998; Gitlin et al., 1995; Keller, Lavori, Coryell, Endicott, & Mueller, 1993), and relapses in BD have been shown to have significant impacts on work and social functioning (J. F. Goldberg, Harrow, & Grossman, 1995).

In addition to high relapse rates, the proportion of time spent ill is significant: individuals with BD spend approximately half of the time experiencing symptoms (Joffe, MacQueen, Marriott, & Trevor Young, 2004; Judd, Akiskal, Schettler, Coryell, Endicott, et al., 2003; Judd, Akiskal, Schettler, & et al., 2002; Judd, Schettler, et al., 2003; Kupka et al., 2007; R. M. Post et al., 2003), demonstrating a significant illness burden even under treatment. Although the defining characteristic of bipolar spectrum disorders is various levels of mania, these same longitudinal studies have shown that time spent unwell in both BD-I and BD-II is predominantly characterised by periods of depression or subsyndromal depressive symptoms. For example, individuals with BD-I have been shown to spend 8.9% of weeks hypomanic/manic as compared to 31.9% of weeks depressed (Judd et al., 2002), and individuals with BD-II spend 1.3% of weeks hypomanic as compared to 50.3% of weeks depressed (Judd, Akiskal, Schettler, Coryell, Endicott, et al., 2003). The experience of chronic symptoms of depression has implications for the burden of BD, with subsyndromal depressive symptoms associated with significant psychosocial impacts (discussed below, 2.2). Cumulatively, this leads to significant burden across the lifespan: BD typically has an early age of onset, with 75% of cases having onset prior to 18 years of age (Perlis et al., 2004), and the risk of mood episode recurrence persists up to the age of 70 or more (J. Angst, Gamma, Sellaro, Lavori, & Zhang, 2003). As such, the majority of suffers’ lives will be impacted by directly impacted by symptoms of BD.

QoL may be considered an outcome of even greater importance in the treatment of individuals with numerous recurrences of mood episodes, for whom pharmacological and psychological interventions may be less effective at controlling symptoms (Berk et al., 2014). For individuals with late stage BD (that is, multiple recurrences, poorer functioning and a greater likelihood of further relapse), existing psychosocial interventions may even be harmful (J. Scott et al., 2006), potentially as a consequence of damaged motivation, self-
esteem, and heightened self-stigma (Berk et al., 2012). A focus on QoL and recovery processes may be particularly relevant at this stage (Berk et al., 2014; Berk et al., 2012; Murray et al., 2017), and indeed QoL-focused therapies for late stage BD are currently under investigation (Murray et al., 2015).

Data on rates of relapse and chronicity of symptoms suggests that currently, BD cannot be cured. At best, it can be managed; however a significant illness burden remains despite best practice treatments (see 1.4.2). Consequently, treatment targets such as QoL drive attention to ways in which the lives of BD sufferers can be improved, even with the experience of symptoms.

1.4.2 The Diverse Impacts of Bipolar Disorder

The burden of BD is significant, with impacts in a range of life domains. Physical health may be impacted both by side effects of BD treatments as well as common medical comorbidities. Psychosocial sequelae include social and occupational functioning, as well as a negatively impacted sense of self and the experience of stigma. These diverse impacts may be best captured with QoL assessment, which looks beyond mood symptoms to an individual’s social, physical, environmental and psychological context.

Physical health problems represent a major burden for people with BD. Medical comorbidities, particularly obesity, cardiovascular, endocrine and metabolic diseases, are common in individuals with the condition (Fagiolini, Kupfer, Houck, Novick, & Frank, 2003; Fiedorowicz, Palagummi, Forman-Hoffman, Miller, & Haynes, 2008; Kilbourne et al., 2004; Krishnan, 2005; McIntyre, Konarski, Misener, & Kennedy, 2005), and BD is associated with increased mortality from medical illnesses as compared to the general population (F. Angst, Stassen, Clayton, & Angst, 2002; Roshanaei-Moghaddam & Katon, 2009). Despite the increased burden of medical comorbidities in BD, critics have noted that these health needs are under-recognised and suboptimally treated (McIntyre, 2009). Treatment of BD itself may be associated with negative impacts on an individual’s physical health: common side effects of pharmacological treatments include gastrointestinal disturbances, weight gain, tremors, sedation, dizziness, skin rash, extrapyramidal symptoms, dry mouth, and impaired renal/thyroid function (Hert et al., 2011; Keck & McElroy, 2003; Strakowski, DelBello, & Adler, 2001). Consequently, clinical benefits of medications may need to be balanced with negative impacts on an individual’s QoL (Sachs & Rush, 2003), and QoL assessments may draw attention to unmet needs in the domain of physical health.
BD is typically associated with significant negative impacts on an individual’s ability to successfully function in work, social roles, study and household management: in the World Health Organization World Mental Health Survey, BD was the second leading cause of days out of role (Alonso et al., 2011). A number of reviews have shown that BD has unfortunate impacts on an individual’s relationships with others (Huxley & Baldessarini, 2007; MacQueen et al., 2001). As compared to the general population, people with BD have fewer social interactions and leisure activities (Coryell et al., 1993; Robb, Cooke, Devins, Young, & Joffe, 1997), lower perceived availability and adequacy of social relationships (Romans & McPherson, 1992), and individuals with BD-I in particular are less likely to be married or live independently (Huxley & Baldessarini, 2007). In terms of occupational functioning, both BD-I and BD-II are associated with high rates of unemployment (Kessler et al., 2006; McMorris, Downs, Panish, & Dirani, 2010; Ruggero, Chelminski, Young, & Zimmerman, 2007) and lower annual income (Coryell et al., 1993). These findings are striking, particularly considering the generally high educational achievement of individuals with BD: in one sample of people with BD over 64% were unemployed despite the fact that 60% had attended college (Kupfer et al., 2002). The finances of individuals with BD are doubly impacted through impaired occupational functioning and the significant economic burden of BD treatment itself: A review of insurance claims found that individuals with BD incurred annual out of pocket expenses averaging more than double the expenses incurred by claimants generally (Peele, Xu, & Kupfer, 2003).

Functional impairment may be an under-recognised issue in BD: although previously inter-episode outcomes in BD were believed to be relatively favourable (based on degree of symptom remission), BD has been shown to have lasting functional impacts not specific to mood episodes (Huxley & Baldessarini, 2007). Deficits in occupational and social functioning have been found to persist even during syndromic remission/euthymic periods (Chengappa et al., 2005; Coryell et al., 1993; Dion, Tohen, Anthony, & Watermaux, 1988; Keck et al., 1998; Özer, Uluşahin, Batur, Kabakçi, & Can Saka, 2002; Pradhan, Sinha, & Singh, 1999; Robb et al., 1997). Coryell et al. (1993) found that even individuals who had been symptom free for two years showed significant functional and QoL impairment. Functional recovery typically lags behind remission of symptoms, with 1-4 year estimates of functional recovery ranging from 24-43% as compared to 48-98% attaining syndromal recovery post-episode (Keck et al., 1998; Tohen et al., 2000; Tohen et al., 2003). Enduring functional limitations may result from chronic subsyndromal depression (Altshuler et al.,
2006; Bonnin et al., 2012), and neurocognitive deficits associated with BD (Depp et al., 2012). Existing pharmacological treatments may be ineffective at improving such outcomes, and research into psychosocial interventions for these broader impacts is limited (Huxley & Baldessarini, 2007).

While some of the psychosocial impacts discussed above may be a consequence of direct effects of the illness on a person’s functioning, others are likely a result of social and structural stigma. A review of external stigma in BD suggests that in regards to stereotypes, emotional and behaviour reactions, BD is viewed more positively than schizophrenia, but less positively than depression (Ellison, Mason, & Scior, 2013). Common stigmatising beliefs include perceiving individuals with BD as dangerous, a desire to socially distance oneself from individuals with BD, and an assumption that recovery in BD is unlikely. People with BD describe feeling socially excluded, restricted in their opportunities and devalued in work and education (Suto, 2012), and indeed perceived social stigma is associated with poorer occupational and social functioning (Hawke, Parikh, & Michalak, 2013). Consequently, it is no surprise that people with BD describe stigma as having a negative impact on their QoL and sense of self (Michalak et al., 2011).

The experience of BD may also be associated with self-stigma and hopelessness. In qualitative interviews, people with BD saw themselves as chaotic and unstable, different from others, rejected and isolated in the community, their lives as marked by loss and deficits, and carried an uncertain or hopeless view of their futures (Lim, Nathan, O’Brien-Malone, & Williams, 2004). Normal development of a sense of self and identity can impaired in BD, with individuals in a qualitative study reporting a sense of confusion, contradiction, and self-doubt undermining any stable sense of self (Inder et al., 2008). These same interviews suggest individuals with BD may base their sense of self on external descriptions of the illness, internalising negative perceptions of the illness (Ellison et al., 2013; Latalova et al., 2013). Individuals with BD may agree with and view themselves through the lens of negative stereotypes about BD and experience consequent low self-esteem, low-efficacy, and impaired QoL.

Given the breadth of life areas impacted by BD, the construct of QoL potentially provides an important framework for holistically assessing patient circumstances. Notably, psychosocial interventions and rehabilitation programs in BD already target broader outcomes such as return to work, improvement of social relationships and participation in
leisure activities, as well as psychological adjustment to and coping with BD (Gitlin & Miklowitz, 2017; Michalak & Murray, 2010c). In fact, some recent psychosocial interventions for BD have nominated QoL as the primary treatment outcome (Poole, Simpson, & Smith, 2012). QoL is integral to the definition of chronic illness self-management (Lorig & Holman, 2003), and psychoeducation (the most common psychosocial intervention in BD; Reinares, Sánchez-Moreno, & Fountoulakis, 2014) teaches individuals with BD strategies for managing illness symptoms as well as impacts on broader life areas (Colom & Lam, 2005). It has been suggested that given that such interventions target more than symptomatology alone, the impact of psychosocial interventions is best evaluated through the lens of QoL improvements (Bigelow et al., 1982; Gigantesco & Giuliani, 2011; Keck, 2004). Routine QoL assessment may therefore add more information regarding patient progress than symptom measures alone (Hope, Page, & Hooke, 2009). Finally, these broad life areas demand attention as the recovery movement highlights they may be of more concern to consumers than the direct weights of symptoms per se.

1.4.3 Quality of Life: Person-Centered, Recovery-Oriented

The increasing prominence of QoL may in part be attributed to its compatibility with two major paradigm shifts in mental health and medicine more generally: the movement towards recovery-oriented practice in the care of severe mental illness, and the rise of person-centered care.

QoL has been identified as an outcome prioritised by the consumer driven recovery movement (Murray et al., 2017). Personal recovery, as contrasted to symptomatic or functional recovery, refers to the process of adaptation to mental illness, such that the individual may live “a satisfying, hopeful and contributing life even with the limitations caused by illness” (Anthony, 1993, p. 17). While recovery is more frequently conceptualised as a process that deemphasises negative impacts of illness, QoL may be thought of as a state-assessment of current circumstances, including the impact of symptoms. Lived-experience perspectives of recovery have highlighted that rehabilitation programs must be comprehensive in focus in order to facilitate people discovering areas of life where one may find fulfilment and meaning (Deegan, 1988; Mead & Copeland, 2000). Indeed, “return to an acceptable quality of life” has been elevated as a central goal in the definition of recovery in BD (Harvey, 2006, p. 14). It has been argued that even when not explicitly stated, recovery defacto places emphasis on QoL due to its nature as a person-centred, consumer-valued
construct that emphasises positive outcomes (Katschnig, 2006b; Stastny & Amering, 2006). As such, an emphasis on improving QoL through pharmacological and psychosocial therapies is coherent with the central tenets of recovery-oriented practice endorsed in mental health policy across the Anglosphere (Commonwealth of Australia, 2013b; Department of Health, 2011b; New Freedom Commission on Mental Health, 2003).

A central assumption of the recovery movement is that individuals with serious mental illnesses such as BD may flourish even with the experience of symptoms. This assertion is backed by studies demonstrating that mental health is not simply the absence of mental illness; rather these concepts are, at least partially, non-redundant (Kendler, Myers, & Keyes, 2011; Keyes, 2005). Some patients with few BD symptoms have been observed to function poorly (as detailed in 1.4.2, above), yet notably others may achieve sustained good outcomes (J. F. Goldberg & Harrow, 2004). The field of positive psychology, which like recovery, emphasises personal growth and meaning in valued goals, has argued that positive psychological processes and characteristics demand equal attention to symptoms in individuals with serious mental illnesses (Rogers, Farkas, & Anthony, 2005). Positive outcomes in BD may represent an important, yet understudied area: a review found five positive psychological characteristics which are associated with BD (Galvez, Thommi, & Ghaemi, 2011) including spirituality, empathy, creativity, realism and resilience. Qualitative studies have shown individuals with BD endorse positive aspects of the experience, including more intense experiences, the development of empathy and self-awareness, and enhanced abilities such as creativity and social gregariousness (Jamison, Gerner, Hammen, & Padesky, 1980; Lobban, Taylor, Murray, & Jones, 2012; Parker, Paterson, Fletcher, Blanch, & Graham, 2012). Many individuals report living well with the disorder (Suto, Murray, Hale, Amari, & Michalak, 2010), and a survey of adults with BD showed that only 54% would push a hypothetical button to take away the illness entirely (Equilibrium: The Bipolar Foundation, 2008). Attention to QoL may address criticisms that psychology as a field has emphasised symptoms and impairment to the exclusion of positive mental health and flourishing (Frisch, 2012). QoL measures which assess how well things are going for an individual may therefore help BD research address the critique of the focus on so-called clinical 'misery statistics' (Murray, 2012), and instead turn attention (at least partly) to a recovery-oriented, positive assessment of strengths, abilities and valued outcomes (Lehman, 1999).
With its holistic focus, QoL is thought to be inherently person-centered as it takes into account the circumstances of consumers’ lives beyond the direct effects of illness, prioritises the person’s perspective (Basu, 2004), and facilitates attention to their unique values and concerns (Bigelow et al., 1982). Increased attention to QoL in BD is consistent with a trend to more humanistic, person-centered care in both mental health and healthcare more generally (Higginson & Carr, 2001; Sartorius, 2006), and has the potential to empower consumers and communicate a sense of respect for their circumstances. Person-centered assessment and practice is particularly important given consumer and clinician opinion may differ in regards to goals for treatment for mental illnesses (Perkins, 2001). Finally, QoL is person-centered as it focuses on what is of most importance to consumers themselves: people with BD seek treatment not to eliminate symptoms not as an end in itself, but in order to improve their lives, and individuals with BD have nominated QoL as an important treatment outcome alongside the amelioration of symptoms (Eiring, Nylenna, & Nytrøen, 2016; Haarig et al., 2016; Mączka, Siwek, Skalski, Grabski, & Dudek, 2010; McIntyre, 2009; Michalak et al., 2012; Sajatovic, Jenkins, Cassidy, & Muzina, 2009). Consequently, attention to personal QoL goals in the context of clinical practice may lead to important impacts on treatment engagement, medication adherence, and therapeutic alliance.

1.4.4 Implications of Quality of Life for Clinical Practice

A number of applications of the QoL construct for clinical practice in BD have been identified, including benefits for treatment planning, enhancing engagement, medication adherence, and therapeutic alliance. Secondly, ongoing QoL assessment may identify unmet needs not accounted for by symptom measures. Finally, it has been suggested that QoL may also play an important prognostic role in estimating the course of BD and risk, and as an independent treatment target QoL improvements may also impact BD symptoms themselves (IsHak, 2011).

As noted above (1.4.3), QoL is a treatment target highly valued by consumers themselves. Attending to QoL in clinical practice with people with BD may therefore have benefits for treatment planning, medication adherence and therapeutic alliance (Hope et al., 2009; Michalak & Murray, 2010a). As noted by Harvey (2006), attention to QoL is particularly important given high rates of treatment non-adherence and disengagement in BD: individuals’ engagement in treatment may depend on the degree to which they experience QoL improvements. QoL may even be valued above symptom reduction in some situations,
potentially leading to treatment non-adherence in the case of negative impacts in valued domains. For example, historically it was reported that 17% of people taking lithium stopped use due to perceived effects on creativity (Marshall, Neumann, & Robinson, 1970; Schou, 1979). Conversely, if QoL is attended to in the context of clinical practice, benefits may ensue for individuals’ engagement in and adherence to treatment. One way QoL assessment may be integrated into current clinical practice is as a treatment planning tool: identifying and prioritising goals valued by consumers is likely to enhance motivation to participate in BD treatment (Berk, Berk, & Castle, 2004) and enhance therapeutic alliances with clinical staff (Skantze & Malm, 1994). Indeed, it has been suggested in psychiatric practice that subjective QoL, rather than diagnosis, is predictive of treatment-seeking behaviour, adherence, and treatment satisfaction (Hunt & McKenna, 1993). QoL and traditional treatment targets may therefore be complementary: attention to QoL is likely to facilitate clinician efforts to address symptoms (Murray, 2015). However, an important caveat to the potential benefits of attention to QoL is that assessment must be followed by action: a study of patients with schizophrenia found that service users who completed a QoL measure but did not receive feedback from clinicians on the outcomes reported lower satisfaction with care than those who received feedback and those who did not complete a QoL measure (Boyer, Lancon, et al., 2013). The authors suggest that QoL assessment, bereft of integration into clinical practice, may result in a mismatch of service user expectations and perceptions of care received.

As previously highlighted (see 1.4.2), BD may have a number of diverse impacts in social, occupational, physical, environmental and psychological domains. Importantly, these impacts have been shown to persist despite symptom remission; consequently, utilising symptom improvement as the sole indicator of treatment effectiveness may neglect areas valued by consumers (see 1.4.3). For example, QoL and symptoms of BD have been shown to improve at different rates in clinical trials: Namjoshi et al. (2002) showed that while symptoms improved during acute phase treatment with olanzapine, QoL domains including social functioning and general health were slower to respond. Routine QoL assessment in clinical practice may therefore provide unique, comprehensive information regarding a consumer’s broader circumstances and direct clinical attention to unmet needs (Michalak, Murray, Young, & Lam, 2008). QoL assessments may also provide information assisting clinicians and consumers to select between various treatment options: for example, two pharmacological interventions may have equivalent impacts on depressive symptom reduction but have differential impacts on QoL (Souetre, Martin, Lozet, & Monteban, 1996).
QoL therefore holds the potential to provide unique information complementary to symptom measures for selecting and assessing treatment that, if ignored, may lead to unmet needs, patient disengagement and non-adherence.

IsHak (2011) noted that as compared to physical illnesses where QoL may not reasonably be expected to play a role in the remission of symptoms, QoL may play a unique role as both outcome and predictor in mental illnesses. Should this hypothetical relationship be demonstrated in empirical studies, QoL may have an important role in clinical practice as a determinant of prognosis. The relevance of specific life domains to the course of BD has been shown in a number of empirical studies. Poor psychosocial functioning (specifically, impaired occupational functioning and poor relationships with family or friends) has been found to be predictive of a shorter time to relapse in BD under maintenance psychotherapy (Gitlin et al., 1995). A later study found that depressive, but not manic, relapses were predicted by poorer social functioning at baseline (in particular, impaired romantic relationships and social activity involvement; Weinstock & Miller, 2008). Longitudinal studies using broader QoL measures (rather than indexing individual aspects of functioning) will be important for confirming the predictive utility of QoL for future clinical outcomes. Impaired QoL may also be a marker of risk of developing mental illnesses: in schizophrenia, QoL impairment has been shown to predate first episode psychosis (Bechdolf et al., 2005; Erickson, Beiser, Iacono, Fleming, & Lin, 1989). Finally, it has been speculated that poor QoL may be involved in the relationship between symptoms of BD and increased rates of suicide (De Abreu et al., 2012). Although this potential relationship has not been explored in BD, a prospective study in the general population showed life dissatisfaction was associated with a higher risk of completed suicide during a 20 year follow-up (Koivumaa-Honkanen et al., 2001). Given the high rates of suicidal ideation, attempts and completed suicide in BD, the role of QoL in assessing risk presents an important avenue of future investigation with clear importance to clinical practice. If such theoretical relationships are upheld in empirical investigations, QoL could be argued as a valuable independent treatment target with downstream benefits for BD symptoms.

1.4.5 Relevance of Quality of Life to Bipolar Disorder: Summary

BD is a chronic, severe mental illness with a number of negative consequences for the lives of sufferers. Given that BD is a lifelong condition, and individuals experience significant rates of relapse and subsyndromal symptoms despite best practice guideline-drive
treatment, attention to QoL may identify ways in which the lives of sufferers could be improved more generally *despite* ongoing symptoms. In addition, BD has a broad range of impacts that may be assessed by QoL measures, including physical health, engagement and functioning in work, leisure, and education, the ability to find and maintain satisfying relationships, and the experience of stigma. Psychosocial treatments in BD similarly target a broad range of outcomes beyond symptoms, and such interventions may therefore be best assessed through the lens of QoL impacts. As a construct that emphasises consumer values and the possibility of positive outcomes, QoL also has relevance from the perspective of the consumer-driven recovery movement which emphasises that individuals with BD may flourish and live rich, meaningful lives. Finally, QoL is argued to have numerous potential benefits for clinical applications, including the enhancement of engagement, as an outcome providing information unique and distinct from symptom changes, and as a potentially significant prognostic indicator. As such, QoL has powerful potential to drive a paradigm shift in BD from a narrow focus on traditional clinical outcomes to broad, holistic and humanistic goals.
CHAPTER 2. HISTORY, DEFINITION AND MEASUREMENT OF QUALITY OF LIFE
2.1 Overview

The previous chapter highlighted that quality of life (QoL) is a construct of great promise in bipolar disorders (BD) research. However, other fields of mental health research have noted that controversies in QoL’s conceptualisation, measurement, and ambiguous boundaries with symptomatology limit its current impact in research and practice (e.g., Awad, 2011; Katschnig, 2006a; see also further discussion in Chapter 4). It is important to note that the current state of affairs in BD research did not develop in a vacuum: QoL assessment has a long history in fields beyond mental health, with according conceptual and measurement tensions that will naturally impact approaches to definition and measurement of the construct in BD.

While philosophers considered the nature of the good life or *eudaimonia* as early as 800 BCE (Michalos & Robinson, 2012), QoL as a term emerged relatively recently in the context of the social indicators movement. As a construct, QoL has only continued to rise in popularity, with a number of QoL-specific journals emerging in the past 20 years (e.g., Quality of Life Research, Health and Quality of Life Outcomes, Applied Research in Quality of Life). This boom in QoL research has included a diversity of applications of the construct: as a measure of the standard of living of communities, to assist cost-benefit analyses in healthcare policy decisions, and as an outcome measure in clinical trials and surveys of the impact of disease, amongst others. The breadth of settings where QoL is used is accordingly reflected in numerous definitions and operationalisations of the construct. While there is no consensus definition of the construct, a number of prominent philosophical perspectives guide thinking on QoL. Perhaps unsurprisingly in the context of definitional ambiguity, a number of tensions regarding the measurement of QoL can be found in the literature. In order to place issues affecting BD research in the appropriate context, the present chapter will review the development of the QoL construct as a technical term in modern scientific literature and its diverse applications, the philosophical traditions underpinning various approaches to definition, and ongoing challenges in the measurement of QoL. Information about the history, definition and measurement of QoL more broadly will provide context for illuminating use of the QoL construct in the BD literature.

2.2 Historical Overview of the Quality of Life Construct

The aim of this historical overview is to describe in brief the spectrum of uses of QoL that have emerged over the years in order to provide context for definitional understandings;
however it is by no means exhaustive (for comprehensive accounts of the history of the QoL concept, see: Land, Michalos, & Sirgy, 2012; Noll, 2004; Sirgy, 2012). For example, the QoL concept is also used in organisational and marketing research, however for the sake of brevity this review will focus on its most prominent uses: as a measure of the level of living of a society (as in the social indicators movement), as a property of the individual (as in the medical and psychological fields), and as a tool for cost-benefit analyses (as in the health economics field).

2.2.1 Quality of Life as a Population-Level Construct

The precise origin of the term QoL as an outcome or goal for a society is uncertain, but is typically attributed to sources outside of the healthcare fields in the latter half of the 20th century. Early references to the term are found in the works of Samuel Ordway (1953) and Henry Osborn (1954), two economists concerned about possible negative impacts of unlimited technological and economic growth on society. Others have credited uptake of the term in research to a 1964 speech by American President Lyndon Johnson (Cummins, 1997a; Noll, 2004), in which it was suggested that as an indicator of society’s achievements, QoL should be emphasised over the quantity of goods. This speech reflects sentiments underpinning the rise of the so-called ‘social indicators movement’ in the 1960s, which sought to identify and research outcomes that reflected the QoL of nations. Prior to this period, gross national product (GNP), an index of a country’s economic activity, was the sole indicator used to describe the standard of living of a society (Veenhoven, 1996). Commentators noted that despite dramatic improvements in the economy in the period following WWII as compared to the Great Depression, other indicators such as family stability and crime rates were in fact deteriorating (Campbell, 1981; Campbell, Converse, & Rodgers, 1976). Evidence that other important areas of life did not necessarily improve with economic prosperity led to the opinion that indicators such as GNP were insufficient to track changes in QoL of societies. The social indicators movement emerged as a consequence of this dissatisfaction, calling for broader assessments of the welfare of populations such as QoL (Land et al., 2012; Noll, 2004). The surge in popularity of social indicators research in the 1960s and 70s was fuelled not only by popularity amongst theorists but also widespread political support and funding (Land et al., 2012). The seminal publication of ‘Towards a Social Report’ (Department of Health Education and Welfare, 1969), an expansion of the traditional American annual economic report which included novel summaries of social issues, (e.g., health and illness, income and poverty, safety, education, science, the arts, and
participation in government), shows the impact of this broader approach to quantifying the success of government actions.

Within the social indicators movement, two prominent perspectives emerged regarding the nature of QoL. Many major government funding reports, including those from NASA (R. A. Bauer, 1966) on the impact of the space program on American society, and the U.S Department of Health, Education and Welfare’s (1969) influential ‘Towards a Social Report’ adopted the so-called ‘Scandinavian tradition’. In this approach, QoL was operationalised as objectively measurable factors such as access to resources, crime and unemployment rates, and life expectancy (Noll, 2004). A contrasting perspective emerged with the work of Campbell and Converse (1972), suggesting that while a focus on objective measures may indicate the extent to which standards benefiting citizens have been achieved by a society, they do not measure the degree to which these factors are valued or appreciated by citizens. The subjective experience of individuals, aggregated at the population level, was therefore drawn upon to speak about life-satisfaction, subjective well-being and happiness of societies (Cummins, Eckersley, Pallant, van Vugt, & Misajon, 2003; Diener, 2006; Veenhoven, 1996). Both objective and subjective factors continue to see use in describing the QoL of populations: the Organization for Economic Cooperation and Development (OECD) Better Life index (Andrews, 1973) annually summarises the status of countries according to objective factors such as housing, income, health and employment as well as life-satisfaction ratings, and the United Nations Human Development Index (United Nations Development Programme, 2015) publishes annual reports characterising countries according to life expectancy, years of education, and per capita income. Although research on QoL at the level of individuals has seen the rise of an alternative, and perhaps more prominent, application of QoL, the ongoing publication of reports at the aggregate level show continuing relevance of QoL as an indicator of societal wellbeing.

2.2.2 Quality of Life as an Individual-Level Construct

Use of QoL as a descriptor of the individual (as contrasted to the aggregate of individual ratings used to describe a society) was first seen as a means to answer questions about trade-offs between survival times and noxious effects of medical interventions (McNeil, Keller, & Adelstein, 1975) – in essence, quality versus quantity of life. QoL was considered a particularly important factor for decision making in cases of incurable conditions, where treatment may provide only temporary or minimal relief from symptoms
(Ebbs, Fallowfield, Fraser, & Baum, 1989). Indeed, in such circumstances, QoL emerged as a goal for care in its own right (Sullivan, 1992).

Paradigm shifts in the guiding philosophies of healthcare in the latter half of the 20th century facilitated the rise of QoL in medical research. With success in treating many acute conditions, an ageing population, and the rise of lifestyle-related illnesses, chronic disease has become the primary concern of developed nations, and as such attention has turned to helping people live well rather than merely survive (Read, 1993). Researchers indicated the role of social, environmental, and economic factors in preventing and treating physical conditions, urging consideration of broader factors in interventions (Land et al., 2012). Health and the goals of medical interventions were reconceptualised to include more than the individual’s physical status, as exemplified in the World Health Organization’s declaration: "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, 1948, p. 1).

QoL assessments also increased in popularity as a consequence of the strengthening voice of the consumer in healthcare decisions and the rise of person-centered medicine: QoL was viewed as a means by which to elevate the often neglected voice of consumers in research and clinical practice, taking some steps to humanise healthcare. For example, Orley et al. (1998, p. 293), state that use of QoL outcome measures “responds to patients’ concerns not to be treated as cases but as human beings, who have lives with many facets not connected directly to their disease”. With the increasing role of patients in decision making regarding healthcare, research began to incorporate outcomes considered more directly relevant to their lives (Read, 1993).

The rising popularity of QoL in the medical field in the early 1970s is reflected in its inclusion as a keyword in the Index Medicus in 1977 (Bech, 1992), where it was described as “a generic concept reflecting concern with the modification and enhancement of life attributes, e.g., physical, political, moral and social environment; the overall condition of a human life” (US National Library of Medicine). QoL is increasingly expected as an outcome in medical research, and many countries recommend or explicitly legislate for the inclusion of patient-reported outcomes such as QoL in clinical trials for the evaluation of drug safety and efficacy, e.g., Australia (Pharmaceutical Benefits Advisory Committee, 1995), America ("Patient Outcomes Research Act of 1989," 1989; US Department of Health and Human Services (USDHHS), 2009), the UK (Fayers et al., 1997), and the European Union (European
Medicines Agency (Committee for Medicinal Products for Human Use), 2005). QoL is used as an individual outcome not only in research, but also in clinical practice. Clinician and patient expectations of treatment targets and judgements regarding the success of interventions may differ; as such, routine QoL assessments have been highlighted as a way to facilitate attention to patient concerns and improve clinician-client communication around treatment outcomes and priorities (Guyatt et al., 1993; Jenkinson, Wright, & Coulter, 1993; Malm, May, & Dencker, 1981), with potential benefits for therapeutic alliance and treatment adherence (Bradley, 2001).

As a property of individuals, QoL also became prominent in the field of mental health, emerging as a goal linked to the deinstitutionalisation process occurring in a number of western countries in the 1970s (Bachrach, 1976). Similar to early uses in the management of incurable conditions in general medicine, QoL was also used in psychiatry as a tool for considering trade-offs between reduced symptoms and the severe side effects associated with first generation antipsychotic use (e.g., Gardos & Cole, 1976)) More recently, increasing uptake of QoL parallels the rapid emergence of the mental health recovery movement (Jacobson, 2004), which emphasises targets beyond reduction of symptoms or risk of relapse(e.g., hope, sense of self, a meaningful and purposeful life despite symptoms; Anthony, 1993). Indeed, improved QoL is a central goal of recovery in mental health, elevating QoL as an outcome in mental health policy (e.g., Department of Health, 2011b; Department of Health and Ageing, 2009; Department of Health Social Services and Public Safety, 2010; Mental Health Commission of Canada, 2012; New Freedom Commission on Mental Health, 2003). QoL has been suggested to have particular relevance in mental health, given the broad impacts of such conditions on social, psychological and environmental domains, and the diverse targets of psychosocial interventions (Bigelow et al., 1982; Gigantesco & Giuliani, 2011).

While QoL has largely been accepted as a treatment target in mental and physical healthcare, there are some who see such broader outcomes as beyond the responsibilities of the healthcare system (Hunt, 1997). It has been argued that factors such as housing, social support and life satisfaction cannot reasonably be expected to improve as a consequence of medical interventions, and as such using QoL to evaluate treatments may give an inaccurate picture of their effectiveness. Furthermore, it has been noted that some patient lobbies see QoL assessment as overmedicalising life (Higginson & Carr, 2001). In particular, the application of QoL to economic decisions (discussed 2.3.3, below) has been seen as a
subversion of the holistic, empowering principles which led to the rise of this construct at the individual level in healthcare.

2.2.3 Quality of Life as a Tool for Economic Evaluations

In the field of health economics, QoL is viewed as a means to evaluate the cost-effectiveness of medical interventions. QoL has been regarded as a tool for economic decision making since the 1960s, where QoL was used to assist in determining how society could best be benefitted through the allocation of limited resources in healthcare (Elkinton, 1966; Long, 1960). A specific variant of QoL, ‘health-related quality of life’, is often used within this domain to describe “the value assigned to duration of life as modified by impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment or policy” (Patrick & Erickson, 1993, p. viii). For this purpose, the Quality Adjusted Life Year (QALY) was developed (Weinstein & Stason, 1977). A QALY is a utility value combining both QoL and longevity: the value of a life year is adjusted based on the QoL experienced by an individual during that period. For example, two years spent in a state of perfect QoL is considered equivalent to two QALYs, whereas two years spent in a state valued as .5 of perfect health is equal to only one QALY. Different types of medical interventions may thus be compared on the basis of costs versus QALY gained (a procedure first seen in Williams, 1985)). These cost-benefit comparisons may be applied in individual clinician-patient discussions regarding treatment options, but may also be applied at the level of policy (i.e., determining which healthcare interventions to fund; Kind, Lafata, Matuszewski, & Raisch, 2009).

As a means of comparing health states, QALYs are different to traditional measures of QoL – they combine life expectancy with value judgements on the disability and distress associated with a particular health state. Value judgements may be made in a number of different ways. For example, using the Rosser Index of Disability (Kind, Rosser, & Williams, 1982; Williams & Kind, 1992) health states are rated at 1 for full health, 0 for death, and values less than 0 for states valued at worse than death. The Kaplan and Bush (1982) approach aggregates preference ratings given by the public to descriptions of particular health states. The standard gamble technique asks individuals to choose between an imperfect health state and a hypothetical gamble with varying chances to die immediately or attain full health (Holloway, 1979; Torrance, 1986). Finally, using trade-off techniques, an individual’s
preferences for a longer period of life lived in imperfect health are compared to their preference for a shorter period of life in full health (Torrance, Thomas, & Sackett, 1972).

A key point of difference between the use of QoL to assist in treatment decisions in the medical field and that of cost-benefit analyses using QALYs is the emphasis on the subjective experiences of the individual. As discussed in 1.4.3, a major reason for the uptake of QoL assessments in healthcare is their ability to represent an individual’s own perspective on their circumstances. In contrast, QALYs combine subjective assessments (ratings of QoL) with objective measures (i.e., life expectancy; Romero, Vivas-Consuelo, & Alvis-Guzman, 2013). Secondly, the subjective assessments of QoL used are typically the opinions of health professionals or healthy populations, rather than individuals suffering from the conditions in question. Use of general population ratings is argued on the basis that “the main stakeholder in health decisions is the community itself”, given the financial burden to society from healthcare costs and lost productivity (Patrick & Erickson, 1993, p. viii). However, some critics have suggested QALYs lack validity as they do not represent the true QoL impacts of particular conditions or interventions, instead being based on the best guesses of clinicians or unaffected members of the public (Carr-Hill, 1989; Carr-Hill & Morris, 1991).

In contrast to the championing of QoL in healthcare as a construct which can empower consumers (by representing valued outcomes other than only symptom reduction), QALYs have been viewed as disempowering as they often reflect the views of the majority or proxy judgements rather than representing the interests of patient groups (Bowling, 2001). Consequently, real-world decisions about allocation of resources or treatment recommendations based on QALYs are considered by some to be ethically problematic (Lawton, 1991). There are arguments that QALYs based on objective measures of disability are dehumanising, and reduce the problem of human suffering to a calculation that prioritises financial savings (Holmes, 1993). In fact, it has been noted that the use of QoL scores to make decisions in healthcare has a tendency to evoke analogies with Nazi-like judgements on the value of human lives (Cohen, 1983). Despite such concerns, the use of QoL as a tool for cost-utility decision making in healthcare is well entrenched in the research landscape, and is likely to continue to grow in prominence (Kind et al., 2009).

2.3.4 Historical Overview of Quality of Life: Summary

Although QoL emerged as a concept speaking to standards of living of societies, it was rapidly incorporated into physical and mental healthcare as a means of assessing the
broader context of an individual as well as the relative cost to utility ratio of healthcare interventions. As such, QoL has come to mean a variety of things depending on the context in which it is used, and this has led to significant controversies when conceptualisations of QoL appear to be based on opposing philosophies (e.g., the subjective/objective approaches to QoL as a social indicator, and ethical opposition to QoL as a tool for economic evaluations). Definitional and measurement ambiguities, therefore, represent an ongoing challenge in the QoL literature across many fields of enquiry and practice.

2.3 Definition of Quality of Life

As evident in the preceding brief review, QoL has been applied in a variety of ways at population, individual and economic levels. Potentially as a consequence of the broad range of fields which have incorporated QoL, numerous definitions of the term are recognised (Farquhar, 1995). Concepts linked to QoL range from objective environmental and economic factors (see 2.3), psychological experiences such as happiness, satisfaction (Campbell, 1976), and wellbeing (Diener, Lucas, & Oishi, 2009), psychological resources including self-efficacy, self-esteem (Andrews & Withey, 1976a), and coping (Lazarus & Folkman, 1984), social comparisons (Calman, 1984), personality factors (e.g., dispositional optimism; Rius-Ottenheim, van der Mast, Zitman, & Giltay, 2012), health (including symptoms of disease or side effects of medication; Fries & Singh, 1996; Ware, 1987), functioning (Patrick & Erickson, 1993), the value or utility of health states (Torrance, 1987), the degree to which universal human needs are met (including personal growth and accomplishment; Maslow, 1943), opportunities for a good life (whether environmental or related to the capabilities of the individual; Sen, 1985; Veenhoven, 2000), amongst numerous others (J. Brown, Bowling, & Flynn, 2004).

A comprehensive review of definitions of QoL across literatures is beyond the present scope (for a taxonomy of definitions, see: J. Brown et al., 2004; Farquhar, 1995). Grappling with the multiplicity of definitions of QoL in existence may be to an extent be simplified by grouping them according to a number of prominent philosophical positions thought to inform various definitions of QoL. The following section will review major philosophical positions on the nature of ‘the good life’ in order to inform understanding of QoL definition and measurement in BD.
2.4 Philosophical Approaches to the Conceptualisation of Quality of Life

Parfit (1984) suggests that definitions of QoL may be categorised according to three broad approaches:

a) Hedonism – The experience of particular positive mental states, whether these are affective (e.g., happiness, pleasure) or cognitive (e.g., satisfaction, enjoyment) and the absence of painful or unpleasant mental states lead to good QoL.

b) Desire-Satisfaction – The objective satisfaction of an individual’s desires and preferences, with few unsatisfied wants, leads to higher QoL.

c) Objective List Theories – Individual preferences or responses to events are not important, but instead the realisation of particular normative ideals is what drives QoL.

Brock (1993) describes the same three categories, calling desire-satisfaction ‘preference-satisfaction’ and objective list theories ‘ideal theories’. Sondoe (1999), in describing views on the good life, also classifies definitions as based on hedonism or desire-satisfaction, but introduce a third concept of perfectionism. Perfectionism approaches to QoL focus on a subset of objective list theories; specifically, the realisation of human potentials is viewed as characterising the goodness of a life. These categorisation schemes show important similarities, reflecting a common-sense view of the most prominent classes of theories of QoL.

The philosophical approaches identified (hedonism, desire-satisfaction, and objective list theories) differ in their understanding of why various states of affairs are considered to be good for QoL: hedonism proposes that things contribute to a good life because they are experienced as enjoyable rather than unpleasant, desire-satisfaction suggests things are good because individuals tend to want them, and objective lists state that these things are good in their own right, or are good because they represent the fulfilment of human potential. It is important to note that while hedonism and desire-satisfaction theories are explanatory – that is, they explain why various states of affairs contribute to QoL, objective list theories and perfectionism theories are enumerative: they list circumstances which are presumed to contribute to QoL, without providing an explanation of why (Rice, 2013).

The influence of these particular approaches continues to be seen in current QoL definition and measurement. To inform later debates regarding the definition and
measurement of QoL, these philosophical approaches and their limitations are briefly reviewed next.

2.4.1 Hedonism

The philosophical approach of hedonism suggests that good QoL is characterised by the experience of positive mental states, whether affective (e.g., happiness, wellbeing, pleasure) or cognitive (e.g., satisfaction, enjoyment, appraisal or comparison). Affective experiences are prominent in theories of QoL, for example Bentham (1834) conceptualised wellbeing as the difference between the sum of pleasurable affective states and the sum of pain and negative affective states experienced by an individual. Positive and negative affect are commonly considered in models of QoL or wellbeing (Bradburn, 1969; Chamberlain, 1988). Happiness, a positive affective state, is elevated as a central component of QoL by some theorists (Veenhoven, 1996, 2000). Positive cognitive mental states include satisfaction (involving implicit preferences or comparisons; Sirgy, 1988) and enjoyment (a favourable attitude to an event; Feldman, 2010; Sumner, 1999). While clearly related in that a sense of satisfaction is likely to evoke positive affect (Sirgy, 2002), these concepts are differentiated on the basis of the involvement of cognitive judgements (Campbell, 1981) and the duration of the experience, with happiness more transitory and changeable than satisfaction (George, 1981). Evidence that these are separable concepts is provided in Campbell (1976), who showed that young individuals tend to score highly in happiness but low in life satisfaction, whereas older individuals tended to score relatively low in happiness but higher in life satisfaction. Many theories of QoL incorporate both affective and cognitive mental states (Andrews, 1974; Diener, 1994).

The utility of mental states in determining QoL has been challenged by theorists who argue that there is stability in people’s QoL ratings over time, suggesting an influence of stable biological or personality traits. Biologically determined ‘set-points’ or ‘adaptation levels’ for QoL have been proposed (Cummins, 2010; Headey & Wearing, 1989; Lykken & Tellegen, 1996). These theorists have suggested that although life events may temporarily move QoL away from baseline levels, homeostatic processes seek to return an individual to their set point. Hedonic states may be heritable, with an estimated 35% of variance accounted for by genetic factors (Bartels, 2015). Stability of hedonic states may also be accounted for by personality: Particular personality traits may not only predispose individuals to higher levels of subjective wellbeing (Diener & Lucas, 1999; Lucas & Fujita, 2000), but also

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particular cognitive styles that affect the likelihood of experiencing positive mental states such as accessibility of positive memories, salience of positive information (Diener et al., 2009).

A philosophical criticism of hedonism argues that basing QoL on the experience of positive affective or cognitive states reduces the highest value of human life to transitory pleasures (as did the philosopher Carlyle, who described hedonism as ‘pig philosophy’; Crisp, 1997). Mill (1863) responded to such criticisms by attempting to rank pleasures as ‘higher’ (those he deemed more morally appreciable such as friendship, self-actualisation or aesthetic appreciation) and ‘lower’ (‘base’ or ‘carnal’ sensory pleasures), suggesting that some hedonistic experiences are more valuable or noteworthy than others. Nozick (1974) similarly suggested that there is more to good QoL than positive mental experiences by proposing a thought experiment in which a person has to choose between a Matrix-like machine that stimulates the brain into believing it is in an ideal world full of positive experiences and actual lived experiences, even if they are less pleasurable.

2.4.2 Preference Satisfaction

According to preference satisfaction theories, good QoL is achieved when an individual’s wants and desires are satisfied. A prominent example of preference-satisfaction theories of QoL are ‘gap’ theories, which conceptualise QoL as influenced by the discrepancy between expectations (whether based on aspirations for the future, past circumstances, or social comparisons) and reality (Carr & Higginson, 2001; Krupinski, 1980; Michalos, 1986). Many preference satisfaction theories conceptualise QoL as a state of affairs rather than a psychological state: a person’s mental state need not be affected by the satisfaction or lack thereof of their preferences. For example, Kagan (1994) proposes that the QoL of a man who desires a loving family is negatively impacted by an unfaithful spouse, regardless of whether or not he is aware of this infidelity. Philosophers have challenged the notion that QoL may be achieved by the objective satisfaction of a person’s preferences without any accordant impact on mental state. Indeed, Hornquist (1982) argues that only the individual with a need may experience the satisfaction of that need. Calman’s (1984) version of gap theory goes towards addressing this criticism by allowing for an individual’s perception of reality to account for the degree of preference satisfaction. Consequently, there is some overlap between hedonism theories that emphasise the mental state of satisfaction and preference satisfaction theories.
It has been argued that preference satisfaction theories fail to adequately describe QoL in cases where a person’s preferences would be widely thought to not contribute positively to their QoL. Utilitarian or informed preference satisfaction theories suggest that an individual has hypothetical ideal preferences – that is, what a person would prefer if they had all relevant information, made no mistakes in reasoning and were not impacted by distorting influences (Goodin, 1986; Griffin, 1986; Scanlon, 1982). This theory thus implies that individuals may have mistaken preferences – actual preferences that are considered ill-informed or poorly reasoned. For example, although consuming illicit substances satisfies the preferences of an individual with substance misuse problems, their preferences may be considered ill-informed if they are not aware of potential harms, poorly reasoned (valuing immediate pleasure above harms), and impacted by the distorting physiological influence of substance cravings. Such approaches to QoL suggest a normative or expert idea of what is good for human lives that would be preferred by well-informed and rational individuals, and consequently some theorists have suggested they fit more coherently with objective list theories (discussed below) rather than preference satisfaction approaches (Parfit, 1984).

2.4.3 Objective List Theories

Objective list theories suggest that there are a number of universal human needs, and that satisfaction of these determines QoL (Finnis, 1980; Fletcher, 2012; Murphy, 2001). Needs may include both physical factors such as health, nutrition, or shelter, or psychological needs such as relatedness, autonomy and knowledge. Under objective list theories, these factors are proposed to be ‘objectively’ or ‘normatively’ good for an individual’s QoL, regardless of whether the individual desires these factors or experiences them subjectively as good. Most objective, population-level approaches to QoL appear to subscribe to this view, in that a number of economic and environmental factors such as housing, health, nutrition, crime levels, education opportunities, and employment rates are judged to indicate QoL (Andrews, 1973; United Nations Development Programme, 2015; Veenhoven, 2002). Psychological needs feature more predominantly in individual-level approaches to QoL, and include self-actualisation, relatedness with others, autonomy, knowledge and moral virtue (Griffin, 1986; Maslow, 1943; Parfit, 1984; Ryff, 1989).

‘Perfectionism’ theories, which focuses on items indexing the fulfilment of human potentials are considered a specific variant of objective list theories of QoL (Brink, 2008). Such a view dates to Aristotle’s conception of the good life or eudaimonia (Ethics), as the
fulfilment of human nature as a rational and deliberative animal through the use of both moral and intellectual virtues. For Hurka (1993), perfectionism represents a moral obligation explicitly differentiated from wellbeing – it is a life that individuals ought to pursue regardless of their individual desires. Taken to extremes, an ascetic existence of philosophical contemplation is the most virtuous form of human life (Kraut, 1989). Modern perfectionism theories may be found in the positive psychology movement, and emphasise individual strengths, virtues, engagement, growth, fulfilment, and meaning (Seligman, 2011).

Objective list theories have been challenged as failing to respect the autonomy of the individual in determining what is important to their own QoL (Sumner, 1992), or their subjective enjoyment of such things (Dorsey, 2010). Items are viewed as “good or bad for people, whether or not these people would want to have the good things, or to avoid the bad things” (Parfit, 1984, p. 499). Such criticisms have been addressed by the point that most people value the same things: similar goods are valued across cultures (Nussbaum, 1993). Additionally, flexibility may be introduced into objective list theories by allowing weighting of the importance of items according to personal preferences or characteristics (Nussbaum, 2000), or observations that specific items in objective list theories may be achieved in vastly different ways (Brey, 2012). For example, modern approaches to perfectionism emphasise that the process of finding fulfilment and meaning in life is unique to the individual (Seligman, 2011).

2.4.4 Philosophical Approaches to the Conceptualisation of Quality of Life - Summary

Despite many years of debate, no particular philosophical approach to QoL has been conclusively endorsed above others. The above philosophical approaches are not always easily separated – for example, if being satisfied and happy are thought to be normative ideals for a human life, where do objective list theories end and hedonic theories begin? If preference satisfaction theories are impacted by a person’s subjective experience and evaluation of reality, does this not necessarily incorporate cognitive and affective hedonic theories? A number of theories and definitions draw upon more than one philosophical foundation to conceptualise QoL. For example, Parfit (1984) suggests that QoL is only achieved if a person enjoys an item that they desire, and if that item would be objectively thought to improve QoL (that is, if it is a normative human need). Such hybrid views propose there are multiple necessary conditions for good QoL drawing across the philosophical approaches outlined above (Kagan, 2009; Kraut, 1994). Seligman and Royzman (2003)
similarly suggest that there is more than one component to QoL: ‘authentic happiness’ incorporates the pleasant life (hedonism), the good life (preference satisfaction) and the meaningful life (so-called ‘higher order’ items from objective list theories). It should be noted that there is substantial common ground between the various philosophical approaches when it comes to considering what things make a life go well or poorly: physical health, relationships, pleasure and the absence of pain, and achievement are items generally considered to improve QoL across theories, although the theories may differ in their reasoning as to why these items are beneficial. In many cases a person’s QoL would be judged the same according to these approaches; however, one can imagine scenarios in which theories would differ on their appraisal of an individual’s QoL. For example, a person with a disability which greatly restricts physical functioning may be viewed by objective list theorists as having poor QoL, while hedonism theories may judge this individual as having good QoL if their daily experiences are characterised by positive feelings due to a satisfying family life. Despite these differences, it is important to recall that these philosophical traditions share a common goal: to find out what makes life go well for individuals and to improve their QoL.

2.5 Measurement of Quality of Life

The lack of a gold standard definition of QoL has necessarily impacted the concept’s measurement: a wide variety of measurement instruments are in use, and tensions exist between a number of positions on how QoL is best measured. Yet without an agreed upon definition of QoL, no measurement instrument may be said to be more valid than the other (Bowling, 2001). Choice of measurement instrument thus reflects implicit assumptions regarding the nature of QoL on behalf of investigators (Patrick & Erickson, 1993; Patrick & Guttmacher, 1983). As such, readers must keep in mind the role of QoL conceptualisations in data analysis and interpretation: the empirical understanding of QoL will depend on the types of measures used to assess it (Higginson & Carr, 2001)

To further the understanding of how the construct of QoL is operationalised and measured, major tensions regarding the measurement of QoL will be reviewed next. These include the questions of whether QoL is best measured with subjective or objective instruments, positive or negative indicators, and whether single global questions or multi-item scales are preferred. The conceptual relationship between QoL and other variables impacts whether questionnaire items may be thought to be causal or indicator variables.
Additionally, the purpose of QoL measurement and the emphasis placed on individuals’ subjective ratings of QoL affects whether generic, disorder-specific, individualised, or qualitative approaches to QoL measurement are endorsed. In order to ensure the relevance of the review to understanding of measurement of QoL in BD, the specific focus here will be on QoL measurement within the medical literature.

2.5.1 Subjective Versus Objective Measurement

A major tension in the literature concerns whether QoL is best measured by an individual’s subjective assessment of their own life circumstances, or by assessment of objectively measurable life circumstances. Arguments for subjective measurement of QoL versus objective QoL are clearly influenced by philosophical approaches to QoL definition as described above: hedonism and certain need-satisfaction approaches suggest that QoL involves the experience of particular mental states, and therefore must be assessed subjectively. In contrast, objective list and some needs-satisfaction theories are more concerned with satisfaction of basic human needs or desires from an objective standpoint. Objectively quantifiable indicators may be drawn from medical records (e.g. marital or employment status), the judgement of an expert (e.g. physician-rated symptoms of health problems), or the individual is asked to provide a description of objectively quantifiable aspects of their life (e.g. frequency of contact with friends).

It has been argued that while objective life circumstances likely impact QoL, the measurement of these does not capture the lived experience of QoL. Campbell (1976, p. 118) states objective measures “describe the conditions of life that might be assumed to impact life experience but do not assess that experience directly”. Evidence supportive of a need for subjective measures of QoL is often drawn from the so-called ‘disability paradox’ (a term proposed by Albrecht & Devlieger, 1999) which describes the tendency for individuals with a variety of significant health problems or disabilities to describe their own quality of life as good. For example, Evans (1991) found that a variety of patients with significant health problems (including transplant patients, haemodialysis patients, and peritoneal dialysis patients) were more likely to rate themselves as ‘very happy’ than the general population. Such findings have been used to argue that objective measures alone will fail to capture important aspects of QoL. Subjective QoL measures are also believed to circumvent ethical concerns about the paternalism inherent in making judgements about the quality of an individual’s life on their behalf (Birnbacher, 1999; Veenhoven, 2002). Subjective measures
of QoL are suggested to respect the autonomy of the individual and empower them to express what is going well or poorly in their own lives (Sumner, 1999; Warner, 1999). Lenz and Demal (2006) cite the example of a young man who moves out of home with the goal of becoming more independent – while his living conditions may be considered objectively worse off than when he lived with his parents, from a subjective viewpoint he may consider his QoL improved. Consequently, it has become accepted by a dominant proportion of the health literature that QoL assessments must include the patient perspective (Bognar, 2005).

The poor correlation between subjective and objective assessments of QoL described in the disability paradox, used by some to argue for QoL self-report, has also been cited in support of objective measures. It has been argued that this lack of correlation is due to the limited validity of self-report, which may be impacted by mood, recall bias, insight, etc. (Atkinson et al., 1997; Brooks, Jordan, Divine, Smith, & Neelon, 1990). It has been assumed that certain objective circumstances such as good health, adequate finances and a comfortable living situation are associated with good QoL, and that in situations where an individual living in an objectively ‘good’ environment perceives it poorly, this reflects an inaccurate assessment on behalf of the individual. Michalos and Robinson (2012) caution that privileging subjective experiences of QoL allows for circumstances where the objective reality and the individual’s experience are diametrically at odds: they posit that individuals in objectively good life circumstances who judge them as bad or feel badly about them experience a ‘fool’s hell’, while individuals in objectively bad circumstances who think of them as good or feel good about them experience a ‘fool’s paradise’. Relatedly, Noll (1996) terms the state where individuals dissatisfied with objectively good circumstances as ‘dissonance’, and the state where individuals are satisfied with objectively bad circumstances ‘adaptation’. This leads to ethical concerns about reliance on subjective assessments of individuals in objectively poor circumstances who have adapted to adverse conditions: it has been argued that basing service delivery on self-reported QoL in such cases may lead to neglect of material needs (Felce & Perry, 1995; Hatton, 1998; M. Rapley, 2001).

It has been argued that subjective and objective measures of QoL represent different kinds of data (Warner, 1999), and that assessment of both aspects is needed to capture the most comprehensive picture of QoL. Lehman (1988) argued that the poor correlation between objective and subjective factors does not provide evidence for or against either measurement option, but suggests that both ought to be assessed. Factor analytic approaches have shown that objective and subjective items form distinct dimensions, with objective factors largely
stable over time and subjective assessments more prone to fluctuation (Ruggeri, Bisoffi, Fontecedro, & Warner, 2001). Veenhoven (2000) suggests objective factors mark the ‘liveability’ of a society, that is, the aspects of the environment that provide opportunities for living a good life yet are not necessarily representative of an individual’s lived experience. A number of QoL measurement instruments in use consequently incorporate both objective and subjective aspects, e.g. the Comprehensive Quality of Life Scale (Cummins, 1997a) and the Quality of Life Interview (Lehman, 1988).

### 2.5.2 Multidimensional Versus Unidimensional Measures

Cummins (1996, p. 303) outlined that “there are two basic approaches to the definition and measurement of subjective quality of life…one regards the construct as a single, unitary entity, while the other considers it to be composed of discrete domains”. The tension he described can also be conceptualised as between multi-item and single-item questionnaires, as few multi-item questionnaires measure QoL globally without also including subscales to represent underlying dimensions.

Proponents of multidimensional QoL assessments suggest that QoL is likely to be a concept with a number of embedded subconstructs, and that multi-item scales are best able to tap into these latent variables. There appears to be broad agreement about the importance of multidimensional operationalisation of QoL, with most measures utilising a number of subscales to represent theorised domains of QoL (Bowling, 1997; Bowling & Windsor, 2001), and recognition that multidimensional measures serve the clinical purpose of highlighting specific areas of life in which an individual is struggling (Andelman et al., 1998). However, there remains controversy over precisely which domains ought to be included under the concept of QoL: In an analysis of 32 studies, Cummins (1997b) identified 173 proposed domains of quality of life, demonstrating there is still a great deal of debate regarding precisely which dimensions should be included in such measures.

In contrast to dimensional views, it has been suggested that the experience of life satisfaction, or an enduring evaluation of life as a whole, is qualitatively different from summed satisfaction across a number of specific life domains (Veenhoven, 2015). For example, Gill (1995) noted that the variety in values and preferences across humans cannot adequately be captured in standardised multidimensional rating scales. That is to say, a scale which assigns the same weighting to satisfaction with family life and work may not accurately represent the QoL experienced by a stay at home parent, who, though unemployed,
finds greater value in caring for family. Other proponents of a unidimensional concept of QoL argue that multidimensional measures confound the QoL with its predictors in various life domains (Beckie & Hayduk, 1997). Unidimensional QoL may be assessed with a single item: global measures of QoL ask some variation of the question “How is your quality of life?” For example, the Perceived Quality of Life Scale (Andrews & Withey, 1976b) asks, “How happy are you these days?” Global questions may be used when researchers subscribe to a unitary view of QoL; alternatively, they may be utilised by researchers who, like Gill (1995), believe that QoL may be multidimensional but too complex and idiosyncratic to be captured by multidimensional scales. Rather, global questions allow patients to judge their QoL in a manner that reflects their own personal preferences while ignoring aspects they do not consider to have an impact. Unidimensional measures have pragmatic advantages: they may be easier and quicker to administer, and less burdensome on respondents (Bowling, 2005b). Additionally, unidimensional measures reduce the complexity of clinical decision making by providing a single overall score, whereas multidimensional profiles may show complex and disparate effects of an intervention across an array of domains, presenting challenges for the clinician who wishes to decide between treatments (Stedman, 1996).

While global measures of QoL confer advantages in allowing individuals to rate their QoL without being constrained by irrelevant domains or weighting in multidimensional measures, their psychometric properties have been challenged. Single-item questionnaires generally are more susceptible than multi-item instruments to the influence of noise, making them less reliable and more prone to measurement error (Spector, 1992). However, this criticism as it applies to global QoL questionnaires has been challenged. A review of published empirical studies showed that single-item measures of QoL can have high reliability (Youngblut & Casper, 1993), and Cummins (1996) found in a meta-analysis that scores on a single item QoL measure did not differ significantly from the overall score derived from a multidimensional version of the scale. Despite the suggestion that global questions may in fact be reliable, their single item structure also presents problems for validity assessments and precision. The validity of global questions cannot be assessed by measures of internal validity such as Cronbach’s alpha. The precision of global questions is limited by the scale of the question, and thus may be less able to detect small but important changes (Guyatt & Jaeschke, 1990). Conversely, multi-item scales have a greater range of possible scores, and are consequently better able to discriminate between individuals or detect change (Fayers & Machin, 2007). Due to these psychometric issues, global questions
may be best used in addition to multi-item questionnaires, as they can tap into areas important to individuals which are not assessed by the scales. An example of a multi-scale questionnaire with a global QoL question is the SF-36 (Ware & Sherbourne, 1992). Gill and Feinstein (1994) have advocated that in order to accurately assess QoL, all instruments should contain a global question.

2.5.3 Positive Versus Negative Indicators of Quality of Life

A number of existing QoL scales have been criticised for focusing on what is going poorly in an individual’s life rather than taking into account what is going well (Bowling, 2008; Keyes, L., & Park, 2012). This focus on negative indicators (e.g., ill health, disability) rather than positive indicators (e.g., ability, happiness, areas of flourishing) may mean that scales underestimate the QoL of individuals. In particular, it has been suggested that scales comprised entirely of negative indicators fail to take into account that doing well in some domains of QoL may compensate for dissatisfaction within others (Bech, Olsen, Kjoller, & Rasmussen, 2003; Frisch, 1998). Measures which focus solely on negative indicators of QoL are also likely to suffer from ceiling effects, such that we are not well informed about what factors contribute to improving the QoL of individuals beyond the upper ranges of ‘normal’ QoL (Patrick & Erickson, 1993). For example, the EuroQoL-5D (Balestroni & Berolotti, 2012) has been criticised for failing to show individuals improving above a certain level of problems (Haywood, Garratt, Lall, Smith, & Lamb, 2008; Naglie et al., 2006; Walters, Morrell, & Dixon, 1999). Specific to mental health contexts, it has been shown that mental health is more than the absence of psychopathology (Kendler et al., 2011; Keyes, 2005). Similarly, it is likely that good QoL involves more than the absence of negative indicators. Hence, it has been advocated that measures include both positive and negative indicators to measure the entire range of QoL.

2.5.4 Causal Versus Indicator Variables

Researchers have suggested that in order to properly structure and interpret QoL questionnaires, it is important to distinguish between causal and indicator variables (Bowling, 2008; Fayers & Machin, 2007). Causal variables are factors believed to impact QoL, and include things like symptoms of disease (Fayers & Hand, 1997). Critically, low scores on a particular causal variable do not necessarily equate to poor QoL, which is likely to have multiple determinants. For example, increased gastrointestinal symptoms may be mitigated by an improvement in financial status. Indicator variables, by contrast, are highly correlated
with a latent construct. For example, Boehmer and Luszczynska (2006) consider emotional functioning to be an aspect of QoL, and consequently view a change in this indicator variable as *ipso facto* a change in QoL. Levels of QoL do not necessarily indicate the presence of certain causal variables, whereas the presence of indicator variables reflects levels of QoL.

Discriminating between causal and indicator variables is not, however, always straightforward. For example, Fayers and Machin (2007) outlined a scenario where pain may initially act as a causal variable negatively impacting QoL, yet become partly indicative of poor QoL as the individual’s level of distress causes them to perceive their pain as worse. In the field of mental health, it is likely that variables indexing subjective distress or depression will present similar challenges for the interpretation of results on QoL measures.

### 2.5.5 Generic Versus Disorder-Specific Measures

The majority of QoL measures are generic – it is assumed that the domains indexed by these measures are relevant to the majority of the population. It has been argued, however, that individuals with particular disorders are likely to perceive different factors as relevant to their QoL as compared to the general population. From this viewpoint, generic QoL measures may not accurately reflect the interests and priorities of specific populations. Qualitative interviews and community surveys have supported this perspective, demonstrating that individuals with particular illnesses or disabilities prioritise or nominate different domains as important to their QoL as compared to healthy individuals (Bowling, 1995; Connell, O'Cathain, & Brazier, 2014). Generic measures may be hampered by ‘floor effects’, where particular patient groups scoring at the lower bound of the scale may nonetheless experience QoL decreases beyond what the questionnaire can show (Bindman, Keane, & Lurie, 1990). In contrast to generic measures, disorder-specific questionnaires include domains thought to be relevant to particular patient groups (particularly if developed in consultation with patient stakeholders) and may therefore be more sensitive to specific effects of treatment (Bowling, 2007; Patrick & Erickson, 1993). Disorder-specific measures have indeed been shown to be more responsive to change (Guyatt, King, Feeny, Stubbing, & Goldstein, 1999; Wiebe, Guyatt, Weaver, Matijevic, & Sidwell, 2003).

The need for disorder-specific measures has been challenged on a number of grounds. Firstly, it has been that proposed that generic measures assess areas of life that may be considered fundamental (Joyce, O'Boyle, & McGee, 1999), therefore precluding any need for specific instruments. The utility of disorder-specific measures for identifying important
change in QoL has been questioned: Stedman (1996) argues that generic measures, being less specific, are likely to reflect more meaningful changes in terms of the individual’s broader life context. Within disability and mental health advocacy, disorder-specific questionnaires have been criticised for assuming that individuals with a particular condition will experience poorer QoL than healthy individuals (Cummins, 1997b; Hunt, 1997; Rosen, 1986). Relatedly, Stedman (1996) also notes that disorder-specific QoL measures appear to index specific limitations of a particular illness rather than QoL as a holistic construct. For example, the schizophrenia-specific Quality of Life scale (Heinrichs, Hanlon, & Carpenter, 1984) is criticised as having a restricted focus on negative symptoms only. However, these concerns have been identified as a reason for disorder-specific QoL measures to be developed in consultation with specific patient groups, rather than avoiding the measurement of domains which may specifically affect their quality of life (Mark Rapley, 2003).

Given that disorder-specific measures cannot, by definition, compare QoL across different patient groups, and generic measures may not be sensitive to aspects of QoL relevant to particular populations, investigators need to carefully consider the purpose of measurement when selecting instruments. Generic measures are well suited to comparing patient groups, investigating aetiological factors, or determining the effectiveness of particular interventions at restoring QoL to a level deemed normal (D. P. Goldberg & Huxley, 1992). Conversely, disorder-specific measures appear to be more sensitive to change within a population, and therefore may be particularly useful for comparing interventions or investigating the impacts of treatments on aspects of life thought to be particularly impacted by a condition.

### 2.5.6 Individualised Versus Nomothetic Measures

Inherent in the subjective approach to QoL assessment is the idea that QoL depends on what is valued by an individual. Population surveys have reflected this fact, showing that individuals’ ratings in areas of life they nominated as most important explained the most variance in QoL (Bowling & Windsor, 2001). Commentators have noted that measures which give equal or standardised weightings to preselected life domains assume that these models are universally applicable, yet it is unlikely that individuals will agree on the domains relevant to their quality of life and their comparative importance (Bishop, 2005; Bowling, 2008; M. Brown & Gordon, 1999; Carr & Higginson, 2008; Ferrans & Powers, 1985; O’Boyle, McGee, & Joyce, 1994; Sirgy, 2012). It has been suggested that even the
development of disorder-specific measures does not go far enough to describe the QoL of individual patients, as they will reflect the values of a group rather than individuals (Hickey et al., 1996). Consequently, some have proposed that ‘individualised’ measures of QoL should be developed, in order to allow individuals to nominate their own valued domains of QoL and indicate how they would weight these components (Carr & Higginson, 2008; Fitzpatrick, 1999). Examples of such questionnaires include the ‘Schedule for the Evaluation of Individual Quality of Life’ (O'Boyle, McGee, Hickey, O'Malley, & Joyce, 1992) and the ‘Patient Generated Index’ (Ruta, Garratt, Leng, Russell, & MacDonald, 1994).

In contrast to both generic and disorder-specific questionnaires, which as nomothetic approaches are particularly suited to comparing groups (e.g., a group with a disorder compared to the general population, or a group receiving an intervention compared to a group receiving placebo), individualised measures are idiographic and sensitive to the reality of the individual. They may be particularly relevant in clinical contexts: for example, planning treatments to address individually valued domains, and auditing treatment progress (D. H. Barlow & Hersen, 1984; Bech, 1990). In contrast to nomothetic measures, changes in patient valued dimensions will not be masked by aggregation with dimensions they have indicated as unimportant (Feinstein, Josephy, & Wells, 1986). A questionnaire ideally suited for comparing groups is unlikely to be useful for identifying small changes in an individual, and vice versa (Kirshner & Guyatt, 1985; Patrick & Deyo, 1989). Finally, the idiographic nature of individualised measures may have benefits in a clinical context: such instruments may be perceived as empowering in that they allow individuals to measure their QoL according to their own unique values, rather than the values of others as reflected in a standardised questionnaire.

Individualised measures, of course, present unique challenges for reliability and complexity of administration/interpretation. The aggregation of data from individualised questionnaires at the group level has been suggested to be like adding up apples and oranges, given individual variation in domains, weighting and standards (Jenkinson & McGee, 1998). It has also been suggested that such measures may be more time consuming to administer and interpret (Bowling, 2008; Carr & Higginson, 2008), and may be difficult for patients to understand and complete (Macduff & Russell, 1998). Despite notable challenges regarding some psychometric properties such as reliability and internal consistency, it has been suggested that individualised measures will outperform generic and disorder-specific in terms of validity due to their ability to more accurately represent the values and perspectives of an
individual (Lacasse, Wong, & Guyatt, 2013). Consequently, while individualised measures of QoL represent an expanding area of investigation, their utility versus standardised measures of QoL has not been fully explored (Fitzpatrick, 1999).

2.5.7 Qualitative Versus Quantitative Approaches to Measurement

It has been argued that the conceptualisation and evaluation of QoL is so specific to the individual that for accurate assessment, the individual must be asked to describe in their own words how well their life is going (Rosenberg, 1995). Even individualised questionnaires that allow an individual to weight or select from a list of predefined domains typically reflect expert opinion and not necessarily that of the respondent (Fernández-Ballesteros, 2003). The open-ended questions of a qualitative QoL interview are likely to elicit detailed information about an individual’s experience, without the constraints of response options on a questionnaire. This rich data comes at a cost, however, as qualitative QoL interviews are likely to be time consuming to conduct and interpret. Additionally, interpretation of such interviews may be subject to researcher bias (Shenton, 2004).

2.5.8 Measurement of Quality of Life: Summary

Controversies regarding the definition of QoL in the medical literature have had significant impacts on the concept’s operationalisation and measurement in research and clinical environments. Debates persist regarding whether QoL is best measured subjectively or objectively, through generic, disorder-specific, or idiographic measures, or with multidimensional or unidimensional scales. The perceived role of positive and negative indicators differs according to how QoL is conceptualised by investigators, and the relationship of QoL to other variables, whether they are causal or indicator, is poorly understood. The resolution of these measurement tensions is constrained by the fact that there is no gold standard of QoL, and as such validity of various measures is difficult to assess.

2.6 History, Definition and Measurement of Quality of Life: Summary

As is evident in the above brief review, a range of approaches to defining and measuring QoL are used in research and theory, with no consensus evident. Part of the challenge of operationalising QoL is that, beyond its use as a construct in a number of diverse fields of research and practice, it is also a term with inherent personal meaning. The phrase ‘quality of life’ is easily understood by laypersons, and individuals have unique and often divergent ideas about what comprises their own QoL. QoL may thus be considered a
multireferential lay construct akin to ‘depression’ or ‘anxiety’ (Boyle, 2002; McKeivitt, Redfern, La-Placa, & Wolfe, 2003): while theorists attempt to tightly restrict and operationalise the construct for use as a scientific term, it also has a common, imprecise understanding in everyday language that complicates this undertaking. Indeed, the opinions of laypersons as to what constitutes QoL may differ from the operationalisations used in research. This challenge was recognised as far back as Aristotle, who noted that “When it comes to saying in what happiness consists, opinions differ, and the account given by the generality of mankind is not all like that of the wise” (Ethics, Book I, p. iv). While the personal significance and breadth of concepts relevant of QoL lends to its appeal and consequent uptake in research and clinical practice, this is also its weakness: the concept of QoL is so broad and individual that it risks becoming vague.

Ongoing ambiguities in the definition of QoL have led some to claim that it cannot, or should not, be measured. Wolfensberger (1994, p. 285), in his call to “hang up quality of life as a hopeless term”, suggests that the lay usage of QoL infuses the term with such “surplus meaning” that shared understanding and clarity of usage will be impossible to obtain. Leplege and Hunt (1997) suggested QoL be left to philosophical consideration rather than practical applications in research given the breadth and idiosyncratic nature of the term. Similarly, Mount and Scott (1983) eloquently compared QoL to the beauty of a rose: no matter how many measurements are made of smell, colour, and arrangement of petals, the full beauty cannot be captured. Campbell (1976, p. 471) summarised the current state of attempts to specify QoL for research and practice as “something that many people talk about, but which nobody very clearly knows what to do about”.

The complexity inherent in defining and operationalising QoL has contributed to some authors in the health literature to avoid explicit definition of the construct, discussion of theory, or links to measurement. In a review of 75 studies claiming to investigate QoL, Gill and Feinstein (1994) reported that only 15% of these conceptually defined QoL. Cummins, Gullone, and Lau (2002) observed a tendency for researchers to rely on lay understanding of the term QoL rather than defining it – however, they challenge, this masks vast differences of opinion in what the QoL construct actually means, such that it is only through careful reading of the article and measures used that a reader can infer what is in fact the referent of the term ‘QoL’. Attempting to side-step theoretical discussion has flow-on effects on measurement: Gill and Feinstein (1994) reported that only 35% of reviewed articles justified their choice of measurement instrument. Similarly, Hunt (1997) noted that definitional ambiguity
surrounding QoL is used as justification for a ‘laizze-faire’ approach to measurement, such that researchers tend to use whatever instrument is available or common.

Naturally, such issues of conceptual clarity also impact the use of QoL in the present project’s field of mental health. As noted by Awad (2011, p. 491) when describing the state of the literature in schizophrenia, QoL is a term which has “unfulfilled promise” due to failure of the field to provide definitional clarity and according appropriate measurement techniques. The same limitations may be expected to impact the nascent QoL in BD literature (the specific focus here). Indeed, issues of definition and measurement have not been systematically addressed in the BD literature, and a plurality of measurement instruments are in use, making the synthesis of existing research challenging (Michalak et al., 2007).

However, as outlined in Chapter 1, QoL represents a construct of disruptive promise in BD. In the absence of an alternative means to support the ongoing paradigm shift in mental health from an exclusive focus on symptoms to including broader, recovery-oriented, consumer valued outcomes, a premise of this project was that QoL should not be abandoned in the face of definitional and methodological challenges (Gladis, Gosch, Dishuk, & Crits-Christoph, 1999; Murri, Fantoni, Antinori, & Ortona, 1998; Testa & Simonson, 1996).
3.1 Overview

Bracketing off for a moment the important conceptual issues canvassed in the first two chapters, the present chapter presents an overview of the current state of the quality of life (QoL) in bipolar disorders (BD) literature. The study of QoL in BD remains an emerging field, with limited investigation commencing in the late 1990s and increasing exponentially over the past 20 years (Murray & Michalak, 2012). To date, five systematic reviews of empirical investigations of QoL in BD have been published (Dean, Gerner, & Gerner, 2004; Ishak et al., 2012; Michalak, Yatham, & Lam, 2005; Namjoshi & Buesching, 2001; Revicki, Matza, Flood, & Lloyd, 2005). The first of these, conducted by Namjoshi and Buesching (2001), included studies published prior to 1999 and identified just 10 studies for inclusion. The second review (Dean et al., 2004) identified 65 articles published prior to November 2002 using broad, inclusive criteria – studies which used single-domain scales or measures widely accepted as functioning indices were allowed in the review. Using more restrictive inclusion criteria (such as the requirement for QoL scales to be multidimensional), Michalak et al. (2005) identified 28 studies published prior to November 2004 for inclusion. Another 2005 review, conducted by Revicki and colleagues (2005), focused specifically on clinical trials published between 1997 and 2002 using HrQoL measures as an outcome: only three trials were identified. Most recently, 30 studies of HrQoL in BD published prior to 2011 were reviewed by IsHak and colleagues (2012); the number of trials investigating QoL as an outcome of treatment interventions increased from Revicki et al.’s review, with eight trials investigating various pharmacological treatments, and three investigating the impacts of psychosocial treatments. Strong growth in the empirical investigation of QoL in BD is evident from these reviews, and given the paradigm shift in the approach to BD from exclusively biomedical to broader recovery, functional and consumer valued outcomes (see Chapter 1), further expansion of this field is expected.

The present chapter will review the empirical literature of QoL in BD. Firstly; the most common or significant measurement instruments used to study QoL in BD will be discussed (3.2). This will be followed by a review of the empirical literature (3.3). A comprehensive review of this rapidly developing literature is beyond the present scope. Instead, the focus here is on a series of questions relevant to overall understanding of QoL in BD, or questions more specific to the present project: QoL in BD as compared to other populations (3.3.1 and 3.3.2), QoL across the BD subtypes (3.3.3), the impact of pathological mood symptoms on QoL in BD (3.3.4), the relationship between QoL measures in BD and
the related concept of functioning (3.3.5), the impact of psychoeducation on QoL in BD (3.3.6), and qualitative investigations of QoL in BD (3.3.7).

3.2 Key Quality of Life Measures

To assist in interpreting the results of the reviewed studies, the most common or significant measures used to study QoL in BD are briefly discussed. A summary of these measures is presented in Table 3.1. Other infrequently used QoL measures are listed in Appendix F.

3.2.1 36-Item Short Form Survey (SF-36) and Derivatives

The SF-36 (Ware & Sherbourne, 1992) is a 36 item self-report measure with eight subscales: 1) Physical Functioning, 2) Role Limitations due to Physical Health (abbreviation: Role Limitations [Physical]) and 3) Role Limitations due to Emotional Health (abbreviation: Role Limitations [Emotional]), 4) Bodily Pain, 5) General Health, 6) Vitality, 7) Social Functioning, and 8) Mental Health. Two summary component scales may be calculated according to formulae in the SF-36 manual (Ware, Kosinski, & Keller, 1994): the Physical Component Score (PCS) summarises mostly Physical Functioning, Role Limitations (Physical), Bodily Pain, and General Health. The Mental Component Score (MCS) mainly summarises Role Limitations (Emotional), Mental Health, Social Functioning and Vitality. Scores are given on a range of 0 (worst possible health) to 100 (best possible health). Summary scores are standardised according to population norms such to have a mean of 50 and standard deviation of 10.

While the SF-36 was originally developed to measure health status, this measure has come to be the most commonly used generic QoL instrument in the medical and mental health literatures (Garratt, Schmidt, Mackintosh, & Fitzpatrick, 2002; Katschnig, 2006a). Items in the SF-36 were selected on the basis of how frequently these appeared in measures of health status and how severely they were impacted by disease and treatment, e.g., “During the past four weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?” Several abbreviated versions of the SF-36 exist, including the SF-20 (Wells et al., 1989), which has 20 items and 6 subscales (Physical, Role and Social Functioning, Pain, Mental Health, and Overall Health Perception) and the SF-12 (Ware, Kosinski, & Keller, 1996), which has 12 items used to calculate summary scores (MCS and PCS). Two studies have investigated the psychometric properties of the SF-36 in patients with BD (Leidy, Palmer, Murray, Robb, & Revicki, 1998; Thunedborg, Black, &
Bech, 1995) and suggest the majority of its subscales scales demonstrate adequate reliability, validity, and responsivity to symptom change.

3.2.2 EuroQol Five Dimensions (EQ-5D) and Visual Analogue Scale (EQ-VAS)

The EQ-5D and EQ-VAS are two components of a commonly used generic self-report measure of health status (Balestroni & Berolotti, 2012). The EQ-5D contains five items (Anxiety/Depression, Mobility, Pain/Discomfort, Self-Care and Usual Activities) for which individuals indicate their degree of impairment from no to severe problems over three levels. For example, response options for the Mobility item are, “I have no problems with walking about”, “I have some problems in walking about”, and “I am confined to bed”. The EQ-VAS is a single item question asking individuals to mark their current health state on a 20cm vertical scale, anchored at 0 (worst imaginable health state) to 100 (best imaginable health state). The EQ-5D was developed for use in economic evaluations estimating QALYs (QoL assessments weighted by time; see 2.3.3). A single summary measure is based on preference weights derived from the general population using the time-trade-off technique (see 2.3.3 for a summary; also Torrance et al., 1972) for each of the 243 EQ-5D health states (unique combinations of levels of problems for each dimension). EQ-5D scores are thus treated as continuous, where 0= “death”, 1= “perfect health”, and negative scores represent health states valued as worse than death. The EQ-VAS is not used in calculation of health states or preference weightings. Although the brevity of the EQ-5D presents advantages for routine clinical use and research, individuals responding to the EQ-5D have indicated they feel it misses significant aspects of health, particularly subjective states: e.g., emotional and spiritual wellbeing, happiness, mental health and cognition (Devlin, Hansen, & Selai, 2004). The EQ-5D may also suffer from ceiling effects, in that it is unable to capture improvement beyond a certain point (Brazier, Roberts, Tsuchiya, & Busschbach, 2004). The psychometric performance of the EQ-5D in BD has been reported to be mixed (Brazier et al., 2014).

3.2.3 World Health Organization Quality of Life Scale (WHOQOL-100) and Brief Version (WHOQOL-BREF)

The WHOQOL-100 (World Health Organization, 1998) and WHOQOL-BREF (The WHOQOL Group, 1998) are two generic, self-report instruments. Importantly, the WHO explicitly describes these measures as assessing QoL, in direct contrast to measures they view as indexing health status or disability/functional status (i.e., the SF-36; World Health Organization Division of Mental Health, 1996). A second distinctive feature of these
### Table 3.1

**Key features of the most commonly used/significant quality of life measures in the bipolar disorders literature.**

<table>
<thead>
<tr>
<th>Measure Name</th>
<th>Subscales/Summary Scores</th>
<th>Generic / Disorder-Specific</th>
<th>Associated/Short-form measures</th>
</tr>
</thead>
<tbody>
<tr>
<td>36-Item Short Form Health Survey (SF-36; Ware &amp; Sherbourne, 1992)</td>
<td>Eight subscales: 1) Physical Functioning, 2) Role Limitations [Physical], 3) Role Limitations [Emotional], 4) Bodily Pain, 5) General Health, 6) Vitality, 7) Social Functioning, and 8) Mental Health. Two summary component scales may be calculated (Ware et al., 1994): the Physical Component Score (PCS) summarises mostly Physical Functioning, Role Limitations (Physical), Bodily Pain, and General Health. The Mental Component Score (MCS) mainly summarises Role Limitations (Emotional), Mental Health, Social Functioning and Vitality.</td>
<td>Generic</td>
<td>SF-20 (Wells et al., 1989); SF-12 (Ware et al., 1996)</td>
</tr>
<tr>
<td>Instrument</td>
<td>Subscales</td>
<td>Type</td>
<td>Reference</td>
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<td>Questionnaire (Q-LES-Q; Endicott, Nee, Harrison, &amp; Blumenthal, 1993)</td>
<td>Two additional items, medication and overall life satisfaction, are not included in the calculation of the overall summed score.</td>
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<td>EuroQoL Five Dimensions (EQ-5D; Balestroni &amp; Berolotti, 2012)</td>
<td>Five items (Anxiety/Depression, Mobility, Pain/Discomfort, Self-Care and Usual Activities) are used to calculate health state; a single summary score is based on preference weights derived from the general population for each unique health state. One optional global item: Visual Analogue Scale (VAS). Individuals are asked to mark their current health state on a 20cm vertical scale, anchored at 0 (worst imaginable health state) to 100 (best imaginable health state).</td>
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measures is that they were designed to include positive as well as negative indicators. For example, the WHOQOL-BREF contains items about negative psychological impacts (i.e., “How often do you have negative feelings such as blue mood, despair, anxiety, depression?”) as well as positive psychological constructs such as meaning and fulfilment (e.g., “To what extent do you feel your life to be meaningful?”). These instruments were developed through a process of focus group meetings across 15 culturally diverse field centres, where items relevant to QoL were generated. Final items for inclusion were selected after clustering semantically related items and field testing. The full WHOQOL-100 has 100 items covering 24 facets of QoL; the more commonly used WHOQOL-BREF has 26 Likert-type items rated from 1 to 5 (with higher scores representing better QoL). Results of structural equation modelling resulted in the development of a four domain structure for both WHOQOL measures, summarising Physical, Psychological, Social, and Environmental QoL. Each of these domains includes items that relate to individual perceptions/feelings (e.g., “How satisfied are you with the conditions of your living space?”). A range of data has been found to support the reliability and validity of the WHOQOL-BREF in populations with psychiatric illnesses (Oliveira, Carvalho, & Esteves, 2016; Trompenaars, Masthoff, Van Heck, Hodiamont, & De Vries, 2005), however this measure’s psychometric properties have not been explored within BD specifically.

3.2.4 Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q)

The Q-LES-Q (Endicott et al., 1993) is a 93 item self-report measure designed to measure enjoyment and satisfaction, and is frequently used in psychiatry research (Stevanovic, 2011). Eight domains are assessed: Physical Health, Subjective Feelings of Wellbeing, Leisure Activities, Work, Household Duties, School/Course, Social Relationships, and General Activities. Ratings are on a 5 point Likert scale, with higher scores representing better QoL. The General Activities subscale is also used as a short form of the Q-LES-Q (Q-LES-Q-SF), with 14 items assessing satisfaction across various life domains (e.g., “Taking everything into consideration, during the past week how satisfied have you been with your family relationships?”). Two additional items, medication and overall life satisfaction, are not included in the calculation of the overall summed score. The Q-LES-Q was developed to provide a measure of life satisfaction and enjoyment in psychiatry, however it is commonly regarded as a generic instrument, and no disorder-specific content was included (Endicott et al., 1993). The Q-LES-Q and short form have shown good psychometric performance in mental health research. For example, in a sample of people with unipolar depression, the Q-
LES-Q was shown to have good reliability and validity, discriminating between those who met criteria for current depression and healthy controls (Endicott et al., 1993). In mixed psychiatric samples, the Q-LES-Q-SF has been shown to be reliable and responsive to change, with no floor or ceiling effects (Stevanovic, 2011). In BD specifically, the Q-LES-Q-SF has been shown to be responsive to clinical change, distinguishing between responders and non-responders in a clinical trial of quetiapine (Endicott, Rajagopalan, Minkwitz, & Macfadden, 2007).

3.2.5 Quality of Life in Bipolar Disorder Scale (QoL.BD)

The QoL.BD (Michalak & Murray, 2010b) was developed relatively recently, it has seen infrequent use in the BD literature. However, as it is currently the only BD-specific measure of QoL, its features are reviewed here. The instrument has 12 core and two optional scales: Physical, Sleep, Mood, Cognitive, Leisure, Social, Spirituality, Finances, Household, Self-Esteem, Independence, Identity, Work and Study. While some domains are similar to those which appear on generic measures (i.e., Physical, Social, Leisure, Mood, Household, Finances, Work and Study), others appear to be more specific to BD (Spirituality, Sleep, Self-Esteem, Independence, and Identity) or severe mental illnesses (Cognition). The 48 core items of the QoL.BD (eight optional additional items relate to work and study) are scored on a 5-point Likert scale, with higher scores indicating better QoL. The development of this measure involved four studies over two phases. Items were generated from qualitative interviews with individuals with BD, carers, and experts in treatment or research, supplemented by a literature review of aspects of life impacted in BD. Item reduction was accomplished with field testing with individuals with BD and experts. Items on the QoL.BD thus include descriptive assessments of factors related to staying well with BD or illness impacts (e.g., “Over the past 7 days, I have kept a routine in my sleep-wake schedule” and “Over the past 7 days, I have had good concentration”) and evaluative assessments of life domains valued by people with BD (e.g., “Over the past 7 days, I have expressed my creativity”). The QoL.BD has been shown to have good reliability, and external validity was demonstrated through correlations with symptom and QoL measures (SF-36, Q-LES-Q) in expected directions (Michalak & Murray, 2010b). Supporting the argument that disorder specific measures are likely to be more responsive to change than generic assessments, change in the Brief QoL.BD (a 12 item short form measure) was found to have the strongest correlation with change in depression scores in the validation sample, and when entered in a hierarchical linear regression with change in other QoL measures, change in the QoL.BD
emerged as the sole significant predictor of change in depression (Michalak & Murray, 2010b).

3.3 Empirical Investigations of Quality of Life in Bipolar Disorder

The following section will review empirical literature on QoL in BD addressing a series of topics. The first two sections provide an important overview of where QoL in BD is situated, by comparing QoL in BD to healthy controls (3.3.1) as well as QoL in BD as compared to other psychiatric illnesses (3.3.2). The relatively understudied area of QoL comparisons across BD subtypes (Michalak et al., 2008) is reviewed next (3.3.3). Understanding the impact of BD on QoL is facilitated by reviewing the relationship between QoL and mood symptoms (3.3.4) as well as functional impacts of BD on QoL (3.3.5). Given that QoL is increasingly used as an outcome measure in BD, yet the impact of psychosocial interventions is less well understood (Michalak et al., 2008), this chapter reviews the impact of psychoeducation (as the most common psychosocial intervention in BD) on QoL (3.3.6). Finally, as highlighted in Chapter 2 (2.5.7), qualitative investigations may provide important insights into the subjective experience of QoL not constrained by the response options or questions in quantitative measures. As such, the present review of empirical literature will also summarise findings from qualitative research on the impact of BD on QoL (3.3.7). Tables summarising reviewed studies are presented in Appendix E.

3.3.1 Quality of Life in Bipolar Disorder as Compared to Healthy Controls

Studies have generally confirmed the common-sense understanding that QoL in symptomatic BD is poorer than that of the general population (see Table 1, Appendix E for a summary of reviewed studies). In a study of people with BD with current moderate levels of depression, for example, QoL was found to be poorer in BD as compared to healthy controls on all SF-36 scales except Physical Health (Arnold, Witzeman, Swank, McElroy, & Keck Jr, 2000). Participants with symptomatic BD have been shown to have worse QoL on all SF-36 subscales and the MCS as compared to healthy controls, however no group differences were seen on PCS (Gutiérrez-Rojas et al., 2008). Similarly, it has been found that combined samples of depressed, (hypo)manic, and euthymic patients had poorer QoL compared to controls on the majority of WHOQOL-BREF (Goossens, Hartong, Knoppert-Van Der Klein, & Van Achterberg, 2008) and SF-36 subscales (Depp, Davis, Mittal, Patterson, & Jeste, 2006). Van Rheenen and Rossell (2014) found that an Australian sample of mildly symptomatic participants with BD had worse QoL on all subscales of the QoL.BD (except
spirituality) as compared to healthy controls. Similar results were found in inpatients with BD as compared to healthy controls on the Brief QoL.BD (Momeni, Shiyasi, & Mirzaasgari, 2017), although these two studies were limited by use of the disorder specific QoL.BD for between-group comparisons, as it is not known whether all domains included in this scale are relevant to the QoL of healthy populations. Individuals in a depressed phase have been shown to report worse QoL on the majority of WHOQOL-BREF domains as compared to healthy controls (Gazalle, Frey, et al., 2007; Hofer et al., 2017). However the presence of mood symptoms may not account for all QoL deficits in symptomatic BD. In a sample of mildly depressed patients, QoL in BD was found to be poorer compared to controls in the Physical and Psychological domains of the WHOQOL-BREF, even after controlling for age, education and current symptoms (Cotrena, Branco, Shansis, & Fonseca, 2016). The QoL of individuals with mania as compared to healthy controls has been explored far less frequently: Gazalle et al. (2007) found that participants with mania reported equivalent QoL to controls on the WHOQOL-BREF for all domains except Social. The question of whether and how mania impacts QoL in BD as compared to depression is explored in more detail in 3.3.4 below.

Numerous studies have found that, even when individuals with BD are in a euthymic phase of illness, QoL is impaired in comparison to the general population. Euthymic patients demonstrated significantly worse scores on all SF-36 subscales than the general population (Sierra, Livianos, & Rojo, 2005); comparable results were shown by Maina et al. (2007). Studies have also demonstrated ongoing QoL impairment in euthymia compared to healthy controls using the WHOQOL-BREF (Brissos, Dias, Carita, & Martinez-Arán, 2008; Brissos, Dias, & Kapczinski, 2008; Dias, Brissos, Frey, & Kapczinski, 2008; Pattanayak, Sagar, & Mehta, 2012; Studart et al., 2016; Yen et al., 2008), Brief QoL.BD (Lee et al., 2017; Xiao et al., 2016), and all subscales of the Quality of Life Index (Eissa, Elghoniemy, Hamed, Omar, & Morsy, 2012). However, some contrasting findings have been reported. Gutierrez-Rojas et al. (2008) found euthymic participants with BD did not significantly differ from healthy controls on the SF-36 summary measures MCS or PCS, nor did they differ on the Role Limitations (Physical), Pain, Vitality, or Mental Health subscales. Using the WHOQOL-BREF, it has been found that participants with BD differed from controls only on the Physical domain (Akvardar et al., 2006), and a mostly remitted sample of individuals with BD reported poorer QoL than controls on the Social domain only (Sum, Ho, & Sim, 2015).

Notably, some studies have reported counterintuitively inflated scores in euthymic bipolar populations as compared to the general public: participants with BD have been found
to report better QoL than controls on the Q-LES-Q Leisure Activities subscale, although the groups did not differ on any other Q-LES-Q or WHOQOL-BREF subscale (Chand, Mattoo, & Sharan, 2004). Similarly, a sample with BD was observed to display numerically higher (although not statistically significant) scores on a number of Q-LES-Q subscales as compared to controls (Latalova, Prasko, Diveky, Kamaradova, & Velartova, 2011).

The extent of the QoL impairment in BD as compared to healthy controls has been shown to be comparable to that of chronic physical illnesses (see Table 2, Appendix E for a summary of reviewed studies). Using the SF-36, Arnold et al. (2000) showed that the impairment experienced by patients with BD on the Mental Health and Role Limitations (Emotional) scales was equivalent to that of a group of patients with chronic back pain, although the BD group had relatively higher scores on the Physical Functioning, Role Limitations (Physical), Pain, and Social Function scales. Numerically similar or worse QoL ratings on the SF-20 in euthymic BD has been observed as compared to eight chronic medical conditions (including hypertension, heart disease and gastrointestinal disorders), but these comparisons were not significance tested (Cooke, Robb, Young, & Joffe, 1996). Finally, after controlling for negative life events, individuals with euthymic BD reported poorer QoL as measured on the Illness Intrusiveness Rating Scale as compared to patients with multiple sclerosis, end stage renal disease and rheumatoid arthritis on the Family Relations, Social Relations, and Self Expression/Self-Improvement domains (Robb et al., 1997). QoL did not differ across the groups for the remaining domains.

Potentially, generic QoL instruments do not capture all domains impacted during euthymic BD. For example, when asked to self-report functioning on the SF-36, a sample of individuals with BD was shown to differ from the general population on the Role Limitations (Physical) subscale only (Hakkaart-Van Roijen et al., 2004). However, when asked to give a subjective global impression of their overall health, the group with BD reported themselves to be significantly worse off. Furthermore, some authors have proposed that inconsistent results may be due to varying definitions of euthymia and consequently differing levels of residual depressive symptoms. For example, Xiang et al. (2014) found their bipolar sample did not differ from healthy controls on any WHOQOL-BREF subscales, but noted that they were experiencing very mild levels of depression. However, this proposal is not upheld by research showing that poorer QoL in euthymic participants with BD-I on all WHOQOL-BREF domains (except Environmental) persisted when mood was introduced as a covariate (Brissos, Dias, Carita, et al., 2008), suggesting the ongoing QoL impairment experienced by
patients with euthymic BD cannot be solely accounted for by residual mood symptoms. As highlighted in the preceding chapter, a number of inter-episode impacts such as functional impairment, stigma, and cognitive deficits, may impact QoL in euthymic BD. Future studies controlling for these variables may better account for between-study differences.

In sum, while existing studies have some well-recognised methodological limitations (e.g., limited controls for demographic differences) a deficit in QoL in BD compared to healthy controls has been reliably demonstrated. Strikingly, deficits are seen outside episodes, and their magnitude is comparable to that seen in chronic physical illnesses.

3.3.2 Quality of Life in Bipolar Disorder as Compared to Other Mental Disorders

BD shares symptoms and phenomenology with two other significant mental health conditions, and comparing QoL to these populations may better contextualise the extent to which QoL is impacted in BD. Firstly, the syndromes of BD shares overlap with major depressive disorder (MDD; Akiskal, 1996). Indeed, as previously stated (Chapter 1), individuals with BD spend the majority of time when symptomatic in a depressed state (Judd, Akiskal, Schettler, Coryell, Endicott, et al., 2003; Judd et al., 2002). However, there are important differences: the experience of mania and chronicity of BD may result in differential impacts to QoL. Secondly, BD has similarities with psychotic disorders such as schizophrenia: psychotic symptoms are common, for example in severe mania, and both are considered lifelong mental illnesses (Maier, Zobel, & Wagner, 2006; Moller, 2003). As such, schizophrenia forms another important comparator for QoL levels in BD.

Studies have generally shown that QoL in BD is comparable or poorer to that in MDD (see Table 3, Appendix E for a summary of reviewed studies). Studies using the SF-36 and derivatives have shown no significant differences between the groups (Engel-Yeger et al., 2016), or poorer QoL in BD on a number of subscales (Ten Have, Vollebergh, Bijl, & Nolen, 2002; Yatham et al., 2004), while comparable QoL has been shown between BD and MDD on the WHOQOL-BREF (Caldirola et al., 2014; Vibha, Saddichha, Khan, & Akhtar, 2013). However, these studies are limited by failing to control for current depressive symptom severity. One study found poorer EQ-5D and WHOQOL-BREF scores in an MDD sample, however after adjusting for current depression levels, the differences became non-significant (Kessing, Hansen, & Bech, 2006). Similarly, when controlling for current depressive symptoms MDD and BD groups did not differ on the Psychological, Social and Environmental scales of the WHOQOL-BREF (Cotrena et al., 2016). In studies where
depressive symptoms did not differ between MDD and BD groups, QoL scores were largely equivalent on the WHOQOL-BREF (Berlim et al., 2004; Grover, Painuly, Gupta, & Mattoo, 2011) and Manchester Short Assessment of Quality of Life Scale (Johanson & Bejerholm, 2017). Depressive symptoms may also explain some differences between MDD and various BD subgroups: Maina et al. (2007) showed BD-II, not BD-I, demonstrates QoL impairment on the SF-36 equivalent to recurrent MDD. As individuals with BD-II face a greater burden of depressive symptoms, this finding highlights the potential role of depressive symptoms in explaining similarities between QoL in MDD and BD. In a case where individuals with BD-I reported impairment greater than MDD on Social Functioning, Role Limitations (Emotional) and Mental Health scales, they were also observed to report significantly more depressive symptoms than those with BD II or MDD (Moreno et al., 2012).

Mixed results have been observed when comparing QoL amongst individuals with BD versus those with schizophrenia (see Table 3, Appendix E for a summary of reviewed studies). Firstly, in euthymic or remitted samples, both BD and schizophrenia have shown comparable QoL on the WHOQOL-BREF (Brissos, Dias, Carita, et al., 2008; Esan et al., 2017; Sum et al., 2015; Yen et al., 2008) and Q-LES-Q (Aykut, Arslan, Özkorumak, & Tiryaki, 2017). However, other studies have demonstrated higher QoL scores in BD on the Q-LES-Q (Chand et al., 2004; Latalova et al., 2011), and the Psychological domain of the WHOQOL-BREF (Akvardar et al., 2006; Chand et al., 2004). Residual symptoms may underpin some of these differences: Sánchez-Morla (Sánchez-Morla et al., 2009) observed a schizophrenia sample to be significantly more depressed than the BD group using the clinician-rated, schizophrenia-specific Quality of Life Scale (QLS). Secondly, demographic differences may also play a role: Chand (Chand et al., 2004) found a BD sample had higher Q-LES-Q scores in all domains and higher scores in the Physical and Psychological domains of the WHOQOL-BREF as compared to participants with schizophrenia, but noted that the BD group was more often married and better off financially. However, changes in objective circumstances may not fully account for group differences. As demonstrated by Latalova et al. (2011), poorer QoL was observed in schizophrenia as compared to BD even when the sample was separated by employment status.

Mixed results have also been observed in comparisons of individuals with BD and those with schizophrenia in acute phases of illness. When symptomatic, some studies have shown that both BD and schizophrenia show comparable QoL on the WHOQOL-BREF (Amini & Sharifi, 2012), while others have shown higher QoL in BD using the QLS
Degree of negative symptoms experienced by individuals with schizophrenia may underscore these results: in a group with schizophrenia stratified by the presence of negative symptoms, those with negative symptoms were shown to have poorer QoL compared to BD on several QLS subscales, while those without did not differ from the BD comparison sample (Bellack, Morrison, Mueser, & Wade, 1989). Similarly, Sum et al. (2015) found that individuals with schizophrenia had similar QoL as assessed with the WHOQOL-BREF to those with BD when both groups were in remission; however symptomatic patients with schizophrenia reported worse QoL in all domains compared to currently unwell patients with BD. Furthermore, within both groups negative symptoms and poorer psychosocial functioning were associated with poorer QoL, potentially accounting for group differences in unremitted patients. In a study using the Quality of Life Index, participants with schizophrenia reported higher subjective QoL relative to those with BD and MDD (Atkinson et al., 1997). However, when compared on objective indicators of QoL including rates of hospitalisation, unemployment, income, and marital status, the opposite trend emerged: those with schizophrenia were identified as having the poorest QoL. In another study with acutely unwell patients using the Quality of Life Interview (QOLI), subjective QoL was comparable in those with schizophrenia and those with bipolar mania, and those with bipolar depression reported poorer QoL (J. Russo et al., 1997). Poor insight on behalf of the patients with schizophrenia and an evaluation bias due to depressed/manic mood in the BD groups was suggested to impact these results.

Overall, existing literature using a range of measures and patient populations suggests that QoL in BD may be broadly located between that of MDD and schizophrenia: BD was often observed to have QoL comparable to or worse than MDD, and comparable to or better than schizophrenia. Unresolved questions remain regarding the role of mood, insight, and objective aspects of QoL (e.g., employment, marital status) in explaining these between-group differences.

### 3.3.3 Quality of Life Comparisons across Bipolar Disorder Subtypes

Relatively few studies have compared QoL across the subtypes of BD (see Table 4, Appendix E for a summary of reviewed studies), and those which have compared BD-I to BD-II have reported inconsistent findings. While some studies in this area propose that QoL in BD-II is more impaired on the SF-36 MCS summary score (Albert, Rosso, Maina, &
Bogetto, 2008), PCS summary score and the majority of SF-36 subscales (Maina et al., 2007), and the Illness Intrusiveness Rating Scale (Robb et al., 1997), others have found no difference between the BD subtypes on Burckhardt’s (Burckhardt, Woods, Schultz, & Ziebarth, 1989) Quality of Life Scale (Mazza et al., 2009), the Q-LES-Q (Datto, Pottorf, Feeley, LaPorte, & Liss, 2016), WHOQOL-BREF (Cotrena et al., 2016; Goossens et al., 2008), and the majority of SF-20 subscales (Cooke et al., 1996). Finally, one study found that participants with BD-II in fact reported higher QoL on the Social Functioning, Role Limitations (Emotional), Mental Health, and PCS scales of the SF-12 (Moreno et al., 2012).

Inconsistent results when comparing QoL across BD subtypes may be due to varying levels of depressive symptoms in these samples. Typically, individuals with BD-II spend more time experiencing subsyndromal levels of depression as compared to BD-I (Judd, Akiskal, Schettler, Coryell, Maser, et al., 2003; Judd, Schettler, et al., 2003). Some studies which have found similar levels of QoL in BD-II as compared to BD-I had restricted their sample to those in a euthymic mood state (Goossens et al., 2008), or found similar levels of baseline depression (Datto et al., 2016; Mazza et al., 2009), potentially eliminating any differences due to residual depression. A surprisingly high number of depressive episodes in BD-I as compared to BD-II in Moreno and colleagues’ (2012) analysis may explain this singular finding of poorer QoL in BD-I. In those studies finding worse QoL in BD-II, depression was thought to underpin this: Maina et al. (2007) noted the degree of QoL impairment in BD-II as compared to BD-I was largely on par with a sample with MDD. Robb et al. (1997) observed that individuals with BD-II reported greater current depression than those with BD-I, which acted as a significant covariate of total illness intrusiveness.

3.3.4 Impact of Mood Symptoms on Quality of Life

Given that the defining feature of BD is extreme states of depression and mania, there is longstanding interest in the impact of pathological moods on QoL. Comparisons of different mood states in BD have generally confirmed the common-sense prediction that QoL in depressed states is less than that of euthymia, however more ambiguous results have been found regarding the QoL impact of hypo/mania.

Numerous studies have compared QoL across the various pathological mood episodes associated with BD which, broadly speaking, suggests progressively poorer QoL from euthymic, to (hypo)manic, to depressed states (see Table 5, Appendix E for a summary of reviewed studies). Using the SF-12 and EQ-VAS, it has been observed that patients with
(hypo)mania reported QoL that was similar (EQ-VAS) or poorer (SF-12 Mental summary scale) to that of euthymic patients (Vojta, Kinosian, Glick, Altshuler, & Bauer, 2001). Participants in a depressive or mixed state reported poorer QoL to those in a euthymic state on both measures. No group differences were observed on the SF-12 Physical summary scale. Similarly, in studies using the WHOQOL-BREF, remitted patients showed higher (Gazalle et al., 2006; Goossens et al., 2008) or comparable scores to those who were depressed (Gazalle, Frey, et al., 2007), while patients in (hypo)manic states scored on par with those in euthymic states (Gazalle, Frey, et al., 2007; Goossens et al., 2008). Persisting subsyndromal symptoms may explain some between-study differences in the rank ordering of QoL in euthymia and hypomania: Piccini et al (2007) found that euthymic patients with persisting depressive symptoms tended to show poorer QoL on SF-36 subscales than those fully remitted for at least two months, or euthymic participants with persisting hypomanic symptoms.

Numerous other studies have investigated the relative predictive power of mood symptoms, rather than comparisons between distinct mood episodes, on QoL in BD (see Table 6, Appendix E for a summary of reviewed studies). Of all the predictors of QoL in BD, current depressive symptoms are hypothesised to have one of the strongest negative impacts. Indeed, negative associations between depressive symptoms and QoL have been observed, even when accounting for other clinical and demographic variables, for all domains of the WHOQOL-BREF (Amini & Sharifi, 2012; De Abreu et al., 2012), overall Q-LES-Q scores (Özer et al., 2002), and the MCS summary score of the SF-36 (Gutiérrez-Rojas et al., 2008) and SF-12 (Abraham, Miller, Birgenheir, Lai, & Kilbourne, 2014). Symptoms of depression have been shown to negatively impact on QoL even in euthymic BD, including the SF-20 subscales of Social Functioning, Mental Health and Overall Health perception (Cooke et al., 1996), both the Quality of Life in Depression scale and the SF-36 subscales of Vitality, Social Function, Role Limitations Emotional, and Mental Health (Leidy et al., 1998), and overall Q-LES-Q scores (Özer et al., 2002).

It is important to note parenthetically that significant negative correlations between depressive symptoms and QoL in BD are variable: while some studies report large correlations, more typically correlations are observed to be moderate in magnitude (see Table 7, Appendix E for a summary of reviewed studies). Correlations between depression and SF-36 subscales range from -.11 (Role Limitations [Physical]) to -.29 (Mental Health) in currently or recently depressed BD-I patients (Yatham et al., 2004), -.41 to -.49 on the EQ-5D and EQ-VAS (respectively) in currently or recently depressed patients (Hayhurst, Palmer,
Abbott, Johnson, & Scott, 2006), -0.27 (Social) to -0.42 (Environmental) on the WHOQOL-BREF in euthymic patients (Brissos, Dias, & Kapczinski, 2008), -0.46 (Environment) to -0.73 (Physical) on the WHOQOL-BREF in a largely euthymic sample (Goossens et al., 2008), and -0.33 (Environmental) to -0.56 (Psychological) on the WHOQOL-BREF in depressed/euthymic patients (Gazalle et al., 2006). The proportion of variance accounted for by depression of overall Q-LES-Q scores was demonstrated in one study to be 13% (Özer et al., 2002).

Consequently, while depression clearly acts as an important predictor of QoL in BD, the two constructs are not mutually redundant.

Data on QoL in mania is more limited. Presumably because of ethical and pragmatic challenges, studies researching QoL in this mood state typically have small sample sizes, and many studies have explicitly excluded participants with mania on the basis of assumed affective bias, impaired insight, presence of psychosis or inability to self-report on QoL when acutely unwell (Michalak, Yatham, & Lam, 2005). Despite this concern, numerous studies have shown it is feasible for many patients with mania to complete QoL assessments (Gazalle, Frey, et al., 2007; Vojta et al., 2001), and it may be services rather than consumers which cannot tolerate the increased time it takes for consumers to complete questionnaires (J. Russo et al., 1997). The limited research on QoL in mania has led to inconsistent results: while a number of studies (above) have generally located QoL in (hypo)mania as on par with that of euthymic BD, the severity of mania included in studies was generally low. In one study of acutely ill hospitalised patients using the QOLI, patients with mania reported more global satisfaction with life than BD depressed, unipolar depressed, and schizophrenia-spectrum diagnoses (J. Russo et al., 1997); however, there were few significant correlations between objective and subjective indices of QoL in mania. In a study of patients with mania, Gazalle et al. (2007) found that although this group reported better QoL on all WHOQOL-BREF domains than the depressed group, they scored more poorly on the clinical rated Global Assessment of Functioning (GAF). In fact, the authors noted an inverse correlation between the GAF and the Psychological QoL domain of the WHOQOL-BREF. However, it was remarked that the high (86.2%) proportion of current psychotic symptoms may mean results do not adequately reflect all manic patients. A lack of concordance between subjective and objective QoL has been observed even in patients with only residual symptoms of mania. Piccini (2007), in a study of euthymic patients with residual depressive or manic symptoms, found that although the residual depression group demonstrated poorer QoL than those with residual mania on the SF-36 subscales of General Health, Vitality, and Mental Health, the
groups demonstrated similar functioning on the GAF. Inflated QoL self-report due to manic symptoms, and poorer insight into objective functional impairments, has been proposed to account for these differences and have caused a number of authors to question the validity of self-report in mania (Atkinson et al., 1997; J. Russo et al., 1997). However, while Zhang, Wisniewski, Bauer, Sachs and Thase (2006) showed higher QoL on the overall Q-LES-Q and the SF-36 Mental summary scale in hypo/mania as compared to recovered states, this apparently ‘supranormal’ QoL disappeared after adjusting for a range of socioeconomic and clinical factors, suggesting that studies which note elevated QoL in mania may be attributable to other demographic and clinical differences.

While it is assumed by some that the experience of mania will artificially inflate QoL self-reports due to the positive feelings often associated with this state (Atkinson et al., 1997; J. Russo et al., 1997), other evidence highlights ways in which this state may be experienced as subjectively unpleasant. Mania is not always a euphoric or pleasant experience: irritable or dysthymic feelings are common, and co-occurring depressive symptoms in mania have been shown to negatively impact QoL on the SF-36 (M. S. Bauer, Simon, Ludman, & Unützer, 2005), SF-12 (Vojta et al., 2001) and Quality of Life Inventory (Shah, Averill, & Shack, 2004). Co-occurring depressive symptoms in mania did not impact EQ-VAS scores (Vojta et al., 2001). Anticipation of and preventative strategies for mania may also negatively impact QoL: many individuals report dampening positive emotions in response to early warning signs for mania, a response which was associated with poorer QoL on the disorder specific QoL.BD (Edge et al., 2013).

The majority of investigations on the impact of manic symptoms in BD have been conducted with hypomanic, subsyndromal or euthymic patients. In these populations, mixed findings have been observed (see Tables 6 and 7, Appendix E, for a summary of reviewed studies). In cases where significant negative correlations were observed between mania and QoL, these were moderate to large, ranging from - .45 to -.72 on the SF-36 MCS summary scale (Depp et al., 2006; Depp et al., 2009). However, these studies were conducted in a sample of older adults only, and may not generalise to other individuals with BD. In a general sample of individuals with BD, small to moderate significant correlations between individual items on the YMRS and WHOQOL-BREF domains were found, ranging from -.19 between Sleep and Psychological QoL and -.33 between Irritability and Physical/Psychological QoL (Gazalle, Frey, et al., 2007). Mania has also been shown to be a significant negative predictor in multiple linear regressions for QoL on the WHOQOL-BREF domains (Gazalle, Frey, et
al., 2007) and SF-36 MCS summary score (Gutiérrez-Rojas et al., 2008). However, other studies have reported no association between mania and QoL on the Q-LES-Q (Michalak, Torres, Bond, Lam, & Yatham, 2013), EQ-5D and EQ-VAS (Hayhurst et al., 2006), or positive associations between mania and QoL on the Q-LES-Q (Sylvia et al., 2017).

Important to note, however, is that these studies typically capture only very low levels of mania in their samples, and as such, results may not accurately reflect the impact of manic symptoms.

In sum, although studies generally confirm a negative impact of depression on QoL in BD, the degree of variance explained by this predictor is only small to moderate, suggesting a need to examine other factors. QoL in euthymia is generally understood to be negatively impacted, but to a lesser degree than in depressive mood states. While a number of studies have shown that QoL in mania is negatively impacted on par with euthymic mood states, others have shown positive impacts of this mood state or a lack of concordance between subjective QoL and objective indicators of QoL that have led to questions regarding the validity of self-report. A significant limitation of the current literature of the relationship between QoL and mood symptoms in BD is the lack of longitudinal studies (Michalak et al., 2008). It is not well understood how and to what degree depression and mania predict later QoL in BD. Further investigation of dynamic relationships between symptoms and QoL is needed to better characterise the impact of symptoms and interventions.

3.3.5 The Relationship of Quality of Life with Functioning

The relationship between QoL and functioning, another outcome of increasing interest in BD (Gitlin & Miklowitz, 2017; Sachs & Rush, 2003), has been explored in some detail. Findings to date are complex (see Table 8, Appendix E for a summary of reviewed studies): while some studies have reported moderate correlations between the two variables, others have found no correlation between QoL and various measures of functioning. These results have been alternately used to question the validity of QoL self-report, and highlight the unique contribution of subjective QoL assessment to understanding of an individual’s circumstances in BD.

Significant correlations have been reported between clinician-rated or objective indicators of functioning and self-reported QoL in a number of studies, including the majority of SF-20 subscales (Cooke et al., 1996), the SF-36 Mental Health and Social Functioning subscales (MacQueen et al., 2000), the SF-36 PCS summary scale (Depp et al., 2006), the Q-
LES-Q (Özer et al., 2002), the WHOQOL-BREF overall (Thomas, Nisha, & Varghese, 2016), Environmental and Social domains (Magalhães, Manzolli, Walz, & Kapczinski, 2012), and the majority of QoL.BD subscales (Van Rheenen & Rossell, 2014). Similarly, negative correlations have been found between QoL and disability measures when using the EQ-5D (Guilera et al., 2014), the WHOQOL-BREF (Thomas et al., 2016) and the Q-LES-Q (Magalhães et al., 2011). As noted above in relation to covariance with depression measures, the concordance between QoL measures and functioning/disability is typically small to moderate (significant correlations were typically in the range of .20 -.40), suggesting that these outcomes in BD are related yet separable concepts.

A smaller number of studies have found no relationship between QoL and various functioning indices. For example, no significant correlations between clinician rated functioning on the GAF and QoL on any of the WHOQOL-BREF domains were found in a sample of patients with BD in a depressive episode (Caldiróla et al., 2014). Similar results were found by Goldberg and Harrow (2005): over an eight year follow-up period, correlations between self-reported life satisfaction and clinician-rated global functioning were largely non-significant. In addition, Amini and Sharifi (2012) found no correlation between WHOQOL-BREF domains and clinician-rated functioning. In a sample of older adults (mean age = 60.2), no significant correlations were observed between SF-36 summary scores and a performance-based measure of functioning (Depp et al., 2009), however a clinician administered QoL scale, the Quality of Wellbeing Scale, showed a significant relationships with performance-based functioning. Self-reported QoL, but not the performance-based functioning measure, was observed to correlate significantly with depressive symptoms. Such findings have been used to suggest self-reported QoL in BD may not accurately represent an individual’s actual circumstances. Goldberg and Harrow (2005), as well as Amini and Sharifi (2012), suggested that the discrepancy between clinician-rated functioning and QoL self-reports was due to limited insight, desensitisation to life stresses, and reduced expectations for life in patients with BD, and that objective assessment of functioning should therefore be prioritised in evaluating outcomes.

The relationship between subjective QoL and functioning may differ according to mood state: as described above (3.3.4), correlations may be weaker in mania as compared to depression/euthymia (J. Russo et al., 1997), or even inverse such that higher QoL is found in mania despite poorer functioning (Gazalle, Frey, et al., 2007). Some support has been found for the role of insight in this discrepancy – awareness of a mental disorder and awareness of
the effects of medication were found to correlate negatively with psychological QoL on the WHOQOL-BREF (Dias et al., 2008), however when the same group was stratified into patients with ‘preserved’ overall insight as compared to patients with ‘impaired’ insight, no differences in QoL were found. Variable reduction techniques, however, have supported the interpretation that QoL and functioning may represent two distinct outcomes in BD. Using principal components analysis to assess outcomes in BD, Brieger, Röttig, Röttig, Marneros and Priebe (2007) extracted a ‘general subjective’ dimension (including WHOQOL-BREF and depression self-report items), a ‘functioning/disability’ dimension and a ‘manic/psychotic symptoms’ dimension. Similarly, an exploratory factor analysis found a two-factor solution, the first capturing clinician-rated functioning/disability and the second incorporating the Q-LES-Q and depression items (Magalhães et al., 2011). Finally, another exploratory factor analysis in BD found a two-factor solution, the first including subjective indicators of depression, QoL (WHOQOL-BREF) and functioning, and the second symptoms of mania and clinician-rated functioning (Magalhães et al., 2012). These factors tend to correlate at a small to moderate rate, in line with the significant correlations observed between QoL and clinician rated functioning described above, further supporting the interpretation of these as related but distinct outcomes in BD.

3.3.6 The Impact of Psychoeducation on Quality of Life

QoL is increasingly used as an outcome measure in clinical trials in BD, with reviews hopefully suggesting that a number of pharmacological and non-pharmacological intervention methods have positive impacts on QoL in BD (Michalak et al., 2008). However, use of QoL as an outcome in studies of psychosocial interventions is less common than its use in pharmacological trials (Michalak et al., 2008), a surprising fact given the argument (detailed in Chapter 1, 1.4.2) that the broad targets of psychosocial interventions may be better measured with similarly holistic QoL measures.

One of the most common psychosocial interventions in BD is psychoeducation (Reinares et al., 2014), potentially due to its cost effectiveness in comparison to other psychosocial therapies (Parikh et al., 2012). Broadly speaking, psychoeducation describes any intervention including information on self-management strategies for the identification, prevention and management of symptoms and impacts of BD. By definition, self-management includes attention to broader life areas and the emotional impacts of illness (Lorig & Holman, 2003): consequently, it would seem important to use QoL to assess the
impacts of such interventions (discussed Chapter 1, 1.4.2). Typical psychoeducation interventions follow the model of Colom and Lam (2005), aiming to reduce symptoms and prevent relapse by giving information about the nature of BD, pharmacological interventions and the importance of medication adherence, potential triggers of mood episodes, the potential negative impacts of alcohol and street drugs, early detection of mood episodes and responding to early warning signs, the importance of regularity in routines, and strategies for stress management and problem solving. Psychoeducation is commonly delivered through in-person group presentations delivered by a clinician, although in recent years novel online, peer-supported and QoL oriented formats have been developed (Janney, Bauer, & Kilbourne, 2014; Leitan, Michalak, Berk, Berk, & Murray, 2015; Murray et al., 2017). Evidence regarding the impact of these interventions on QoL in BD, however, is mixed (see Table 9, Appendix E for a summary of reviewed studies).

The results of some studies have indicated positive impacts of psychoeducation on QoL. Doğan and Sabanciogullari (2003) found that compared to treatment-as-usual (TAU), participants who completed three sessions of lithium-focused psychoeducation showed significant improvements on the WHOQOL-BREF Physical and Social domains at follow-up. Similar results were observed in Castle et al.’s (2007) pilot evaluation of a group psychoeducation program. Euthymic patients were randomised to either TAU or 12 weeks of psychoeducation; at follow-up the psychoeducation group showed significant improvement on the Social domain of the WHOQOL-BREF compared to TAU. Two other studies showed improvements in QoL following psychoeducation: eight weeks of group psychoeducation significantly improved the Q-LES-Q Physical Health and General Activities scales in a sample of patients who were euthymic or mildly symptomatic at baseline, however this study was limited in being a retrospective investigation with no control group (Michalak, Yatham, Wan, & Lam, 2005). Lauder et al. (2014) compared patients randomised to receive either Mood Swings (an online psychoeducation program) or Mood Swings Plus (the same program with additional interactive cognitive behaviour therapy elements). Both groups demonstrated significant improvement on a global self-report QoL item; however this study was limited by the lack of a control group.

Other evaluations of psychoeducation programs have shown limited or no impact on QoL. Cardoso et al. (2014) conducted a randomised control trial of six sessions of psychoeducation in young adults (18-29 years) with BD. Immediately post-intervention, it was observed that for both the psychoeducation and TAU control group, QoL (as measured
by the SF-36) improved significantly in five domains (Physical Functioning, Social Functioning, Vitality, Role Limitations [Emotional], and Mental Health). Similar results were observed by Smith et al. (2011), who investigated the impact of Beating Bipolar (an online psychoeducation intervention) on QoL as measured by the WHOQOL-BREF. Individuals with BD in clinical remission were randomised to either receive eight online modules of Beating Bipolar over four months or treatment as usual. It was observed that six months following the conclusion of the intervention, the two groups did not differ on overall QoL or any WHOQOL-BREF subscales. Javadpour, Hedayati, Dehbozorgi, and Azizi (2013) showed that euthymic participants who were randomised to receive eight weeks of psychoeducation did not significantly improve their WHOQOL-BREF scores from baseline.

Interestingly, one study showed a potentially negative impact of psychoeducation. Participants in remission were randomised to either 16 weekly sessions of psychoeducation or the same amount of relaxation (De Barros Pellegrinelli et al., 2013). At endpoint, both groups showed a trend to worsening Environmental QoL on the WHOQOL-BREF, and no other subscales showed significant change or difference between groups. The authors noted that depressive symptoms significantly worsened over the course of this study, which may account for the trend towards worsening QoL. An alternative explanation is proposed by Gladis (Gladis et al., 1999), who suggested that psychotherapy may sometimes lead to negative impacts on QoL if participant’s expectations are raised but change in their objective circumstances does not ensue.

Thus far, investigations of psychoeducation in BD have been unable to conclusively demonstrate the efficacy of this intervention for QoL. The majority of studies are limited by small sample sizes and brief follow-up periods. Additionally, some studies were unable to assess for the specific effects of psychoeducation due to lack of a control group. Restricting samples to euthymic populations may not present a realistic picture of populations engaging in psychoeducation - there may be ceiling effects for improvement when a population is already well at baseline. Finally, the lack of impact on QoL outcomes observed in a number of studies may be a consequence of the type of psychoeducation interventions investigated. Typically, interventions were brief, and based on the Colom and Lam (2005) approach to psychoeducation which emphasises the medical model of BD (prioritising medication adherence and behavioural strategies to prevent relapse of symptoms). Limited investigation has been conducted of novel QoL-focused psychoeducation (Leitan et al., 2015; Murray et al., 2017): it is possible that such interventions may have more positive effects on QoL.
Importantly, one study showed that treatment dropout was associated with significantly poorer Social QoL on the WHOQOL-BREF (De Barros Pellegrinelli et al., 2013), supporting the suggestion in Chapter 1 that QoL outcomes may impact engagement, and further highlighting the need for specific QoL-focused therapies.

3.3.7 Qualitative Investigations of Quality of Life in Bipolar Disorder

There has been limited qualitative investigation of the impact of BD on QoL: only one known qualitative study has explicitly asked individuals with BD about their QoL. However, inferences can be drawn from a related small group of qualitative studies asking individuals with BD about the broader impacts of BD or factors which support living well with the condition (see Table 10, Appendix E, for a summary of reviewed studies). The sole qualitative study to explicitly ask about QoL identified a range of ways in which people experience their QoL as impacted by BD, including the ability to find work and remain employed, obtain education, experience positive social and intimate relationships, and have an integrated and stable sense of self (Michalak, Yatham, Kolessar, & Lam, 2006). A number of areas of life nominated as important (routine, independence, stigma, identity, social support and spirituality) clearly extend beyond the direct impact of mood symptoms, and include aspects likely specific to the experience of BD. These qualitative findings were used as the foundation of a BD-specific QoL measure, the QoL.BD (Michalak & Murray, 2010b) (see 3.2.5).

A number of other qualitative studies, while not investigating QoL directly, nonetheless highlight impacts of the disorder on broader life areas from the experience of people with BD. A qualitative study by Rusner, Carlsson, Brunt and Nyström (2010) investigated the lived experience of the meaning of conditions that enable a good life in BD. Mirroring the findings of Michalak (above), a range of disorder-specific needs were identified: individuals with BD indicated the importance of managing the illness and their own energy levels, having relationships with reliable and trusted others, finding meaning by being needed in relationships or at work, and maintaining a sense of independence. Lim et al. (2004) asked people with BD-I about their experiences of the disorder and how it impacted their lives. Themes identified highlighted a sense of instability and lack of control, feelings of loss related to deficits in relationships and employment, stigma and rejection from the broader community, and hopelessness and uncertainty about the future. Finally, one other study asked participants about the impact of BD on their lives, highlighting the importance of
autonomy and how this can be eroded when unwell (Crowe et al., 2012). We can infer from this group of related investigations a number of disorder-specific impacts in broad life areas, particularly feelings of instability, challenges to independence/autonomy and an unstable sense of self.

3.4 Empirical Investigations of Quality of Life in Bipolar Disorder: Summary

In summary, the literature to date on QoL in BD has addressed a number of important questions regarding the impact of this chronic mood disorder. QoL in BD has generally been shown to be more impaired than the general population, on par with or worse than unipolar depression, and better or on par with schizophrenia. Limited comparisons of BD subtypes have suggested that BD-II may have a greater QoL impairment than BD-I, potentially attributable to the greater burden of depression faced in this diagnostic sub-group. Of BD mood symptoms, depression has been shown to have a consistent negative impact on QoL. However, the size of correlations between depression and QoL suggest they are related but distinct outcomes. The impact of mania is less certain: a number of studies have shown that QoL in (hypo)mania is similar to QoL in euthymic BD, and that manic symptoms correlate negatively with QoL. However, some studies have questioned the validity of self-report in mania due to elevated QoL scores in this state, or lack of concordance between subjective QoL and objective measures of functioning. QoL is generally correlated with the related outcome of functioning, although the size of these correlations and variable reduction techniques suggests that they are distinct concepts. Investigations of the impact of psychoeducation on QoL have presented mixed results – while some studies show positive impacts, more often these interventions have no or limited efficacy compared to treatment as usual. Finally, a small number of qualitative investigations have explored the impact of BD on the lives of sufferers – while only one explicitly asked participants to consider their QoL, these studies tend to highlight similar valued/impacted domains.

The literature is as a whole is limited by small sample sizes and infrequent investigation of manic mood states (Michalak et al., 2008). The majority of studies are cross-sectional; meaning potentially important information regarding the longitudinal relationship between QoL and symptoms in BD is not available. Additionally, the diversity of QoL measurement instruments used in this literature makes comparison across studies complicated, and may potentially underpin some of the variability in results.
The present brief literature review, when considered in the context of issues identified in the treatment of QoL in the broader medical and psychiatric literature (see Chapter 2) and the parallel schizophrenia literature specifically (see Chapter 4) highlights a number of opportunities to advance the study of QoL in BD. These gaps in understanding (to be addressed by the research plan of the current project) will be reviewed in Chapter 4.
CHAPTER 4. CONCEPTUAL GAPS IN THE BIPOLAR DISORDERS QUALITY OF LIFE LITERATURE
4.1 The Future of Quality of Life in Bipolar Disorder Research: A Roadmap – and a Warning

Compared to other medical and psychiatric fields the investigation of quality of life (QoL) in bipolar disorders (BD) is immature: limited investigation was conducted prior to 2000 (Namjoshi & Buesching, 2001), and the most recent systematic review in this field identified only 30 studies for inclusion (Ishak et al., 2012). One advantage of this nascent stage of the literature is the opportunity for the BD field to draw questions and guidance from other, more developed bodies of work. The related study of QoL in schizophrenia, a similarly chronic, severe, mental illness, has a long and rich history dating to the 1970s where it emerged as a goal linked to the deinstitutionalisation process occurring in a number of western countries (Bachrach, 1976), and as a tool for considering trade-offs between reduced symptoms and severe side effects associated with first generation antipsychotic use (Gardos & Cole, 1976). The relative maturity of QoL research in schizophrenia can be seen in comparing the numbers of published articles referring to QoL: A systematic review of QoL instruments in mental health showed that nearly two thirds of reviewed articles focused on schizophrenia (Prigent, Simon, Durand-Zaleski, Leboyer, & Chevreul, 2014), with comparatively small focus on BD and unipolar depression. More recently, as of the start of 2016, a Scopus search of the keywords “schizophrenia” and “quality of life” returns 3202 articles, while a search of “bipolar disorder” and “quality of life” returns 948 articles (see Figure 4.1).

Despite the sizeable body of research on QoL in schizophrenia, progress in this field has been challenged as failing to have the expected real-word impact. Awad (2011) stated in his commentary about the ‘unfulfilled promise’ of QoL that lack of clarity around conceptual issues has led to a lack of impact on healthcare, clinical trials, allocation of resources or policy. Awad observed that the dearth of conceptual work in the schizophrenia literature had significant impacts at the level of measurement: the various QoL measures in use were criticised for lacking theoretical underpinnings, presenting challenges for combining data. In addition, ongoing questions about the relationship of QoL to psychopathology limit understanding of the boundaries of the construct: Awad noted that little is known about whether QoL itself may act as a mediator or predictor for outcomes in schizophrenia. Finally, Awad criticised the field for failing to investigate clinical applications of QoL data. Other reviews in schizophrenia have raised similar issues: Boyer et al. (2013) pointed to the lack of a clear conceptual basis of QoL in schizophrenia, limitations in understanding and
interpreting individual responses to QoL measures and how these may change over time, and the integration of QoL measurement into clinical practice. Similar to concerns raised by Awad, Priebe et al. (2011) suggested that in the face of criticisms that QoL is too heavily dependent on symptomatology to represent an independent construct worth investigating, investigation of associations between changes in QoL and symptoms over time is required. Such information is key not only for defining the boundaries of the QoL construct and its relationship to other concepts, but also for clinical applications of QoL. Also underrepresented in conceptual investigations of QoL in schizophrenia is the lived experience of consumers (Awad & Voruganti, 2012; Awad, Voruganti, & Heslegrave, 1997; Bobes, Garcia-Portilla, Bascaran, Saiz, & Bouzoño, 2007): It has been suggested that qualitative research is necessary to explore the QoL construct from the perspective of individuals with schizophrenia, or risk restricting the construct to factors presumed to be important from the top-down perspective of psychiatrists and researchers (Angermeyer, Holzinger, Kilian, & Matschinger, 2001; Bengtsson-Tops & Hansson, 1999).

![Figure 4.1 Number of articles referencing quality of life by year (2005-2015) in bipolar disorder as compared to schizophrenia (SCOPUS database, terms in abstract, title or keywords).](image)
Such commentaries in the parallel schizophrenia literature highlight potential consequences facing the BD field if gaps in conceptual understanding of QoL are not addressed. Specifically, areas in need of investigation include the controversial definition and usage of the QoL construct in BD, exploration of the time-varying relationship of QoL with related variables such as symptomatology, and subjective elements of QoL from the perspective of consumers. Without attention to these conceptual issues, the BD field is at risk of not fulfilling the promise of QoL as a pivotal disruptive concept. To date, empirical research on QoL in BD has focused on exploring QoL in BD relative to other populations, the impact of mood and other correlates on QoL, and QoL as an outcome in trials of pharmacological and non-pharmacological interventions (for a brief review of this literature, see Chapter 3). Critically, the important conceptual gaps in the schizophrenia literature identified as contributing to a lack of real-world impact for QoL have not yet been adequately addressed in BD research.

Reviews of QoL in BD have not systematically considered the conceptual and methodological issues that are well recognised in the schizophrenia literature: lack of consensus around definition and measurement has been noted to lead to inconsistent findings in the literature and difficulties integrating current evidence (Michalak et al., 2007). The interplay between symptoms of BD and QoL over time has not been investigated using appropriate methods, and indeed this gap has been identified in previous reviews of QoL in BD (Michalak et al., 2007; Michalak et al., 2008; Michalak, Yatham, & Lam, 2005). Analysis of time-lagged effects in longitudinal data is possible with the technique of multilevel modelling (Duckworth, Tsukayama, & May, 2010), yet no such studies have been completed in this field. As such, the boundaries between the construct of QoL and symptoms in BD are poorly understood, leading some to challenge the utility of adding QoL measures alongside traditional outcomes (Katschnig, 2006a). Qualitative studies of the lived experience of QoL from the perspective of individuals with BD are lacking: while some studies may inform understanding of the subjective burden of QoL (see Chapter 3, 3.3.7 for a review) only one study specifically asked individuals with BD about their QoL to support the development of a BD-specific measure (Michalak & Murray, 2010b; Michalak et al., 2006). Consumer voices are needed to scrutinise assumptions regarding the cognitive processes by which individuals with BD make QoL judgements used by a number of critics to dispute the validity of subjective QoL assessment in BD (S. Evans & Huxley, 2005; Katschnig, 2006a; Mechanic, 2006). Finally, investigations of clinical applications of QoL in BD are urgently required.
While QoL has largely been studied as an outcome of existing interventions developed from this biomedical perspective (i.e., pharmacological treatments, psychosocial treatments aimed at controlling symptoms), the development of interventions that primarily target QoL is increasingly called for (Murray et al., 2017).

Attention to improving QoL has been heralded as part of a paradigm shift in mental health in which the approach to BD moves from exclusive focus on traditional clinical outcomes to psychosocial variables such as recovery and QoL. As noted in Chapter 3 (3.3.6), psychoeducation (typically focused on controlling symptoms through medication and behavioural strategies) has shown limited efficacy at improving QoL, potentially as a consequence of its medical-model orientation. While contemporary variants of psychoeducation are being developed from the QoL-orientation (Leitan et al., 2015; Murray et al., 2017), it is unknown how interventions developed from this perspective will be experienced by individuals with BD. Clearly, many of the gaps identified in the schizophrenia literature, including attention to conceptual issues, dearth of longitudinal and qualitative evidence, and limited practical application of QoL understandings, have not been adequately addressed in the study of BD.

4.2 Four Study Design of the Current Project

I have argued above that QoL is a goal relevant to BD as a chronic illness with broad-ranging impacts. As an outcome coherent with the growing recovery-oriented, person-centered perspectives in mental health, QoL may play a vital and disruptive role in clinical practice with BD. However, the field of QoL research in BD remains limited, and a review of the parallel schizophrenia QoL literature suggests a number of critical issues for the BD field to address in order to maintain the relevancy and impact of this patient-valued outcome. The overarching aim of the present project was to incrementally advance understanding of the nature of QoL in BD. Using the parallel schizophrenia literature as a guide to identify important issues in the study of QoL in mental health, and referring to the BD literature to highlight understudied areas, three issues for urgent attention in the BD field were identified:

1. Definitional issues in the existing QoL in BD literature
2. The relationship between QoL and symptoms over time amongst people with BD
3. The subjective experience of QoL for people with BD, including:
   a) The nature of QoL appraisals
   b) The experience of QoL-focused interventions
These issues for attention address different yet overlapping aspects of the conceptualisation of QoL in BD: the specification of QoL as a theoretical construct, measurement of QoL dynamics in relation to other constructs, and the subjective lived experience of QoL. However, it is also recognised that investigation of practical applications of QoL is needed to move this construct from abstract discussion to tangible impacts on the lives of consumers. The investigation of the experience of QoL-focused interventions is therefore needed in parallel with conceptual work to ensure the ongoing practical relevance of the construct.

While it has been argued by some that conceptual ambiguities must be resolved before accurate measurement can be undertaken (Bowling, 2001), others have noted a need to find a means to proceed in the face of such confusion. Ware, who developed the SF-36, one of the most commonly used measures of QoL, noted that while top down work to clarify definition of QoL and optimise measurement must continue, empirical research must continue to guide healthcare decision making. He notes that the improbability of perfect definition and measurement being obtained, suggesting that if the field waits for such issues to be resolved “progress will be held hostage to perfection” (Ware, 1995, p. 349). As such, the present project, while seeking to add clarity to the conceptualisation of QoL in BD, also recognises the need for pragmatic solutions to support empirical investigation and clinical applications of QoL in the face of conceptual ambiguities. While a common approach in psychology is to study one pressing issue in detail, the field of QoL in BD has been shown to be relatively immature. Consequently, attention is needed to multiple aspects in order to advance the literature as a whole. The project therefore aims to address identified issues of definition, dynamics, lived experience and QoL-specific interventions in BD with four parallel studies. Pragmatic considerations influenced the specification of research questions addressing these issues and the selection of appropriate research methods.

**Study 1:** A systematic review of the definition and usage of the QoL construct in existing BD literature

**Study 2:** A longitudinal quantitative study of the interplay between QoL and symptoms of BD

**Study 3:** A qualitative investigation of the lived experience of changes in QoL in BD

**Study 4:** A qualitative investigation of consumer perspectives of an intervention targeted at improving QoL
The following chapters present the articles, as published, which summarise the background, aims, methods, results, and discussion (including limitations and future areas of research) for the four studies outlined above. As previously stated (Chapter 1, section 1.2) the present thesis is presented as in the style of a series of published papers as per Swinburne University of Technology’s Higher Degree by Research requirements. As such, there is a degree of unavoidable repetition across chapters, for example there is repetition of background information in each article. Further, given that they drew data from the same overarching mixed-methods study, Study 3 and 4 repeat content within the methods section.

The aim of the present project was to make incremental advances in the understanding of each of these issues separately. However, it is expected that findings in each of these areas would inform interpretation of the others, and a final integrative analysis in the planned Discussion will generate novel questions for future research into the nature of QoL in BD. Lived experience will inform the interpretation of findings about definitions and dynamics (e.g., whether certain definitions resonate or conflict with lived experiences; whether quantitatively measured interactions between QoL and symptoms over time accord with subjective reports of attempting to improve QoL), and findings about dynamics will inform interpretation of findings about definitions (e.g. measurement of dynamics will inform understanding about the boundaries of the QoL construct and its relationship with illness factors) and vice versa (e.g. improved definitional clarity will increase confidence in the accuracy of interpretation of quantitative results and methodological considerations). Finally, investigation of consumer experiences of an intervention targeted at improving QoL in BD will provide a practical test of the relevance and impact of current understandings of the QoL construct. Following Jenkins (1992), the present work serves the larger function of answering the question of what questions need to be asked regarding QoL. The exploratory nature of this thesis will therefore generate a range of questions for future investigation while simultaneously providing a framework for forward movement in this important, consumer-valued field.
CHAPTER 5. STUDY 1: THE DEFINITION, USAGE AND MEASUREMENT OF QUALITY OF LIFE IN THE BIPOLAR DISORDERS LITERATURE – A SYSTEMATIC REVIEW
5.1 Chapter Guide


Given that the present thesis is structured around published articles, there is some unavoidable repetition in the text. The preceding chapters focused on justifications for investigating quality of life (QoL) in bipolar disorder (BD), the construct’s history, definition and measurement in a broader context (i.e., medical, sociological and philosophical fields), and a review of the empirical findings to date regarding QoL in BD across a number of clinically important questions. In this chapter (containing a version of a published article formatted to be consistent with the overarching thesis), a number of key points emerging from the previous reviews are revisited. Specifically, the clinical/personal relevance of QoL in BD, as well as the potential existence of ambiguities in the definition and measurement of QoL are highlighted as reasons for delving further into the treatment of this construct within the BD literature.

The present chapter extends on arguments made in previous chapters by conducting a top-down analysis of how the QoL construct is defined, used and measured in the BD literature. The core novel approach taken in this systematic review is to investigate the way QoL is used in text by researchers in order to allow inferences to be made about their conceptualisation of the construct. The overarching aim of the present investigation was therefore to address the question “What does ‘quality of life’ refer to in the bipolar disorders literature” in order to clarify current conceptualisations and measurement tensions, identify areas in need of further theoretical clarification, and generate pragmatic strategies for addressing definitional and measurement complexities in empirical research.

A supplementary table (Appendix F) presents a summary of QoL measurement instruments used in the reviewed studies. The online version of the published article ([http://www.jad-journal.com/article/S0165-0327(16)31892-4/](http://www.jad-journal.com/article/S0165-0327(16)31892-4/)) presents a supplementary table summarising studies included in the present review; this table is not presented here due to length.
5.2 Abstract

**Background:** Quality of life (QoL) is increasingly investigated in bipolar disorders (BD) research, yet little attention has been paid to its optimal definition and measurement. This is a significant limitation, as the broader QoL literature recognises a number of divergent meanings and measurement tensions. The aim here was to advance understanding of QoL in BD by clarifying use of the construct in the existing literature and considering measurement implications.

**Methods:** Thematic analysis techniques were used to interrogate articles identified via systematic search for (a) explicit discussion of QoL definitional/measurement issues, and (b) usage of the term QoL.

**Results** A total of 275 articles were included in the analysis. A range of definitional and methodological issues confounding the study of QoL in BD were identified. While explicit definition of QoL proved rare, thematic analysis of usage of the construct revealed the concepts of functioning, health, subjective experience and wellbeing were thought to be relevant to QoL in BD.

**Limitations:** The review does not engage in top-down theory development. Our analysis was grounded in the empirical literature to support future theoretical work relevant to existing usage of QoL in BD.

**Conclusions:** There was no evidence of a consensus definition of QoL in BD. A plurality of QoL definitions is not necessarily a flaw in the literature, but points to empirical and conceptual issues demanding attention. Awareness of the diversity of constructs associated with QoL will enable clinicians to better select treatments on the basis of specific QoL outcomes. A research agenda and provisional considerations for empirical research are outlined based on the present analyses.
5.3 Introduction

The construct of Quality of Life (QoL) is receiving increasing attention in studies of bipolar disorder (BD; (Murray & Michalak, 2012), but the field remains characterised by a wide variety of measurement instruments, underpinned by an absence of consensus definition (Michalak, Yatham, & Lam, 2005). Earlier work on QoL in schizophrenia suggests these conceptual issues are not trivial: In that domain, QoL has been described as an ‘unfulfilled promise’, with unaddressed definitional and measurement issues limiting real world impact in clinical care, trial design, and allocation of healthcare resources (Awad, 2011). We contend that the relatively immature field of QoL in BD should therefore address definitional and measurement issues as a matter of urgency. The aim of this study was to take a first step towards this goal by systematically interrogating the definition of QoL in the existing BD literature.

While traditional outcome measures in mental health are symptom-oriented, QoL is a holistic concept assessing the context of consumers’ lives. QoL was initially adopted in the general medical field as a means of contrasting symptom benefits with broader impacts of an intervention (Pennacchini, Bertolaso, Elvira, & De Marinis, 2011), and was further recognised as a means for representing consumer interests in research as well as clinical practice (Higginson & Carr, 2001). The concept of QoL holds particular appeal as a target for interventions in chronic, severe mental illnesses such as BD (Li-Yu & Su-Ting, 2011), and has been viewed as a means of moving beyond focus on so-called ‘misery statistics’ to the individual as a whole (Murray & Michalak, 2012). As such, the integration of QoL in BD research and practice converges with the recovery movement which emphasises the importance of living a meaningful life despite the impacts of illness (Anthony, 1993). Indeed, patients with BD have rated improvements in QoL as the most important treatment outcome (Mączka et al., 2010). QoL has enormous potential as a disruptive concept in BD, and a broad range of potential real-world applications for QoL in BD have been highlighted in the literature, including developing interventions that directly target QoL, weighting medication effects with QoL impacts, incorporating the patient perspective in treatment, and individualised treatment planning (Murray & Michalak, 2012).

The intuitive appeal of the QoL concept is reflected in its use in fields beyond mental health, including economics, general medicine and philosophy. The inherent personal meaning of QoL makes its specification as a scientific construct challenging, and the QoL
literature often relies on lay understanding rather than explicit definition (Ferrans, 2005). While there is no consensus, the vast number of existing definitions may be at least partly understood by considering three broad philosophical approaches to QoL (Parfit, 1984):

a) Hedonism – The experience of positive mental states (either affective, such as happiness, or cognitive, such as satisfaction) leads to good QoL.

b) Desire-satisfaction – Good QoL is achieved when an individual has many satisfied wants and few unsatisfied wants.

c) Objective list theories – There are a number of universal human needs, the satisfaction of which contributes to good QoL.

Unsurprisingly, complexity at the level of definition engenders tensions at the level of measurement of QoL. Controversy exists over the dimensional structure of QoL, with the idea that there may be a global construct of QoL contrasted by multidimensional perspectives (Cummins, 1996). The number of dimensions incorporated into multidimensional views of QoL also varies – one review identified 173 proposed domains (Cummins, 1996). Questions of whether QoL is best described through objective factors such as housing status or employment, or evaluated by individual themselves, naturally lead to radically different measurement instruments. It has been argued that purportedly universal measures of QoL are unlikely to adequately reflect the priorities and experiences of particular patient groups, and disorder-specific instruments are required (Bowling, 1995). Finally, the focus on growth and wellness seen in the recovery-oriented approach to QoL is often not reflected in operationalisation of the construct, with indices typically focusing on indicators of ill health and disability (Bowling, 2008; Keyes et al., 2012). As highlighted by Awad (2011), such definitional and measurement tensions have immediate, practical impacts on the use and relevance of QoL in the mental health field.

The burgeoning use of the QoL construct in BD research and practice now demands the field grapple with such definitional issues, given their clear implications for measurement. While previous systematic reviews of QoL in BD have tackled important empirical questions (Dean et al., 2004; Ishak et al., 2012; Michalak, Yatham, & Lam, 2005; Namjoshi & Buesching, 2001), issues of definition and measurement have not yet been systematically addressed. The primary aim of the present study was to undertake the first review of the definition and usage of the QoL construct in the BD literature, with a secondary aim to explore the impact of definition and usage on measurement. The project had a single overarching question – What does ‘quality of life’ refer to in BD research?
The present project. To achieve the project’s aim, a systematic literature review of empirical papers investigating QoL in BD was conducted. Identified papers were analysed using thematic analysis which integrated: (a) explicit discussion of QoL definitional/measurement issues, and (b) usage of the term QoL, as indicated by its pattern of referents and associated constructs in text. Thematic analysis was deemed appropriate for the aims of the present systematic review, as it permits identification of underlying concepts. Thematic analysis also provides clarity on how concepts were identified and grouped, addressing the lack of transparency noted in narrative systematic reviews (Dixon-Woods, Agarwal, Jones, Young, & Sutton, 2005).

5.4 Methods

5.4.1 Search Strategy and Inclusion/Exclusion Criteria

We performed a search of titles, abstracts and keywords through the databases Psychnet, Pubmed and Scopus as of 14th April 2015 (no backward time constraint was used) for variants of the terms “bipolar disorder” and “quality of life”. Articles were included if they used a measure with “quality of life” in the name, defined a measure as indexing QoL or used the 36-item Short Form Health Survey (SF-36; Ware & Sherbourne, 1992), a high profile measure commonly understood to represent QoL in general medical research (Higginson & Carr, 2001).

Exclusion criteria were applied to tighten focus of the review. Articles were excluded if they, 1) included diagnoses other than BD in reports of QoL data, 2) reported on a BD sample identified by self-report, a screening measure, or the quantitative dimension ‘bipolarity’ 3) did not report original data, or 4) were written in a language other than English.

The full texts of all identified articles were screened against eligibility criteria by the first author. A second reviewer screened a random 10% sample. As reviewer agreement of the sample exceeded the accepted criterion ($k = .085$; Higgins & Deeks, 2008), the first reviewer was responsible for screening all articles for eligibility.
5.4.2 Data Analysis

Figure 5.1 summarises the approach to data analysis.

Following Boyatzis (1998), thematic analysis was conducted through a line-by-line analysis of included papers where relevant text was coded using qualitative data analysis software NVivo (Version 10 for PC, QSR International Pty Ltd). Data was inductively open coded: codes were not presupposed (Morse & Richards, 2012; Richards, 2015). The reviewed articles contained only limited discussion of the definition and measurement of QoL, so little interpretative analysis was warranted. Consequently, findings are primarily presented at the level of descriptive, literal categories rather than themes (Braun & Clarke, 2006). Vote counting was used at this stage to as a descriptive technique to make explicit the prevalence of categories across studies (Guest, MacQueen, & Namey, 2012).

To address the overarching aim of the systematic review, data was coded addressing both, (a) explicit discussion of QoL definitional/measurement issues, and (b) usage of the term QoL. Usage of the QoL construct was inferred from the text describing QoL or the measurement instruments used (a subsidiary analysis investigated congruence between individual articles’ usage of the QoL construct and item content of utilised measurement instruments, as a means of exploring measurement implications of identified usage categories). Investigation of the co-occurrence of categories (that is, the occurrence of data representing different categories within the same extract) was used as a means to identify possible relationships within the data (Guest et al., 2012). The conceptual implications of co-occurrence were further investigated with exploration of commonalities and differences in authors’ usage of QoL.
5.5 Results

5.5.1 Studies Identified

Figure 5.2 presents a flowchart illustrating the search and identification of relevant articles. 1246 unduplicated research articles were identified; of these, 971 were excluded. A total of 275 studies were included in the analysis. For a full summary of the details of included studies, refer to the supplementary materials in the online version of the published article (http://www.jad-journal.com/article/S0165-0327(16)31892-4/).
The majority of studies were conducted in Western countries with adult populations (61 articles included a non-Western sample, and 12 studies investigated child/adolescent groups). Sixty-seven articles reported on randomised control trials (44 of which investigated pharmacological interventions, and 12 investigated psychosocial interventions). The trend of increasing interest in QoL in the BD literature noted by Murray and Michalak (2012) was observed to continue, as shown in the proportion of identified studies published over the previous 15 years (see Figure 5.3).
As expected, a variety of QoL measurement instruments were used in the BD literature. A total of 53 different measures were observed (variants of measures such as the SF-36, SF-20, and SF-12 were counted separately). The majority of instruments were used in less than 10 articles each. The seven measurement instruments used in more than 10 articles are listed in Table 5.1. For a full summary of measurement instruments used to assess QoL in the BD literature, refer to Appendix F.

Table 5.1.

*Frequency of use of common quality of life measurement instruments in the reviewed literature.*

<table>
<thead>
<tr>
<th>Measurement Instrument</th>
<th>Number of sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>SF-36</td>
<td>67</td>
</tr>
<tr>
<td>WHOQOL-BREF</td>
<td>52</td>
</tr>
<tr>
<td>Q-LES-Q</td>
<td>39</td>
</tr>
<tr>
<td>SF-12</td>
<td>22</td>
</tr>
<tr>
<td>EQ-5D</td>
<td>21</td>
</tr>
<tr>
<td>Q-LES-Q SF</td>
<td>13</td>
</tr>
<tr>
<td>EQ-VAS</td>
<td>10</td>
</tr>
</tbody>
</table>
5.5.2 Explicit Consideration of Quality of Life Definitional/Measurement Issues in the Bipolar Disorder Literature

Four major categories of issues were identified from thematic analysis of text explicitly addressing QoL definitional/measurement issues.

5.5.2.1 The definition of quality of life

As expected, explicit definitions of QoL were rare in the BD literature, and across papers providing an explicit definition, no consensus definition of QoL in BD was observed. A small number of articles (n = 7, 2.5%) explicitly addressed the absence of a consensus definition in the BD literature. Lack of conceptual clarity was described as presenting challenges for empirical work: e.g., Watson, Swan and Nathan. (2011, p. 265) raise the issue of synthesising research using diverse definitions of QoL: “Integrating research…is challenging due to differences across studies in QoL conceptualisation”. Relatedly, a section of the literature (n = 8 articles, 2.9%) noted the plurality of QoL measurement instruments in use is a barrier to integrating empirical evidence.

An explicit definition of QoL was provided in n = 36 articles (13.1%). The single most common definition (n = 15, 41.7% of definitions) originated from the World Health Organization (WHO; The WHOQOL Group, 1995, p. 1405) viz., “an individual’s perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”.

A subset of definitions emphasised QoL in BD as being determined by health (n = 8, 22.2% of definitions). For example, Kolotkin et al. (2008, p. 749) referred to Testa and Simonson’s (1996) definition of health-related QoL as, “the impact of health or disease on physical, mental, and social wellbeing from the patient’s point of view”. In contrast, several papers (n = 5, 13.9% of definitions) explicitly characterised QoL as extending beyond the impact of disorders. For example, Akvardar et al. (2006, p. 693) referenced the definition of Quilty, Van Ameringen, Mancini, Oakman and Farvolden, (2003) stating, “[QoL] encompasses those aspects of life that make it particularly fulfilling and worthwhile. The scope of [QoL] therefore extends beyond traditional symptoms and includes patients’ subjective feelings of wellbeing, satisfaction, functioning and impairment”.

While most definitions of QoL in the BD literature emphasised the role of an individual’s own perception of their QoL, some incorporated objective factors (n = 3, 8.3% of
definitions). For example, Guan, Deng, Cohen and Chen (2011, p. 294) referred to Lochner et al. (2003): “The concept of [QoL] covers a range of objective and subjective domains that reflect an individual’s global physical and mental wellbeing, including family and social relations, scholastic and work function, financial and health status, and living situation”.

5.5.2.2 Limitations of self-report

Despite frequent emphasis on an individuals’ own evaluation of QoL in explicit definitions (above), the inherent subjectivity of self-report measures was sometimes described as a limitation (n = 52, 18.9%). Concerns included, “demand characteristics” (Fulford, Peckham, Johnson, & Johnson, 2014, p. 496), “social-desirability bias” (Goossens et al., 2008, p. 282), and inability to verify self-reports (e.g., J. Russo et al., 1997, p.173, state: “We have no real knowledge of the veracity of the responses to the objective functional items”). The most commonly cited concern relates to the influence of mood state on QoL reports in patients with BD, or affective bias.

Affective bias was described as a limitation of self-report measures of QoL in n = 28 articles (10.18%). Authors suggested that manic symptoms may lead to inflated self-reports of QoL, while depressive symptoms might negatively bias ratings. For example, Russo et al. (1997, p. 173) note: “The elevated mood characteristic of mania may inflate satisfaction scores, regardless of their functional correlates”. Gazalle et al. (2007, p. 250), observe, “Inner feelings of worthlessness and pessimism might influence bipolar depressives to underestimate their aspects of QoL”.

Indeed, some studies restricted study inclusion to avoid affectively biased reports. Sierra et al. (2005, p. 162) for example, used an exclusively euthymic sample: “As depressive mood could distort patients’ perceptions and cause them to overestimate their levels of functional impairment, we selected patients who were actively euthymic at the time of the study”. It was also observed that item content of some QoL questionnaires may tap current affective state, potentially impacting interpretability of results. Fenn et al. (2005, p. 54) note as a limitation of the SF-36 Mental Component Summary (MCS) score: “MCS is heavily weighted toward symptoms commonly found in depressive and anxiety disorders (e.g. lack of energy, nervousness) so that some correlation with current depression and anxiety may be suspected on this basis alone”.

Relatedly, the impaired insight associated with clinically significant changes in mood in BD was identified as a potential factor impacting self-report (n = 18, 6.55%). Goldberg
and Harrow (2005, p. 87) suggest that impaired insight may explain observed discrepancies between objective and subjective ratings of QoL: “Such a phenomenon could involve the denial of illness and its consequences, and refusal to acknowledge unfavourable life circumstances”.

In contrast to concerns about affective bias as a potential confound, however, a small number of papers explicitly considered mood state a valid contributor to subjectively experienced QoL ($n = 4, 1.45\%$). For example, Bonnin et al. (2012, p. 656), while acknowledging the potential overlap between symptoms of depression and item content of the QoL measure SF-36, emphasise that this provides useful information regarding a patient’s own perspective of their QoL: “The SF-36 may be biased with the depressive residual symptomatology…nevertheless, these instruments may be useful to know the patients’ point of view with regard to their functioning and quality of life”. Hodgson, Pattison, Bostock, Murphy and Stewart (2007, p. 270) comment more emphatically on the ethical implications of disregarding subjective ratings due to the perceived influence of psychopathology: “There is a risk of marginalising patients with mental illness if the validity of their perspectives is discounted”.

### 5.5.2.3 Generic versus disorder specific measures of quality of life

A tension between generic versus disorder-specific measurement of QoL was evident in the BD literature. A number of studies ($n = 7, 2.54\%$) described generic measures as conferring benefits to the measurement of QoL, primarily due to their ability to support comparisons across groups. For example, Macqueen et al. (2000, p. 375) support the use of generic measures as, “…not only because broad domains are assessed but also because comparisons between illness groups can be made”.

However, a greater number of papers ($n = 24, 8.7\%$) described their use of generic measures as a limitation. Authors noted that generic measures may not capture aspects of QoL that are particularly relevant to individuals with BD or be sufficiently sensitive to detect change in BD populations. For example, Goldberg et al. (2010, p. 33) wrote: “an advantage of disease-specific instruments is their greater sensitivity to detect change by focusing on areas of functioning most affected by the disorder. It is also uncertain whether generic measures adequately encompass or accord due weight to domains that are unique to bipolar illness, such as affective dysregulation, sleep and other chronobiological variations, and cognitive deficits.”
A number of authors called for the development of a BD-specific instrument. For example, Gazalle et al. (2007, p. 251) state: “[The development of] QoL instruments addressing particular aspects that are relevant in course of BD is a necessary step in understanding the subjective burden of the bipolar illness.” Later studies observed that the first disorder specific QoL measure, the Quality of Life in Bipolar Disorder scale (QoL.BD; (Michalak & Murray, 2010b), constituted a useful alternative for researchers concerned about the limitations of generic measures: “[The QoL.BD] has shown improved sensitivity to changes in clinical state compared to the Q-LES-Q” (2013, p. 196).

5.5.2.4 Use of multiple quality of life measures

Multiple QoL measures were used in 37 of the reviewed articles (13.5%). Justification for the application of multiple QoL measures, however, varied. The tension between generic and disorder-specific measurement of QoL was addressed through use of multiple measures. Hakkaart-Van Roijen et al. (2004, p. 391), suggest: “Future [QoL] study of patients with [BD] should include diagnosis-specific [QoL] instruments as well as generic health-rating instruments”. Alternatively, use of multiple measures was presented as capturing a broader spectrum of QoL. For example, Caldirola et al. (2014, p. 984) state: “Subjective QoL was assessed by different instruments that probably capture distinct concepts related to QoL”. Other authors described capturing both broad and more specific aspects of QoL. Michalak et al. (2013, p. 190), for example, used multiple measures and described the Q-LES-Q as, “[representing QoL] broadly, rather than health-related QoL, which is the specific focus of the SF-36”.

5.5.3 Usage of the Term ‘Quality of Life’ in the Bipolar Disorder Literature

The second step of analysis was to move beyond authors’ explicit discussion of definitional issues in QoL by investigating the construct’s usage in the reviewed articles. Four usage categories emerged: QoL as related to functioning: \( n = 103 \) sources; 37.5%), QoL as related to health \( n = 91 \); 33.1%), QoL as related to subjective experience \( n = 88 \), 32%), and QoL as related to wellbeing \( n = 44 \), 16%). These categories will be examined individually here: Consideration of the relationship between explicit (above) and implicit meanings of QoL (next) in the BD literature is reserved for the Discussion.

5.5.3.1 Quality of life as related to functioning

The most common referent of QoL in identified articles was functioning \( n = 103 \) sources, 37.5%). The meaning of the term ‘functioning’ itself was rarely explicated, although
42 sources (40.8% of functioning usage examples) either described domains of functioning or further specified the type of functioning under consideration, including: physical, mental, emotional, social, occupational, familial, health and role functioning.

Usage of the QoL construct in relation to functioning took a number of forms. In some sources, functioning was considered subsidiary to QoL. For example: “Quality of life may be viewed as the overall concept, encompassing both symptoms and functioning” (van der Voort et al., 2015, p. 14). The inverse relationship was also observed, where QoL was presumed to be subsidiary to functioning: “QoL has gained increasing attention as an important, yet underappreciated component of functional outcome” (Eissa et al., 2012, p. 222).

Of note, a number of sources connected functioning to disability or impairment, implying negative deviance from normative standards of functional status. For example, Rubio et al. (2013, p. 446) introduce concepts of disability when discussing subscales of the SF-12 (a derivative of the SF-36): “Each SF-12 disability scale is a norm-based score …with higher scores indicating less disability”. Functional limitations were also described as a causal influence on QoL: “Many recovered BD patients have functional impairments, which can lead to poor [QoL]” (Kim et al., 2013, p. 246).

The most common instrument used in articles where a functioning referent was observed was the SF-36 (Ware & Sherbourne, 1992). Item content of the SF-36 broadly reflected this usage: respondents are asked to judge the degree to which their health (physical or emotional) limits them in activities they may do in a typical day.

5.5.3.2 Quality of life as related to health

While \( n = 8 \) articles explicitly defined QoL in BD as being related to health (above), usage of QoL as related to health was observed in 91 sources (33.09%). A commonly occurring referent within this category described QoL with the acronym ‘Health-related QoL’ (HrQoL). While the role of illness in determining QoL was sometimes made explicit in such usage (e.g., Bajor et al., 2013, p. 2 state: “[HrQoL] is reliable indicator of disease burden”), more frequently the term HrQoL was not expanded upon. Similar to functioning referents, usage of QoL as related to health emphasised the role of illness and symptoms (e.g., ‘disease burden’) in causing deviations from normative health status.
A variety of relationships between the QoL construct and health were observed. For example, QoL appeared as an indicator variable for health: “[QoL] is an important indicator of health” (Cardoso et al., 2014, p. 896). In some uses, health as a referent for QoL appeared to describe a more specific aspect of QoL, e.g., Guilera et al. (2014, p. 355) specify their interest in QoL as related to health: “[The EQ-5D] was applied to consider [QoL] in relation to health status”. Of note, usage of QoL as related to health was sometimes linked to economic applications. For example, Martín-Subero et al. (2014, p. 1542) describe the EQ-5D as, “a non-disease specific instrument for describing and valuing health states”.

The EuroQol Five Dimensions (EQ-5D; Balestroni & Berolotti, 2012) was most frequently used in articles where usage of QoL as related to health was observed. Item content accordingly reflects a health focus: respondents are instructed to indicate “which statements best describe your own health state today” in areas including mobility, self-care, usual activities, pain, and anxiety/depression.

Suggesting some overlap between usage of QoL as related to health and functioning, the SF-36 was also commonly used in articles where a health referent was observed. As detailed above, item content of the SF-36 links disease to functioning by asking respondents to specifically consider the physical and emotional limitations imposed by their ill-health.

### 5.5.3.3 Quality of life as related to subjective experience

While the subjectivity of QoL measures was often cited as a limitation (above), the construct of QoL was frequently linked to subjective experience in the reviewed literature ($n = 88, 32\%$). Text referring to an individual’s first-person assessment of their own QoL (indicated by terms such as ‘subjective’, ‘perceived’, ‘satisfaction with’ and ‘self-rated’) was grouped under this category.

A subset of text grouped under the category of subjective experience was considered to represent a more specific variant of usage, namely *satisfaction* ($n = 40, 45.4\%$ of subjective usage examples). In some sources, satisfaction was considered an indicator variable for QoL (e.g., “life satisfaction, which is one of the indicators of the subject well-being and is related to QoL”; De Abreu et al., 2012, p. 128), while a number of papers elevated satisfaction as *integral* to the construct of QoL (e.g., “The basic concept of QoL emphasises the patient’s subjective appraisal of their own satisfaction”; Latalova et al., 2011, p. 21).
Two measures emerged as associated with use of a subjective experience referent: The World Health Organization Quality of Life (Brief) scale (WHOQOL-BREF; The WHOQOL Group, 1998) and the Quality of Life Enjoyment and Satisfaction Questionnaire (Q-LES-Q; Endicott et al., 1993). The WHOQOL-BREF asks respondents about a variety of subjective experiences, such as “How good or satisfied you have felt?” The Q-LES-Q emphasises satisfaction, asking participants to rate their satisfaction in various life areas.

5.5.3.4 Quality of life as related to wellbeing

A total of 42 sources (15.3%) contained references to QoL as related to wellbeing. As seen above with ‘functioning’, the term ‘wellbeing’ was rarely explicated. In a subset of these articles, \( n = 14, 31.8\% \), wellbeing was characterised as multidimensional (e.g., physical, social, emotional, and mental wellbeing). Specific references to psychological wellbeing were made in a number of articles \( n = 6, 14.3\% \) of wellbeing usage examples.

QoL was most often referred to as an indicator variable of wellbeing. For example, Mackala, Torres, Kozicky, Michalak and Yatham (2014, p. 119) describe the assessment of QoL in BD as, “…an indicator of patient wellbeing and subjectively reported outcomes”. However, some authors considered these equivalent constructs, e.g., Brissos, Dias, and Kapczinski (2008, p. 518) state: “[the] subjective feeling of wellbeing… closely relates to the concept of QoL”.

Of note, wellbeing was characterised as a positive experience, e.g., Kebede et al. (2006, p. 241) explicitly differentiate wellbeing from limitations: “sub-scales of the SF-36, such as mental health, vitality, and general health perception, assess the patient’s subjective sense of wellbeing and depression rather than disability.”

Measures commonly used in articles with a subjective experience referent (WHOQOL-BREF and the Q-LES-Q) were similarly found in articles containing a wellbeing referent, suggesting some overlap between these constructs. Item content of these measures was coherent with the wellbeing construct: for example, the WHOQOL-BREF asks respondents about positive emotional experiences (above).

5.5.4. Exploring Usage of Quality of Life: Inferences from Co-occurrence

It was an assumption of this review that the absence of a consensus definition of QoL in the BD literature would lead to a complex pattern of usage. Patterns of co-occurrence of
categories of usage (summarised in Table 5.2) were examined as an initial step in integrating some of this conceptual complexity.

Table 5.2.

Frequency of co-occurrence of themes of quality of life usage within the same article.

<table>
<thead>
<tr>
<th>Functioning (n = 103)</th>
<th>Health (n = 91)</th>
<th>Subjective experience (n = 88)</th>
<th>Wellbeing (n = 44)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functioning</td>
<td>40</td>
<td>45</td>
<td>31</td>
</tr>
<tr>
<td>Health</td>
<td></td>
<td>28</td>
<td>23</td>
</tr>
<tr>
<td>Subjective experience</td>
<td></td>
<td></td>
<td>25</td>
</tr>
</tbody>
</table>

Close examination of co-occurrence examples suggested health, wellbeing and functioning were sometimes described as separable facets of QoL: Revicki et al. (2005, p. 185), for example, describe the SF-36 as measuring both “patient functioning and wellbeing”. The co-occurrence of these three referents suggests a point of view in which the construct of QoL is multi-faceted, emerging from a combination of good health, functioning and wellbeing. Unsurprisingly, given the conceptual overlap noted above, health and functioning were closely linked in the usage of QoL, with a number of examples synthesising health and functioning into one concept, e.g., “functional health status” (Lev-Ran, Le Foll, McKenzie, George, & Rehm, 2013, p. 460) and “general health functioning” (Kilbourne et al., 2008, p. 762).

Co-occurrence analysis showed wellbeing was often characterised as a subjective experience, such as a ‘feelings of wellbeing’ or ‘sense of wellbeing’. For example, Cramer, Torgersen and Kringlen (2010, p. 59) described subjective wellbeing as an affective experience, asking participants, “to characterise their life from very happy to very unhappy”. Overlap between the concepts of QoL as related to subjective experience and QoL as related to wellbeing reflects the association of these concepts with the same measures (above). Co-occurrence of satisfaction and wellbeing referents suggested an interwoven yet distinct relationship between these concepts, in which feelings of wellbeing emerged as a
consequence of satisfaction with various life domains: “an individual’s sense of wellbeing that stems from satisfaction or dissatisfaction with areas of life that are important to him/her” (Eissa et al., 2012, p. 223).

Subjective experience referents were also used to characterise QoL as related to functioning. For example, MacQueen et al. (2000, p. 375) describe a measurement instrument as reflecting an individual’s subjective assessment of their functional status: “[A] self-report measure of function”. Of note, proximal overlap of codes representing QoL as related to functioning and QoL as related to satisfaction were less common, suggesting a distinction between an individual’s description of their functional status and the more evaluative satisfaction with functioning. This conceptual distinction was mirrored in a number of co-occurrence examples which described functioning as an objective concept distinct from satisfaction and subjectively experienced wellbeing, as in Russo et al. (1997, p. 167) who described the Quality of Life Interview as assessing “both objective functional status and subjective patient satisfaction”. There was little overlap between the usage of QoL as related to health and QoL as related to subjective experience, paralleling the distinction observed in thematic analysis of explicit definitions (above). The few examples of co-occurrence between health and subjective experience referents suggest that similar to functioning, there is a conceptual distinction between self-reported descriptions of health as compared to evaluative, satisfaction based subjective experiences. For example, the EQ-5D and a satisfaction-based single item measure were differentiated on the basis of the former’s concern with assessment of symptoms and functioning and the latter’s individualistic, value-laden assessment: “Whereas the HrQoL instruments used require answers to a predefined set of questions concerning symptoms and functioning, the subjective QoL here means global life satisfaction as defined by the respondent” (2010, p. 387).

5.6 Discussion

The present systematic review sought to address the question ‘What does ‘quality of life’ refer to in BD research?’ A total of 275 articles were investigated with thematic analysis of, (a) explicit discussion of QoL definitional/measurement issues in the BD literature, and (b) usage of the term QoL in the BD literature. As expected, a series of important, currently unresolved definitional and measurement issues were identified. These findings will be reviewed as a basis for proposing a research agenda to move the field forwards.
The construct of QoL was rarely explicitly defined in identified articles; no consensus definition was evident across studies (Section 5.5.2, above). Definitional tensions discussed include the role of mood in QoL in BD, and generic versus disorder-specific measurement. The issues of the impact of mood states intrinsic to BD was divisive, with some authors concerned that depression and mania may bias self-report, while others considered mood central to the experience of QoL in BD. The utility of generic measures in supporting comparison across populations was noted, however a substantial number of articles described such measures as poorly suited to capturing aspects of QoL specific to the experiences of individuals with BD. Some authors recommend utilising multiple measurement instruments to circumvent definitional ambiguity and measurement tensions.

The present analyses aimed to go beyond the limited explicit discussion of QoL definitional/measurement issues to also systematically review the usage of the term QoL, as captured in its referents and the constructs with which it is associated (Section 5.5.3, above). Thematic analysis of usage of the QoL construct identified four major categories, namely, QoL as related to functioning, QoL as related to subjective experience, QoL as related wellbeing, and QoL as related to health. Critically, significant ambiguities were identified: for example, researchers alternately described functioning as a construct subsidiary to QoL and vice versa. Some trends emerged: functioning was sometimes characterised by the experience of disability or impairment, whereas wellbeing was described as a positive experience that extended beyond the impact of health and symptoms. QoL as a subjective experience was often further characterised as satisfaction, suggesting a cognitive process of appraising one’s own life circumstances and feelings towards these. When health referents were used to characterise QoL, thematic analysis suggested authors were interested in aspects of QoL impacted by or specific to health. Identified usage categories parallel explicit definitions: the relationship between QoL and subjective experience, health or wellbeing was considered in more detail in explicit definitions. Of note, functioning did not emerge as prominently in explicit definitions as it did in the usage analysis of the QoL construct. Use of subjective experience referents of QoL contextualises the discussion of the limitations of self-report: despite concerns about potential biasing impact of mood, in the BD literature the QoL construct was frequently associated with subjective experience.

Not surprisingly, the above usage categories were not independent. Analysis of co-occurrence of categories found existence of multiple referents of QoL in the same article was common, and analysis of co-occurrence was able to illuminate patterns of associations.
between common referents of QoL in BD. Co-occurrence analysis suggests that wellbeing is largely characterised as a subjective experience, sometimes positioned as a positive, affective experience that arises out of cognitive appraisals of satisfaction with life domains. The concepts of functioning and health were closely interwoven, at times elevated to a singular concept, e.g., ‘functional health status’, and as noted in the usage analysis are conceptually similar in their focus on symptom-influenced deviations from normal status. In cases where health and functioning were self-reported, this was more often descriptive as compared to evaluative, satisfaction-based assessments. This co-occurrence analysis therefore suggests broad groupings of the identified QoL referents under two overarching ‘fuzzy’ concepts, as illustrated in a provisional figurative representation (Figure 5.4). One concept refers to the ideographic/evaluative nature of subjective experience, satisfaction, and wellbeing referents of QoL, which were sometimes emphasized as positive, unique to the individual, and impacted by affective states. The other encompasses functioning and health referents, which share focus on normative aspects of QoL which may be objectively observed or described by the individual, deviations from which are framed as disability and limitations. The two concepts have important overlap: as noted in the usage analysis and few examples of explicit definition, satisfaction and wellbeing may be influenced by health and functioning, while the focus of health and functioning can broaden beyond negative illness impacts to incorporate positive psychological variables such as wellbeing. Overall, patterns of usage suggest identified referents relate to one another in unique ways, and theoretical work is required to clarify these concepts in the context of QoL in BD.

The diversity of meanings of QoL in BD highlighted by the preceding review and the resulting range of measurement instruments in use might lead researchers to despair about choice of measurement instrument. However, a reassuring coherence was found at the level of individual articles between the usage of QoL and authors’ choice of measurement instruments. This presents one strategy for empirical researchers seeking guidance regarding the selection of QoL measures, namely, to choose between the most prevalent instruments in the BD literature on the basis of their alignment with various concepts relevant to the definition of QoL.

The conceptual work undertaken is important in highlighting unrecognised problems in the existing literature. For example, the systematic review of Ishak et al. (Ishak et al., 2012) concluded that HrQoL often improves with pharmacological and psychosocial interventions. However, upon closer inspection, the majority of articles reviewed by Ishak et
al. addressing this question utilised the Q-LES-Q. As discussed (Sections 5.5.3.3 and 5.5.3.4, above), item content of the Q-LES-Q appears to be relevant for investigating QoL as related to subjective experience and wellbeing, concepts which co-occurrence analysis suggest have little overlap with health. In addition, it follows that by critically examining articles for their usage of QoL and corresponding choice of measurement instrument, clinicians will be better able to select treatments on the basis of specific QoL outcomes and assist consumers to choose between treatments according to patient-valued outcomes.

![Figure 5.4. ‘Fuzzy’ concepts organising quality of life referents identified in the bipolar disorders literature.](image_url)

**5.6.1 Research Agenda**

The present review suggests that an urgent task facing the BD field is to confront definitional and measurement tensions. A series of questions arising from the present review are outlined for the consideration of the field, with relevant insights introduced from the broader QoL literature. Although a return to more conceptual work is clearly required, we recognise that this process will occur in parallel with ongoing empirical investigation of QoL in BD. Provisional, pragmatic suggestions for addressing definitional and measurement issues in empirical investigations are therefore outlined in Box 1. The strategies summarised in Box 1 should not be understood as methodological prescriptions; they are provisional conceptual considerations arising from the present analyses, and do not address more concrete assessment issues such as psychometric properties of individual instruments, trajectory of assessments, etc. (Bowling, 2001; Higginson & Carr, 2001).
5.6.1.1 Definition of quality of life in bipolar disorder

As discussed above, there was no consensus definition of QoL in BD. The present review identified a diverse range of concepts thought to be important to QoL in BD, and ways in which these concepts may relate to one another. We can make sense of identified usage categories according to philosophical approaches to QoL described by Parfit (above; 1984): The usage of QoL as related to functioning and QoL as related to health accord with objective list theories of QoL, which suggest there are a number of normative standards of living which must be achieved for good QoL (including good health and role functioning). Hedonism approaches to QoL were also apparent in the BD literature, with wellbeing referents of QoL suggesting the importance of positive affective states, and satisfaction referents of QoL suggesting a role of cognitive appraisals. While no usage categories explicitly considered the preferences of individuals, the commonly cited WHO definition of QoL (1995, p. 1405) is consistent with the desire-satisfaction approach. Existing work regarding QoL following the above philosophical approaches may serve as guidance for developing theories of QoL in BD.

It has been observed that QoL in BD likely shares conceptual overlap with QoL generally, QoL in psychiatric illnesses, and has components specific to the experience of individuals with BD (Michalak & Murray, 2010b). While conceptual work in the broader QoL literature may provide direction, the present study found that QoL was frequently presumed to have a disorder-specific component – specific domains of QoL are prioritised by individuals with BD, or the disorder specifically impacts certain domains of QoL. Accordingly, the BD literature cannot rely exclusively on definitions and models drawn from the broader QoL literature. Rather, development of theory specific to the experience of QoL in BD is required (for some observations on this issue, see Michalak & Murray, 2010b).

Theoretical clarification of QoL in BD may be achieved by exploring relationships between existing measurement instruments. For example, large sample cross-sectional studies using multiple QoL measures would support factor analyses to identify potential underlying structures (Dixon, 2001). Comparing QoL measures to symptom ratings across time will provide further clarity around the role of mood changes. Additionally, there is a dearth of qualitative studies regarding the experience of QoL in BD, despite prominent usage of QoL as related to subjective experience. It has been suggested in the schizophrenia literature that
work in which individuals are asked to define their own QoL is required to complement top-down theoretical work (Gee, Pearce, & Jackson, 2003).

Description of the same constructs as either causal or indicator variables is a point of ambiguity in the BD literature. In the broader QoL literature, the distinction between these classifications is recognised as critical in conceptualising QoL: Causal variables are factors believed to impact QoL such as symptoms of disease (Fayers & Hand, 1997): Low scores on a particular causal variable do not necessarily equate to poor QoL, which will have multiple determinants. Indicator variables, by contrast, are highly correlated with a latent construct. For example, Boehmer and Luszczynska (2006) consider emotional functioning to be an aspect of HrQoL, and consequently view a change in this indicator variable as ipso facto a change in HrQoL. The BD literature must pay closer attention to the distinction between such variables when conceptualising QoL.

Theoretical work must address an explicit concern in the BD literature: Does the experience of pathological mood states in BD confound QoL self-report, or is mood to be considered an integral factor of QoL in BD? It would be of interest to quantify the extent to which mood influences different measures of QoL, and for future empirical research to include mood measures in models of QoL in order to gather further data on this central question (see Box 1).

Across reviewed articles, functioning referents of QoL were often associated with negative indicators such as disability and ill health. In the broader QoL literature, measures focusing solely on negative indicators have been criticised for excluding positive concepts (e.g., ability, satisfaction, or wellbeing), such that the full range of QoL is not adequately represented (Bowling, 2008; Keyes et al., 2012). Scales comprised entirely of negative indicators may fail to recognise that satisfaction in some domains of QoL may compensate for dissatisfaction in others (Bech et al., 2003). Perspectives from the broader literature thus suggest caution when applying a functioning referent to QoL in BD: A compensatory strategy may be to also include referents of wellbeing and appropriate measures, which were described in positive terms in the BD literature.

The existence of multiple meanings of QoL in the BD literature suggests that immediate consensus definition of QoL in BD is neither appropriate nor feasible. We propose that the plurality of meaning of QoL observed in the BD literature is not necessarily a weakness. As noted above, the plurality of meanings is consistent with a variety of
philosophical approaches to QoL in the literature, suggesting that fundamentally different concepts may be encompassed by the umbrella term of QoL. Indeed, Katschnig (2006b, p. 139) stated the term QoL may better describe “a field of interest rather than corresponding to a single variable”. What may be required for the advancement of the field of QoL in BD is recognition of and tolerance for diverse perspectives, combined with greater accountability for researchers to explicitly define QoL and justify choice of measurement instrument. Following Awad (2011), it is incumbent upon editors of journals to enforce such standards in the publication process to ensure a higher standard in the QoL in BD literature.

5.6.1.2 Measurement of quality of life in bipolar disorder

Given tensions between different measurement approaches and the diversity of constructs thought to be relevant to QoL in BD identified in the current analyses, specification of a single ‘gold standard’ measure of QoL in BD is unlikely. Rather, researchers need to carefully consider which measurement instrument best serves the aim of a research project or clinical purpose. One pragmatic strategy emerging from this conceptual analysis is to select between prominent, recognised measures on the basis of their overlap with concepts thought relevant to QoL in BD (see Box 1).

A particular tension between measurement approaches identified in the literature concerns the relative applicability of generic or disorder-specific instruments to the measurement of QoL in BD. Generic questionnaires may not adequately capture the experience of particular patient groups (Bowling, 1995; Connell et al., 2014). For example, the disorder-specific QoL.BD (Michalak & Murray, 2010b) contains a number of domains not often seen in generic questionnaires (e.g. spirituality, finances, and identity), and may therefore be more sensitive to small but clinically important changes (Guyatt, Feeny, & Patrick, 1991; Jenkinson & McGee, 1998; Patrick & Deyo, 1989). Both disorder-specific and generic measurement instruments are likely to have unique and important uses: Generic questionnaires, as nomothetic approaches, are useful for investigating aetiological factors and comparing QoL across patient groups (D. P. Goldberg & Huxley, 1992). Conversely, disease-specific ideographic approaches may be more useful for following the progress of an individual over time (D. H. Barlow & Hersen, 1984; Bech, 1990). Common generic measures such as the SF-36, EQ-5D, Q-LES-Q, or WHOQOL-BREF can support comparisons between individuals with BD and other patient groups, while disorder-specific questionnaires such as the QoL.BD may have more relevance in clinical settings or investigations of the effects of a
BD-specific intervention. Although the QoL.BD is likely to have immediate relevance as a tool to promote engagement and facilitate attention to consumer-valued areas in clinical practice (Murray & Michalak, 2012), further attention to its psychometric properties is needed for use in clinical trials. In particular, while the practical importance of an intervention targeting traditional symptom outcomes or concepts of QoL with normative reference points (i.e., functioning, health status) can be benchmarked against clinician-determined clinically significant change, less is known about meaningful change in evaluative, positively framed QoL data such as the QoL.BD in which the occurrence of meaningful change depends on who is being asked (Higginson & Carr, 2001). Methods which explore the minimally important difference by asking individuals with BD to provide a global rating of change in QoL will improve practical utility of the QoL.BD (Guyatt & Schunemann, 2007).

The use of multiple measures adopted by a number of authors in the BD literature (5.5.2.4, above) may form a pragmatic strategy to address conceptual and measurement tensions. In order to develop an optimal profile of QoL tools, greater understanding of the properties of measurement instruments used in BD populations is required, including exploration of underlying constructs and sensitivity to change. Correlations between measurement instruments may provide clarity around the selection of profile of QoL tools. For example, Depp et al. (2006) showed that for older adults, the physical component of the SF-36 correlates positively with the Quality of Wellbeing scale while the mental component did not. Such a finding suggests a need to investigate in more depth the relationships between common QoL measures.

Box. 1

Implications of the present review for empirical research

1. Consider the influence of conceptualisation and measurement of QoL when reviewing relevant background literature.
2. When developing research questions, refer to existing QoL models and definitions.
3. Consider whether nomothetic or ideographic measurement strategies are most appropriate for the research aims: when seeking to identify changes over time in a BD population, consider a disorder-specific measure.
4. One strategy guiding the selection of QoL measures is to choose between major recognised instruments in the BD literature on the basis of their alignment with concepts thought to be relevant to QoL:
   a. The SF-36 (Ware & Sherbourne, 1992) is linked to QoL as related to functioning.
   b. The EQ-5D (Balestroni & Berolotti, 2012) is linked to QoL as related to health.
   c. The Q-LES-Q (Endicott et al., 1993) and WHOQOL-BREF (The WHOQOL Group, 1998) are linked to QoL as related to subjective experience, satisfaction and wellbeing.

5. Consider using multiple measures that index different concepts related to QoL, as well as both generic and disorder-specific instruments (such as the QoL.BD; Michalak & Murray, 2010b), to capture a broader spectrum of QoL.

6. Future research on QoL in BD will benefit from quantification of the extent to which mood impacts various QoL measures. Including mood in models of QoL in BD will add data to inform understanding of this key question.

7. When using recognised referents or definitions of QoL, consider whether research interests align with associated philosophical approaches (Parfit, 1984) as a starting point for interpreting empirical results through the lens of QoL theory:
   a. Hedonism: Wellbeing referents of QoL accord with affective hedonism approaches, while satisfaction referents may suggest a view that QoL is derived from cognitive appraisals.
   b. Desire-satisfaction: The WHO definition (The WHOQOL Group, 1995) explicitly relates QoL to an individual’s consideration of life circumstances in relation to their preferences.
   c. Objective List Theories: Health and functioning referents evoke ideas of normative standards associated with good QoL.

5.6.2 Limitations

The review had a number of limitations. First, potentially informative studies were excluded due to reliance on self-reported diagnoses of BD (e.g., Michalak and Murray's development of the QoL.BD; 2010b). Second, reliability of thematic analysis was optimised.
by discussion through the research group, however, no verification of reliability of coding decisions occurred. To maintain transparency regarding identified categories, vote counting was used to explicitly describe the prominence of QoL referents, and illustrative quotes provided. Due to the lack of expected richness of discussion of QoL definition and measurement in the reviewed literature, interpretative themes could not be produced to explore the role of QoL in BD in greater depth. Finally, the review does not speak to how existing definitions of QoL may be relevant in a BD context. Rather, our analytic approach was grounded in the existing empirical literature to support specification of definitions relevant to existing usage of QoL in the BD literature, and the development of evidence-informed considerations to support empirical research.

5.7 Conclusion

The present review sought to answer the question of ‘What does ‘quality of life’ refer to in BD research?’ Two complementary approaches allowed us to examine both explicit discussion of definition and measurement, and implicit meanings derived from usage/co-occurrence analysis. Given the dearth of explicit consideration of definition of QoL in BD, a key advantage of our analysis of usage and co-occurrence is that it has made explicit the meanings and concepts thought to be relevant to QoL in BD. Instead of pressing to reduce the field to a single definition, or an optimal ranking of measurement instruments, we propose that the onus is on individual researchers to reflect on and explicate the assumptions of their approach to QoL and associated measurement choices. Hopefully, the present project has facilitated this process for future researchers in this important and expanding area.
CHAPTER 6. STUDY 2: A PROSPECTIVE INVESTIGATION OF THE TRAJECTORY AND DYNAMIC RELATIONSHIP BETWEEN SYMPTOMS OF BIPOLAR DISORDER AND QUALITY OF LIFE
6.1 Chapter Guide


The preceding chapters provided an exploration of the relevance of quality of life (QoL) as an outcome of interest in bipolar disorders (BD), a historical overview of use and measurement of the construct in a broader context (i.e., medical, sociological and philosophical fields), and a summary of current empirical research regarding QoL in BD. The previous systematic review delved further into the conceptualisation of QoL in BD through an investigation of the construct’s definition, usage and measurement. An identified gap in the preceding chapters was the relationship between QoL and affective symptoms of BD: while some cross-sectional analyses had been conducted, the relationship had rarely been examined in a longitudinal context. The present chapter (containing a version of a published article formatted to be consistent with the overarching thesis) describes a prospective investigation of a) the trajectory of QoL in a sample treated according to current best-practice guidelines, and b) the relationship between objective symptom measures and subjective QoL assessments over time. In addition, the present investigation bears relevance for conceptual queries regarding the boundaries of the QoL construct in BD: investigation of the dynamic relationship will inform understanding of the overlap and distinction between mood symptoms and QoL in this condition. Finally, novel analyses using QoL as a predictor for BD symptoms will add to understanding of potential clinical applications of this construct.
6.2 Abstract

Background: Although quality of life (QoL) is receiving increasing attention in bipolar disorder (BD) research and practice, little is known about its naturalistic trajectory. The dual aims of this study were to prospectively investigate: a) the trajectory of QoL under guideline-driven treatment and b) the dynamic relationship between mood symptoms and QoL.

Methods: 362 patients with BD receiving guideline-driven treatment were prospectively followed at 3-month intervals for up to five years. Mental (MCS) and physical (PCS) QoL were measured using the self-report SF-36. Clinician-rated symptom data was recorded for mania and depression. Multilevel modelling was used to analyse MCS and PCS over time, QoL trajectories predicted by time-lagged symptoms, and symptom trajectories predicted by time-lagged QoL.

Results: MCS exhibited a positive trajectory, while PCS worsened over time. Investigation of temporal relationships between QoL and symptoms suggested bidirectional effects: earlier depressive symptoms were negatively associated with mental QoL, and earlier manic symptoms were negatively associated with physical QoL. Importantly, earlier MCS and PCS were both negatively associated with downstream symptoms of mania and depression.

Conclusions: The present investigation illustrates real-world outcomes for QoL under guideline-driven BD treatment: improvements in mental QoL and decrements in physical QoL were observed. The data permitted investigation of dynamic interactions between QoL and symptoms, generating novel evidence for bidirectional effects and encouraging further research into this important interplay. Investigation of relevant time-varying covariates (e.g., medications) was beyond scope. Future research should investigate possible determinants of QoL and the interplay between symptoms and wellbeing/satisfaction-centric measures of QoL.
6.3 Introduction

Bipolar disorder (BD) is a severe mental illness associated with a chronic course and recurring periods of mania and depression, ranked by the World Health Organization as the fifth leading cause of disease burden among mental disorders (Ferrari et al., 2016). Research attention in BD has broadened to include quality of life (QoL) as an important outcome of care alongside symptom management (Morton, Michalak, & Murray, 2017; Murray & Michalak, 2012), and indeed both patients with BD and clinicians have rated improvements in QoL as the most important outcome in the treatment of BD (Mączka et al., 2010). As a person-centred, recovery oriented construct, QoL has powerful potential to represent consumer interests in research and clinical practice (Murray et al., 2017). Naturalistic, prospective investigations offer the opportunity to investigate trajectories of QoL under real-world treatment regimens and inform our understanding of its relationship to symptoms of BD.

While it is sometimes assumed that absence of mental illness equates to mental wellbeing, the two concepts share only a small portion of variance (Keyes, 2005). Consequently, constructs such as QoL have emerged as treatment goals in their own right in the care of mental illnesses generally (Basu, 2004) and in BD specifically (Morton, Michalak, & Murray, 2017; Murray & Michalak, 2012). QoL is prioritised by consumers and thus the personal recovery movement views QoL improvement as an outcome of equal importance to symptom remission (Murray et al., 2017). Popular interest in QoL is paralleled in the scientific BD literature, with publications referencing QoL increasing exponentially over recent years (Murray & Michalak, 2012). These studies show that QoL is impaired in individuals with BD relative to the general population, even during euthymic periods (Brissos, Dias, Carita, et al., 2008; Gutiérrez-Rojas et al., 2008), suggesting that attention needs to be paid to improving this patient-valued outcome. We propose that a critical step towards this goal is to develop understanding of a) the impact of current guideline-driven treatment on QoL in BD, and b) the dynamic relationship between symptoms of BD and QoL: Existing relevant literature is briefly reviewed before introducing the present study.

Attention to the impact of treatment regimens on QoL is needed to validate the assumption that current best practice improves QoL from the consumer perspective. Pharmacological interventions form the bedrock of current treatment guidelines, with psychosocial interventions and self-management strategies increasingly recognised and
encouraged (Yatham et al., 2013), While QoL is increasingly used as a primary outcome variable to judge the *efficacy* of pharmacological and psychosocial interventions through randomised controlled trials (RCTs; e.g., Endicott, Paulsson, Gustafsson, Schiöler, & Hassan, 2008; Endicott et al., 2007; Michalak, Guiraud-Diawara, & Sapin, 2014; Namjoshi et al., 2002; Namjoshi, Risser, Shi, Tohen, & Breier, 2004; Lizheng Shi et al., 2004; L. Shi et al., 2002), it is important to note that RCTs do not represent the reality of clinical practice in which polypharmacy, medication changes and combined pharmacological and psychosocial strategies are common, and patient characteristics are heterogeneous (R. M. Post, 2009). The *effectiveness* of current best practice BD treatment at improving subjective QoL is unknown: naturalistic, longitudinal studies are therefore required to accurately gauge the impact of real world BD treatment strategies on QoL.

A second assumption in need of further investigation relates to the impact of mood symptoms on QoL in BD. Data from cross-sectional studies generally suggest that depressive symptoms are associated with poorer QoL (Gazalle et al., 2006; Gazalle, Frey, et al., 2007; Hayhurst et al., 2006; Simon, Bauer, Ludman, Opserskalski, & Unützer, 2007; Vojta et al., 2001; Yatham et al., 2004; Zhang et al., 2006). The cross-sectional influence of manic symptoms on QoL is less well understood, with some articles finding mania to be associated with poorer QoL, (Gazalle, Hallal, et al., 2007; Simon et al., 2007; Vojta et al., 2001) and others finding no negative impact of mania (Gazalle, Frey, et al., 2007; Hayhurst et al., 2006). However, cross-sectional studies cannot illuminate directionality of effects. Limited investigation of the trajectory of QoL following first episode psychotic mania did not reveal an effect of symptoms at baseline with QoL at 18 months (Oldis et al., 2016): more sensitive analyses of time-varying relationships in the general BD population is needed to illuminate possible relationships. Additionally, although QoL change is typically assumed to be a downstream consequence of symptom changes in BD, it is not known whether changes in QoL may have reciprocal impacts on BD symptoms: potentially, improvements in wellbeing and functioning could moderate symptoms of the disorder (Murray & Michalak, 2012). Longitudinal studies are therefore required to inform understanding of the relationship between BD symptoms and QoL over time.

*The present study.* The present prospective observational study analysed data from the Health Outcome and Patient Evaluation-Bipolar Disorder (HOPE-BD) project, a multisite prospective naturalistic investigation of patients receiving guideline-driven treatment for BD in Canada. The primary aim of the HOPE-BD project was to prospectively examine treatment
patterns, clinical outcomes, quality of life and resource utilisation of a Canadian BD sample receiving guideline-driven treatment.

As we have recently reviewed, it is important to recognise different emphases across existing measures of QoL in BD (Morton, Michalak, & Murray, 2017). Here, we chose the 36-item Short-Form Survey (SF-36; Ware & Sherbourne, 1992) as a commonly used measure of QoL qua psychosocial and physical functioning. A further advantage of the SF-36 for the present purposes was its generation of two well-understood subscale scores (physical and mental functioning) for exploration.

The aim of the present analyses was to investigate: i) the trajectory of QoL under guideline-driven treatment and ii) the relationship between objective symptom measures and subjective QoL ratings over time. It was hypothesised that QoL would increase over time with guideline-driven treatment. Additionally, it was hypothesised that lower levels of depression would predict a positive change in QoL. Analyses of the impact of mania on trajectories of QoL and QoL as a predictor of change in symptom ratings were exploratory.

To the authors’ knowledge, this is the first study to use multilevel modelling to examine the naturalistic trajectory of QoL in a population receiving guideline-driven treatment. Additionally, it is the first study to report on the time-varying relationship between symptoms of BD and QoL.

6.4 Materials and Method

6.4.1 Study Design

Participants were recruited from 12 sites across Canada, including university and community hospitals and outpatient clinics, and prospectively followed every three months for a period of up to five years. Treating psychiatrists retained responsibility for delivering pharmacotherapies and other treatments according to Canadian Network for Mood and Anxiety Treatments guidelines (Canadian Network for Mood and Anxiety Treatments (CANMAT), 1997). Patients or legally accepted delegates gave informed written consent for data to be collected. The study was approved by the University of British Columbia Research Ethics Board and the Ethics Boards at all sites that collected data.
6.4.2 Participants

Psychiatrists at participating sites referred eligible patients for participation. Inclusion criteria were: i) diagnosed with BD-I, BD-II or BD not otherwise specified (NOS); diagnoses were confirmed at intake using the Mini-International Neuropsychiatric Interview (MINI; Sheehan et al., 1998), ii) currently meeting or recently (within the past 3 months) met criteria for a (hypo)manic or depressive episode, or recently (within the past 3 months) changed treatment, iii) under the care of a participating psychiatrist, iv) aged fifteen years or older, v) competent and willing to provide informed consent (or consent given by a legally accepted delegate), and vi) fluent in either English or French. Exclusion criteria for the study were: i) diagnosed with either a) non-affective psychotic disorder, b) substance-induced mood disorder, c) mood disorder secondary to a medical condition, or d) personality disorder with only subthreshold hypo/manic or depressive symptoms; ii) unwilling or unable to participate in follow-up assessments (e.g., moving out of area), iii) currently participating in a clinical treatment trial, or iv) hospitalised longer than six months.

6.4.3 Measures

6.4.3.1 Symptoms

Both symptom measures were validated, widely used clinician-rated scales. Mania was assessed using the Young Mania Rating Scale (YMRS; R. C. Young, Biggs, Ziegler, & Meyer, 1978), an 11-item scale with scores ranging from 0 to 60. Depression was measured on the Montgomery-Asberg Depression Rating Scale (MADRS; Montgomery & Asberg, 1979) a 10-item instrument with scores ranging from 0 to 60. All investigators were members of the Canadian Network for Mood and Anxiety Treatments, had received training on inter-rater reliability and had demonstrated excellent inter-rater reliability on previous clinical trials.

6.4.3.2 Quality of life

QoL was measured with the SF-36 (Ware & Sherbourne, 1992), a 36 item self-report questionnaire. The SF-36 has eight subscales assessing: Physical Function, Role Limitations due to Physical Health, Bodily Pain, General Health, Vitality, Social Function, Role Limitations due to Emotional Problems, and Mental Health. Two component scores may be derived (Ware et al., 1994): one summarising physical QoL (Physical Component Score – PCS), and the other summarising mental QoL (Mental Component Score – MCS). The eight
subscales and two component scores are scored 0-100, with higher scores representing better QoL. Scores were standardised according to Canadian norms (Hopman et al., 2000).

**6.4.3.3 Assessment schedule**

Confirmation of BD diagnosis via the MINI occurred at baseline. Symptom measures (YMRS and MADRS) and QoL (SF-36) were assessed at baseline and at follow-up assessments which were conducted at 3-month intervals (within a two-week window).

**6.4.4 Trajectory Analyses**

Multilevel modelling (MLM) was used due to the hierarchical structure of the data (that is, longitudinal observations are nested within individuals). This data structure, which would violate the assumption of independence of residuals required for linear regression models, is accounted for in MLM (J. Hox, 2010). In addition, MLM methods were chosen as they support estimation in situations where observations are missing. Data were analysed using the MIXED procedure of SPSS using full maximum likelihood estimation (IBM SPSS statistics for Windows, Version 22.0; 2013). Predictors where zero is a non-interpretable value (e.g., age) were centred around the sample mean. Given the exploratory nature of the study, the alpha level was set at 0.05.

Fixed and random effects were specified for the intercept and slope parameters in models unless otherwise stated. Random effects were removed in cases where models failed to converge due to lack of random variance (Heck, Thomas, & Tabata, 2014). Residual terms at Level 1 were specified as having an autoregressive covariance matrix: unobserved variance was assumed to differ between the time points, and it was assumed that correlation between occasions of measurement would decrease with greater duration between occasions of measurements (Heck et al., 2014). Level 2 residuals were specified as having a diagonal covariance matrix: it was assumed that the random effects for the intercepts and the slope did not correlate. The Level 2 covariance structure was chosen as it permitted the estimation of intercept and slope variances. Models without random effects for slope must be estimated using a scaled identity covariance matrix.

MLM was employed as follows:

1. **Unconditional QoL growth models.** To examine the trajectories of QoL over time, growth models with linear and quadratic terms were fitted individually for MCS and PCS. Significant terms were retained for following analyses.
*Exploratory subscale analyses.* Additional growth models were created to compare the trajectories of the SF-36 subscales (General Health, Role Limitations (Emotional), Social Functioning, Physical Functioning, Role Limitations (Physical), Pain, Vitality, and Mental Health).

2. *Level 2 predictors of QoL.* Age, sex, and BD diagnosis were entered as Level 2 predictors in the growth models for PCS and MCS. Significant predictors were retained for following analyses.

3. *Time-lagged covariate analysis.* Possible temporal relationships between symptoms and QoL were investigated as follows.
   a. Firstly, significant growth models for QoL were analysed controlling for earlier symptom covariates (MADRS and YMRS). That is, a model was created where QoL variables at the present visit (time) were predicted by symptom data from the previous visit (time - 3 months). The 3-month time lag was chosen due to the data structure.
   b. Secondly, to test the directionality of any relationship between QoL and symptoms of BD, models where symptom ratings (MADRS and YMRS) were predicted by earlier QoL (PCS and MCS) were calculated. Unconditional growth models for symptom measures and models evaluating Level 2 predictors were created to permit identification of significant parameters to retain in models where lagged MCS and PCS acted as predictors. However, they are not the focus of the present analysis and are presented in Supplementary Tables 1 and 2 respectively (Appendix G).

6.5 Results

6.5.1 Participant Characteristics

A total of 362 participants aged 18-72 ($M = 42.75, SD = 12.18$) were recruited. The majority of participants ($n = 207$) were female, and approximately equal numbers were of Caucasian ($n = 158$) and non-Caucasian ($n = 164$) ethnicity. The majority of participants were recruited through teaching hospitals in i) Vancouver, British Columbia ($n = 56$), ii) London, Ontario ($n = 64$), and iii) Montreal, Quebec ($n = 82$); and a private practice in Montreal ($n = 53$). Participants completed between 1 and 13 assessments ($M = 4.90, SD = 3.30$).
BD-I was the most common diagnosis \((n = 185)\), followed by BD-II \((n = 120)\) and BD-NOS \((n = 21)\). Mood episodes at baseline were predominantly depressive \((n = 121)\) with fewer manic \((n = 44)\), hypomanic \((n = 20)\), or mixed recorded \((n = 15)\). At baseline, 106 (29%) were prescribed lithium, 84 (23%) sodium valproate, 14 (4%) carbamazepine, 36 (10%) risperidone, 40 (11%) olanzapine, 41 (11%) quetiapine, 41 (11%) lamotrigine, and 95 (26%) an antidepressant.

Mean MCS at baseline was lower than the Canadian norm (31.13 vs 51.7), as was PCS (48.16 vs 50.5; Hopman et al., 2000).

6.5.2 Trajectory Analyses

6.5.2.1 Unconditional quality of life growth models

The results of the unconditional growth models for MCS and PCS are displayed in Table 6.1. The linear slope parameter for MCS was positive and significant \((\text{Estimate} = .45, p < .001)\), with a significant negative quadratic \((\text{Estimate} = -.006, p < .05)\) indicating the rate of growth slowed over time. The linear slope parameter for PCS was negative and significant \((\text{Estimate} = -.14, p < .05)\), with a significant positive quadratic \((\text{Estimate} = .003, p < .05)\) indicating the decrement in PCS slowed over time. No random effect for slope was specified in the growth model for PCS.

Table 6.1.

Unconditional growth model results for MCS and PCS

<table>
<thead>
<tr>
<th></th>
<th>MCS</th>
<th>PCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>33.09**</td>
<td>47.49**</td>
</tr>
<tr>
<td>Main Effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Linear slope</td>
<td>.45**</td>
<td>-.14*</td>
</tr>
<tr>
<td>Quadratic slope</td>
<td>-.006*</td>
<td>.002*</td>
</tr>
<tr>
<td>Variance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within person</td>
<td>120.91</td>
<td>51.98**</td>
</tr>
<tr>
<td>Between-person (intercept)</td>
<td>.14**</td>
<td>78.05**</td>
</tr>
<tr>
<td>Between-person (slope)</td>
<td>179.62**</td>
<td>(b)</td>
</tr>
</tbody>
</table>

Note: *\(p < .05\), **\(p < .001\), \(b\) Parameter was not calculated
**Exploratory subscale analyses.** Growth models were created for each of the eight SF-36 subscales (see Supplementary Table 3). Paralleling the trends seen in MCS (above), a significant positive linear effect and significant negative quadratic effect were found for the SF-36 subscales Role Limitations due to Emotional Problems (*Linear estimate* = 1.01, *p* < .001; *Quadratic estimate* = -.01, *p* < .05), Social Functioning (*Linear estimate* = .68, *p* < .001; *Quadratic estimate* = -.008, *p* < .05) and Mental Health (*Linear estimate* = .48, *p* < .001; *Quadratic estimate* = -.007, *p* < .05). A significant positive linear effect was found for the subscales General Health (*Estimate* = .11, *p* < .05) and Vitality (*Estimate* = .26, *p* < .05); no significant quadratic effects were observed for either of these subscales. No random effects for slope were retained in the models for Physical Functioning, Role Limitations due to Physical Problems, or Pain; in addition, no significant change over time was observed in these subscales.

### 6.5.2.2 Level 2 predictors of quality of life

Age, sex, and BD diagnosis were entered as predictors for the growth models for MCS and PCS (Table 6.2). The only predictor to reach significance and be retained in future models of MCS was the main effect for sex (*Estimate* = 3.54, *p* < .05): males had higher baseline mental QoL than females. There was a significant negative main effect of age on PCS (*Estimate* = -.20, *p* < .001): individuals older than the sample mean (42.75) had poorer baseline physical QoL. There was a positive main effect of sex on PCS (*Estimate* = 4.57, *p* < .05): males had higher baseline physical QoL than females. Sex and age were retained as predictors in future PCS models. No significant interaction (slope) effects were observed for either MCS or PCS.
**Growth model results for MCS and PCS with Level 2 predictors (age, sex, and bipolar diagnosis)**

<table>
<thead>
<tr>
<th></th>
<th>MCS</th>
<th>PCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>27.29**</td>
<td>43.85**</td>
</tr>
<tr>
<td>Main effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Linear slope</td>
<td>.61</td>
<td>-.05</td>
</tr>
<tr>
<td>Quadratic slope</td>
<td>-.005*</td>
<td>.003*</td>
</tr>
<tr>
<td>BD-I</td>
<td>6.50</td>
<td>2.27</td>
</tr>
<tr>
<td>BD-II</td>
<td>2.13</td>
<td>1.09</td>
</tr>
<tr>
<td>BD-NOS</td>
<td>0(b)</td>
<td>0(b)</td>
</tr>
<tr>
<td>Age</td>
<td>.13</td>
<td>-.20**</td>
</tr>
<tr>
<td>Sex (male)</td>
<td>3.54*</td>
<td>4.57*</td>
</tr>
<tr>
<td>Interaction (slope) effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>BD-I</td>
<td>-.08</td>
<td>-.06</td>
</tr>
<tr>
<td>BD-II</td>
<td>-.20</td>
<td>-.05</td>
</tr>
<tr>
<td>BD-NOS</td>
<td>0(b)</td>
<td>0(b)</td>
</tr>
<tr>
<td>Age</td>
<td>-.002</td>
<td>-.0002</td>
</tr>
<tr>
<td>Sex (male)</td>
<td>-.15</td>
<td>-.07</td>
</tr>
</tbody>
</table>

Variances:
- Within person: 123.48**, 51.67**
- Between-person (intercept): 80.20**, 72.74**
- Between-person (slope): .04*, \(b\)

*Note:* *\(p < .05\), **\(p < .001\), \(b\) Parameter was not calculated, \(\theta^b\) Redundant parameter set to zero

### 6.5.2.3 Models with time-lagged covariates

**Symptoms as time-lagged covariates.** The growth models for MCS and PCS controlling for the effects of both MADRS and YMRS ratings from the previous visit (-3 months) are displayed in Table 6.3. There was a significant negative main effect of earlier depression (MADRS) on MCS (Estimate = -.40, \(p < .001\)): lower depression ratings were
associated with higher MCS ratings at the following visit. There was no significant main
effect for earlier mania (YMRS) on MCS (Estimate = -.08, p = .58).

There was a significant negative main effect of earlier YMRS on PCS (Estimate = -.19, p < .05): higher YMRS ratings were associated with lower PCS at the following visit. There was no significant main effect for earlier MADRS ratings on PCS (Estimate = -.06, p = .15).

Table 6.3.

*Growth models for MCS and PCS with effects of earlier (time – 3 months) MADRS and YMRS*

<table>
<thead>
<tr>
<th></th>
<th>MCS</th>
<th>PCS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>37.26**</td>
<td>47.94**</td>
</tr>
<tr>
<td>Main effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Linear slope</td>
<td>.36*</td>
<td>-.17</td>
</tr>
<tr>
<td>Quadratic slope</td>
<td>-.005</td>
<td>-.003</td>
</tr>
<tr>
<td>Earlier MADRS</td>
<td>-.40**</td>
<td>-.06</td>
</tr>
<tr>
<td>Earlier YMRS</td>
<td>-.08</td>
<td>-.19*</td>
</tr>
<tr>
<td>Sex (male)</td>
<td>1.37</td>
<td>3.10*</td>
</tr>
<tr>
<td>Age</td>
<td>b</td>
<td>-.19**</td>
</tr>
<tr>
<td>Variance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within individuals</td>
<td>129.73**</td>
<td>55.98**</td>
</tr>
<tr>
<td>Between individuals (intercept)</td>
<td>65.30**</td>
<td>68.54**</td>
</tr>
<tr>
<td>Between individuals (slope)</td>
<td>.04*</td>
<td>b</td>
</tr>
</tbody>
</table>

Note: *p < .05, **p < .001, b Parameter was not calculated

*Quality of life as time-lagged covariates.* Unconditional growth models and investigation of Level 2 predictors (age, sex, BD diagnosis) for MADRS and YMRS are displayed in Supplementary Tables 1 and 2 (Appendix G), respectively. Random effects for slope were not specified for MADRS and YMRS growth models. Of the Level 2 predictors, only the main effect and interaction (slope) effect for sex were retained for future MADRS models. No Level 2 predictors were retained for future PCS models.
MCS and PCS were added as time-lagged covariates to growth models for symptom measures (MADRS and YMRS; see Table 6.4). There was a significant negative main effect of earlier MCS on both MADRS ($\text{Estimate} = -0.16, p < .001$) and YMRS ($\text{Estimate} = -0.03, p < .001$): higher levels of MCS were associated with lower symptom ratings at the following visit. Similarly, there was a significant negative main effect of earlier PCS on both MADRS ($\text{Estimate} = -0.07, p < .05$) and YMRS ($\text{Estimate} = -0.03, p < .05$): higher levels of PCS were associated with lower symptom ratings at the following visit.

Table 6.4.

**Growth models for MADRS and YMRS with effects of earlier (time – 3 months) MCS and PCS**

<table>
<thead>
<tr>
<th></th>
<th>MADRS</th>
<th>YMRS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>18.68**</td>
<td>4.59**</td>
</tr>
<tr>
<td>Main effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Linear slope</td>
<td>-0.08*</td>
<td>-0.02*</td>
</tr>
<tr>
<td>Earlier MCS</td>
<td>-0.16**</td>
<td>-0.03**</td>
</tr>
<tr>
<td>Earlier PCS</td>
<td>-0.07*</td>
<td>-0.03*</td>
</tr>
<tr>
<td>Sex (male)</td>
<td>-1.99*</td>
<td>b</td>
</tr>
<tr>
<td>Interaction (slope) effects</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sex (male)</td>
<td>0.08</td>
<td>b</td>
</tr>
<tr>
<td>Variance</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within individuals</td>
<td>36.22**</td>
<td>8.22**</td>
</tr>
<tr>
<td>Between individuals (intercept)</td>
<td>10.68**</td>
<td>1.46**</td>
</tr>
<tr>
<td>Between individuals (slope)</td>
<td>b</td>
<td>b</td>
</tr>
</tbody>
</table>

*Note:* *p < .05, **p < .001, b Parameter was not calculated

6.6 Discussion

The HOPE-BD study naturalistically followed 362 patients with BD receiving guideline-driven treatment over a period of up to five years. Here, we analysed both symptoms and QoL at 3-month intervals. Mental QoL (measured on the MCS) was found to increase over time, and the rate of improvement in mental QoL slowed over time. Physical QoL (PCS) was found to worsen over time, with a gradually slowing rate of decrement.
Novel analyses of the dynamic relationship between symptoms of BD and mental QoL found, a) reduction in depressive symptoms was associated with later improvements in mental QoL, b) reduction in manic symptoms was associated with later improvements in physical QoL, and c) improvements in both physical and mental QoL were associated with subsequent reduction in symptoms of BD.

MLM analyses led to the hopeful finding that, with guideline driven treatment, mental QoL improves over time amongst people with BD, albeit with a gradual reduction in rate of improvement. Improvement in the subscales social functioning, role limitations due to emotional problems, and mental health paralleled the MCS growth curve. Positive impacts on role and social functioning as a consequence of guideline-driven treatment may be expected given the known negative impact of manic and particularly depressive symptoms on social and occupational functioning in BD (Rosa et al., 2010). If replicated, these novel findings have significant implications for prognostic discussions with patients.

In contrast to mental QoL, PCS ratings in this population were observed to decrease over time in a non-linear fashion. In addition, PCS ratings were poor in this BD population as compared to Canadian norms. The finding that physical QoL is poor in individuals with BD is not unexpected: individuals with BD not only suffer from higher rates of physical health comorbidities than the general population (Kilbourne et al., 2004; Krishnan, 2005), but may also face added burden from adverse physical effects of psychotropic medication on their QoL (Yen et al., 2008). However, the finding that physical QoL worsened in this sample demands further attention to methods to improve physical health and functioning in BD (for a review of the emerging evidence for lifestyle interventions for physical health in BD, see I. E. Bauer et al., 2016). Lack of significant change on the role limitations due to physical problems, physical functioning, vitality, and pain subscales, along with positive change in the general health and vitality subscales may seem counterintuitive given the growth curve results observed for PCS (above). However, this is due to the nature of the MCS/PCS scoring algorithms: these are norm-based scores, such that MCS and PCS here reflect the QoL of this population relative to Canadian averages (Hopman et al., 2000). Additionally, summary scores are produced from positively and negatively weighted physical and mental subscales in order to remove shared variance (Ware et al., 1994).

The study’s novel investigation of dynamic relationships between symptoms of BD and mental QoL supported common assumptions, but also identified new associations
warranting further study. Improvements in mental QoL were found to be predicted by improvements in the preceding visit’s depression ratings, while depression did not significantly impact subsequent physical QoL ratings. This is consistent with (but permits stronger causal inference than) the numerous cross-sectional analyses suggesting a negative influence of depressed mood on QoL (Gazalle, Frey, et al., 2007; Hayhurst et al., 2006; Simon et al., 2007; Vojta et al., 2001; Yatham et al., 2004). The present study contributes to ongoing clarification of the role of mania in QoL in BD: earlier mania did not impact on mental QoL at the following visit, however improvements in physical QoL were predicted by improvements in the preceding visit’s mania ratings. It may be expected that higher levels of mania would be associated with subsequent decrements in physical QoL, given the intense physical effects of this highly dysregulated state and the side effect profile of anti-manic medications required to address it (Hert et al., 2011); further research is required to elucidate mechanisms through which mania may impact QoL.

Most strikingly, modelling analyses also found that improvements in mental and physical QoL were associated with subsequent benefits for the symptoms of BD: improvements in both mental and physical QoL were associated with later reduction in mania and depression. To our knowledge, this is the first empirical study supporting the longstanding humanistic assumption that improvements in subjective QoL may predict clinical improvements in BD (Murray & Michalak, 2012). QoL may play a uniquely predictive role in mental health (IsHak et al., 2011): improved subjective perception of life circumstances and positive impacts in valued life areas such as leisure and social relationships would intuitively be expected to stabilise mood. In fact, evidence based and emerging treatments for BD such as cognitive behaviour therapy, interpersonal and social rhythm therapy, and mindfulness training target aspects of QoL such as perceptions of self, others and the future, engagement in positive activities, and management of stressful life circumstances (Frank, Swartz, & Kupfer, 2000; Lam, Jones, & Hayward, 2010; Murray et al., 2017). The impact of subjective QoL on later symptoms may also relate to changes to objective circumstances (e.g., functioning): scores on functioning measures and employment status have been shown to predict treatment response (Deckersbach et al., 2016). Finally, the potential role of physical QoL as a predictor of future manic symptoms suggests attention to the developing field of interventions for physical health in BD (I. E. Bauer et al., 2016): for example, exercise has been associated with improved sleep quality in BD (Nusslock, Abramson, Harmon-Jones, Alloy, & Hogan, 2007), which would be expected to have
downstream impacts on manic symptoms (Frank et al., 2000). The subjective nature of the QoL assessment used in this study directs particular attention to interventions which target evaluations of physical health (e.g., yoga, mindfulness, relaxation training; Bernstein et al., 2016). Investigation of possible mechanisms through which QoL may impact later symptoms will illuminate this relationship further and identify additional therapeutic targets.

Through the use of large scale, longitudinal data, the present study is able to illustrate for the first time the common-sense prediction that QoL improvements are associated with downstream impacts on both depressive and manic BD symptoms (Malhi et al., 2015). If this finding proves robust in future research, it will encourage renewed therapeutic effort on interventions for BD specifically targeting consumers’ QoL goals (Leitan et al., 2015; Murray et al., 2017). A focus on QoL as a treatment outcome is consistent with calls to attend to broader psychological, physical and functional outcomes in mental health (Slade, 2010). The novel analyses of the present study add weight to this call by suggesting that interventions directly targeting QoL have the potential for downstream benefits for the symptoms of BD. Future research could specifically test mechanisms by which subjective QoL may have impacts on mood symptoms, including the impacts of cognitive strategies (as in cognitive therapy, mindfulness) and behavioural interventions (such as lifestyle changes and interpersonal and social rhythm therapy).

6.6.1 Limitations

A number of limitations should be noted. While the long-term prospective design has marked advantages over cross-sectional methods, temporal precedence alone is insufficient to establish causality. Additionally, the naturalistic design precludes specific statements about the variety of treatments received by participants beyond the broad criterion of ‘guideline-driven treatment’. A comprehensive investigation of all relevant time-varying covariates (e.g., medication use, psychosocial treatments) is beyond the current scope. This study represents an initial attempt to track QoL and symptoms across time, and generates hypotheses for future investigation. Future studies should account for other possible determinants of QoL, (e.g., treatment changes, life events, disease progression, etc.). The present study was not designed to evaluate the relative predictive power of QoL compared to other determinants of symptoms in BD (e.g., physical health, unemployment, etc.), and indeed there is no agreed upon method to calculate effect sizes as they are commonly understood in other statistical analyses (Peugh, 2010; Roberts & Monaco, 2006). However,
the exploratory findings here suggest that QoL is an important predictor which should be taken into account in future studies which evaluate multiple competing variables. The use of the SF-36 to measure QoL situates the present study within a body of work characterising QoL as related to functioning (Morton, Murray, et al., 2017) – results may not generalise to measures associated with conceptualisations of QoL as wellbeing or satisfaction.

Missing data was a limitation of the present dataset. As with any long term, prospective, multisite study, data was lost due to participant dropout, erratic attendance, or site-related issues in data collection. The issue of missing data does raise some questions that the present analysis is unable to clarify, for example mechanisms explaining the interaction between age and physical QoL. An advantage of the analysis used is that multilevel modelling supports estimation in situations where observations are missing (Heck et al., 2014). As number of completed assessments correlated only weakly with MCS ($r_s = .19$), PCS ($r_s = -.04$), and symptom ratings (MADRS: $r_s = -.12$; YMRS: $r_s = -.08$), we inferred that missing data from participant dropout was unlikely to systematically bias findings.

6.7 Conclusion

Within its limitations, the present study demonstrates for the first time that individuals receiving consensus treatment for BD show linear improvements in their mental QoL. Investigation of temporal relationships between QoL and symptoms of BD suggested bidirectional effects, and generates novel hypotheses for future research. Guideline-driven treatment was found to positively impact symptoms and subsequent QoL. Evidence for positive impacts of QoL on downstream symptoms encourages further research into optimising QoL in BD.
CHAPTER 7. STUDY 3: A QUALITATIVE STUDY OF IMPLICIT PROCESSES OF QUALITY OF LIFE SELF-APPRAISALS IN BIPOLAR DISORDER.
7.1 Chapter Guide


The introductory chapters in this thesis highlighted that an understudied area within the field of quality of life (QoL) research in bipolar disorders (BD) is an individual’s subjective experience. As highlighted in Chapter 2 in the review of broader approaches to QoL within medical, sociological and philosophical fields of research, an individual’s own evaluation of their circumstances is frequently highlighted as central to the QoL construct. Reasons for elevating an individual’s own perspective on QoL as reviewed in Chapter 2 are congruent with the paradigm shift to consumer-central, recovery oriented approaches to BD (as reviewed in Chapter 1). However, beyond exploration of *what* domains are important in QoL in BD from the perspective of consumers (as reviewed in Chapter 3), little work has been done to investigate *how* the construct is experienced by individuals with BD. This chapter contains a version of a published article (formatted to be consistent with the overarching thesis) investigating the question of how individuals with BD appraise their QoL, using qualitative methods. This analysis further enriches the understanding of the construct of QoL in BD from a consumer perspective, presents implications for the measurement of QoL, and furthermore suggests novel therapeutic approaches to improve QoL in BD.

**Footnote:** Studies 3 and 4 were conducted within the context of an overarching mixed methods investigation of a QoL-focused psychoeducation intervention for BD. This intervention was developed from a satisfaction and wellness-centric, BD-specific framework: strategies were presented across the range of domains identified as important to people with BD in qualitative interviews (Michalak & Murray, 2010b; Michalak et al., 2006), and positive outcomes were deliberately emphasised. As the design of the intervention was not relevant to the analyses presented in the papers, little detail is discussed in the manuscript. A summary of the intervention and quantitative outcomes is presented elsewhere (Michalak et al., 2018).
7.2 Abstract

*Background:* Quality of life (QoL) is increasingly a target of interventions for bipolar disorders (BD). While the subjective experience of consumers is often elevated as central to the construct of QoL in BD, limited investigation in this area means subjective QoL remains poorly understood. The present qualitative study seeks to address this by investigating how people with BD appraise the quality of their lives in the context of a QoL self-management intervention.

*Methods:* Semi-structured interviews were conducted with 43 individuals who had participated in a self-management intervention for improving QoL in BD. Individuals were questioned about experiences of the intervention and perceptions of their QoL. Thematic analysis was used to explore participants’ appraisal of their QoL.

*Results:* An overarching theme concerned the intrinsic relativity of subjective QoL: individuals located QoL as relative to self, others and possible futures. Incorporating illness-related reference points for QoL (‘given my circumstances…’) was associated with perceptions of improved QoL. Deliberately modifying reference points for QoL was perceived as self-compassionate.

*Conclusions:* The present study generates novel hypotheses about how individuals with BD make sense of their QoL. Data suggests that individuals located their QoL relative to a variety of reference points, use of which was flexible. In accord with gap theories of QoL, individuals experienced acceptance of illness-impacts as improving subjective sense of QoL. Rather than ‘settling for’ a lower standard of QoL, individuals experienced these changes as adaptive and positive. Findings are discussed in relation to the measurement and amelioration of QoL in BD.
7.3 Introduction

Quality of life (QoL) is the subject of increasing interest in bipolar disorders (BD) research and care (Murray & Michalak, 2012). In the BD literature, QoL is understood to act as a referent for a diversity of constructs (Morton, Michalak, & Murray, 2017); however, little is known about how consumers with BD themselves experience the construct. Thus, for the present purposes here QoL is broadly conceptualised to act as shorthand for a collection of outcomes other than traditional symptom measures (Ware, 1995), including an individual’s social, physical, psychological and environmental context. QoL is an outcome of particular interest in BD given the condition’s chronic, relapsing course and broad range of illness impacts in various life domains (Gitlin & Miklowitz, 2017; Murray & Michalak, 2012; Sachs & Rush, 2003). Consumers themselves prioritise QoL as an important, if not the most important, goal of treatment (Eiring et al., 2016; Haarig et al., 2016; Mączka et al., 2010; McIntyre, 2009; Michalak et al., 2012; Sajatovic et al., 2009), and QoL has powerful potential to represent consumer perspectives in BD research and practice (Murray et al., 2017).

Although an individual’s perception of QoL is considered central to the construct in the BD literature (Morton, Michalak, & Murray, 2017), our understanding of subjective QoL in this disorder remains limited. Recent work by Michalak and colleagues has made significant advances in understanding what life domains are valued from the perspective of consumers with BD (Michalak & Murray, 2010b; Michalak et al., 2006), but people’s ongoing process of experiencing and judging the quality of their lives is yet to receive attention in the BD literature. A more sophisticated understanding of these subjective processes is needed to advance QoL theory and to support measurement of, and ultimately interventions for subjective QoL in BD. Qualitative investigations are optimally positioned as a first step in this endeavour.

The present study. The present study aimed to use qualitative methods to build on existing work on the content of subjective QoL in BD by delving into the processes involved in an individual’s lived experience of QoL. An opportunistic sample consisting of individuals who recently participated in a self-management (SM) intervention developed by the Collaborative RESearch Team to study psychosocial issues in Bipolar Disorder (CREST.BD; Michalak et al., 2018) were interviewed about their QoL. The aim was to identify salient aspects of the experience of QoL from the perspective of individuals with BD themselves.
7.4 Method

Using descriptive qualitative methods (Vaismoradi, Turunen, & Bondas, 2013), the present study leverages off a broader mixed methods (i.e., both quantitative and qualitative) project investigating the impact of SM in BD (Michalak et al., 2018). The overarching project aimed to investigate the effectiveness of various information delivery modalities (described below) at communicating and encouraging use of various SM strategies. Participants were given access to a website (Bipolar Wellness Centre; www.bdwellness.com) focusing on SM strategies related to a range of domains identified as relevant to QoL in BD, e.g., mood, relationships, sleep, independence, and identity (Michalak & Murray, 2010b; Michalak et al., 2006). Participants also received additional SM information delivered via: a) webinars, b) videos, c) online peer support, or d) in-person group workshops. As part of the SM website, an online version of the QoL.BD self-report measure (based on the domains identified as relevant to BD; Michalak & Murray, 2010b) was made available to participants as a QoL self-monitoring tool (QoL Tool; www.bdqol.com). Participants were free to choose the information delivery modality they would receive and the SM strategies they would focus on. To address the present study’s aim to identify processes involved in QoL meaning-making in BD, the focus is on participants’ experience of QoL rather than differences between modalities and specific strategies.

7.4.1 Participants

Participants for the present study were a subsample of those in the overarching project who agreed to participate in a follow-up telephone interview.

7.4.1.1 Inclusion/exclusion criteria

Participants in the overarching project were required to be: i) age 19 years or above, ii) able to communicate in English, iii) able to provide informed consent, iv) a resident of Canada, and v) have a self-reported diagnosis of BD. Individuals were excluded if their current mental state (symptoms of [hypo]mania or depression) would interfere with study participation.

7.4.1.2 Recruitment

Recruitment in the overarching project was conducted via: a) notices sent to research participants in prior BD studies in the Mood Disorders Centre, Department of Psychiatry (University of British Columbia) who consented to be contacted in the future regarding new
studies of potential interest b) healthcare providers affiliated with the CREST.BD network were provided with information about the current project and asked to place informational leaflets in their waiting room, and c) advertisements in print (e.g., community newspapers) and online (e.g., blogs) media.

At enrolment, individuals indicated their consent to be contacted at a later date regarding participation in a telephone interview. For the present study, purposive sampling (described below) was used to identify consenting participants, who were then contacted via email and invited to participate in the qualitative interview. Participants received a $20 (CAD) honorarium in the form of a gift certificate as compensation for time spent on the interview.

Purposeful criterion sampling (Patton, 2002) was used to establish a sample representing the key demographic variables of the original investigation. As participants were enrolled in the current qualitative study, future participants were selected based on specific criteria – age, gender and BD diagnosis - to ensure that the sample reflected the demographic diversity of the original sample. Purposive sampling was used to recruit individuals based on engagement with specific content, such that experiences with the full spectrum of SM strategies across the different information delivery modalities were represented in the overarching mixed methods study. For the purposes of the present study these sampling criteria were not applied in the analytic framework or the description of the findings, given that in practice, the majority of participants had engaged with content across multiple information delivery modalities and SM strategies.

7.4.2 Qualitative Interview

A semi-structured interview schedule was developed based on three main sets of topics informed by the research questions. The first set of questions asked participants about their engagement with information on SM strategies (e.g., “Did you learn anything new about self-management strategies?”). The second set of questions explored any attempts to implement SM strategies (e.g., “Since the intervention, have you applied the information you learned?”). Finally, participants were asked about their QoL (e.g., “From your perspective, did this have any impact on your quality of life over the past few weeks?”). Probes and reflective listening were used to elicit depth in participant responses.
7.4.3 Procedure

Approval for the study was granted by the University of British Columbia’s Behaviour Research Ethics Board. All participants received written information on the study and gave written consent to be contacted for an interview. Data in the study was treated confidentially and transcripts de-identified.

Consenting participants were contacted via email approximately two weeks after participating in the self-management intervention to schedule a telephone interview. Interviews occurred approximately three to four weeks following participation.

In total, 67 participants were invited to participate in the qualitative interview; of these, 24 declined to participate or did not respond. A total of 43 interviews were conducted by the first author. Interviews ranged from 20 to 70 minutes in length ($M = 39.4$ minutes, $SD = 11.2$). They were digitally recorded and transcribed verbatim by the first author ($n = 24$, 55.8%) or research assistants (checked by the first author for accuracy; $n = 19$, 44.2%).

7.4.4 Data Analysis

Braun and Clark’s (2006) guidelines for inductive thematic analysis were followed. Thematic analysis provides a flexible research tool, which can provide a rich, detailed and complex account of data. It is a method for identifying, condensing, and abstractive qualitative data that describes themes or patterns across an entire data set. Thematic analysis involves an examination of underlying ideas, assumptions, and conceptualisations that shape the content of the data: interpretative work is used to abstract the data into themes. The first author was familiarised with the data through the process of transcribing interviews and re-reading transcripts. Data were assigned brief descriptive codes (meaning units) in the qualitative data management software NVivo (QSR International, 2016). Codes were examined and through a process of abstraction and interpretation overarching themes identified (Braun & Clarke, 2006). The content of themes was reviewed for coherency, and transcripts were revisited as the themes were developed to ensure all relevant data were adequately captured and described. The essence of the most important themes in relation to the study aim were then described in a comprehensive report with illustrative transcript extracts (repetitions, stutters and non-verbal utterances were removed for readability). To reduce the risk of bias and to address analytic validity, co-authors EM and RH reviewed both the descriptive accounts of themes and transcripts for coherency and validity of interpretation, with disagreements resolved via consensus.
7.5 Results

7.5.1 Participants

The modal age range was 45-54 years. The majority of participants \((n = 30, 69.8\%)\) were female. The most frequently reported diagnosis was BD-I \((n = 24, 55.8\%)\), followed by BD-II \((n = 16, 37.2\%)\).

7.5.2 Overview of Key Findings

Two themes were identified that relate to how these individuals with BD understood and described their QoL: a) subjective perceptions of QoL are relative to reference points, and b) Use of QoL reference is flexible and adaptive. A summary of these themes is displayed in Figure 7.1.

![Figure 7.1](image)

*Figure 7.1.* Figurative representation of emerging themes. Individuals with bipolar disorder use a variety of reference points to locate their quality of life; changing reference point to the experiences of others with bipolar disorder was experienced as normalising and adaptive.
7.5.2.1 Subjective perceptions of quality of life are relative to reference points

The first theme describes how individuals with BD, in judging their own QoL, locate it as relative to a variety of reference points, such that QoL was judged to be ‘better off’ or ‘worse than’.

Commonly, when reflecting on past periods of poor QoL associated with pathological mood states, participants described their current QoL as positive. Importantly, current QoL could be judged as good despite limitations if one’s present situation was described as an improvement from prior experiences of illness:

*When I’m crashed my quality of life is horrible, horrible, horrible. There's no quality of life essentially. So, to have not gone there as much has made my quality of life way higher, even though it's not perfect, like I have been fighting it off this month, at least I have a quality of life and there's a lot of things that are good.* (F, 25-35, BD-II)

While typically participants situated their current QoL as an improvement compared to past experiences of illness, a few (*n* = 2) individuals experienced their present situation as negative in comparison to periods of pathologically elevated mood:

*I miss my manic stages, that was like a natural high. You know people take drugs to feel the way I would normally feel. I did have a few people ask me, “You must be on cocaine or something. You can’t work like that and not be on something.” I’m like, “No that’s just normal”…But now it’s like it took away all the ups... if this is normal I hate it. If this is what people have to go through every day I don’t know how people do this. This isn’t what I had before.* (M, 35-44, BD-II)

Participants’ perception that life had not met their expectations was associated with negative judgements of QoL. For example, in describing negative impacts of BD on their QoL, a participant stated, “*My life has not been anywhere near what I have hoped for*” (M, 55-64, BD-II). Exceeding one’s expectations of the future was conversely associated with a higher perception of QoL: for example, a participant said of a predicted negative experience, “*It could throw me off, but it hasn’t and that’s been quite good*” (F, 45-54, BD-I).

Individuals also compared their life circumstances to others’ with varying impacts on QoL. People who reflected on others in poorer positions than themselves described a sense of appreciation for their own situation:
I always try to look at the glass half full, I walk into my condo and it’s mine, no one can evict me, and I can go to the grocery store and buy whatever I feel like eating. I don’t have to be scrounging for dinged cans, which I used to do on a regular basis with my clients, and I do have family and I do have friends; so I always on a daily basis basically consciously or unconsciously comparing how my life, I’m fortunate that my mental illness is much more under control. (F, 65-74, BD-II)

Individuals who perceived others as doing better than themselves judged their QoL more negatively; for example, a participant positioned themselves as worse at managing consequences of BD than an actor in the video intervention:

*I didn’t connect with the video as much as I would have liked to, because I felt like a bit of a personal failure because it wasn’t that easy for me, it was so much harder.* (F, 45-54, BD-II)

In some cases, individuals located their QoL between conflicting reference points, describing a tension between QoL that was better than when ill, yet worse than periods of wellness. One participant described their improved management of BD as a positive, but contrasted this with a sense of frustration that she was dealing with challenges that would have been unthinkable pre-diagnosis:

*I have every confidence that every year that goes by I get better and I get stronger, I find different ways and better ways to manage things... Now, if you had told me eight years ago I wouldn’t be able to keep my house tidy, I would have been shocked by that comment, and yet I look at it today and that’s part of the frustration.* (F, 45-54, BD-II)

### 7.5.2.2 Use of quality of life reference points is flexible and adaptive

The second identified theme captured the flexible use of reference points in locating QoL in BD: A number of participants \((n = 14)\) described a process of modifying existing reference points or introducing a novel comparison point in response to new information about BD contained in the intervention, with corresponding impacts on QoL. This process was described as adaptive, with individuals stating that accepting the limitations or challenges associated with BD allowed them to feel more content with their present circumstances.

Normalisation of experiences through increased awareness of the challenges shared by others living with BD was described as a consequence of the self-management
intervention and associated QoL Tool. One participant, in reviewing their results on the QoL Tool, felt more satisfied with their circumstances when viewed from the perspective that they faced the same struggles as others with BD. The contrasted this with the sense of dissatisfaction and self-recrimination associated with comparisons to their own expectations of self in the past:

Where I’m satisfied it reminds me, “Okay, I’m doing well here, I’m doing well at my job, I’m good at this so don’t be upset about this. I did it,” and I was like, “Okay, there are some things that I want to change,” but I wasn’t mad at myself when I looked at the results… a couple of years ago, I would have been like “what’s wrong with me”, but I mean based on the types of questions that are being asked, it obviously shows other people have these… you know that other people go through similar things. (F, 25-34, BD-II Rapid Cycling)

Comparing one’s circumstances to other people with BD who face similar difficulties was associated with a less self-critical, more compassionate perspective, leading to improved QoL. Importantly, this was a deliberate process, reinforced by self-talk and attending to areas where one was satisfied:

It made some things easier, so I didn’t feel as guilty…I realised that if that was said it was because other people have that problem as well, so why not like, I’m not unique in that sense, so saying, ‘Okay this is kind of normal it happens to other people so it’s okay, just try to live with it a little bit more.’ It makes it easier to live with. (M, 45-54, BD-I).

Coming to terms with what is ‘normal’ for BD was associated with self-compassionate practices, such as recognising and valuing efforts which may have previously been dismissed as insignificant. One participant identified with the struggles in maintaining a clean household depicted by an actress in a video depiction of self-management strategies, and described a shift from expecting herself to do “ten, twenty things that have to be big enough” to looking for the positives in what she was able to achieve:

I’m a bit nicer to myself, it sort of gave me permission to realise that well, just doing one thing coming back from a dip is - is a big thing. It just seemed like it was a bigger thing for her than I give to myself… it gave me permission to look at me just a bit different. I was just kinder to myself. (F, 45-54, BD-II)
One participant marvelled at the power of such self-compassionate practices to impact their QoL even in the absence of changes to objective circumstances. They highlighted that drawing upon normalised reference points influenced their responses on the QoL Tool, but noted that the change resulted from adopting a different perspective rather than the implementation of self-management strategies:

*I think the information that I’m getting from the Quality of Life Tool is that these experiences I’m having are normal for the illness. So instead of it just being kind of overwhelming and kind of being in a fog, I’m like... the fog’s okay, it’s just part of it... You know, it’s interesting how subjective it is...it doesn’t actually really matter whether I’m working on it or not, it’s whether I believe I’m working on it or not. I think the interesting thing is that those graphs, that are all lined up there, is that I can see that since I’ve been using them my overall quality of life has improved, but really what has happened is that my perception of my overall quality of life has improved.*

(F, 45-54, BD-II)

7.6 Discussion

The findings of the present qualitative study show that individuals with BD who participated in a SM intervention, in appraising their own QoL, locate it in relation to a variety of reference points. Appraisal of QoL was flexible and complex: use of reference points varied between and within individuals, and importantly, a number of participants reported a process of modifying their use of QoL reference points to accommodate limitations and impacts associated with BD as a consequence of information they were exposed to in the SM intervention. Individuals also recognised the adaptive nature of this process of changing QoL reference points, and described the shift as being kind to oneself, less self-critical, and more self-compassionate.

The finding that individuals within this sample use various reference points (e.g., well and ill self, others, or imagined futures) in evaluating their QoL parallels earlier discussions of the nature of subjective QoL. Gap theories of QoL propose that subjective QoL is a product of the difference between an individual’s evaluation of their current circumstances and their expectations, social comparisons, or past experiences (Calman, 1984; Michalos, 1985). Present findings extend on gap theories by suggesting that the episodic nature of BD, characterised by extreme mood states interspersed by periods of relative wellness, introduces further complexity in the use of reference points to appraise subjective QoL. In the present
sample, periods of mania, depression and euthymia were used as reference points when people described their QoL, with distinctive impacts on perceptions of current circumstances. Alternating between use of various reference points derived from past experiences associated with BD, therefore, has the potential to radically alter subjective QoL in this population. That is, while euthymic or subsyndromal individuals with BD have experienced crushing depressions and periods of extremely impaired functioning which make current QoL seem improved in comparison, the same people have also experienced extended periods of normal or even superior functioning (sometimes attributed to the illness itself, e.g., the heightened creativity and productivity associated with hypomania), relative to which current circumstances seem worse. In addition, due to the experience of diametrically opposed mood states, individuals’ use of reference points could be multifaceted: people with BD sometimes described a process of locating their QoL between multiple conflicting reference points (i.e., ‘better than when I was depressed, but worse than when I was hypomanic’). The present findings therefore suggest that while gap theories of QoL are likely applicable to the experiences of individuals with BD, the unique course of this disorder is a source of added complexity in individuals’ subjective evaluations.

Critically, the findings suggest that reference points for evaluating QoL could be employed adaptively by people with BD: by adopting the new reference point of ‘what is normal for BD’, these individuals were observed to achieve more positive evaluations of their circumstances. This productive ‘response shift’ has been noted in the chronic illness/disabilities literature: as people acclimatise to their condition, normative reference points recognising the limitations of illness are used, leading to higher than expected QoL ratings (Rapkin & Schwartz, 2004). In the mental illness literature, response shift has been characterised in fatalistic terms: Individuals have been described as ‘settling’ for or being ‘resigned’ to an objectively poor standard of living (S. Evans & Huxley, 2005; Katschnig, 2006a; Mechanic, 2006). The present study offers a different perspective: people with BD described the process of changing their reference point for QoL evaluations as a deliberate and adaptive response to changed circumstances. While using ‘what life was like when I was well’ as a QoL reference point was associated with negative evaluations, people participating in the SM intervention saw adopting normalised reference points (‘for someone with BD’) as an appropriately self-compassionate perspective. This new perspective was seen as facilitating coping with the impacts of BD and empowering people to have a better QoL. The present findings accord with recovery-oriented perspectives on coping with BD: the induction
of reasonable response shift (i.e., a focus on living well despite symptoms, finding meaning in other areas of life) should consequently be a goal of clinical care.

7.6.1 Measurement Implications

The present findings highlight a fundamental conceptual tension in the measurement of subjective QoL in BD. As noted above, a variety of reference points were flexibly applied by the sample in the assessment of their own QoL, with the likely consequence that self-reported QoL scores may have low test-retest reliability or weak correlations with changes in objective circumstances. A recent systematic review of QoL in BD (Morton, Michalak, & Murray, 2017) highlights two contrasting perspectives on this state of affairs. While a descriptive/objective viewpoint seeks QoL self-reports that are robust to within- and between-person variation in psychological processes (i.e., flexible reference points are a confound to be minimised), an alternative perspective prioritising subjective/evaluative QoL in BD suggests that reliability may not be as critical as accurately capturing an individual’s lived experience (i.e., flexible reference points are intrinsic to the phenomenon). For investigations from the former descriptive viewpoint, we propose, a pragmatic strategy to control for reference point variability, viz., inducing specific frames of reference in the wording of QoL questionnaires (Fayers & Machin, 2016). For example, a general population reference point (e.g., “compared to most people I know”) may elicit relevant comparisons for the purposes of comparing individuals with BD to other populations, while ideographic investigations may encourage within-person consistency by asking an individual to think of “the healthiest I have ever been”.

7.6.2 Clinical Implications

The positive view that participants had of normalising, BD-relative reference points suggests potential therapeutic strategies to improve QoL in BD. For example, proposed change mechanisms in acceptance and commitment therapy (ACT) closely resemble the self-reported experiences of participants with BD. ACT suggests that while struggling with the gap between expectations of how life ‘should’ be and present circumstances introduces suffering, acceptance of the reality of one’s circumstances facilitates coping (Hayes, Strosahl, & Wilson, 1999). Paralleling the present study, ACT rejects descriptions of acceptance as passive tolerance of unpleasant circumstances - rather, it is framed as an active process that enables individuals to focus attention on valued goals. Importantly, some participants here described reframing their perspective after hearing about the experiences of others with BD.
as part of the SM intervention. Future clinical research could test the hypothesis that a productive response shift towards compassionate acceptance of difficult circumstances is maximised when interventions include the voices of others with BD.

7.6.3 Limitations

The study had a number of limitations. Firstly, the opportunistic sample was drawn from an evaluation of different modalities of information delivery on self-management strategies for BD. As such, the adaptive view of response shift observed in the present study may not generalise to individuals with BD not engaged in such psychosocial interventions. Future research should investigate whether and how flexible use of reference points is experienced across a broader range of individuals with BD. Relatedly, participants who engaged with different modalities were grouped together for the purposes of the present study, as there were insufficient numbers to make strong inferences on the impact of different knowledge delivery modalities on individual’s subjective evaluation of QoL. Future research should explore the potential impacts of psychosocial interventions on subjective QoL appraisal.

7.7 Conclusion

The present qualitative study highlights the novel finding that individuals with BD locate their QoL in relation to a variety of reference points drawn from their past experiences, social context, or expectations for the future. Importantly, a number of individuals described a process of flexibly applying these reference points in order to adaptively preserve their QoL. Much remains unknown about subjective QoL in BD: the present study should be seen as a first step in a program of research that seeks to accommodate the relativity of QoL judgements in BD. While recognising the fundamental relativity of subjective realities brings substantial scientific challenges that are beyond present scope (Dowd & Pace, 1989), the present findings underscore that future research should not ignore, and can work productively with, the intrinsic relativity of these appraisals.
CHAPTER 8. STUDY 4: A QUALITATIVE STUDY OF THE MEANING AND EXPERIENCE OF QUALITY OF LIFE SELF-MANAGEMENT IN BIPOLAR DISORDER.
8.1 Chapter Guide


The preceding chapters have presented the results of three studies aimed at advancing understanding of the quality of life (QoL) construct in bipolar disorders (BD): an investigation of current definition, usage and measurement of QoL in the BD literature; a longitudinal investigation of QoL and its dynamic relationship with mood symptoms; and a qualitative investigation of processes in QoL self-appraisal. However, as highlighted in the introductory chapters, investigation of clinical applications of QoL in parallel to theoretical clarification is necessary to ensure that this consumer valued construct continues to have practical impact. QoL has been highlighted as a concept with significant potential for clinical applications (see 1.4.4, Chapter 1), particularly in the context of novel QoL-focused therapies which are consistent with the shift from an exclusive biomedical focus to broader strengths focused, person-centred and recovery-congruent approaches to the treatment of BD. Little is known about how interventions developed from this perspective will be experienced by consumers with BD. The present chapter contains a version of the published article formatted to be consistent with the overarching thesis. This qualitative investigation aimed to explore the meaning and experiences of a QoL-focused self-management intervention from the perspective of consumers with BD. Although the article as written for publication emphasises experiences of self-management, it is important to note that this study was conducted in the context of a QoL-focused self-management intervention, and as such the themes presented may be interpreted as particularly relevant to novel QoL-focused therapeutic approaches in BD.

Footnote: Studies 3 and 4 were conducted within the context of an overarching mixed methods investigation of a QoL-focused psychoeducation intervention for BD. This intervention was developed from a satisfaction and wellness-centric, BD-specific framework: strategies were presented across the range of domains identified as important to people with BD in qualitative interviews (Michalak & Murray, 2010b; Michalak et al., 2006), and positive outcomes were deliberately emphasised. As the design of the intervention was not a central focus of the analyses presented in the papers, little detail is discussed in the manuscript. A summary of the intervention and quantitative outcomes is presented elsewhere (Michalak et al., 2018).
8.2 Abstract

Background: Self-management (SM) is increasingly emphasised as a key aspect of bipolar disorder (BD) treatment. However, little is known about the subjective experience of SM, which might have both positive and negative impacts. The present study aimed to advance this literature through qualitative investigation of the experiences of people with BD who participated in an SM intervention targeting quality of life (QoL).

Methods: Forty-three individuals with BD engaged with an SM intervention and were later questioned about personal experiences of engagement with the intervention, including attempts to enact self-management strategies. Thematic analysis was used to identify important aspects of the experience of SM in BD.

Results: Four themes describing people’s experiences of SM were identified: 1) SM for BD is empowering, 2) individual responsibility to self-manage BD, 3) SM strategies lack power to control BD, and 4) the relationship of SM to the healthcare system.

Limitations: Potential limitations to generalisability may occur from self-selection bias in favour of SM and the QoL-focused nature of the present intervention.

Conclusions: The findings of this research generate novel insights into ways in which individuals with BD engage with SM interventions. For most people with BD, SM invokes a sense of empowerment and responsibility, although some feel symptoms remain beyond their control. A sense of partnership between consumers and clinicians may emerge from attention to SM, but traditional medical approaches were perceived as neglecting this aspect of care. Considerations from consumer perspectives are presented to assist clinicians and researchers utilising SM interventions in BD.
8.3 Introduction

There is growing consensus that optimal management of bipolar disorder (BD) includes the consumer’s active involvement in treatment (e.g., medication adherence, mood monitoring) and as such self-management (SM) is increasingly recognised in treatment guidelines (Kendall et al., 2016; Malhi et al., 2015; Yatham et al., 2013). A growing number of interventions supporting people to develop knowledge and skills for optimally managing their BD have been developed (Janney et al., 2014). Critically, little is known about how individuals with BD experience such invitations to become actively involved in managing their illness.

SM describes the ongoing process of the individual monitoring and responding to the signs, symptoms and consequences of a chronic illness (J. Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Bodenheimer, Lorig, Holman, & Grumbach, 2002). The process of SM extends beyond control of symptoms (Lorig & Holman, 2003), and includes an individual’s ability to cope with illness and act to maintain their quality of life (QoL). As a chronic mental disorder, BD is optimally managed when consumers themselves are actively involved in treatment, and treatment guidelines for BD describe SM as an important complement to therapies delivered by a healthcare worker (Kendall et al., 2016; Malhi et al., 2015; Yatham et al., 2013).

Evidence-supported SM strategies for BD include: medication adherence, monitoring mood, sleep and lifestyle regularity, exercise, healthy diet, detecting and responding to early signs of relapse, and stress-management (Janney et al., 2014; Jones, Deville, Mayes, & Lobban, 2011; Michalak, Suto, et al., 2016). SM interventions, whether clinician-led, peer-led or delivered via unguided materials (e.g., workbooks) can facilitate the development of effective SM strategies in BD (Janney et al., 2014). Clinician-led psychoeducation, in which consumers are provided with information about SM, forms one of the major evidence-supported therapies in BD and has demonstrated efficacy in improving medication adherence and increasing time to relapse (Bond & Anderson, 2015). Novel approaches to SM in BD are also receiving empirical support, with interventions increasingly peer-led (Janney et al., 2014), delivered online, or primarily focused on recovery and QoL (Leitan et al., 2015).

SM depends on active consumer involvement, and thus it is important to understand SM from the perspective of the individuals who may enact it. Limited existing literature suggests that experiences of SM for people with chronic illnesses can vary in important ways.
from theoretical expectations (Sadler, Wolfe, & McKeivitt, 2014). For example, a study of people with asthma found that for some the role of the consumer in SM was understood in terms of compliance with healthcare provider prescriptions (Koch, Jenkin, & Kralik, 2004). More fundamentally, some individuals with chronic illnesses reject the notion their illness can be actively self-managed, in favour of attributing responsibility to healthcare providers or carers (Audulv, Asplund, & Norbergh, 2010). The perceived meaning of SM has implications for engagement in SM interventions: locus of control and self-efficacy beliefs have been hypothesised to influence SM behaviours (Bodenheimer et al., 2002; Reich, Erdal, & Zautra, 1997). Furthermore, the nature of SM in BD does not directly parallel that of other chronic illnesses. In diabetes, for example, quantitative indicators (i.e., blood glucose levels) and well-understood biological mechanisms guide SM responses: when glucose levels are regulated, hypo/hyperglycaemic attacks may be avoided. By contrast, in BD warning signs are often ambiguous, and the ability to control symptoms imperfect: mood episodes commonly occur despite best practice pharmacological and psychosocial treatment (Perlis et al., 2006). Consequently, the experience of SM in BD may differ to those reported in the physical chronic illness literature. No research to date has investigated these issues in a BD population: Rigorous exploration of SM from the perspective of individuals with BD is needed to inform the development and delivery of SM interventions for this group.

The present study. The aim of the present study was to explore the meaning and experience of SM interventions from the perspective of people with BD. To achieve this, qualitative interviews were conducted with people with BD in the context of a QoL-focused SM intervention.

8.4 Method

Using descriptive qualitative methods (Vaismoradi et al., 2013), the present study leverages off a broader investigation of the efficacy of various knowledge translation strategies in sharing evidence-based SM strategies to individuals with BD. As part of this overarching mixed-methods study (i.e., both quantitative and qualitative), all participants had access to a website focusing on SM strategies related to QoL in BD (Bipolar Wellness Centre; www.bdwellness.com), a QoL self-monitoring tool ('QoL Tool'; Michalak & Murray, 2010b), and additional active SM support delivered via: a) webinars, b) videos, c) online peer support, or d) in-person group workshops. Participants were free to choose the information delivery modality they received and the SM strategies they would focus on. Here, the focus is
on the experience of participating in a SM intervention rather than on differences between modalities and specific strategies.

8.4.2 Participants

Participants in the present study were a subsample of those in the overarching study who agreed to participate in a follow-up telephone interview.

8.4.2.1 Inclusion/exclusion criteria

Participants in the overarching study were required to be: i) age 19 years or above, ii) able to communicate in English, iii) able to provide informed consent, iv) a resident of Canada, and v) have a self-reported BD diagnosis.

8.4.2.2 Recruitment

Recruitment was conducted via: a) notices sent to individuals enrolled in a mailing list for research participation, b) healthcare providers, and c) advertisements in print (e.g., newspapers) and online (e.g., blogs) media.

At enrolment in the overarching study, individuals indicated their consent to be contacted at a later date regarding participation in a telephone interview. Consenting participants were contacted via email to explain the qualitative interview and invite them to participate. Participants in the interview received a $20 honorarium in the form of a gift certificate.

Purposeful criterion sampling (Patton, 2002) was used to establish a sample representing the key demographic variables of the original investigation. Participants in the qualitative study were selected based on specific criteria – age, gender and BD diagnosis - to ensure that the sample reflected the demographic diversity of the original sample. Purposive sampling was used to recruit individuals based on engagement with specific content, such that the full spectrum of SM strategies across the different information delivery modalities was represented in the overarching mixed methods study. For the purposes of the present study these sampling criteria were not applied in the analytic framework or description of findings. In practice, the majority of participants engaged with content across multiple information delivery modalities and SM strategies.
8.4.3 Qualitative Interview

A semi-structured interview schedule was developed with three sets of open-ended questions. Participants were encouraged to describe their experiences, positive and negative, of the SM intervention. The first set of questions asked participants about their engagement with information on SM strategies. The second set explored any attempts to implement SM strategies. Finally, participants were asked about their QoL. Probes and reflective listening were used to elicit depth in responses.

8.4.4 Procedure

Approval for the study was granted by the University of British Columbia’s Behaviour Research Ethics Board. All participants received written information on the study and gave written consent to be contacted for an interview. Data in the study was treated confidentially and transcripts de-identified.

Consenting participants were contacted via email approximately two weeks after participating in the SM intervention to schedule a telephone interview. Interviews occurred three to four weeks following participation.

A total of 43 interviews were conducted by the first author. Interviews ranged from 20 to 70 minutes in length ($M = 39.4$ minutes, $SD = 11.2$). They were digitally recorded and transcribed verbatim by the first author ($n = 24$, 55.8%) or research assistants (checked by the first author for accuracy; $n = 19$, 44.2%).

8.4.5 Data Analysis

Braun and Clark’s (2006) guidelines for thematic analysis were followed. The first author was familiarised with the data through the process of transcribing interviews and re-reading transcripts. Data were assigned brief descriptive codes in the qualitative data management software NVivo (QSR International, 2016). Codes were examined and overarching themes identified. The content of themes was reviewed for coherency, and transcripts were revisited as the themes were developed to ensure all relevant data were adequately described. The essence of the most important themes in relation to the study aim were then described in a comprehensive report with illustrative transcript extracts. To reduce the risk of bias and to address analytic validity, authors EM and RH reviewed both the descriptive accounts of themes and transcripts for coherency and validity of interpretation, with disagreements resolved via consensus.
8.5 Results

8.5.1 Participants

Forty-three participants were interviewed for the qualitative study (42.2% of the overarching study sample). The modal age range was 45-54 years. The majority of participants (n = 30, 69.8%) were female. The most frequently reported diagnosis was BD-I (n = 24, 55.8%), followed by BD-II (n = 16, 37.2%). One participant reported a diagnosis of rapid cycling BD-II, and two reported a diagnosis of BD-NOS.

8.5.2 Overview of Key Findings

Four core themes relating to the meaning and experience of SM for individuals with BD were identified: 1) SM for BD is empowering, 2) individual responsibility to self-manage BD, 3) SM strategies lack power to control BD, and 4) the relationship of SM to the healthcare system.

8.5.2.1 Self-management for bipolar disorder is empowering

This theme captured the prominent sense of empowerment participants described as arising from learning about or engaging in SM. Individuals described SM strategies as fostering an active role in the management of BD, with an according increase in self-reliance: “It’s important to self-manage and it’s great to have people that you can reach out to and rely on, but sometimes it’s good to know how to handle yourself because you need to know that you know yourself best” (F, 25-34, Rapid cycling BD-II). Further, SM was seen as restoring a sense of control to the consumer by lessening dependence on healthcare workers or medication. One participant shared,

I thought it was really empowering because even though we’re in the midst of it here, we’re trying to gain autonomy over our situation and not have to rely on the doctors, I’m not on medication but you know, we’re trying to take back the reins. (F, 45-54, BD-I)

This sense of autonomy was also supported by an individual’s independence in engaging with and enacting SM strategies, rather than having their course of action dictated by a psychiatrist or healthcare worker: “It’s very empowering, because it was me doing it and not somebody like a psychiatrist or therapist telling me to do it, it was me learning about it and then applying it to myself” (F, 25-34, BD-II).
Also empowering was the sense of control over symptoms granted by SM, in contrast with a past sense that the illness was uncontrollable or manageable only through medication:

*I think a lot of the time with bipolar disorder the first thing the doctor wants to do is put on you on meds or whatever and you will feel like you’re out of control from it, like you have to rely on the meds to keep you balanced or you know make sure you’re in therapy... it feels kind of helpless to the ups and downs... you realise that there’s steps that you can take that aren’t those options, you can do it in your everyday life and you won’t have to wait for meds to work or you don’t have to completely rely on them, you don’t have to completely rely on the therapist to be there for you. You can make changes for yourself.* (F, 25-34, BD-II)

Empowerment for consumers in this intervention was described as arising from SM – in particular, this experience was characterised by self-determination, self-reliance, and decreased dependence on healthcare workers or medication. A feeling of control over symptoms was described as a key element of this experience.

**8.5.2.2 Individual responsibility to self-manage bipolar disorder**

A second theme described how the decision to learn about or enact SM strategies related to an individual’s sense of personal responsibility to self-manage BD. This theme captures a process of taking ownership of SM tasks, whether this was in response to the present intervention or part of a broader journey towards wellness.

A sense of personal ownership of SM was described as a motivating factor for implementing strategies: “*This is something that I should be doing, and you know telling myself that I’m the one that has to do this, not somebody else*” (F, 65-74, BD-II).Feelings of responsibility were often linked to the theme of empowerment (3.2.1, above). An individual’s awareness of the possibility of taking an active role in the management of BD evoked an according sense of duty to enact SM strategies:

*The thing I realised is that I do have some control over [sleep], you can manage sleep and it’s not something to just play with and say oh well, I’ll just stay up until 2 in the morning today and then get back on schedule tomorrow.* (M, 55-64, BD-I)

Similarly, changing ideas about control of BD described above (3.2.1) were linked to a sense of being accountable for SM. For example, a participant noted that the knowledge that BD management involves more than medication led them to engage in SM strategies:
I know now mostly my moods are up to me once I’m on the right medication, the rest of it is up to me, so I can take responsibility for my moods...In my particular case I think medication is about 75% of it, because once I started on the right medication I was just a different person, so then the last 25% is all the others things I can do, like eat right and make sure I get enough sleep and stuff like that. (F, 45-54, BD-II)

Responsibility to learn about or attempt SM strategies not only emerged in response to the SM intervention but was also situated as part of an ongoing journey towards wellness. A few participants described SM strategies they attempted outside of the context of the intervention and related these to a sense of personal ownership of managing BD. One individual explained,

Over the years I learned the things to do. I see my doctor regularly every couple of months, I take my medication twice a day as prescribed, I really believe very strongly in peer support, and learning, I educated myself about my illness, and I read things about it, and I subscribe to Moods Magazine and Bipolar. I keep myself informed, I think if it’s your illness you have to. You have to count on yourself and not other people really. (F, 65-74, BD-II)

A sense of ownership of SM was colourfully illustrated in metaphor by one participant, who described an ongoing, active process of self-monitoring and making adjustments as necessary:

I sort of see now that with the bipolar illness it’s kind of like I’ve got a dashboard that’s got a lot of knobs on it. And they constantly need a little bit of adjusting, you know? So there’s a series of knobs there that need to be tended to all the time, because it’s easy for me to either become hypomanic or depressed. (F, 45-54, BD-II)

Overall, responsibility to engage in SM was characterised as arising from a sense of personal ownership of maintaining wellness. Linked to the description of empowerment (3.2.1, above), feelings of self-determination and independence played a key role in motivating individuals in this intervention to take up the mantle of SM in BD.

8.5.2.3 Self-management strategies lack power to control bipolar disorder

Contrasting the sense of empowerment described in 3.2.1, an important minority of voices did not perceive SM strategies to be effective in the face of BD symptoms. SM for BD, while perceived as having some relevance to broader QoL areas outside of the context of
mood episodes, were described as lacking power to circumvent relapses. In such circumstances, only medication was viewed as capable of restoring stability:

*It may be okay for after one recovers from a let’s say a manic attack, but to bring you down in the first place requires medication, you can’t just sit down with a therapist and hope that if you’re in a manic episode or whatever that it’s going to disappear because it’s not.* (M, 65-74, BD-I)

Past experiences of limitations of SM strategies for relapse prevention had a lingering impact on people’s confidence in SM strategies and sense of helplessness in the face of BD:

*I have a lot of frustration because even if you do all the things that the video tells you to do, at the end of the day I still feel like I’m at the mercy of my disorder... I can not have any caffeine past 12, I can turn off all the electronics at 10, I can do everything and not have a nap, and depending on where I am in the cycle, or cycling, I would not be able to sleep.* (F, 35.44, BD-NOS)

Linked to this ongoing sense of powerlessness, a small number of individuals described negative emotional reactions to the promotion of SM strategies in the intervention. Frustration that QoL-focused SM strategies were superficial was expressed:

*Somethin’g like ‘be kind yourself’... it’s not meaty, that’s the first thing that you’re not doing for yourself, and then if anybody tells you in a bad state, ‘Oh, you’re being tough on yourself ... ’ it just sounds like a very kinda condescending.... I don’t know, it’s just, it’s too lightweight, it’s not meaty enough as a strategy. Tough times require tough things... I do have to be nicer to myself but right now, it feels more like survival and how are you going to keep everything together so you’re not going to jump off of a building, you know, so just even having that conversation can feel so ridiculous in light of how serious the situation is.* (F, 45-54, BD-II)

While some participants viewed SM as enhancing a sense of control (3.2.1), others perceived strategies as ineffective or targeted at superficial aspects of wellness. For these participants, an ongoing sense of powerlessness in the face of mood symptoms resulted in a doubtful outlook on the efficacy of SM.
8.5.2.4 The relationship of self-management to the healthcare system

A final theme captured individuals’ experiences of SM described in relationship to their experience of the healthcare system. The nature of this relationship differed across people in important ways: for some, SM was described as part of a healthcare-inclusive team approach to management of BD. A greater proportion, however, viewed SM and the according sense of empowerment as overlooked by a system overly focused on medication and symptoms.

For a small number of participants, SM was perceived as integrated with the healthcare system. A collaborative relationship with healthcare providers was described, with individuals portraying themselves as a key player in a team approach towards managing BD. For example, a participant explained their choice to share the Bipolar Wellness Centre with their counsellor and psychologist as, “We’re all trying to figure this out together” (F, 45-54, BD-II). However, for a larger number of participants, SM was perceived as neglected by what they viewed as a predominantly medicalised treatment model of BD management. A number of individuals stated that they had never received information on SM from healthcare providers. For this group, their experience of BD management thus far had been largely focused on symptoms and medication. This approach was viewed as reductive: “Just making sure they are taking their meds and that’s the only thing” (F, 25-34, BD-I). Paralleling the theme of empowerment in 3.2.1, lack of information about SM in a clinical setting was associated with a view by some that BD was out of one’s control; however this could be addressed through sharing knowledge on possible active roles in BD management. For example, one participant shared,

\[ I \text{ feel that they were most concerned with making sure my mood was okay, that my biology was okay, and that’s kind of where they left off and nobody picked up from that. It’s like handing me the reins to something I don’t even know how to control… You come out of a healthcare professional’s office and they’ve given you a medication. They’ve told you to just make sure you’re sleeping okay and don’t be stressed, but they don’t tell you how not to be stressed. They don’t tell you that you need to make sure your study is going to be okay, that your work’s going to be okay, that you might have issues with family or friends or anything like that, that your lifestyle might just change they don’t tell you any of that. And that’s what I got out of } \]

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the quality of life questionnaire is finally realising that there’s actually a lot more to work on; it’s not just take a pill at night. It’s so much more. (F, 19-24, BD-I)

Individuals in this sub-group experienced SM as different to the approach they had experienced thus far in the healthcare system. In particular, the description of SM strategies in the intervention was noted as being more hopeful or positive: “There is a message of hope there... That’s a message you never hear in a doctor’s office. Ever” (M, 45-54, BD-NOS). Individuals felt QoL-focused strategies, in contrast to medical management, focused on outcomes valued by the individual. For example, one individual explained, “At the end of the day I don’t care about what all the medical stuff says, I want to know how to make my life better” (F, 45-54, BD-II).

In contrast to views that SM was inadequately addressed in routine clinical practice or overly focused on medication and symptom management, the present QoL SM intervention was viewed by participants as conveying optimism and targeting areas of personal significance and value to the individual.

8.6 Discussion

The aim of the present qualitative study was to explore the meaning and experience of SM from the perspectives of individuals with BD. Most participants spoke of a sense of empowerment gained from engaging in a SM intervention and a corresponding responsibility to enact SM behaviours. These experiences contrasted against those of a minority who described the SM intervention as lacking power to control BD symptoms. Some individuals described a positive experience of collaborating with healthcare providers to self-manage BD.

More frequently, however, participants described SM as overlooked by a system they perceived as overly medication and symptom-focused. Consumer experiences of SM offer considerations for clinicians and researchers seeking to optimise engagement in SM interventions in BD.

A majority of participants experienced SM as empowering. This reassuring finding accords with guiding principles of SM generally, the central aim of which is to grant individuals the skills and confidence to manage the symptoms and impacts of chronic illness (J. Barlow et al., 2002; Bodenheimer et al., 2002; Lorig & Holman, 2003). The present study extends this conceptualisation by exploring empowerment from the perspective of individuals with BD. Participants described their active role in managing BD as empowering, contrasting this with previously internalised messages about the uncontrollable nature of the illness. The
knowledge that SM could be effective at managing the symptoms and impacts of BD strengthened this optimistic message, with participants reporting a resultant increase in feelings of control, hope, and greater confidence in attempting strategies. These subjective experiences have important links to action: self-efficacy (an individual’s belief that they can successfully enact an action and produce the desired effect) is thought to underpin behavioural change (Bandura, 1977). Furthermore, these findings suggest impacts on locus of control, the perceived ability of the individual to impact their own circumstances (Levenson, 1981). Engaging with an SM intervention appeared to promote an internal locus of control over BD symptoms, an attitude thought to serve a critical function in facilitating people’s adoption of health behaviours (Wallston & Wallston, 1978). Individuals contrasted this new perspective to their prior external locus of control (i.e., medications, doctors) and consequent sense of helplessness. Further research using validated scales of self-efficacy, empowerment and locus of control is likely to be of use in exploring their role in individuals’ behaviour following a SM intervention.

Participants also found it empowering to independently engage in SM, rather than have a course of action dictated by healthcare workers. This was experienced as positioning the consumer in the driver’s seat of BD management, as contrasted to traditional approaches to mental health care in which the expert provider dictates treatment course to a passive patient (Laurie Davidson, 2005). Given that consumers with severe mental illnesses often report feeling excluded from decisions regarding their care (Dahlqvist, Schon, Rosenberg, Sandlund, & Svedberg, 2015), SM interventions may play a vital role in restoring a sense of autonomy and participation in the treatment process for individuals with BD.

Of note, the perception of SM in BD as restoring control was not universal, with a small group describing an ongoing sense of powerlessness in the face of BD symptoms. For these individuals, SM strategies were not viewed as effective at preventing relapse, sometimes leading to feelings of frustration in reaction to the intervention content. Relatedly, staging models of recovery have suggested that a focus on living well with BD may be counterproductive or upsetting for individuals who have not come to terms with diagnosis (Leamy, Bird, Le Boutillier, Williams, & Slade, 2011; Tse et al., 2014). There may be a need to tailor interventions: for example, individuals who feel a lack of control over their illness may be more interested in symptom management rather than broader QoL-focused strategies. Alternatively, specific hope-building strategies may be of use in promoting recovery and addressing the demoralisation experienced by such individuals (Michalak, Suto, et al., 2016).
A sense of personal responsibility was described as a consequence of participating in the SM intervention. Importantly, responsibility here was not described in terms of duty to comply with practitioner recommendations, but rather was personally chosen. Previous work in the diabetes literature emphasises the limitations of responsibility-as-compliance, with SM interventions delivered through this lens frustrating consumers and clinicians alike (Anderson & Funnell, 2000). This literature suggests that by contrast, motivation to engage in SM strategies is enhanced when responsibility is actively entered into by consumers. The present study highlights that in BD, responsibility to engage in SM is closely linked to an increased sense of empowerment (discussed above), suggesting an important component of future SM interventions will be to promote autonomy. Quantitative investigation of the degree to which engagement in SM strategies follows self-reported ideas of personal responsibility is needed to further explore this potential pathway to SM behaviours.

Participants spoke about the concept of SM in relation to their experience of healthcare systems: For a minority, SM was well-integrated with existing supports, and consumer saw themselves as a member of a collaborative team. For the majority, however, SM was experienced as a contrast to the healthcare system. Healthcare providers were described as excessively focused on medication adherence and symptom monitoring, to the detriment of the consumer who consequently missed opportunities to develop broader SM skills. QoL-focused strategies were described as particularly neglected by the traditional healthcare system, an oversight which has been found in other qualitative research to lead consumers to withdraw from services (Todd, Jones, & Lobban, 2012). The experience of participants in the present study mirrors criticisms of the traditional medical-model approach to BD treatment, which has been described as paternalistic and disempowering due to an excessive focus on biological factors (Munetz & Frese, 2001). By contrast, the present SM intervention was experienced as person-centered, empowering, and optimistic. The present findings, therefore, highlight a potential gap in the application of treatment guidelines emphasising the importance of SM in routine clinical practice, particularly in relation to broader, QoL-focused SM strategies (Kendall et al., 2016; Malhi et al., 2015; Yatham et al., 2013). Numerous resources to support SM in BD are available (e.g., www.bdwellness.com; Janney et al., 2014), and clinicians may assist consumers to identify SM-goals and strategies through use of QoL self-monitoring tool (www.bdql.com). Research approaches which draw on the expertise of both consumers and clinicians will be vital in addressing the translational gap between research, treatment guidelines and practice (Michalak, Jones, et al., 2016).
Encouragingly, the present findings point to a critical opportunity for clinicians to facilitate empowerment and productive self-responsibility by integrating SM education and support, particularly in broader QoL domains, with medication and symptom-focused care. Indeed, it has been argued that the term ‘partnership management’ better describes the process of BD management, given the vital role clinicians play in supporting SM and facilitating access to evidence-supported programs/tools/skills (Janney et al., 2014). Clinician-initiated conversations around SM in BD offer the opportunity to develop a collaborative alliance: while symptom-focused SM strategies have a vital role in living well with BD, it has been suggested that consumers particularly value attention to broader QoL areas, and incorporating QoL-focused SM strategies may therefore enhance engagement (Murray & Michalak, 2012). Importantly, improvements in therapeutic alliance may in turn enhance medication adherence and predict lower symptoms of mania (Berk et al., 2004; Strauss & Johnson, 2006), pointing to synergies between SM and more traditional clinical approaches. Finally, the experiences of participants here underscores the importance of clinicians adopting a hopeful tone on the prospect of recovery in BD or utilising specific hope-building strategies (Michalak, Suto, et al., 2016): through communicating the message that there are actions that can be taken to manage the symptoms and impacts of BD, consumers are likely to feel empowered and take ownership of managing this chronic illness.

8.6.1 Limitations

Limitations to the present design should be noted. First and foremost, the sample volunteered to participate in a SM trial and a qualitative interview of their experiences. A bias in favour of SM interventions and notions of empowerment and responsibility cannot be ruled out (Bodenheimer et al., 2002). To address this, the experiences of important, albeit small, groups who expressed contrasting opinions on SM were explored. Quantitative exploration of SM attitudes in a representative sample of people with BD will illuminate the proportion of the population who share views highlighted in the present study.

Second, the present study did not group participants according to the modes of information delivery they engaged with in order to present a realistic depiction of self-directed engagement with SM interventions. Consequently, any interaction between people’s experiences of SM and the specifics of the SM intervention they were exposed to were not investigated. Future research should explore the impact of intervention delivery modality on the experience of SM.
Third, results are specific to a SM intervention targeted at improving QoL in BD, and may not generalise to interventions largely focused at preventing relapse and reducing symptoms (e.g., Colom & Lam, 2005). QoL-oriented SM is linked with recovery (and by association, empowerment, responsibility, and holistic, person-centred views) at a conceptual level (Leitan et al., 2015; Murray et al., 2017), and consequently one may expect an intervention designed according to these philosophies to have the impacts observed in this study. Finally, data on validated diagnosis, ethnicity, income or education were not collected and consequently the representativeness of the study sample is unknown. Despite these limitations, the present study identified clinically relevant information for the emerging field of SM in BD, and provides valuable insights from the consumer perspective which suggest novel avenues of investigation.

8.7 Conclusions

For the first time, consumers with BD have commented on the experience of engaging with a SM intervention. The present study emphasises that the importance of SM interventions extends beyond improving knowledge of skills: participants spoke of a sense of empowerment gained from SM strategies and a corresponding responsibility to self-manage their BD. A small but important group of contrasting voices described SM strategies as ineffective at controlling BD symptoms. Finally, while traditional approaches to management of BD were perceived by consumers as neglecting SM, the present study optimistically concludes that healthcare providers and researchers have powerful potential to support SM by conveying hope, adopting a collaborative approach to SM, and empowering consumers to play an active role in the management of their BD.
CHAPTER 9. DISCUSSION, CRITICAL INTEGRATION, LIMITATIONS, AND CONCLUSION
9.1 Chapter Overview

The overarching aim of the present project was to advance understanding of the QoL construct in BD. Four empirical studies have investigated various aspects of the QoL construct in BD, including a systematic review of its definition, usage and measurement in the BD literature (Study 1), a quantitative investigation of the trajectory of QoL and its dynamic relationship with symptoms of BD under guideline driven treatment (Study 2), a qualitative exploration of implicit processes involved in self-appraisals of QoL in BD (Study 3), and the lived-experience of a QoL-focused psychosocial intervention in BD (Study 4). This final chapter will leverage findings from across these studies in a generative discussion of future directions for the study and application of QoL in the BD literature. Given the overarching aim of the present project, an extended discussion of the QoL concepts identified in the literature review of Study 1 will first be presented (9.2). This will be followed by a critical, integrative discussion (9.3) aiming to draw points of intersection between the project’s studies to generate novel questions for future research as well as theoretical, clinical and measurement implications. Throughout this chapter, some repetition of content from the four published papers is unavoidable. However, the extended and integrative discussion here aims to move beyond the published material by drawing points of synthesis across multiple studies to better characterise the potentially paradigm-changing implications of the present project for the BD literature. This integration will be leveraged to generate a provisional heuristic framework for understanding QoL in BD (9.4).

Limitations of the individual studies have been comprehensively discussed in the context of each published paper: in order to avoid repetition, limitations will be discussed only if they impact the design and interpretation of the project as a whole (9.5).

Finally, the chapter will conclude with an overall statement regarding the contributions of the present project to the QoL in BD literature, and critical gaps to be addressed in future research (9.6).

9.2 Extended Discussion of Study 1: Insights into the Conceptualisation of Quality of Life in Bipolar Disorder

9.2.1 Review of Study 1 Findings and Discussion

The systematic review (Study 1) investigated the definition, usage and measurement of the QoL construct in the empirical BD literature. A challenge facing the BD literature was
identified, namely, QoL was infrequently defined, and there was no consensus as to how the term should be used. However, careful examination of the usage of the term QoL in text revealed four categories of usage: QoL as related to functioning, QoL as related to health, QoL as related to subjective experience (with the sub-category of satisfaction), and QoL as related to wellbeing. Reassuringly, there was coherence between authors’ usage of QoL and the measurement instrument chosen, based on an inspection of item content.

Examination of QoL usage within categories, co-occurrence of usage examples and the association between major QoL measurement instruments and usage types suggested these categories could be further reduced into two major approaches with associated measurement techniques. One perspective favours a normative/descriptive approach: that is, assessing negative deviations from ‘normal’ status. While QoL in this approach could be self-rated, it was more often from a descriptive perspective (i.e., quantifying own performance) than the individual’s own phenomenological assessment of the importance or impact of this. The spectrum of life areas assessed in this approach was closely tied to the impacts of BD on health and functioning. The second perspective favours an ideographic/evaluative approach to QoL: that is, an emphasis on the individual’s own evaluation of their QoL based on their unique priorities, values and experiences. This perspective encompassed assessment of what is going well in an individual’s life as well as what is negatively impacted, and incorporated broader domains of QoL such as leisure activities, and social relationships.

The published article for Study 1 concludes by proposing a research agenda for further theoretical clarification of the QoL construct as it applies to BD, as well as pragmatic suggestions for conducting empirical research in the context of such definitional ambiguity. The present discussion will extend on this commentary, by comparing results of the systematic review to similar works conducted outside the BD literature, as well as delving more deeply into the constructs identified as relevant to QoL in BD (functioning, health, subjective experience and wellbeing).

9.2.2 Quality of Life Definition and Usage in Bipolar Disorder as Compared to Other Fields

The lack of consensus or explicit definition of QoL identified in BD publications also exists in the broader healthcare literature. In a review of the medical literature generally, Gill and Feinstein (1994) randomly sampled 75 papers with ‘quality of life’ in the title, and found that less than half indicated the domains of QoL to be investigated. Furthermore, only 15% of
articles conceptually defined the term – that is, provided a definition of the underlying QoL construct. Controversy regarding specification of the overarching QoL concept adds further complexity to the understanding of QoL in the broader healthcare literature (Moons, Budts, and De Geest, 2006): even if definitions agree on which areas of life are important for QoL, the lens through which these are evaluated may significantly impact interpretation of an individual’s circumstances. The conceptual approaches taken in the BD literature and their implications for QoL assessments in this population will be discussed further below (9.2.3).

The identified referents for QoL in the BD literature do show some similarities with general trends in the usage of QoL in healthcare. In line with Study 1, which found functioning and health to be the most common referents of QoL in BD, a tendency to use these constructs to represent QoL has been observed in other domains. Garret and colleagues (2002) found that in a review of 690 unidimensional instruments, 55% represented QoL as physical functioning, pain, or symptoms, while 38% described psychological wellbeing. Similarly, other bibliographic reviews of available QoL measures have highlighted a tendency for instruments to focus on physical functioning and symptoms of disease (Bowling, 1997, 2001). Of note, the operationalisation of QoL in the medical literature with measures of functioning and health status diverges from definitions of QoL generally, which, as identified by Cummins (1997a) in a review of 27 QoL definitions, typically include a broader range of constructs. While 70% of reviewed definitions did include physical health, 85% included emotional wellbeing, 70% social and family connections, 59% material wealth and 56% work or other productive activities. Meeberg (1993) identifies life satisfaction as the most common synonym for QoL, with happiness and wellbeing also occurring frequently in the literature. This contrast between QoL theory and application in the broader literature is similar to the divergence between definitions and usage/measurement of QoL identified in the BD literature: while the most common referent was functioning (and accordingly the most common measurement instrument was the SF-36), explicit definitions of QoL tended to include emotional, social and psychological wellbeing.

When examining conceptualisations of QoL in other fields of study, important areas of overlap and divergence with the BD literature can be noted. While the BD literature does highlight wellbeing as an important component of QoL, this was the least commonly occurring referent across studies. In contrast, the successful ageing literature, for example, places more focus on QoL as a set of positive psychological characteristics that enable the individual to flourish and find meaning despite physical limitations (Bowling, 2005a).
Paralleling the findings of Study 1, the schizophrenia literature also prioritises functioning, symptoms of illness and side effects of medication as referents of QoL (Awad & Voruganti, 2012), however in contrast to the BD literature this is typically conducted from an objective, clinician-rated perspective. Clearly, there are important contrasts in the usage of the QoL construct in BD as compared to some other health fields, and thus Study 1 serves to focus future conceptual work in clarifying those concepts which were identified as relevant to BD.

9.2.3 Further Exploration of Quality of Life Concepts in Bipolar Disorder

The concepts identified in Study 1 provide a framework for moving beyond comparisons of QoL approaches at the domain level (that is, what areas of life are considered important, as in Cummins, 1997a) to a consideration of the meaning of the overarching QoL construct. This higher-level perspective provides greater clarity about how approaches to QoL in the empirical BD literature may differ: for example, while the measurement instruments SF-36 and Q-LES-Q both include a social domain, these measures interrogate this domain with differing assumptions about how QoL is represented within this life area. As highlighted in Study 1, the SF-36 appraises QoL in the social domain from a functionalist perspective, by asking an individual to rate the degree to which their normal social activities have been impacted by physical or emotional problems: “During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?” In contrast, the Q-LES-Q interrogates emotional and cognitive aspects of the respondent’s subjective appraisal of their social activities with questions such as “During the past week, how much of the time have you enjoyed talking with or being with friends or relatives?” As noted by Moons et al. (2006), authors’ underlying assumptions as to the meaning of QoL itself may result in radically different appraisals of a person’s circumstances. Introducing this overarching conceptual framework is likely to have implications for synthesising empirical literature on QoL in BD. As stated in Study 1, previous reviews in this area have not systematically attended to differing conceptualisations of QoL when interrogating the literature. For example, Ishak and colleagues (2012) review of QoL in BD draws conclusions about the impact of interventions on health related QoL, despite the majority of reviewed studies using the Q-LES-Q (a measure identified in Study 1 as linked to satisfaction). The analysis of Study 1 thus suggests it is critical to look beyond the domains addressed by QoL measures to the conceptual approach taken towards QoL.
While the systematic review of Study 1 has taken some steps towards identifying and clarifying concepts used in the BD literature, these referents were rarely explicated in the reviewed papers. Here, the broader QoL literature is used as a basis to illuminate these concepts, their benefits, limitations, and potential relevance to QoL in BD. Given that functioning, health, subjective experience, satisfaction and wellbeing (as related to QoL) are broad concepts; the discussion here will focus on each referent’s critical attributes - that is, the characteristics which appear repeatedly across definitions and theoretical discussion (Walker & Avant, 1994).

9.2.3.1 Quality of life as related to functioning

In the broader healthcare literature, definitions of QoL that follow a functionalist approach are concerned with indexing an individual’s ability to perform roles deemed ‘normal’ for their age and social position (Leidy, 1994). These include, for example, gainful employment, successfully managing the demands of schoolwork or housework, positive marital and social relationships, and possession of the physical and cognitive capacity to care for oneself (Patrick, Bush, & Chen, 1973). Functionalist approaches to QoL, similar to those that prioritise health status or HrQoL, focus on outcomes that may be more relevant to healthcare interventions (e.g., it could be said that a client’s satisfaction with his job is of less concern to a physician than ensuring the client does not miss days of work or get fired; Patrick & Erickson, 1993). In the case of BD, there is a clear reason to focus on improving functioning: the illness is associated with significant negative impacts to an individual’s social, occupational, and general functioning (reviewed in Chapter 1 of the present project; 1.4.2). Indeed, it has been argued that in the treatment of BD, functional outcomes may be more meaningful measures of treatment success than ratings on symptom measures (Keck, 2004). A caveat to the use of functioning as a referent of QoL in BD is that existing measures may not capture aspects relevant to this population. As shown in Study 1, the functioning inventory most commonly used to assess QoL in the BD literature (the SF-36) is a generic measure of health status with a particular focus on an individual’s ability to perform usual roles (Ware & Sherbourne, 1992). However, as highlighted by Goldberg et al. (2010) very few of the generic functional status measures used in mental health research assess cognitive functioning (Robinson & Ferrier, 2006; Robinson et al., 2006), emotional regulation (Green, Cahill, & Malhi, 2007) or sleep quality (Murray & Harvey, 2010), areas that may be particularly relevant to individuals with BD.
While functioning is widely recognised as an important outcome in BD (Gitlin & Miklowitz, 2017; Sachs & Rush, 2003), a number of authors in the broader medical field who prioritise the subjective experience of QoL have argued that measures of functioning do not optimally assess the construct within this population. In particular, the focus of functional approaches on descriptions of behavioural performance rather than the capabilities or subjective experience of individuals themselves has been argued to be inappropriate (Coons, Rao, Keining, & Hays, 2000; Leventhal & Colman, 1997; Moons et al., 2006). Functionalist approaches to QoL in medicine have been criticised for valuing the individual based on their contributions to society (Bowling, 2005a), and consequently reflecting the interests of politicians, doctors and administrators rather than the service user (Hunt, 1993). Similarly, functioning conceptualisations tend to focus on negative indicators of QoL such as disability and limitations (Bowling, 2001). For example, although the SF-36 is the most frequently used QoL measure in BD as in the mental health literature more generally (Prigent et al., 2014), it has been described as a measure of health and functioning rather than QoL per se (Lepige & Hunt, 1997). Indeed, historically the SF-36 was developed as a measure of health status (Ware & Sherbourne, 1992).

One limitation of defining QoL according to an individual’s functioning is that it may inadvertently devalue those with chronic illnesses or disabilities who are unable to perform in socially prescribed roles of employment, schoolwork or housework, while neglecting to assess meaningful engagement in activities which are key to the individual’s own perception of themselves as living rich and fulfilling lives (Hunt, 1997; Milton, 2013; Patrick & Erickson, 1993). This contrasts with recovery-based perspectives, which suggest that individuals may achieve meaning through personally valued (not necessarily normatively valued) activities (Onken, Craig, Ridgway, Ralph, & Cook, 2007). Another consideration for the use of functionalist approaches in the context of severe mental illnesses is that individuals with BD may not achieve functional recovery due to factors external to the individual, i.e., stigma against employing persons with severe mental illnesses (Moons et al., 2006), despite individuals having the potential to perform in these domains (for example, individuals with BD are often underemployed in contrast to their high level of educational attainment; Kupfer et al., 2002). As such, QoL improvements in BD may not be recognised if they occur outside of the context of normatively prescribed domains (e.g., employment, marital status, independent living).
An alternative approach that remains aligned with functionalist perspectives is to focus on participation in activities and community: by adopting a broader lens on contribution to society (i.e., incorporating leisure, family role participation, civic and social activities) functioning-oriented QoL measures may become more inclusive of valid and ethical indicators for individuals with chronic mental illnesses (Kindig, Asada, & Booske, 2008).

9.2.3.2 Quality of life as related to health

Study 1 found that health-related QoL (HrQoL) and health status were common synonyms of QoL in the BD literature. Blurred boundaries between the concepts of HrQoL, health status and QoL is not unique to the BD literature: Gill & Feinstein (1994) discovered in a review of empirical applications of QoL in the medical literature that the concept of HrQoL was not routinely distinguished from QoL. Despite ambiguities and overlap in usage, there is broad agreement that it is useful to distinguish between the two concepts (Karimi & Brazier, 2016). As an umbrella term, HrQoL has come to mean aspects of life that are directly impacted by the experience of a health condition (Testa & Simonson, 1996). Although referents of QoL as functioning and QoL as health share some similarities, namely a focus on negative deviations from ‘normal’ health/functional status and a narrow focus on illness-related aspects of life, important distinctions can be drawn (Bergner, 1989; Gill & Feinstein, 1994). Functioning measures typically conceptualise QoL as performative, that is, a person’s ability to fulfil their usual roles or possession of the basic physical and mental capacities that would enable this. A distinction can be drawn between functionalist measures and instruments that imply QoL to be representative of health status or health related: the latter typically describe the direct experience of illness and treatment, including symptoms and adverse effects of medication (for example, a schizophrenia-specific QoL scale assesses common antipsychotic side effects, such as “I am troubled by a dry mouth”; Wilkinson et al., 2000), or the impact of illness and treatment on physical, psychological and social factors. As an example, an item from the SF-36 asks: “During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?”

As with functioning referents, conceptualisations that focus on health are preferred by some as a means of tightening the scope of the broader, overarching QoL concept to aspects which may be modifiable with healthcare interventions (Fries & Singh, 1996; Ware, 1987).
For example, while Patrick and Erickson (1993) recognise that QoL may include social, environmental, and economic factors, they argue that these aspects are not under the control of the healthcare system, and consequently clinical trials ought to measure the narrower construct of HrQoL. From this perspective, broad definitions of health and QoL such as that employed by the World Health Organization (1948) could be criticised for fostering responsibility for aspects of life unrelated to medical care on the healthcare system, potentially diverting limited resources (Saracci, 1997). Moreover, it has been suggested that overly broad QoL assessments may in fact be harmful as they instil in the patient an expectation that these areas will be attended to (Higginson & Carr, 2001), creating an ethical argument to narrow their focus to areas under the control of usual medical care. Such a rationale may explain the relative prominence of health/functioning referents of QoL in BD (as shown in Study 1): interest in the aspects of QoL impacted by symptoms specifically would be expected, particularly in intervention trials, as it would follow that these are aspects malleable through treatment.

Despite pragmatic benefits conferred by narrowing scope to health-related aspects of QoL, it has been suggested that focusing on health does not do justice to the spirit of QoL as a holistic concept (Oliver et al., 1996). For example, Bradley (2001) notes that while health likely impacts an individual’s QoL, the concept is considerably broader than this focus allows, and important effects of interventions (particularly negative impacts) may be neglected by a narrower focus on health. Although broader definitions of health include positive aspects such as flourishing (e.g., World Health Organization, 1948), this is not reflected in many measures associated with the QoL as related to health perspective. Indeed, two common measures used as QoL measures in the BD literature, the SF-36 and EQ-5D, have been criticised as indexing negative indicators of illness (i.e., symptoms, disability) to the neglect of positive factors and broader aspects of QoL (Bowling, 2007; Bradley, 2001; Hunt, 1997; Speight, 2002). Similarly, conceptualisations of QoL as related to health share limited overlap with lay perspectives of good health: the EQ-5D, for example, was flagged as measuring only 39% of domains regarded by the general public as important to health (DeptHealth, 1995). This emphasis on negative indicators was seen in the BD literature in the analysis of Study 1, with concepts of disability and limitations emerging as linked to health and functioning. As with criticisms of health-related approaches generally, such measures may not adequately address domains valued by individuals with BD as relevant to QoL (Michalak et al., 2006).
9.2.3.3 Quality of life as related to subjective experience

An individual’s own subjective experience of their QoL was emphasised in a proportion of the BD literature, reflecting widespread endorsement in the medical literature that QoL is a concept best measured by an individual’s own assessment of their life circumstances and feelings (e.g., Bognar, 2005). Two associated constructs in the BD literature were identified: the sub-theme of satisfaction and the associated referent of wellbeing (however, wellbeing is not restricted to subjective experiences, discussed below 9.2.3.4). Although it may be assumed that the distinction between assessment of subjective (internally experienced) and objective (observable) QoL domains parallels the evaluative/descriptive division in approaches to QoL in the BD literature identified in Study 1, closer examination suggests they are orthogonal. Indeed, the co-occurrence analysis of Study 1 highlighted some overlap and interchangeable use of health, functioning and subjective experience referents within the BD context, particularly in relation to self-report of observable circumstances. Figure 9.1 illustrates that the evaluative (i.e., a judgement of value or worth) and descriptive (i.e., estimation of the frequency or intensity) lenses identified in Study 1 may be used to assess both internal and external aspects of QoL. For example, self-report measures of functioning like the SF-36 present a descriptive report of an observable outcome (typically behaviour), while a satisfaction-based measure such as the Q-LES-Q indexes a person’s satisfaction (i.e., evaluative assessment) of those behaviours in work or social environments. Similarly, assessments of subjective experience may be evaluative (e.g., an individual describes their own sense of wellbeing or satisfaction) or descriptive (e.g., a clinician-rated assessment of symptoms). Discussion of the importance and validity of subjective aspects of QoL in the broader medical literature (see 2.5.1) and BD (discussed further below) may be better understood as a tension between descriptive and evaluative QoL assessment.
The use of subjective experience as a QoL referent has clear links with the philosophical approach of hedonism (reviewed in Chapter 2, 2.4.1), where QoL is assumed to derive from cognitive and affective experiences. Preference satisfaction and gap theories (discussed Chapter 2, 2.4.2) are also relevant when considering the subtheme of satisfaction identified in Study 1 and the cognitive processes involved in making such judgements. However, within the BD literature there was little discussion of precisely how QoL is subjectively experienced within this population: further exploration of this construct from the perspective of individuals with BD will help illuminate how existing theories regarding the subjective experience of QoL (i.e., affective experience, cognitive appraisals, gap theories) may apply in this group. Studies 3 and 4 of the present project were designed as a novel investigation of this idea; their contributions to understanding the ideographic/evaluative perspective to QoL in BD are discussed in the integrative discussion of this chapter (9.3).

While medical fields more broadly emphasise the importance of the individual’s own assessment of QoL, the validity of self-reported QoL in mental illnesses is debated. In BD...
specifically (as noted in Study 1), a number of theorists believe that the extreme mood states characteristic of QoL may distort or bias an individual’s perception, satisfaction with or affective state associated with particular objective circumstances. Specifically, the elevated mood states of hypomania and perhaps mania may artificially inflate QoL beyond what would be appropriate for a person’s given circumstances, while the low mood and pessimistic interpretation of events associated with depression may negatively skew QoL appraisals (Atkinson et al., 1997). The potential for an individual’s mood state to ‘bias’ their self-reports has been cited as a limitation impacting the study of QoL in BD (e.g., Fenn et al., 2005), or as a reason to avoid investigating QoL in acutely ill individuals (e.g., Sierra et al., 2005). An extension of this argument proposes that given the overlap between mood and subjective QoL, the two constructs are in fact tautologically related: good QoL is merely the opposite pole of depressed mood (Fleck, 2001; Gladis et al., 1999; Katschnig, Krautgartner, Schrank, & Angermeyer, 2006). Furthermore, the coherence between satisfaction-based assessments of QoL and an individual’s objective circumstances is questioned in chronic illnesses like BD: a number of theorists have proposed that individuals with long standing, severe mental illnesses may reduce their expectations of life, such that they may report being satisfied with circumstances that would be considered intolerable to healthy controls (Atkinson et al., 1997; Jenkins, 1992; Katschnig, 2006b; Mechanic, 2006).

What evidence exists for the potential biasing impact of mood on subjective QoL in BD? As reviewed in Chapter 3 above (3.3.4), depression has consistently been found to be a negative predictor of QoL in BD. Furthermore, there is some evidence to suggest that QoL self-reports during depression diverge from objective circumstances: Atkinson et al. (1997) found that individuals with BD or unipolar depression reported poorer QoL on a satisfaction-based measure than a group with schizophrenia, despite the latter group experiencing objectively more unpleasant circumstances. While lack of insight was raised as a possible clinical characteristic impacting the satisfaction ratings of consumers with schizophrenia, Atkinson et al. note the objective circumstances and subjective ratings of those with schizophrenia were comparable to a group of haemodialysis patients. Consequently, the poor QoL of the mood disorder groups were attributed by Atkinson et al. to depressed mood negatively biasing satisfaction ratings. Furthermore, within individuals there may be a lack of concordance between QoL ratings when experiencing a depressed mood and ratings when euthymic: following remission of symptoms, individuals with depression have been found to retrospectively rate their QoL as higher than they had indicated when symptomatic.
(Morgado, Smith, Lecrubier, & Widlocher, 1991). On the other hand, there are data supporting the interpretation that subjectively experienced QoL and symptoms of mental illness, while overlapping, are distinct concepts. As reviewed in Chapter 3 (3.3.4), for example, the correlation between depression and QoL self-reports is typically low to moderate, suggesting that the two concepts are not mutually redundant. Differential impacts of pharmacological interventions on QoL and symptoms have also been observed: in comparative trials for antidepressants in unipolar depression, two medications have been shown to similarly improve depressive symptoms, yet differ in the degree of subjective QoL improvement (Pedersen, Pallay, & Rudolph, 2002; Souetre et al., 1996).

Whether or not affective states in BD can be considered to ‘bias’ subjective QoL ratings may depend on theoretical stance – functionalist approaches tend to value descriptive assessments of QoL, and would thus consider internal experiences that impact individuals’ description of their QoL independent of objective circumstances as introducing unnecessary bias. In contrast, researchers who subscribe to a position which prioritises an individual’s own evaluation of their QoL may consider affective state an integral component of QoL (e.g., Orley et al., 1998). Through a perspective which values subjective QoL evaluations, any discrepancy between subjective QoL and objective circumstances (whether a result of mood or altered expectations) provides valuable information about factors such as coping style, self-efficacy beliefs, and perceived social support (Michalak et al., 2007; Ritsner, 2007), that ought to be specifically targeted by interventions rather than dismissed as an artefact of illness (Orley et al., 1998). Similarly, as discussed in Study 3, changing reference points used in QoL self-appraisals to accommodate the limitations of BD has been experienced as a useful self-compassionate strategy to improve QoL, and encourages potential novel clinical applications. Finally, the consumer-driven, person-centred recovery movement emphasises the possibility for an individual to live well and experience good QoL despite the presence symptoms of mental illness (Anthony, 1993). As summarised in Chapter 1 (1.4.3), the measurement of QoL in BD has been highlighted as a means to draw attention to consumer voices and values which have historically been overlooked or de-emphasised. The characterisation of QoL as an evaluative, subjective construct would be therefore be considered vital to serve the desired purpose of this ideological movement (and indeed, mental health policy; Commonwealth of Australia, 2013b; Department of Health, 2011b; New Freedom Commission on Mental Health, 2003).
9.2.3.4 Quality of life as related to wellbeing

Study 1 identified that the least frequent referent of QoL in the BD literature was wellbeing. As discussed above (9.2.3.3), there is some conceptual overlap between wellbeing, subjective experience and satisfaction in the BD literature, given the shared focus on evaluative representations of QoL. However, two prominent theories drawn from the broader philosophical literature suggest important ways in which QoL as wellbeing may be differentiated from related concepts: One tradition places emphasis on wellbeing as affective experiences (Forgeard, Eranda, Kern, & Seligman, 2011), while secondly wellbeing is understood by the positive psychology movement to encompass a set of adaptive psychological characteristics that facilitate coping, self-actualisation and finding meaning in life (eudaimonia; Seligman, 2004, 2011). These two theories (affective and eudaimonic) will be reviewed below and their utility for representing QoL in BD will be discussed. In particular, although representations of QoL as eudaimonia were not seen in the analysis of Study 1, its potential to draw attention to recovery outcomes and offer new perspectives on the discrepancy between objective and subjective QoL may represent an important new avenue of research in BD.

QoL as represented by wellbeing is frequently discussed in terms of affective experiences such as happiness or a preponderance of positive moods over negative moods (Diener, 1984; Headey & Wearing, 1992; Orley et al., 1998). Wellbeing as an affective experience is often differentiated from cognitive components such as satisfaction (Campbell, 1981; Cummins, 1998; Lawton, 1984; Stedman, 1996), mirroring the separation of cognitive and affective components within the hedonism approach to QoL (see Chapter 2, 2.4.1). Wellbeing is proposed to be a diffuse, overarching affective experience, impacted but not wholly explained by life satisfaction (Diener, 1984; Haas, 1999). Empirical research has suggested that these two concepts can be distinguished, with life satisfaction accounting for approximately 50% of the variance in wellbeing ratings (Bharadwaj & Wilkening, 1977; Campbell et al., 1976; Diener, 1984).

Given the significant negative impacts of depression on QoL in BD (see 3.3.4), affective wellbeing likely represents an important component of QoL in this population – however, the affective focus of some wellbeing theories has been met with criticisms that they are tautologically related to mood. For example, Bradley (2001) suggests that measures of wellbeing which focus on affective states (including depression, anxiety, energy, and
positive mood) assess mental health rather than QoL, which they propose should encompass a broader range of factors than the absence of mental illness. Rebuttals against similar criticisms of subjective/satisfaction referents of QoL, discussed above (9.2.3.3), may also apply here: i.e., there is data suggesting that subjectively experienced aspects of QoL like satisfaction and wellbeing are concepts related but distinct from mood, and from a theoretical perspective in which the individual’s perspective is prioritised the impact of mood on subjective experiences represents an important area of investigation (Orley et al., 1998).

Alternative theories of wellbeing, such as eudaimonia, address Bradley’s (2001) concern by taking a broader lens on the meaning of this construct as it relates to QoL.

Wellbeing as defined from a eudaimonic perspective may be differentiated from affective wellbeing, and furthermore may offer additional benefits as an intervention target as compared to the affective approach. The field of positive psychology has characterised wellbeing as a collection of positive psychological characteristics essential for adaptive functioning (Maslow, 1943; Ryff, 1989; Seligman, 2011). Following the eudaimonic tradition of Aristotle and perfectionism theories (discussed 2.4.3), wellbeing has been linked to autonomy, engagement, mastery, a sense of identity, self-actualisation, purpose and meaning in life, and the realisation of one’s potential. While discussion of the full breadth of these concepts is beyond the present scope, interested readers may find the review of Forgeard (2011) informative. Although naturally there would be some overlap between affective wellbeing and the concept of wellbeing used in positive psychology - that is, an individual with numerous adaptive psychological resources is more likely to experience positive moods - correlation analyses have identified some distinction between these concepts (e.g, Waterman, 1993). Moreover, a focus on adaptive processes has been suggested to be more realistic than striving to achieve uninterrupted positive mood (Huppert, 2009). This also aligns with third wave approaches to psychological therapies, which suggest that an exclusive focus on attaining positive mood may itself generate suffering, given the unavoidable experience of pain in life (Hayes, Wilson, Gifford, Follette, & Strosahl, 1996). Moreover, it has been suggested that conceptualising wellbeing as qualities like autonomy, engagement, and etcetera serves a pragmatic function: it explains why individuals feel satisfied with life or experience positive feelings, and from a clinical perspective identifies specific areas of intervention or unique strengths to draw on (Seligman, 2011).

Importantly, eudaimonic wellbeing may offer a novel perspective on the relationship between mood symptoms and QoL in BD. Firstly, the eudaimonic tradition suggests that
discrepancies between internally experienced and external aspects of QoL may result in part from mood symptoms, but also from limited abilities to cope with negative emotions or stressful life events, a perceived lack of meaning or engagement in life, or a divergence between values and actions, areas which may form useful targets for clinical intervention (Seligman, 2011). Secondly, characterising QoL as a collection of adaptive qualities suggests mechanisms through which low QoL may act as a risk factor for symptoms of BD (a hypothetical relationship discussed in Chapter 1, and supported by empirical data in Study 2). Low eudaimonic wellbeing has been found to be a vulnerability factor for poor mental health, with individuals reporting low positive wellbeing (self-acceptance, autonomy, purpose in life, positive relationships with others, environmental mastery, and personal growth) over twice as likely to be depressed 10 years later, after controlling for personality, functioning, history of depression, demographic, economic and physical health variables (Wood & Joseph, 2010). Potential pathways through which QoL may impact mood, including eudaimonic processes (e.g., positive coping, acceptance) are suggested in the integrative discussion below (9.3.1.2).

Discussion of QoL as wellbeing through a eudaimonic lens was not explicit in reviewed papers of Study 1, nor did the measurement instruments used in association with wellbeing referents (i.e., WHOQOL-BREF and Q-LES-Q) assess such concepts to any significant extent. However, theoretical links may be drawn between eudaimonic ideas of QoL and another prominent concept in BD research and practice, namely, personal recovery (Slade, 2010). Similar to the adaptive psychological processes emphasised by the positive psychology approach to QoL and wellbeing, definitions of recovery in mental illness characterise it as a process drawing upon active use of adaptation and coping strategies, value-driven action, the development of an identity beyond illness, and discovering new ways to find meaning and engagement in life (Anthony, 1993; Onken et al., 2007). Broadening the elements of wellbeing attended to in QoL research in BD to be inclusive of eudaimonic concepts is therefore likely to increase the relevance of QoL-focused interventions to recovery-focused mental health policy in many countries (e.g., Commonwealth of Australia, 2013b; Department of Health, 2011b; New Freedom Commission on Mental Health, 2003). Implications of this perspective for the developments of recovery and QoL-focused interventions in BD will be further explored in the integrative discussion below (9.3.2.1).
9.2.3.5 Extended discussion of quality of life concepts in bipolar disorder:

Summary

The systematic review of Study 1 identified four major concepts thought to be relevant to QoL in BD. The present extended discussion of the definition and usage of these concepts in the broader medical and philosophical literature has further characterised their meaning as related to QoL, and clarified their utility for understanding the lives of individuals with BD. Both descriptive (i.e., health related and functionalist definitions) and evaluative (i.e., subjective experience and wellbeing) approaches offer unique strengths and limitations for characterising QoL in this population. As emphasised in Study 1, it is unlikely that any one referent can be elevated as the ‘core’ defining characteristic of QoL, nor would such a choice represent a useful step forward for the field. Rather, taken together these referents constitute a spectrum of QoL concepts in BD, spanning aspects tied more closely to illness factors and external events, to a more holistic and personally experienced view of QoL. Furthermore, while attending to conceptual distinctions between these constructs forms a useful framework for understanding the meaning of QoL and choosing between numerous measurements instruments, it is important to note that the above referents are likely additive and interrelated within people, speaking to an overarching experience of QoL. Potential interrelationships between and organisation of these QoL concepts and other important factors in BD (e.g., symptoms, personal recovery) will be discussed in a provisional heuristic framework (9.4) developed from this concept clarification and the following analysis of points of intersection across studies in the present project (9.3).

9.3 Intersection of Studies

The four studies contained in this project approached the issue of improving understanding of the QoL construct in BD from different perspectives. While these four studies are diverse in nature and address discrete components of this overarching aim, there are a number of areas in which the studies speak to or enrich understanding of one another. Novel questions for future research and implications for theory, measurement and clinical practice emerge out of this critical, integrative synthesis.

9.3.1 Intersection of Studies 1, 2 and 3: Change in Quality of Life - Evaluative Versus Descriptive Perspectives

Study 1 highlights two separable approaches to the conceptualisation of QoL in BD: a normative/descriptive approach that encompasses usage of QoL as a referent for functioning
or health, and an ideographic/evaluative approach that is characterised by use of QoL as a referent for subjective experience and wellbeing. This conceptual clarification contextualises Studies 2 and 3 as part of two relatively distinct bodies of research: Study 2, having used the SF-36 (a measure most frequently associated in the BD literature with usage of QoL from a functionalist/health-related perspective) adds clarity to our understanding of QoL within the normative/descriptive approach. Study 3, by contrast, sought to investigate implicit processes in QoL meaning-making by asking individuals to describe and appraise QoL in their own words, and as such is firmly embedded in the QoL as ideographic/evaluative tradition. While both of these studies individually contributes to clarification of the concepts identified as relevant to QoL in the BD literature in Study 1, taken in the context of the project’s other findings they also highlight gaps and points of potential synthesis in the complementary perspective that should be addressed in future research.

9.3.1.1 Understanding trajectories of evaluative versus descriptive quality of life

Study 2 used multilevel modelling to explore, for the first time, the trajectory of QoL in BD under guideline driven treatment. The use of the SF-36 in this analysis allowed findings to be specifically related to QoL as functioning/health. Therefore, from a normative/descriptive perspective, mental QoL in BD improves over time with treatment, while physical QoL decreases over time. However, as emphasised in the conceptual analysis of Study 1 and extended discussion (9.2), the SF-36 was originally developed as a measure of health status (Ware & Sherbourne, 1992) and is most frequently tied to concepts of health and functioning in the BD literature. As such, the trajectory of change in SF-36 scores with guideline-driven treatment identified in Study 2 appears not to describe the spectrum of concepts identified in this project as relevant to QoL in BD. In particular, the in-depth analysis of the subjective experience of QoL through interviews with people with BD in Study 3 suggests ways in which QoL may change over time from an ideographic/evaluative perspective that may not align with a normative/descriptive trajectory. Specifically, the flexible use of reference points against which individuals with BD located their QoL may in fact create change in QoL without objective changes to circumstances. The present section will first review evidence to support the contention that trajectories of evaluative and descriptive QoL can differ, and potential implications of this for the study of QoL in BD. Next, the possible role of cognitive processes in longitudinal change in QoL in BD will be explored, drawing on findings from Study 3. Finally, guidance regarding the role of evaluative QoL measurement in future longitudinal studies of QoL will suggest, a) methods
to grapple with the influence of cognitive processes in QoL self-appraisals, and b) optimal methods for investigating the impacts of common interventions in BD on QoL.

Given the different perspectives on QoL in the BD literature identified by Study 1, it is important to recognise that the trajectory observed in Study 2 may not reflect that which would be found using measures linked to an ideographic/evaluative approach. While it may be expected that positive growth curves would be observed for the Q-LES-Q and WHOQOL-BREF under guideline driven treatment, given the negative cross-sectional impacts of depressed mood on these measures (for a review, see Chapter 3, 3.3.4), research in medicine more generally has suggested the potential for differences in trajectories to emerge. For instance, in a sample of patients with breast cancer followed for two years post diagnosis, HrQoL as measured by the European Organization for Research and Treatment of Cancer QLQ-C30 (Aaronson et al., 1993) deteriorated over the first year and stabilised during the second, while QoL as measured with the Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985) remained stable across this period (Tessier, Blanchin, & Sébille, 2017). A study in patients with lower extremity fractures compared trajectories of health status/HrQoL as assessed by the Short Musculoskeletal Function Assessment questionnaire and QoL as assessed by the WHOQOL-BREF (Van Son et al., 2016). It was demonstrated that although participants experienced a dip in HrQoL one week following injury before fully recovering by six months, QoL decreased one week post injury and either did not significantly improve between this point and the six-month follow-up, or if improved, did not return to pre-injury levels.

To date, only one study has compared change in different QoL measures over time in a BD population: Michalak et al. (2013) followed patients recovering from a first episode of mania for 18 months using both the SF-36 (a measure associated with functioning/health status in BD) and Q-LES-Q (a measure associated with subjective experience/wellbeing). Similar trajectories were observed across some subscales: for example, the Social dimension on both the SF-36 and Q-LES-Q improved, as did Wellbeing dimensions across both measures. However, some divergence in trajectories was noted: perceptions of Physical Health on the Q-LES-Q improved over time, while no change was observed on the analogous Pain, General Health and Physical Functioning subscales of the SF-36. This important point of divergence between evaluative and descriptive trajectories is consistent with the qualitative findings of Study 3: change to subjective perception of QoL in BD may occur apart from changes to objective circumstances.
Further research is needed to explore this issue in BD, as the highly specific sample (first episode mania) in Michalak et al.’s (2013) study means the trajectory of descriptive as compared to evaluative QoL in BD more generally or following recovery from other mood states (depression, hypomania, recurrent mania) is unknown. In addition, trajectories for other common QoL measures in BD (EQ-5D, WHOQOL-BREF and QoL.BD) have not been followed or compared. However, taken as a whole, these studies (both in BD and in medicine more generally) suggest that trajectories using QoL measures that draw on various approaches may differ. This divergence would have significant clinical implications, as there is potential for improvements as a result of treatment or unmet needs to be missed if focusing on only one aspect of QoL. The possible divergence between change in evaluative and descriptive QoL in response to treatment places onus on researchers to carefully consider which QoL-related outcomes could be expected to be impacted (positively or negatively) by a particular intervention, and ensure these are measured. As noted in the commentary on measurement issues in Study 1, use of multiple QoL measures is a pragmatic strategy to compensate for conceptual gaps in any single measure. Future research in BD would ideally investigate trajectories for all of the various referents of QoL, drawing upon the major measurement instruments linked to each (i.e., investigation of health and functioning with the EQ-5D and SF-36, investigation of subjective experience, satisfaction and wellbeing with the Q-LES-Q and WHOQOL-BREF) as well as relatively understudied approaches like the disorder-specific QoL.BD. Finally, the development of a measurement instrument assessing the full spectrum of concepts identified as relevant to QoL in BD in this project will be of use to the field.

The role of cognitive processes in ideographic/evaluative QoL in BD was explored through the qualitative interviews of Study 3, however little is known about how this may impact quantitative trajectories of QoL from either the evaluative or normative/descriptive perspective. Study 3 highlights that QoL self-appraisals in BD are made in relation to reference points (e.g., own past experiences of wellness or illness, experiences of others, or expected futures) that can vary within and between individuals. Furthermore, use of reference points could change in response to an intervention (e.g., adopting a normalising reference point that improved QoL self-appraisals in response to learning of the experiences of others with BD). This has clear implications for longitudinal modelling of self-reported QoL, as the way people respond to QoL measures may not remain consistent over time; in addition, longitudinal change in QoL self-appraisals may not be consistent with changes to objective
circumstances. It may be expected that flexibility in cognitive processes would have less of an impact on descriptive measures like the SF-36 as compared to instruments which demand a more evaluative response, i.e., the largely satisfaction based Q-LES-Q and WHQOL-BREF (Schwartz & Rapkin, 2004), however this has not yet been tested in BD.

The impact of changes to internal standards, the importance placed on various life domains, or an individual’s conceptualisation of QoL itself is a recognised issue for longitudinal studies in the broader medical literature. Established methods to track what has been termed ‘response shift’ may help characterise the extent to which this occurs when following either descriptive or evaluative QoL measures over time (Schwartz & Sprangers, 1999). For example, Cantril’s Ladder (1966) is a single item measure rating global life satisfaction from 0 to 10: respondents are asked to describe in their own words what their ‘worst possible’ and ‘best possible’ QoL would be. Their conceptualisation of each anchor point is thus made explicit, and change to an individual’s ideal and worst possible QoL may be identified over time. The ‘then-test’ is a commonly used quantitative method to assess response shift (Schwartz & Sprangers, 1999): respondents are asked to rate their current QoL at baseline (pre-test), then again at follow-up (post-test) along with a retrospective assessment of their QoL at baseline (then-test). It is assumed that the same frame of reference will be utilised at follow-up for both post-test and then-test appraisals, and thus comparison of baseline to the retrospective self-assessment can identify the amount and direction of response shift. Other commonly used methods seek to control for response shift by recalibrating earlier QoL reports based on a person’s current standards and values. For example, the Ideal Scale approach (Zmud & Armenakis, 1978) asks respondents to complete a questionnaire twice: first describing their actual circumstances, the second describing their ideal QoL. If significant changes to ideal scores over time are detected, this is taken to be an indicator of response shift and differences between ideal and actual scores at each time point are used to calculate ‘unconfounded’ QoL change. In a similar vein, pragmatic suggestions for controlling for reference point variability were discussed in Study 3, such as including frames of reference in questionnaires themselves so as to encourage the use of a constant, normative reference point (e.g., “Compared to other people my age…”). This strategy has been used in developing the Congruity Life Satisfaction measure (Meadow, Mentzer, Rahtz, & Sirgy, 1992; Sirgy et al., 1995): frames of reference are induced in various items in the questionnaire (e.g., “Compared to the accomplishments of relatives [parents, brother, sister, etc.], how satisfied are you?”) to calculate an overall QoL score relative to common reference
points (e.g., relatives, friends, goals, what one feels one deserves, etc.). Similarly, the Satisfaction with Life Scale (Pavot & Diener, 1993; Pavot, Diener, Colvin, & Sandvik, 1991) asks participants to rate the degree to which their life is close to their idealised expectations (e.g., “In most ways my life is close to my ideal”).

Future empirical investigations of QoL in BD should critically consider the approach to QoL measurement that best reflects the targets of various interventions. Interventions designed to address mood symptoms or manage the impacts of BD on functioning such as cognitive remediation (Deckersbach et al., 2010; Demant, Vinberg, Kessing, & Miskowiak, 2015), functional remediation (Torrent et al., 2013; Vieta, 2011), supported employment (Tse, 2002), family focused therapy (Miklowitz & Goldstein, 1997), or traditional symptom-focused psychoeducation (Colom & Lam, 2005), may place more emphasis on tracking objective changes to an individual’s QoL framed as functional and health status over time, and trials assessing the effectiveness of such interventions would typically draw upon a nomothetic approach. From this perspective, change in QoL appraisal over time would be viewed as a source of measurement error (Bjorner, Ware, & Kosinski, 2003), and as such, response shift methods to induce particular frames or reference or retrospectively eliminate response shift may be considered desirable. By contrast, as suggested by Study 3, certain psychosocial interventions in BD may act to improve QoL through adaptive change in reference point usage. Studies of the impacts of such strategies would likely benefit from embracing the ideographic and flexible processes involved in QoL appraisal, as this may represent an important therapeutic mechanism. For example, Cognitive Behaviour Therapy (CBT), a commonly used psychosocial intervention in the treatment of BD (Lam et al., 2010), targets appraisals of life events that contribute to affective symptoms. In CBT, a client presenting with an exaggeratedly pessimistic interpretation of circumstances would be prompted to reevaluate these having corrected for depressogenic thinking styles. The findings of Study 3 suggest that in BD, CBT may benefit QoL by targeting comparisons to self or others that promote an overly negative evaluation of QoL. Therapeutic approaches of emerging interest in BD are Acceptance and Commitment Therapy (ACT; Hayes et al., 1999) and mindfulness-based techniques (Murray et al., 2017). Both these ‘third wave’ approaches place emphasis on accepting the occurrence of negative experiences and thereby reducing the suffering associated with denial of or preoccupation with circumstances, a mechanism that has clear parallels with the change in QoL reference point usage observed in Study 3 of this project. Change in QoL appraisal over time may therefore provide an important lens through
which the impacts of these therapies are better understood, and indeed adoption of a normalising or self-compassionate reference point may represent a desirable treatment outcome. Intervention trials designed from this evaluative perspective may therefore preferentially use methods such as Cantril’s Ladder or the Then-Test, as these may help identify clinically important changes in reference point usage. Individual therapeutic work with consumers may similarly benefit from an awareness of and attention to the possibility of ideographic change in QoL reference point usage over time. Future research in BD therefore must be cognisant of the possible role of changes to appraisal standards in self report, and further explore the potential for such processes to impact longitudinal modelling of QoL or indeed act as therputic mechanisms in psychosocial therapies.

9.3.1.2 Understanding the relationship between mood and evaluative versus descriptive quality of life

The literature review of Chapter 3 shows that understanding the relationship between mood and QoL forms a significant point of interest for the BD literature. The present section reviews this issue in light of findings from Study 1, 2 and 3. Through the novel analysis investigating dynamic relationships between mood and QoL, Study 2 speaks to the questions regarding boundaries between QoL and mood symptoms in BD that were identified in Study 1. The results of Study 2 suggest, for health/functioning aspects of QoL, mood does act as an important predictor but does not explain all change in QoL. Importantly, unique effects were found for QoL as a predictor of mood, further validating QoL as a construct of independent interest with potential downstream clinical benefits on traditional treatment targets. The conceptual clarification of Study 1 serves as a reminder that the results of Study 2 may not generalise to other referents of QoL such as subjective experience or wellbeing. Furthermore, even if similar relationships between mood and evaluative QoL are observed, the mechanisms of action may differ. Potential mechanisms for the identified bidirectional relationship between descriptive QoL and mood identified in Study 2, as well as hypothetical relationships between evaluative QoL and mood drawn from the qualitative findings of Study 3 are presented below. Clarification of these relationships and possible mechanisms may facilitate the development of new therapeutic approaches both targeting the spectrum of QoL in BD and improving clinical symptoms via direct clinical attention to QoL.

The design of Study 2 did not permit conclusions about the mechanisms supporting the observed bidirectional relationship between mood and QoL. Drawing upon conceptual
clarification of the normative/descriptive perspective in Study 1, and the extended discussion above (9.2), a number of predictions can be generated to explain how mood may impact QoL in BD and vice versa (see Figure 9.2).

![Figure 9.2](image)

**Figure 9.2.** Hypothetical mechanisms in bidirectional relationships between mood and descriptive quality of life.

Study 2 used the SF-36 to assess QoL, a descriptive measure identified by Study 1 as most frequently used to assess aspects of functioning and health status in BD (and indeed, the SF-36 was originally designed as a health status instrument; Ware & Sherbourne, 1992). Numerous aspects of functioning are impacted by mood in BD, including physical, social, work and cognitive aspects (see Chapter 1, 1.4.2), and may explain Study 2’s finding that symptom reduction predicts later improvements in QoL as measured by the SF-36. For example, symptoms of depression such as loss of interest and pleasure, fatigue, and depressed mood/irritability may impact both an individual’s willingness to engage in social/occupational activities, and the degree of success they may experience in this domain (e.g., there is some evidence to suggest that frequent reassurance-seeking in the context of depression is met with social rejection; Joiner Jr, 1996; Joiner, Alfano, & Metalsky, 1992). A reduction in these symptoms would naturally be expected to result in improvements to role functioning. Improvements in descriptive QoL as a result of symptom change may also result from measurement redundancy, given the direct impact of symptoms is also typically captured by health status measures. For instance, the SF-36 has a subscale assessing mental health, which includes items such “Have you felt so down in the dumps that nothing could cheer you up?” Adverse effects of medications may also explain the predictive effect of mania on later physical QoL observed in Study 2: antimanic agents typically have burdensome side effects (including gastrointestinal disturbances, weight gain, tremors,
sedation, dizziness, skin rash, extrapyramidal symptoms, dry mouth, and impaired renal/thyroid function; Hert et al., 2011; Keck & McElroy, 2003; Strakowski et al., 2001), and decreases to physical health/functioning may be partly a consequence of the treatment of manic phases in BD with such medications.

Predictive effects of improvements to functional QoL on later symptoms may be explained by behavioural and biological mechanisms. For example, a major trigger of mood episodes in BD is sleep irregularity (Murray & Harvey, 2010). Positive impacts from improvements to physical QoL on later symptoms could therefore be explained through improved sleep quality and regularity. For example, physical activity is known to benefit sleep in the general population (Santos, Tufik, & De Mello, 2007), and amongst people with BD physical activity has been shown to improve mood (Wright, Everson-Hock, & Taylor, 2009) and sleep quality (Nusslock et al., 2007; Wright, Armstrong, Taylor, & Dean, 2012). Similarly, improvements to work and social function may help stabilise social rhythms, which helps support sleep regularity and reduce the likelihood of mood symptoms (Frank et al., 2000). Greater contact with family and friends presents more opportunities for experiencing rewards, which is thought to ameliorate depressive symptoms (Kanter, Puspitasari, Santos, & Nagy, 2012). Finally, improved functioning across domains is likely to mean lower frequency of stressful events (e.g., improved work functioning reduces the stress of unemployment, improved physical health reduces the likelihood of stressful health crises), which have been shown to contribute to relapses in BD (Johnson, 2005a).

To date, dynamic relationships between mood and evaluative QoL have not been explored in the context of BD. The concept analysis of Study 1 and qualitative investigation of Study 3 suggest important ways in which the relationship between mood and QoL in an ideographic/evaluative sense may differ from that observed between mood and normative/descriptive QoL (see Figure 9.3 for a summary of hypothetical variables of interest in bidirectional relationships between mood and evaluative QoL). On one hand, one may expect there to be a greater influence of mood on evaluative QoL than descriptive QoL. Cognitive theories of depression, for example, suggest the role of a negative perception of self, the environment and the future (Beck, 1976): measurement approaches which assess an individual’s satisfaction or positive feelings (i.e., the Q-LES-Q or WHOQOL-BREF) would be more susceptible to any ‘biasing’ effects of mood than measures which ask for the individual’s estimate of the frequency of a behavior or symptom (i.e., the SF-36 or EQ-5D).
Another impact of mood on the evaluative assessment of QoL may be hypothesised by expanding on the exploration of cognitive processes in Study 3: mood may impact not only perception of the current situation but also the reference point used in calculating satisfaction with events. For example, maladaptive social comparisons associated with depressive thinking styles (Swallow & Kuiper, 1988) would be expected to have flow on negative effects on QoL self-assessments through increasing the gap between expectations and reality. Mood impacts on this appraisal process could also explain some findings of negative impacts of mania on QoL (Chapter 3, 3.3.4). Past and present mania has been associated with dysfunctionally elevated goals or perfectionistic attitudes (i.e., heightened expectations of life; J. F. Goldberg, Gerstein, Wenze, Welker, & Beck, 2008; Lam, Wright, & Smith, 2004; J Scott, Stanton, Garland, & Ferrier, 2000), which would be associated with poorer evaluation of present circumstances by comparison.

Figure 9.3. Hypothetical variables of interest in bidirectional relationships between mood and evaluative quality of life.

Some impacts of mood on QoL judgements may be counterintuitive. Study 3 highlighted that people with BD can change how they make self-appraisals in order to adaptively preserve QoL despite ongoing difficulties. Potentially, the experience of symptoms themselves may initiate use of coping strategies, such as the observed self-compassionate shift in reference points, to stabilise or improve QoL. Research in other chronic illnesses has highlighted a variety of cognitive techniques used by individuals to maintain QoL in the face of negative changes to health status (Sprangers & Schwartz, 1999). Besides adopting normalising QoL reference points that accommodate the impacts of illness (as observed in Study 3), individuals with chronic conditions may also reprioritise areas of life not impacted by the condition (e.g., placing more weight on social relationships than
physical health in QoL appraisals; Tessier et al., 2017). Responses to symptoms of chronic illness appear to vary between individuals: while some people respond adaptively to stressors, others may use unhelpful coping strategies such as rumination or avoidance that negatively impact QoL (e.g., Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004; Myaskovsky et al., 2003; van der Zaag-Loonen, Grootenhuis, Last, & Derkx, 2004). Further longitudinal studies in this area are required to explore the potential impact of mood on coping strategies in BD. Qualitative techniques in which people are asked how their QoL has changed in the context of mood episodes, focusing on implicit processes of meaning-making (as in Study 3) may help illuminate ideographic applications of adaptive or maladaptive coping styles. Additionally, longitudinal studies drawing upon techniques used in the study of response shift may help clarify the dynamics between mood, coping strategies and evaluative QoL in BD. Of note, in stress/coping research, perceived controllability of an event is related to positive adaptation and coping styles (Fontaine, Manstead, & Wagner, 1993; Steptoe & Appels, 1989). Study 4, which demonstrated a role of QoL-focused psychoeducation on enhancing empowerment in BD, suggests the promotion of QoL self-management in a clinical setting may facilitate use of adaptive coping styles in response to mood symptoms.

Hypothesised relationships between QoL and later mood symptoms in BD may differ when considering evaluative versus descriptive QoL. There is likely to be some overlap in mechanisms: the behavioural and biological mechanisms suggested above to explain the predictive effects of descriptive QoL on later mood are also likely to be relevant when considering QoL from the evaluative perspective. Further to the previously discussed mechanisms, cognitive processes involved in evaluative QoL identified in the qualitative analysis of Study 3 may also impact downstream symptoms. In Study 3, some individuals with BD were found to be able to preserve QoL by adopting normalising reference points: change in use of reference points that improves evaluative QoL may generalise to cognitive processes involved in the experience of pathological moods, resulting in flow-on improvements from QoL to BD symptoms. As reviewed above, cognitive processes are theorised to underpin depressogenic thinking in BD: change towards more self-compassionate, normalising reference points in QoL self-appraisals is comparable with strategies offered in CBT to improve mood (i.e., realistic/helpful reappraisals of circumstances). Furthermore, the role of cognitive processes in QoL change illustrated in Study 3 emphasises potential synergies between novel QoL-focused therapeutic approaches
and traditional treatment goals (i.e., symptom reduction). Third-wave cognitive therapies such as Mindfulness-Based Cognitive Therapy (Deckersbach, Hölzel, Eisner, Lazar, & Nierenberg, 2014), Acceptance and Commitment Therapy (Hayes et al., 1999), and Compassion Focused Therapy (Gilbert, 2009) encourage acceptance of current circumstances through normalising or compassionate expectations, and may thereby act to improve both symptoms of depression and QoL.

Processes of QoL self-appraisal explored in Study 3 may also explain predictive effects of evaluative QoL on mania. Dysfunctional attitudes towards goal attainment frequently endorsed in BD, particularly during mania (e.g., “I should be happy all the time”, “A person should do well at everything”; Lam et al., 2004), suggest unrealistically high expectations of life. As suggested above, the gap between increased expectations in BD and actual circumstances may result in lower QoL as a result of this mood state. However, use of high QoL reference points may also trigger manic symptoms: inappropriately elevated goals and excessive goal striving underpins vulnerability to mania in BD (Johnson, 2005b), and thwarting of goals (i.e., a large expectation-reality gap) may in fact reinforce maladaptive goal striving (Johnson, Fulford, & Carver, 2012). Downstream benefits for mania may similarly result from adaptive change to normalising reference points for QoL appraisal observed in Study 3. Gilbert’s (2009) model of Compassion Focused Therapy suggests that use of self-compassionate reframes activates a hypothetical soothing-affiliative system oppositional to goal-pursuit and reward systems. Given the recognised role of neurological systems of reward in promoting mania in BD (S. J. Russo & Nestler, 2013; Urošević, Abramson, Harmon-Jones, & Alloy, 2008), the potential for self-compassionate, normalising QoL reference point usage to downregulate this activity further emphasises the importance of investigating impacts of mindfulness, acceptance and compassion-focused therapies in BD on both symptoms and QoL.

9.3.1.3 Intersection of Studies 1, 2 and 3: Summary

In summary, examining the results of Studies 2 and 3 through the lens of the concept clarification conducted in Study 1 supports a more complete analysis of the contributions of each of these empirical studies to our theoretical understanding of QoL in BD, as well as highlighting unresolved questions for future study. Future research investigating the trajectories of various QoL measures, their relationship with mood, and hypothetical change mechanisms will further clarify these conceptual approaches and suggest therapeutic
approaches to address both the spectrum of QoL in BD and, potentially, downstream symptom improvement through QoL changes. Potential bidirectional relationships between pathological mood and QoL further emphasise the need to prioritise QoL goals alongside traditional symptom reduction targets – a possible framework for QoL-based formulation is discussed below (9.4).

9.3.2 Intersection of Studies 1, 3 and 4: QoL and Recovery – Clarifying Conceptual Overlap and Identifying Strategies for Clinical Practice

Previous commentary on QoL and recovery in BD has implied a great degree of theoretical and ideological overlap. Noted in Chapter 1 (1.4.3), the emergence of the consumer-driven recovery movement has explicitly encouraged attention to QoL in serious mental illnesses, BD included. Increasing emphasis on QoL and recovery in mental health research and practice is part of an ideological shift in psychiatry from an exclusively biomedical approach to a person-centered framework that is characterised as wellness-oriented (MacQueen et al., 2001; Sachs & Rush, 2003). Theoretical links between the concept of recovery and QoL may also be drawn, given that both fields of interest take a broader lens to mental wellbeing and health, are typically person centered, and call attention to positive outcomes (Katschnig, 2006b; Murray et al., 2017; Stasny & Amering, 2006). However, the review of Study 1 encourages a more granular perspective on the boundaries and interrelationships between these concepts. Study 1 suggests the construct of QoL in the BD literature encompasses a variety of perspectives, not all of which align with the priorities of the recovery movement.

Specifically, the analysis of Study 1 (and extended discussion of 9.2.3) identifies a tension between ideas of QoL described as health or functioning and the recovery ethos that it is possible to live well despite symptoms. Conceptualisations of QoL in BD emphasising subjective experience, satisfaction, wellbeing and positive indicators share a greater degree of conceptual overlap with ideas of recovery, which are similarly person-centered, holistic, strengths-based and hopeful (Goldstrom et al., 2006; Schauer, Everett, del Vecchio, & Anderson, 2007). Despite this, the review of Study 1 chose not to prioritise any one definition of QoL. Indeed, it is contended in this thesis that both health/functioning and satisfaction/wellbeing oriented perspectives to QoL interrogate important and relevant aspects of the lives of individuals with BD (see 9.2.3). The value of embracing a broader spectrum of QoL concepts than would necessarily be indicated by recovery perspectives on
the construct is supported by the qualitative investigation of Study 4, which highlighted that for some individuals with BD a therapeutic focus on symptom control and functional outcomes is primary.

Having reemphasised that the full spectrum of QoL concepts (from functioning/health through wellbeing/satisfaction) should be considered in the evaluation and treatment of BD, the present section focuses on synergies between recovery and QoL that emerged from the qualitative analyses of Study 3 and 4. Studies 3 and 4 were conducted within the context of a QoL-focused psychoeducation intervention developed from a satisfaction- and wellness-centric, BD specific framework (Chapter 7). As such, these analyses speak specifically to the evaluative perspective on QoL identified in the BD literature in Study 1. As may be expected, given the conceptual overlaps between recovery and evaluative QoL discussed above, the experiences of participants in Studies 3 and 4 identified a number of recovery-congruent processes that emerged through participation in this intervention. Such benefits, however, offer important pragmatic directions for recovery-oriented practice in BD, given a recognised gap in the treatment of BD is the absence of interventions developed from a recovery perspective (Jones et al., 2015). Evaluative QoL-focused therapeutic approaches may be useful for providing a clear, practical framework for targeting recovery in clinical practice, consistent with the goals of mental health policy in many countries (e.g., Commonwealth of Australia, 2013b; Department of Health, 2011b; New Freedom Commission on Mental Health, 2003).

9.3.2.1 Potential implications of quality of life-focused clinical approaches for addressing recovery in bipolar disorder

QoL-focused interventions in BD may provide a pragmatic therapeutic strategy for addressing recovery goals. Despite the elevation of recovery as a guiding principle of mental health practice at the level of policy, little attention has been paid to developing therapeutic approaches to support this process in BD (Jones et al., 2015). It has been noted that this difficulty may stem from the complexity of specifically targeting broadly defined and personally experienced recovery processes such as hope, connectedness or a sense of meaning (Huguelet et al., 2016; Leitan et al., 2015). Recovery guidelines for mental health practice may not be applied at a practical level due to clinician uncertainty about ways to address such broad and ambiguous targets (Tickle, Brown, & Hayward, 2014). In addition, evidence-based interventions for recovery have been slow to develop, partly because this
literature has traditionally occupied space outside of academic circles (e.g., grey literature and personal narratives; Slade, 2010). This has led some commenters to note a risk that practice has outstripped research in the delivery of recovery-focused interventions (Huguelet et al., 2016; Silverstein & Bellack, 2008; Tse et al., 2014). Finally, the development of recovery-specific interventions has been suggested to be counter to the concept’s central ethos as a personally experienced and defined process. Not only is this challenging to instigate in manualised psychosocial treatments (Lieberman et al., 2008), but by definition standardised interventions may no longer be considered to be directly addressing recovery in its truest sense (Tse et al., 2014). Given the breadth of challenges facing the development of recovery-focused interventions, QoL has been suggested as a pragmatic, alternative focus to use as a foundation for such interventions, as it will provide greater clarity around action and measurement (Lieberman et al., 2008), and structuring therapeutic approaches around QoL goals may be expected to support recovery processes (Leitan et al., 2015). The qualitative results of Studies 3 and 4 speak to ways in which this may occur in BD, and provide suggestions about important elements to include in future QoL/recovery-focused interventions.

The qualitative findings of Studies 3 and 4, conducted within the context of a QoL-focused self-management programme for BD, highlighted a number of experiences emerging as a consequence of the intervention that align with recovery processes. Study 3 demonstrated that contact with peers with BD or exposure to normalising information about the illness could, for some individuals, initiate a change in personally adopted QoL reference points to one that accommodated illness impacts and adaptively preserved QoL (e.g., “For someone in my position, I am managing well”). Rather than passive resignation to a life constrained by BD, this process was described by participants as an appropriately self-compassionate, active way of accepting the consequences of BD and directing attention to what is going well in one’s life, comparatively. Acceptance of illness has been positioned as an important initial step in the recovery process (Larry Davidson & Roe, 2007; Deegan, 1988): through accepting the presence of a psychiatric illness and its according symptoms and limitations, the individual can look to move beyond struggle/denial of illness to develop meaning in personally valued life domains. Furthermore, this process of acceptance in QoL self-appraisal accords with recovery emphasis on living well despite symptoms (Anthony, 1993). Study 4 found that feelings of empowerment and responsibility to engage in self-management emerged in the context of
the QoL-focused intervention, both of which have been described as core tenets of recovery in severe mental illness. Empowerment (and relatedly, self-determination and sense of agency; Onken et al., 2007) frequently emerges as a central component of the recovery process (Leamy et al., 2011; S. L. Young & Ensing, 1999). Similarly, the process of taking responsibility for one’s own wellness has been described as essential for supporting recovery (Larry Davidson & Strauss, 1992; Mead & Copeland, 2000). The connection between QoL and recovery, observed in Studies 3 and 4, is also supported by quantitative findings. For example, QoL has been found to mediate the relationship between social support and recovery in schizophrenia (Roe, Mashiach-Eizenberg, & Lysaker, 2011), and to uniquely predict recovery in BD even after controlling for current symptoms (Jones et al., 2013). While further qualitative studies are necessary to support this link, the emergence of acceptance, empowerment, and responsibility in the context of a specifically QoL-focused intervention suggests potential for such therapies to benefit recovery processes in BD.

The presence of peers, a hopeful tone in intervention content, and tailoring of intervention content to match an individual’s QoL goals were highlighted within the qualitative analyses of Study 3 and 4 as elements that supported recovery processes. Firstly, peer support has been highlighted as an essential element in recovery (Mead & Copeland, 2000; Onken et al., 2007); in Study 3 and 4, contact suggested that this may occur through normalising of struggles with BD, modelling self-compassionate practices, and inspiring hope that self-management can result in positive outcomes. Hope that change is possible has been mapped onto the transtheoretical model of change (Leamy et al., 2011): through developing beliefs that change is possible, individuals may move from contemplation of self-management and recovery through to preparation and action. Finally, the need to tailor intervention focus to match an individual’s QoL goals was suggested in Study 4, after noting that a minority of individuals expressed a preference for strategies to address symptoms and functioning rather than evaluative, internal QoL outcomes such as identity and self-esteem. Individuals who espoused this view typically felt BD symptoms were beyond their control. This mirrors conceptual work in the recovery literature that integrates personal and clinical recovery outcomes (e.g., Andresen, Oades, & Caputi, 2003; Larry Davidson & Roe, 2007; Leamy et al., 2011): gaining control over symptoms paves the way for individuals to become more independent and empowered, and allows broadening of attention to personal recovery goals such as the development of
meaning and identity. As such, self-management psychoeducation in BD may benefit from tailoring interventions to match individuals’ recovery stage: individuals new to the illness or who perceive a lack of control over symptoms may benefit from education on illness triggers, preventative strategies and greater clinician contact, while those with more experience at managing symptoms may desire tailored self-management advice for attaining personal goals with limited clinician contact (Todd et al., 2012; Todd, Jones, & Lobban, 2013). Possible staging of QoL concepts will be further explored in a provisional heuristic framework below (9.4).

In sum, these findings reinforce suggestions that novel QoL-focused therapies align conceptually and functionally with, and could be adapted as part of recovery-oriented practice in BD (Leitan et al., 2015). It is recognised that in psychotherapy generally, supporting an individual to attain personally chosen QoL goals may be easier than directly targeting experiences such as ‘meaning’ or ‘empowerment’, but that change in such elements would naturally be expected as a downstream outcome of such clinical focus (Yalom, 1980). QoL-focused therapies and frameworks for formulation (9.4) may therefore provide a structured means to look at patient goals (Leitan et al., 2015) with according benefits for the highly ideographic, personal process of recovery. Future QoL-focused therapies may also benefit the recovery process by emphasising a hopeful tone, peer presence and tailoring the focus on descriptive versus evaluative outcomes to match individuals’ QoL goals.

9.3.2.3 Intersection of Studies 1, 3 and 4: Summary

Taken together, Studies 1, 3 and 4 deepen understanding of points of overlap and distinction between the concepts of QoL and recovery. Although the evaluative perspective to QoL in BD may be more synergistic with recovery than normative/descriptive traditions, the lived experience of a QoL-focused intervention developed from this evaluative perspective reinforces the importance of the full spectrum of QoL concepts identified in Study 1 to individuals with BD. The lived experience of consumers in Studies 3 and 4 highlighted recovery-congruent processes that emerged in the context of a psychosocial intervention targeting evaluative QoL, including acceptance, empowerment and responsibility. Given a recognised lack of therapeutic strategies to support recovery processes in BD, interventions specifically targeting evaluative QoL may offer pragmatic benefits for recovery-oriented practice. Furthermore, these qualitative investigations suggest that interventions which are peer-led or highlight consumer voices, convey a hopeful tone and tailor delivery of QoL
content to match an individual’s QoL goals show potential for improving both QoL and recovery processes. As suggested in 9.3.1, advancing the development and delivery of QoL-focused interventions may be considered particularly valuable given the findings of Study 2, which suggest that symptom improvement in BD may be achieved through positive changes to QoL. Alongside potential benefits to traditional treatment targets, however, the lived experiences of consumers with BD explored here highlight powerful impacts that QoL-focused interventions may be uniquely positioned to offer.

9.4 Advancing the Study of Quality of Life in Bipolar Disorder: Discussion Summary and Integrative Heuristic Framework

The present project aimed to advance the study of QoL in BD by clarifying its definition and usage in the empirical literature, its longitudinal trajectory and relationship with mood, salient aspects of QoL self-appraisal, and the experience of QoL as a target of psychosocial interventions. The above extended and integrative discussions highlights suggests points of distinction and interrelationships between various approaches to QoL. Taken together, this examination has contributed to the development of a provisional, organising framework of QoL concepts that may be used to guide future research and clinical work in this field.

The analysis of Study 1 identified a range of concepts considered relevant to QoL in BD. Attending to conceptual distinctions between these constructs forms a useful first step for understanding the meaning of QoL and choosing between numerous measurements instruments. However, as emphasised in Study 1, each of these concepts captures aspects of life of significance to individuals with BD that are not addressed by symptom measures alone, and no one single concept likely represents the totality of QoL. Rather, they are likely additive and interrelated, contributing to the overarching experience of QoL. Figure 9.4 presents an illustrative representation of some of these hypothetical interrelationships of QoL concepts and related constructs in BD: the below summary describes the components and interrelationships within this heuristic framework based on the work of the present project.
As in the analysis of Study 1, this provisional framework chooses not to prioritise any one definition of QoL. However, the work of the overarching thesis suggests potential ordering of concepts and differential relationships with other concepts in BD (symptoms, positive psychological traits, recovery, and individual values/preferences/standards of reference) which I aim to summarise here. Firstly, although there are important conceptual distinctions between the evaluative and descriptive approaches to QoL in BD (9.2.3), and attending to these will assist researchers and clinicians in the selection of appropriate measurement instruments and reviewing empirical evidence (Study 1), an individual’s sense of satisfaction and wellbeing would be expected to be influenced, in part, by the impacts of BD, their health status and ability to function in normatively prescribed roles (see arrow 1, Figure 9.5). The discussion of a potential need to stage QoL goals (9.3.2.1) reinforces that, consistent with recovery frameworks, improvements to QoL in a descriptive/normative sense act as a necessary but not sufficient foundation to support an individual to develop greater satisfaction, wellbeing and meaning in life.

The relationships between QoL (broadly defined) and associated concepts (symptoms, recovery, and positive psychological processes) may also be clarified by positioning these within a heuristic framework. Symptoms of BD would likely impact QoL directly at both descriptive (bidirectional arrow 2) and evaluative levels (bidirectional arrow 3): that is, they
would be expected to impact both functioning/health as well as the subjective experience of satisfaction and wellbeing. Furthermore, it might be expected that mood would exert some influence on the relationship between these descriptive and evaluative levels, through the potential influence of mood on the individual’s sense of satisfaction or wellbeing emerging from these circumstances (i.e., a person with depression may interpret their circumstances more negatively, discussed above 9.3.1.2; represented in arrow 4 of Figure 9.4). The consideration of QoL as eudaimonia (positive psychological characteristics that facilitate adaptation and coping), although not widely considered in the BD literature, suggests another avenue by which QoL may be impacted at both levels. A person with a high level of adaptive resources is likely to function better and may experience improved HrQoL (see 9.2.3; represented as arrow 5 of Figure 9.4). Furthermore, their subjectively experienced sense of QoL is likely to be impacted by these processes, both directly (i.e., a person with high levels of self-esteem and sense of meaning is likely to experience greater wellbeing; represented as bidirectional arrow 6) and indirectly (that is, the degree to which functional limitations and health status impacts the evaluation of circumstances may be impacted by positive coping strategies, as shown in the qualitative analysis of Study 3; represented as arrow 7).

Furthermore, as explored in the integrative discussion, there is potential for QoL across descriptive and evaluative levels to impact mood in BD (described 9.3.1.2; represented in Figure 9.4 as bidirectional arrows 2 and 3 respectively), as well as promote adaptive psychological processes associated with recovery (described 9.3.2.1; represented in Figure 9.4 as bidirectional arrow 6). Finally, the role of an individual’s own values, preferences, and standards of reference, explored in detail in the qualitative analysis of Chapter 7, is depicted as a further moderating influence on a person’s perception of their own QoL (arrow 8).

The integrated conceptual framework presented in Figure 9.5 provides direction for future research in the study of QoL in BD. Current trends in QoL research in BD have been influenced by the broader medical and psychiatric literature, which has presented complications when considering the specific experiences associated with BD (see Study 1, Chapter 5). This framework represents an initial attempt, based on the findings of the present project, to organise QoL concepts as they apply to BD specifically: suggested distinctions and relationships between constructs encourages a more granular approach to QoL than had previously been recognised in the BD literature. As such, future research in this field may be guided by this framework in conjunction with the project’s published findings. Firstly, attention to distinctions between concepts will assist researchers in selecting appropriate
measurement instrument for theoretically important independent and dependent variables. Secondly, proposed relationships between constructs will assist researchers in hypothesising relationships between variables of interest as well as interpretation of findings. The framework may also guide analytic decisions: in particular, as more studies draw upon structural equation modelling (J Hox & Bechger, 2007) in which the relationships between multiple variables can be investigated simultaneously, this framework suggests important potential pathways and moderators for inclusion. Future studies using SEM will be required to validate this proposed organisation of constructs and quantify suggested interrelationships.

In addition to offering guidance for researchers, the heuristic framework in Figure 9.4 may provide a useful tool for formulation in clinical practice with individuals with BD. As suggested in Chapter 1 (1.4.4), attention to QoL may benefit treatment planning and therapeutic alliance (Hope et al., 2009; Michalak & Murray, 2010a; Murray, 2015; Skantze & Malm, 1994). However, systematic attention to QoL is not yet well integrated with clinical approaches in mental health. For example, definitional ambiguities surrounding QoL in the parallel schizophrenia literature were suggested to present a barrier to using QoL data to guide clinical practice (Awad, 2011). Therefore, the identification of QoL concepts in Study 1 and their organisation within the provisional framework in Figure 9.4 may provide guidance for clinicians around collaboratively assessing QoL and identifying relevant therapeutic strategies. Firstly, enquiring about a service user’s QoL across functional, health-related, and evaluative levels in the breadth of domains thought to be relevant to individuals with BD (Michalak & Murray, 2010b; Michalak et al., 2006) may provide a more granular assessment of an individual’s QoL than any one single measure. For example, an individual may be in stable employment (i.e., good QoL from a functionalist perspective) but feel their career progression falls short of what they had hoped to achieve (i.e., poor QoL as defined by satisfaction). Secondly, this assessment framework will assist in operationalising therapeutic goals, by providing a more fine-grained perspective as to what QoL improvement in each domain may involve. As has been explored in the integrative discussion, recognition of points of distinction and overlap between evaluative and descriptive QoL in BD is likely to assist in selection of optimal therapeutic strategies. Finally, discussion of the interrelationship between QoL across these constructs will be useful for drawing links between a consumer’s goals and traditional clinical targets. Knowledge of how aspects of QoL more closely tied to illness may influence QoL from a holistic perspective may improve medication adherence, and identifying links between values, adaptive psychological processes and QoL provides a
justification for engaging in psychosocial therapies. Recognition of possible bidirectional impacts between QoL and mood also validate attention to consumer goals. This may promote collaboration between consumer and clinician, potentially enhancing therapeutic alliance for both parties.

9.5 Limitations and Strengths

The present project used a multi-modal approach to tackling the overarching research aim of advancing the study of QoL in BD. This involved a diverse range of studies drawing on both qualitative and quantitative methods, investigating issues of conceptualisation and measurement, dynamic relationships between constructs, and aspects of the lived experience of QoL judgements and interventions. Limitations and strengths of each individual study contained in the present project are discussed in each of the published papers (Chapters 5, 6, 7 and 8). Here, limitations and strengths relevant to the overarching multi-modal methodological approach of the paper for addressing the research aim are discussed.

Firstly, the project as a whole has placed emphasis on ideographic and evaluative aspects of QoL; potentially, this has downplayed the importance of symptom management and functioning. For example, the use of the SF-36, rather than an evaluative measure of QoL was suggested to be a limitation of Study 2. Similarly, in interpreting the results of Study 3, the influence of ideographic and flexible usage of reference points was highlighted as a marker of a potentially adaptive coping strategy. While strategies to control for change in reference point usage over time were suggested (9.3.1.1), ultimately the individual’s own evaluation, inclusive of ideographic reference point usage, was suggested to be a preferential source of QoL estimates. Potentially, this focus on the individual’s own evaluation and personal feelings underplays the significant impact of symptoms and objective circumstances on QoL in BD. It has been suggested that research in chronic illnesses has a moral imperative to focus on objective circumstances, regardless of the individual’s reported satisfaction with these (Hayry, 1991). Attention to QoL as descriptive assessments of functioning and environmental circumstances can challenge the view that QoL is a property (and consequently, responsibility) of an individual, and draw attention to the role of mental health services and broader community in promoting equitable access to resources, social inclusion and citizenship, and combatting stigma (Le Boutillier et al., 2011). I have made efforts to address potential impacts of this evaluative focus by noting the experiences of individuals who did not experience a QoL-focused intervention as appropriate for their needs (Study 4),
highlighting potential therapeutic strategies that may improve functioning in QoL (and reciprocally, symptoms; 9.3.1.2), and finally by reinforcing in a provisional, heuristic framework the need for continued emphasis on objective/symptom factors in this complex condition.

A limitation of this multimodal approach is the existence of a number of unresolved questions that emerged from the limited scope of each study as taken individually. For example, as noted in the discussion of Study 2, the full spectrum of possibly relevant predictors (e.g., medication usage, adjunctive psychosocial interventions, behavioural change) were not investigated, and as such the precise mechanisms by which guideline driven treatment impacted QoL, as well as mechanisms involved in the bidirectional relationship between mood and QoL remain unknown. An alternative approach within the present project could have been to explore any single facet of the overarching aim in greater detail: for example, the naturalistic trajectory of QoL (including the relationship of mood to QoL) could have been examined by conducting a longitudinal study following a wider complement of possible predictors and covariates. Through use of a technique such as structural equation modelling (J Hox & Bechger, 2007), the relationships between a number of variables could have been investigated simultaneously, allowing a more fine-grained analysis of the dynamics of QoL than was possible in the present approach.

Despite these limitations, the multimodal approach of the present project offers significant strengths I hope have been demonstrated through the integrative, critical discussion. Understanding of the results of each individual study is enriched by drawing upon findings from the other parallel aspects of the project, and the identification of novel areas for future research is made possible as a result. As such, the limited scope of any single study should be weighed against the useful synthesis of findings across the multiple approaches. For example, in the context of the concept clarification of Study 1, the results of Study 2 can be interpreted with the awareness that the SF-36 is linked to functioning/health in BD and may not represent the full spectrum of QoL in this disorder. This allows the generation of suggestions for future research that will better clarify understanding of QoL, such as investigation of the trajectories of evaluative QoL measures (i.e., Q-LES-Q, WHOQOL-BREF, and QoL.BD). Furthermore, the analysis of Study 1 clarifies pre-existing literature on QoL in BD, allowing the selection of predictors for future studies that are most relevant to the descriptive/normative perspective. If not for the analysis of Study 3, Study 2 would be interpreted without the awareness of complexity in self-reporting QoL in BD stemming from
within-person variation in reference point usage. Critical future research in identifying the extent to which reference point variability impacts longitudinal modelling of QoL in BD is highlighted as a result of this integration. Through looking across the range of studies, the study of QoL in BD as a whole is advanced further than would be possible through a project focusing its exploration on any single facet.

9.6 Conclusion

QoL is an outcome of emerging interest in BD, yet the literature in this area is faced with unresolved questions regarding the construct’s definition, relationship with mood, and lived experience. The present project aimed to advance the study of QoL through a series of four studies drawing upon both qualitative and quantitative methods. By paying careful attention to the construct of QoL itself, this project has progressed understanding of how QoL is conceptualised and measured in BD, its trajectory and dynamic relation to mood symptoms, cognitive processes associated with subjective QoL-j judgements, and the experience of novel QoL-focused interventions. Taken as a whole, this project bears implications for theory, measurement and clinical practice that will further the utility and relevance of QoL in BD, and has highlighted critical avenues of future research.

The project has introduced additional complexity into the BD literature. No longer can QoL be treated as a monolithic, intuitively understood concept – instead, the diversity of uses in the BD literature must be recognised in both reviews of preceding literature and future empirical endeavors. While some aspects of the relationship between mood and QoL were as expected, the project introduced evidence to support the radical concept that QoL is not just a consequence of mental illness/health, but an independent treatment target that can influence traditional outcomes. Self-evaluation of QoL in BD was shown to be contingent on use of various reference points, which could be flexibly and adaptively employed to preserve QoL. While this may present challenges for QoL measurement, it widens the spectrum of therapeutic approaches that may be relevant in treating BD. Finally, QoL-focused psychoeducation was suggested to have positive impacts, not just for individual’s sense of empowerment and engagement in managing the impacts of BD, but in their appraisal of QoL itself. Neat resolution of these issues not possible nor sought within the context of the present project. However, as a result of this investigation, QoL is no longer a construct whose meaning, measurement and function can be taken for granted in the BD literature, and as such, new avenues of research have opened to the field. The present project has taken steps to
address gaps which, in the related schizophrenia literature, had caused QoL to be termed an ‘unfulfilled promise’ (Awad, 2011) – it is hoped, therefore, that this investigation can generate renewed optimism in the ongoing promise of QoL in BD.
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Specific effects of mania and depression. *Journal of Clinical Psychiatry, 68*(8), 1237-1245.


APPENDIX A: SUMMARIES OF JOURNALS PUBLISHED IN AND CITATIONS AS OF MAY 2018

Journal of Affective Disorders

Impact factor (2016): 3.432

The journal of affective disorders is an international, peer-reviewed journal publishing on depression, bipolar and anxiety disorders. It is the official journal of the International Society for affective disorders.

Psychological Medicine

Impact factor (2016): 5.23

Psychological Medicine is a leading international journal covering clinical psychology and psychiatry. The journal is ranked 7 of 77 of psychology journals (SCIE), 17 out of 142 of psychiatry journals (SCIE), and 6 out of 121 of clinical psychology journals (SSCI). Articles are subject to peer review. The calibre of articles published in Psychological medicine is reflected in its consistently high impact factor since inception.

Quality of Life Research

Impact factor (2016): 2.344

Quality of life research is the preeminent Quality of Life journal, covering all aspects of quality of life theory and methodology in all the health sciences, including medicine, psychology, philosophy, and outcomes research. It is the official journal of the International Society of Quality of Life Research. Articles are subject to peer review.


Citations as of May 2018


Cited by 4 papers:


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Morton, E. M., Murray, G., Michalak, E. E., Lam, R. W., Beaulieu, S., Sharma, V.,
Cervantes, P., Parikh, S. V., & Yatham, L. N. (2017). Quality of life in bipolar disorder:
Towards a dynamic understanding. *Psychological Medicine, 48*(7), 1111-1118.
doi:10.1017/S0033291717002495

Cited by:

Bonnin, C. M., Yatham, L. N., Michalak, E. E., Martinez-Aran, A., Dhanoa, T.,
Torres, I., Santos-Pascual, C., Valls, E., Carvalho, A. F., Sanchez-Moreno, J., Valenti, M.,
the well-being index (WHO-5) Spanish version in a sample of euthymic patients with bipolar
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Journal: Journal of Affective Disorders
Our reference: JAD0426
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G

Cristina

The study was completed a while ago and we are no longer collecting the data. Hence, there is no way to add any one as investigator to the study.

It is OK for Emma to write a paper from these data with our permission.

As to other analyses, I will send you some of the analyses plans we have and you can ask Emma to do the analyses if she has time.

For her contribution, we would be happy to include her on the paper along with yourself.

Laishmi
To: I. Velkova

From: Gregory Murray

Subject: HOPE analysis

Dear Ivelina,

I hope you are well. I have student Emma Moro and I have written a conference presentation about the HOPE 2010 (dataset). This will turn into a very nice publication and opens up the possibility of future HOPE papers, depending on the lead CO analysis plan.

Emma is a student and therefore needs everything clear and clean regarding ethics. She should really be added as a named investigator on the HOPE ethics. While we are adding Emma, it would be advantageous to add everyone and enrich (if she's not already listed).

It all works with you and how can I facilitate it?

Best wishes,

Greg

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I. Velkova, MS, PhD
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Mental Health and Addictions
Vancouver Coastal Health and Providence Health Care

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To: I. Velkova

Hi Ivelina,

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<td>Erin Michalak</td>
<td>UBC/Medicine, Faculty</td>
<td>H14-01196</td>
</tr>
</tbody>
</table>

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

<table>
<thead>
<tr>
<th>Institution</th>
<th>Site</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other locations where the research will be conducted:
Any research events of this study will be held in spaces that are convenient to reach for our participants and that take
their needs into consideration (i.e. either a classroom or event setting on the UBC or another university's campus or a
centrally located community space such as a school or community centre).

CO-INVESTIGATOR(S):
Melinda Suto
Gregory Murray
Steven Banes
Rachelle D. Hole

SPONSORING AGENCIES:
Canadian Institutes of Health Research (CIHR). "Like a ship that's always righting itself. Self-management of BD, from
evidence to action"

PROJECT TITLE:
"Like a ship that's always righting itself. Self-management of BD, from evidence to action"

CERTIFICATE EXPIRY DATE: June 10, 2015

DOCUMENTS INCLUDED IN THIS APPROVAL: DATE APPROVED:

<table>
<thead>
<tr>
<th>Document Name</th>
<th>Version</th>
<th>Date</th>
</tr>
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<tr>
<td>Ship/KTA Research Module</td>
<td>1</td>
<td>December 1, 2012</td>
</tr>
<tr>
<td>Consent Forms:</td>
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<td></td>
</tr>
<tr>
<td>Community Members Consent Form</td>
<td>N/A</td>
<td>June 4, 2014</td>
</tr>
<tr>
<td>Healthcare Providers Consent Form</td>
<td>N/A</td>
<td>June 4, 2014</td>
</tr>
<tr>
<td>Questionnaire, Questionnaire Cover Letter, Tests:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Qol. BD Instrument</td>
<td>N/A</td>
<td>June 1, 2010</td>
</tr>
<tr>
<td>Healthcare Providers Demographic Form</td>
<td>N/A</td>
<td>April 29, 2014</td>
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<td>Community Members Demographic Form</td>
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<td>Community Consultation Guiding Questions</td>
<td>N/A</td>
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<tr>
<td>Other Documents:</td>
<td></td>
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</tr>
<tr>
<td>Media Form</td>
<td>N/A</td>
<td>April 29, 2014</td>
</tr>
</tbody>
</table>

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found
to be acceptable on ethical grounds for research involving human subjects.
Swinburne University: Ethics Approval and Acknowledgement of Final Report

Dear Greg and Emma,

SHR Project 2015/104 "Like a ship that's always fighting itself": Self-management of BD, from evidence to action

Prof Greg Murray, BPsych(FHAD), Dr Emma Morton et al

Approved duration: 10/02/2015 to 22/02/2016

(UBC/REB No H1401186, Sponsored Agency: Canadian Institutes of Health Research (CIHR); CI: Dr Ellie Michalos)

I confirm that the application for Swinburne ethics clearance for Swinburne staff and student involvement in the above University of British Columbia (UBC) collaborative project and given ethics clearance by CIHR's Behavioural Research Ethics Board (BIHER).

Relevant documentation pertaining to the application, as emailed on 6 May 2015, was given expedited ethics review on behalf of Swinburne's Human Research Ethics Committee (SUNHEC) by Committee delegates significantly at the request of the prior ethics review conducted (UBC/REB No H1401186) as being sufficiently in line with the National Statement on Ethical Conduct in Human Research (2007).

I am pleased to advise that ethics clearance has now been given for the Swinburne involvement in the project to proceed in line with sponsorship going forward, clearance conditions have outlined as applicable.

(UBC's BIHER or relevant agency may need to be advised about the Swinburne ethics clearance)

- All human research activity undertaken under Swinburne auspices must conform to Swinburne and/or relevant regulatory standards, including the current National Statement on Ethical Conduct in Human Research and with respect to secure data use retention and disposal.

- The named Swinburne Chief Investigator/Supervisor remains responsible for any personnel.
The above project has been approved as submitted for ethical review by or on behalf of SUHREC. Amendments to approved procedures or trial protocols ordinarily require prior ethical approval. SUHREC must be notified immediately of: (1) any serious or unexpected adverse effects on participants and any rescue measures; (2) proposed changes in protocols; and (3) unforeseen events which might affect the continued ethical acceptability of the project.

At a minimum, an annual report on the progress of the project is required as well as at the conclusion (or discontinuance) of the project. The report should include: (a) a copy of any progress, annual or final report submitted to the REO; and (b) any issues that may arise during the course of the project. The SUHREC REO may request information or any other requirements. Please ensure that all reports are submitted to the REO.

A duly authorised external or internal audit of the project may be undertaken at any time.

Please contact the Research Ethics Office if you have any queries about Swinburne on-going ethics approval. All queries should be directed to the SUHREC project number. A copy of this document should be retained as part of the project record-keeping.

Best wishes to you, Dr. Micaliak and colleagues for the project.

Yours sincerely,

Keith

-----------------------------------------
Keith Micaliak

Swinburne Research & Research Ethics Officer

Swinburne Research (HREC)

Swinburne University of Technology

P.O. Box 218

HAWTHORN VIC 3122

Tel: +61 3 9214 8218

Fax: +61 3 9214 8257

Gregory Murray gmvit@swin.edu.au
FW: Acknowledgement of Report for SUHREC Project - 2015/104

2 messages

RES Ethics <resethics@swin.edu.au>  Mon, Jun 5, 2017 at 8:12 AM
To: Emma Morton <emorton@swin.edu.au>, "emma.e.morton@gmail.com" <emma.e.morton@gmail.com>

Dear Emma,

FYI

Kind regards,
Arien

--- Original Message ---
From: resethics@swin.edu.au [email] [email]@swin.edu.au]
Sent: Monday, 5 June 2017 8:14 AM
To: Emma Morton <emorton@swin.edu.au>
Cc: RES Ethics <resethics@swin.edu.au>
Subject: Acknowledgement of Report for SUHREC Project - 2015/104

Dear Greg,

Ref: Final Report for the project 2015/104

"Like a ship that's always signing itself" Self-management of R.1, from evidence to art or (report) Our
to: 06-06-2017

The final report for the above project has been processed and satisfies the reporting requirements set
under the terms of ethics clearance.

Thank you for your attention to this matter.

Regard,
Research Ethics Team
Swinburne Research (1961)
Swinburne University of Technology
PO Box 216
HAWTHORN VIC 3122
Tel: 03 9905 5555
Fax: 03 9905 5567
Email: resethics@swin.edu.au

--- Original Message ---
From: resethics@swin.edu.au [email] [email]@swin.edu.au]
Sent: Monday, 5 June 2017 8:12 AM
To: Emma Morton <emorton@swin.edu.au>, "emma.e.morton@gmail.com" <emma.e.morton@gmail.com>
Cc: RES Ethics <resethics@swin.edu.au>
Subject: Acknowledgement of Report for SUHREC Project - 2015/104

Dear Greg,

Ref: Final Report for the project 2015/104

"Like a ship that's always signing itself" Self-management of R.1, from evidence to art or (report) Each
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Swinburne University of Technology
PO Box 216
HAWTHORN VIC 3122
Tel: 03 9905 5555
Fax: 03 9905 5567
Email: resethics@swin.edu.au
### APPENDIX E: CHAPTER 3 TABLES OF REVIEWED STUDIES

#### Table 1.

*Summary of studies comparing quality of life (QoL) in bipolar disorder (BD) to healthy controls (HCs)*

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>HC comparison</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Akvardar et al., 2006)</td>
<td>WHOQOL-BREF</td>
<td>$N = 28$</td>
<td>$N = 49$</td>
<td>BD sample demonstrated poorer QoL than HCs on Physical subscale. No difference between groups on any other subscale.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Euthymia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Arnold, Witzman, Swank, McElroy, &amp; Keck Jr, 2000)</td>
<td>SF-36</td>
<td>$N = 44$</td>
<td>$N = 2474$</td>
<td>Poorer QoL in BD on all subscales except Physical Health compared to HC.</td>
</tr>
<tr>
<td>(Brissos, Dias, Carita, &amp; Martinez-Arán, 2008)</td>
<td>WHOQOL-BREF</td>
<td>$N = 30$</td>
<td>$N = 23$</td>
<td>Poorer Physical, Psychological and Social scores compared to HC. No significant difference was observed on the Environmental domain.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Brissos, Dias, &amp; Kapczinski, 2008)</td>
<td>WHOQOL-BREF; Q-LES-Q</td>
<td>$N = 55$</td>
<td>$N = 50$</td>
<td>BD group was found to have worse QoL on all domains as compared to HCs.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author(s)</td>
<td>Scale</td>
<td>Mood state</td>
<td>BD subtype</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>-----------</td>
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<td>-----------</td>
</tr>
<tr>
<td>Chand, Mattoo, &amp; Sharan, 2004</td>
<td>WHOQOL-BREF; Q-LES-Q</td>
<td>Euthymia</td>
<td></td>
<td>ICD-10</td>
</tr>
<tr>
<td>Cotrena, Branco, Shansis, &amp; Fonseca, 2016</td>
<td>WHOQOL-BREF</td>
<td>Euthymia</td>
<td>BD I (n = 37) &amp; II (n = 34)</td>
<td>DSM-5</td>
</tr>
<tr>
<td>Dias, Brissos, Frey, &amp; Kapczinski, 2008</td>
<td>WHOQOL-BREF</td>
<td>Euthymia</td>
<td>BD I</td>
<td>DSM-IV</td>
</tr>
<tr>
<td>Depp, Davis, Mittal, Patterson, &amp; Jeste, 2006</td>
<td>Quality of Wellbeing Scale (QWB) (Kaplan, Atkins, &amp; Timms, 1984); SF-36</td>
<td>Depression</td>
<td>BD I</td>
<td>DSM-IV</td>
</tr>
<tr>
<td>Study</td>
<td>QoL Instrument</td>
<td>BD Sample</td>
<td>HC comparison</td>
<td>Findings</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>----------------------</td>
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<td>---------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>(Depp et al., 2009)</td>
<td>QWB; SF-36</td>
<td>$N = 30$ older adults (age 45-85)</td>
<td>$N = 31$</td>
<td>Participants with BD had lower QoL than HCs on the SF-36 PCS and MCS summary scores, as well as the QWB.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtypes: BD I ($n = 28$) &amp; II ($n = 2$)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Eissa, Elghoniemy, Hamed, Omar, &amp; Morsy, 2012)</td>
<td>Quality of Life Index (Ferrans &amp; Powers, 1985)</td>
<td>$N = 30$ (age and sex-matched)</td>
<td>$N = 30$ (age and sex-matched)</td>
<td>BD sample reported poorer QoL across all subscales (Health of functioning, social and economic, psychological and spiritual, family, and overall QoL).</td>
</tr>
<tr>
<td>(Gazalle et al., 2007)</td>
<td>WHOQOL-BREF</td>
<td>$N = 120$</td>
<td>$N = 40$</td>
<td>Participants with depression scored poorer on all domains. Euthymic participants scored poorer on all domains except Environmental. Participants with mania reported QoL on par with HC in all domains except Social, where manic participants reported poorer QoL than HC.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Mania ($n = 40$), depression ($n = 40$), &amp; euthymia ($n = 40$).</td>
<td>$N = 157$</td>
<td>BD sample reported poorer QoL on all subscales except Environmental.</td>
</tr>
<tr>
<td>(Goossens, Hartong, Knoppert-Van Der Klein, &amp; Van)</td>
<td>WHOQOL-BREF</td>
<td>$N = 157$</td>
<td>$N = 630$</td>
<td>BD sample reported poorer QoL on all subscales except Environmental.</td>
</tr>
<tr>
<td>Source</td>
<td>Measure</td>
<td>Sample Size</td>
<td>Mood State</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>--------------------------------------------</td>
<td>------------------</td>
<td>-------------</td>
<td>-------------------------------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Achterberg, 2008</td>
<td></td>
<td></td>
<td>No recent severe symptoms of mania or depression</td>
<td></td>
</tr>
<tr>
<td>(Gutiérrez-Rojas et al., 2008)</td>
<td>SF-36</td>
<td>N = 108</td>
<td>Diagnosis: DSM-IV</td>
<td></td>
</tr>
<tr>
<td>(Hakkaart-Van Roijen et al., 2004)</td>
<td>SF-36; EQ-5D</td>
<td>N = 40</td>
<td>Mood state: Euthymia (n = 48), symptomatic (n = 60)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>BD subtypes: BD I (n = 14), II (n = 14), NOS (n = 7), cyclothymia (n = 3), &amp; substance-induced (n = 2)</td>
<td></td>
</tr>
<tr>
<td>(Hofer et al., 2017)</td>
<td>WHOQOL-BREF</td>
<td>N = 60</td>
<td>Diagnosis: DSM-IV</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
<td></td>
</tr>
</tbody>
</table>

The symptomatic BD group reported poorer QoL in BD on all SF-36 subscales and MCS, while no group differences were observed between HCs and the non-euthymic BD group on PCS. Euthymic participants reported poorer QoL than HCs on the Physical Functioning, General Health, Social Functioning, and Role Limitations (Emotional). The BD sample scored lower on the EQ-5D. On the SF-36, the BD and HC samples did not differ except on the Role Limitations (physical), on which participants with BD scored lower.

The BD sample scored lower compared to HCs on all WHOQOL-BREF scales except environmental.
<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>HC comparison</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Latalova, Prasko, Diveky, Kamaradova, &amp; Velartova, 2011)</td>
<td>Q-LES-Q</td>
<td>N = 41</td>
<td>N = 40</td>
<td>Participants with BD rated their QoL as equivalent to HCs in all domains except for the Work and Household Duties domains, in which participants with BD rated their QoL as higher than HCs (however, this difference was not statistically significant).</td>
</tr>
<tr>
<td>(Lee et al., 2017)</td>
<td>WHOQOL-BREF</td>
<td>N = 68</td>
<td>N = 68</td>
<td>BD group reported worse QoL than HCs across the Social, Physical and Psychological subscales. No difference was observed on the Environmental subscale.</td>
</tr>
<tr>
<td>(Maina et al., 2007)</td>
<td>SF-36</td>
<td>N = 142</td>
<td>N = 50</td>
<td>Individuals with BD I and BD II reported worse QoL than HCs on the Vitality, Physical Functioning, Role Limitations (Physical), Role Limitations (Emotional), Mental Health, and the summary score MCS. Additionally, individuals with BD II reported worse QoL than HCs on the General Health, Social Functioning, and the summary score PCS. Neither BD I nor BD II differed from HCs on the Bodily Pain subscale. Individuals with BD reported poorer overall QoL than HCs.</td>
</tr>
<tr>
<td>(Momeni, Shiyasi, &amp; Mirzaasgari, 2017)</td>
<td>Brief Qol.BD</td>
<td>N = 118</td>
<td>N = 132</td>
<td>Mood state: Current inpatients demonstrating improvements in mood</td>
</tr>
<tr>
<td>Study</td>
<td>Measure</td>
<td>N (BD)</td>
<td>N (HCs)</td>
<td>BD subtype</td>
</tr>
<tr>
<td>-------</td>
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<td>--------</td>
<td>------------</td>
</tr>
<tr>
<td>(Pattanayak, Sagar, &amp; Mehta, 2012)</td>
<td>WHOQOL-BREF</td>
<td>30</td>
<td>20</td>
<td>BD I</td>
</tr>
<tr>
<td>(Sierra, Livianos, &amp; Rojo, 2005)</td>
<td>SF-36</td>
<td>50</td>
<td>1250</td>
<td>BD I (n = 45) &amp; II (n = 5)</td>
</tr>
<tr>
<td>(Studart et al., 2016)</td>
<td>WHOQOL-BREF</td>
<td>119</td>
<td>63</td>
<td>BD I</td>
</tr>
<tr>
<td>(Sum, Ho, &amp; Sim, 2015)</td>
<td>WHOQOL-BREF</td>
<td>44</td>
<td>56</td>
<td>BD I</td>
</tr>
<tr>
<td>Study</td>
<td>QoL Instrument</td>
<td>BD Sample</td>
<td>HC comparison</td>
<td>Findings</td>
</tr>
<tr>
<td>-------------------------------</td>
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<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>(Van Rheenen &amp; Rossell, 2014)</td>
<td>QoL.BD</td>
<td>$N = 51$</td>
<td>$N = 52$</td>
<td>Individuals with BD reported poorer QoL on all core subscales except spirituality. Of the two optional subscales (Work and Education), individuals with BD reported poorer QoL than HCs on the Education subscales.</td>
</tr>
<tr>
<td>(Xiang et al., 2014)</td>
<td>WHOQOL-BREF</td>
<td>$N = 47$</td>
<td>$N = 47$ (age and education matched)</td>
<td>Individuals with BD reported QoL on par with HCs across all domains.</td>
</tr>
<tr>
<td>(Xiao et al., 2016)</td>
<td>Brief QoL.BD</td>
<td>$N = 101$</td>
<td>$N = 130$</td>
<td>Both subsyndromic and asymptomatic participants reported lower total QoL than healthy controls.</td>
</tr>
<tr>
<td>(Yen et al., 2008)</td>
<td>WHOQOL-BREF</td>
<td>$N = 96$</td>
<td>$N = 106$</td>
<td>Individuals with BD reported poorer QoL than HCs across all domains.</td>
</tr>
</tbody>
</table>
Table 2.

Summary of studies comparing quality of life (QoL) in bipolar disorder (BD) to chronic physical illnesses

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Comparison</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Akvardar et al., 2006)</td>
<td>WHOQOL-BREF</td>
<td>$N = 28$</td>
<td>Patients with diabetes ($n = 35$)</td>
<td>BD sample did not differ from diabetic sample on any subscale.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood State: Euthymia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Arnold et al., 2000)</td>
<td>SF-36</td>
<td>$N = 44$</td>
<td>Patients with chronic low back pain ($n = 30$)</td>
<td>BD sample less impaired in Role Limitations (Physical), Bodily Pain and Social Function compared to back pain sample. No difference to back pain sample on any other subscales.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtypes: BD I ($n = 38$), II ($n = 5$), &amp; BD NOS ($n = 1$)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Cooke, Robb, Young, &amp; Joffe, 1996)</td>
<td>SF-20</td>
<td>$N = 68$</td>
<td>Patients with chronic medical conditions (e.g., hypertension, heart disease, gastrointestinal disorders; $n = 9385$)</td>
<td>BD sample reported QoL within the range found in studies with people with chronic medical conditions for the Physical, Role Limitations, and Pain subscales. The BD sample reported numerically QoL poorer than the range reported in studies with people with chronic medical conditions for the Social, Mental Health and Health Perceptions subscales.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-III</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Euthymia</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Robb, Cooke, Devins, Young, &amp; Joffe, 1997)</td>
<td>Illness Intrusiveness</td>
<td>$N = 68$</td>
<td>Individuals with multiple sclerosis ($n = 94$), rheumatoid arthritis ($n = 110$) or end stage renal disease ($n = 101$).</td>
<td>After controlling for negative life events, illness intrusiveness was higher in the BD sample compared to other groups in the Family Relations, Social Relations, and Self Expression/Self-Improvement domains. QoL did not differ across the groups for the remaining domains.</td>
</tr>
<tr>
<td></td>
<td>Rating Scale (Devins et al., 1983)</td>
<td>Diagnosis: DSM-III</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Euthymia</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 3.

Summary of studies comparing quality of life (QoL) in bipolar disorder (BD) to major depressive disorder (MDD) or schizophrenia (SC)

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Comparison</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Akvardar et al., 2006)</td>
<td>WHOQOL-BREF</td>
<td>N = 28</td>
<td>SC (n = 38)</td>
<td>Patients with BD had higher QoL than patients with SC in the Psychological and Social domains. The groups did not differ on the Environmental or Physical domains.</td>
</tr>
<tr>
<td>(Amini &amp; Sharifi, 2012)</td>
<td>WHOQOL-BREF</td>
<td>N = 59</td>
<td>SC (n = 43), recent hospitalisation for a psychotic episode</td>
<td>Participants with BD did not differ from participants with SC on any QoL dimension.</td>
</tr>
<tr>
<td>(Atkinson, Zibin, &amp; Chuang, 1997)</td>
<td>Quality of Life Index</td>
<td>N = 37</td>
<td>SC (n = 69), MDD (n = 35)</td>
<td>Participants did not differ in the importance ratings of QoL domains. Participants with SC reported higher QoL in each domain than participants with MDD or BD.</td>
</tr>
<tr>
<td>(Aykut, Arslan, Özkorumak, &amp; Tiryaki, 2017),</td>
<td>Q-LES-Q</td>
<td>N = 92</td>
<td>SC (n = 102) currently not in acute phase of illness.</td>
<td>The BD and SC groups did not differ across any QoL domain.</td>
</tr>
<tr>
<td>Study</td>
<td>Measure</td>
<td>Sample Size</td>
<td>Diagnosis</td>
<td>Mood State</td>
</tr>
<tr>
<td>-----------------------</td>
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<tr>
<td>(Bellack, Morrison,</td>
<td>Quality of Life</td>
<td>$N = 29$</td>
<td>DSM-III</td>
<td>Current inpatient</td>
</tr>
<tr>
<td>Mueser, Wade, 1989)</td>
<td>Scale (QLS)</td>
<td></td>
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<tr>
<td>(Heinrichs, Hanlon,</td>
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<tr>
<td>Carpenter, 1984)</td>
<td></td>
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<tr>
<td>(Berlim et al., 2004)</td>
<td>WHOQOL-BREF</td>
<td>$N = 25$</td>
<td>DSM-IV</td>
<td>Depression</td>
</tr>
<tr>
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</tr>
<tr>
<td>(Brissos, Dias, Carita, et al., 2008)</td>
<td>WHOQOL-BREF</td>
<td>$N = 30$</td>
<td>DSM-IV</td>
<td>Euthymia</td>
</tr>
<tr>
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</tr>
<tr>
<td>(Caldirola et al., 2014)</td>
<td>WHOQOL-BREF</td>
<td>$N = 28$</td>
<td>DSM-IV</td>
<td>Depression; current inpatients.</td>
</tr>
<tr>
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</tbody>
</table>

$N$ denotes the sample size. SC refers to schizophrenia.
<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Comparison</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Chand et al., 2004)</td>
<td>WHOQOL-BREF; Q-LES-Q</td>
<td>$N = 50$</td>
<td>SC ($n = 20$) in a non-acute and clinically stable phase</td>
<td>Participants with BD reported higher QoL than participants with SC on the Physical and Psychological domains of the WHOQOL-BREF. Participants with BD reported higher QoL on all subscales of the Q-LES-Q.</td>
</tr>
<tr>
<td>(Cotrena et al., 2016)</td>
<td>WHOQOL-BREF</td>
<td>$N = 71$</td>
<td>MDD ($n = 45$)</td>
<td>After controlling for age, education and mood symptoms, there was no difference in QoL between participants with BD-I and MDD across all QoL dimensions. Individuals with BD-II reported poorer QoL than MDD on the physical domain only.</td>
</tr>
<tr>
<td>(Depp et al., 2006)</td>
<td>QWB</td>
<td>$N = 54$ older adults (age 45-85)</td>
<td>SC ($n = 55$)</td>
<td>No difference was observed between participants with BD as compared to SC on the SF-36 subscales or QWB.</td>
</tr>
<tr>
<td>Source</td>
<td>Measure</td>
<td>N</td>
<td>Diagnosis</td>
<td>Mood state</td>
</tr>
<tr>
<td>---------------------------------------------</td>
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<td>------------------------------------------------</td>
</tr>
<tr>
<td>(Engel-Yeger et al., 2016)</td>
<td>SF-12</td>
<td>110</td>
<td>MDD (n = 157)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>BD subtypes: BD I (n = 46), II (n = 51) or cyclothymia (n = 13)</td>
<td>Diagnosis: DSM-IV-TR</td>
</tr>
<tr>
<td>(Esan et al., 2017)</td>
<td>WHOQOL-BREF</td>
<td>54</td>
<td>SC (n = 75) in remission</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
<td>Diagnosis: DSM-IV</td>
</tr>
<tr>
<td>(Grover, Painuly, Gupta, &amp; Mattoo, 2011)</td>
<td>WHOQOL-BREF</td>
<td>22</td>
<td>Recurrent MDD (n = 22)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Diagnosis: ICD-10</td>
<td>Mood state: Euthymia</td>
</tr>
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<tr>
<td>(Johanson &amp; Bejerholm, 2017)</td>
<td>Manchester Short Assessment of Quality of Life Scale (Priebe, Huxley, Knight, &amp; Evans, 1999)</td>
<td>19</td>
<td>MDD (n = 69)</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Diagnosis: Treating psychiatrist-recorded diagnosis obtained from medical records.</td>
</tr>
<tr>
<td>(Kessing, Hansen, &amp; Bech, 2006)</td>
<td>EQ-5D; EQ-VAS; WHO Wellbeing Index (Bech, Olsen, Kjoller, &amp; Rasmussen, 2003)</td>
<td>235</td>
<td>MDD (n = 258)</td>
<td></td>
</tr>
</tbody>
</table>
Table 3. (cont)

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Comparison</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Latalova et al., 2011)</td>
<td>Q-LES-Q</td>
<td>$N = 41$</td>
<td>SC ($n = 40$)</td>
<td>Participants with BD reported higher QoL than those with SC in the domains of Physical Health, Subjective Feelings, Work, Household, Leisure, and Social Activities.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Diagnosis: ICD-10</td>
</tr>
<tr>
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<td></td>
<td></td>
<td>Mood state: Euthymia</td>
</tr>
<tr>
<td>(Maina et al., 2007)</td>
<td>SF-36</td>
<td>$N = 142$</td>
<td>Recurrent MDD ($n = 61$), currently euthymic</td>
<td>When controlling for age, participants with BD II reported equivalent QoL to individuals with depression on all domains. Individuals with BD I reported higher QoL than those with depression on the Role Limitations (Physical), General Health, Social Functioning, Role Limitations (Emotional), Mental Health, and the summary scores MCS and PCS, and equivalent QoL to those with depression on the Vitality and Physical functioning subscales.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>BD subtypes: BD I ($n = 90$) and II ($n = 52$)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Mood state: Euthymia</td>
</tr>
<tr>
<td>(Moreno et al., 2012)</td>
<td>SF-12</td>
<td>$N = 1429$</td>
<td>Current or lifetime MDD ($n = 5695$)</td>
<td>Individuals with BD I reported poorer QoL than those with MDD on the Mental Health, Social Functioning and Role Limitations (Emotional) subscales. Individuals with BD II reported higher PCS scores than those with MDD.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>BD Type: BD I ($n = 935$) and II ($n = 494$)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Diagnosis: Current/lifetime DSM-IV diagnoses</td>
</tr>
<tr>
<td>(Owoeye et al., 2013)</td>
<td>QLS</td>
<td>$N = 73$</td>
<td>SC ($n = 73$), recent first episode psychosis.</td>
<td>Individuals with BD were assessed as having higher overall QoL than those with schizophrenia.</td>
</tr>
<tr>
<td></td>
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<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
</tr>
<tr>
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<td></td>
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<td>Mood state: Recent first manic episode.</td>
</tr>
</tbody>
</table>
(Russo et al., 1997) Quality of Life Interview (Lehman, 1988)  
N = 138  
Diagnosis: DSM-III-R  
Mood state: Depression (n = 138) or mania (n = 103); current inpatients  
Current inpatients: (SC, schizoaffective disorder; n = 182), MDD (n = 374)  
Individuals with schizophrenia-spectrum diagnoses or BD (current manic episode) reported higher QoL in the domains of Finances, Family Relations, Social Relations, and Leisure Activities as compared to those with bipolar or unipolar depression. There were no group differences regarding satisfaction with Safety. Participants with unipolar or bipolar depression reported lower satisfaction with Work and Living Situation than those with mania. Participants with mania reported higher Global life satisfaction than all other groups, while participants with schizophrenia-spectrum diagnoses reported higher satisfaction than the depressed groups. Individuals with BD were assessed as having higher QoL than those with SC.

(Sánchez-Morla et al., 2009) QLS  
N = 73  
Diagnosis: DSM-IV  
Mood state: Euthymia  
SC (n = 89) in a non-acute and clinically stable phase.
<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Comparison</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Sum et al., 2015)</td>
<td>WHOQOL-BREF</td>
<td>$N = 44$</td>
<td>Schizophrenia ($n = 122$)</td>
<td>Individuals with BD reported higher QoL compared with participants with SC in the Environmental dimension as well as overall QoL. When participants in remission only were considered comparable QoL across all domains was observed between BD and SC. Unremitted participants with SC reported poorer QoL in all domains compared to those with unremitted BD.</td>
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<tr>
<td>(Ten Have, Vollebergh, Bijl, &amp; Nolen, 2002)</td>
<td>SF-36</td>
<td>$N = 136$</td>
<td>Unipolar mood disorders (MDD, dysthymia; $n = 509$)</td>
<td>Participants with BD I reported poorer QoL than unipolar mood disorders on the General Health Perception, Pain, Mental Health, Role Limitations (Emotional), Social Functioning, and Vitality. Individuals with BD NOS reported poorer QoL than unipolar mood disorders on the Mental Health subscale.</td>
</tr>
<tr>
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</tr>
<tr>
<td>(Vibha, Saddichha, Khan, &amp; Akhtar, 2013)</td>
<td>WHOQOL-BREF</td>
<td>$N = 50$</td>
<td>SC ($n = 52$) in remission; recurrent MDD ($n = 48$) in remission.</td>
<td>Overall QoL was highest in the BD group, followed by MDD, followed by SC.</td>
</tr>
<tr>
<td>(Yatham et al., 2004)</td>
<td>SF-36</td>
<td>$N = 920$</td>
<td>Combined sample from seven previously published studies of MDD, each with a sample</td>
<td>The BD sample reported significantly lower QoL than the MDD samples in all studies in the Social Functioning, Role Limitations (Physical), and Role Limitations (Emotional). The BD group reported lower QoL than the MDD sample in all studies bar one for the</td>
</tr>
</tbody>
</table>
General Health, Mental Health and Vitality subscales. On the Pain subscale, the BD sample reported higher QoL than 6 out of 7 MDD samples.

(Yen et al., 2008) WHOQOL-BREF $N = 96$

BD Type: BD I
Diagnosis: DSM-IV
Mood state: Euthymia

Individuals with BD and SC did not differ in terms of QoL.
### Table 4.

*Summary of studies comparing quality of life (QoL) across bipolar disorder (BD) subtypes*

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Albert, Rosso, Maina, &amp; Bogetto, 2008)</td>
<td>SF-36</td>
<td>(N = 105) BD subtypes: BD I ((n = 44)) and II ((n = 61))</td>
<td>Individuals with BD-II reported poorer QoL than those with BD I on General Health, Vitality, Mental Health, and the MCS summary score.</td>
</tr>
<tr>
<td>(Cooke et al., 1996)</td>
<td>SF-20</td>
<td>(N = 68) Mood state: Euthymia</td>
<td>Individuals with BD II reported worse QoL than those with BD I on the Social Functioning and Mental Health subscales.</td>
</tr>
<tr>
<td>(Cotrena et al., 2016)</td>
<td>WHOQOL-BREF</td>
<td>(N = 66) Mood state: Euthymia</td>
<td>Individuals with BD-I and BD-II did not differ on any QoL subscales.</td>
</tr>
<tr>
<td>(Datto, Pottorf, Feeley, LaPorte, &amp; Liss, 2016)</td>
<td>Q-LES-Q</td>
<td>(N = 1791) BD subtypes: BD I ((n = 37)) and II ((n = 35))</td>
<td>Individuals with BD-I and BD-II did not differ on overall QoL.</td>
</tr>
<tr>
<td>(Goossens et al., 2008)</td>
<td>WHOQOL-BREF</td>
<td>(N = 157) outpatients BD subtypes: BD I ((n = 105)), II ((n = 40)), and NOS ((n = 12))</td>
<td>The three BD subgroups did not differ on any QoL subscale.</td>
</tr>
</tbody>
</table>
Mood state: No severe mania or depression in past month

*Maina et al., 2007*

- SF-36
- $N = 142$
- BD subtypes: BD I ($n = 90$) and II ($n = 52$)
- Diagnosis: DSM-IV
- Mood state: Euthymia

Individuals with BD II reported poorer QoL across the majority of QoL subscales (Role Limitations [Physical], Bodily Pain, General Health, Vitality, Social Functioning, Role Limitations [Emotional], Mental Health) and the MCS summary score, even after controlling for age, age at illness onset, and length of illness. Individuals with BD II were found to have equivalent QoL to those with BD I on the Physical Functioning and PCS summary score.

*Burckhardt’s Quality of Life Scale*

*Burckhardt & Anderson, 2003*

- $N = 131$
- BD subtype: BD I ($n = 65$), II ($n = 29$) and cyclothymia ($n = 37$)
- Diagnosis: DSM-IV

No significant differences were observed between BD I, BD II or cyclothymia.

*Modabbernia et al., 2016*

- Brief QoL.BD
- $N = 184$
- BD Type: BD I ($n = 134$) and II ($n = 50$)
- Diagnosis: DSM-IV

Individuals with BD-I reported lower scores compared to BD-II.

*Moreno et al., 2012*

- SF-12
- $N = 1429$
- BD Type: BD I ($n = 935$) and BD II ($n = 494$)
- Diagnosis: Current/lifetime DSM-IV diagnoses

Individuals with BD I reported poorer QoL than those with BD II across the Social Functioning, Role Limitations (Emotional), and Mental Health subscales, and the PCS summary scale.
<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Robb et al., 1997)</td>
<td>Illness Intrusiveness Rating Scale (Devins et al., 1983)</td>
<td>N = 68</td>
<td>Individuals with BD II reported higher levels of Illness Intrusiveness than those with BD I on the Health, Active Recreation, Passive Recreation, and Financial Situation subscales, as well as Total Illness Intrusiveness.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD Type: BD I (n = 55) and II (n = 13)</td>
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<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-II</td>
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<tr>
<td></td>
<td></td>
<td>Mood state: Euthymia</td>
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</tbody>
</table>
Table 5.

Summary of studies investigating quality of life (QoL) across mood episodes in bipolar disorder (BD)

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Gazalle et al., 2006)</td>
<td>WHOQOL-BREF</td>
<td>N = 60</td>
<td>Higher QoL scores were found in remitted participants across all domains, followed by subsyndromal participants, followed by the depressed group.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtype: BD I, II &amp; NOS</td>
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<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Depression (n = 27), subsyndromal (did not meet DSM-IV criteria for a mood episode, experiencing residual symptoms; n = 14), and euthymia (n = 19)</td>
<td></td>
</tr>
<tr>
<td>(Gazalle et al., 2007)</td>
<td>WHOQOL-BREF</td>
<td>N = 120</td>
<td>Participants with mania reported similar QoL to those with euthymia, and better QoL than those in a depressed state, across all QoL domains barring Social (depressed participants reported equivalent QoL to those with mania and poor QoL than euthymic participants within this domain).</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Mania (n = 40), depression (n = 40), &amp; euthymia (n = 40).</td>
<td></td>
</tr>
<tr>
<td>(Goossens et al., 2008)</td>
<td>WHOQOL-BREF</td>
<td>N = 157</td>
<td>The depressed mood group reported poorer QoL on all domains than the hypomaniac/euthymic groups. The hypomaniac and euthymic groups did not differ.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV-TR</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Depression (n = 20), euthymia (n = 105), &amp; hypomania (n = 29). Severe depression and mania excluded.</td>
<td></td>
</tr>
</tbody>
</table>
Table 5. (cont)

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Findings</th>
</tr>
</thead>
</table>
| (Kline Leidy, Palmer, Murray, Robb, & Revicki, 1998) | Quality of Life in Depression Scale (QLDS; Hunt & McKenna, 1992); SF-36; Mental Health Index-17 (Stewart, Ware, Sherbourne, & Wells, 1992) | $N = 62$  | BD subtype: BD I  
Diagnosis: DSM-IV  
Mood state: Depression ($n = 28$) & euthymia ($n = 34$)  
At baseline, depressed participants reported poorer QoL on Vitality, Role Limitations (Emotional) and Mental Health subscales, the MHI-17, but not QLDS. |
| (Piccinni et al., 2007)                     | SF-36                                                                         | $N = 90$  | BD subtype: BD I  
Diagnosis: DSM-IV  
Mood state: Euthymia. Participants were further categorised on the basis of persisting symptoms: fully remitted (asymptomatic for $> 2$ months; $n = 32$), 1 month remitted (asymptomatic for $> 1$ and $< 2$ months; $n = 13$), persisting manic symptoms (manic symptoms present but not meeting criteria for at least 2 months; $n = 22$), and persisting depressive symptoms (depressive symptoms present but not meeting criteria for at least 2 months; $n = 23$).  
The fully remitted group reported better QoL than the group with persisting depressive symptoms on the Physical Functioning, General Health, Vitality, Social Functioning, and Mental Health subscales. Participants with persisting manic symptoms reported higher QoL on the General Health, Vitality, and Mental Health scales as compared to those with persisting depressive symptoms. |
| (Vojta, Kinosian, Glick, Altshuler, & Bauer, 2001) | SF-12; EQ-VAS                                                                | $N = 86$  | Diagnosis: DSM-IV  
QoL as measured by the SF-12 Mental subscale (MCS) was higher in the euthymic group as compared to the (hypo)mania group, which was in turn higher than both the mixed and depressed groups (which did not |
Mood state: (Hypo)mania ($n = 16$), depression ($n = 26$), mixed ($n = 14$), & euthymia ($n = 30$). No group differences were found on the Physical summary scale. QoL as measured by the EQ-VAS was higher in euthymia as compared to depressed and mixed groups, and in the (hypo)manic group as compared to the depressed group.
Table 6.

**Summary of studies investigating the relative predictive power of mood symptoms on quality of life (QoL) in bipolar disorder (BD)**

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Abraham, Miller, Birgenheir, Lai, &amp; Kilbourne, 2014)</td>
<td>SF-12</td>
<td>$N = 141$ BD subtypes: BD I, II &amp; NOS</td>
<td>Lower levels of depression were associated with improved MCS but not PCS after controlling for a variety of demographic and clinical variables. Mania was not associated with either summary scale.</td>
</tr>
<tr>
<td>(Amini &amp; Sharifi, 2012)</td>
<td>WHOQOL-BREF</td>
<td>$N = 59$ BD subtype: BD I</td>
<td>At the majority of time points, depression was negatively associated with Physical, Psychological, Social and Environmental domains after controlling for various clinical and demographic variables. Mania was a significant negative predictor of Social and Environmental QoL at one time point only.</td>
</tr>
<tr>
<td>(De Abreu et al., 2012)</td>
<td>WHOQOL-BREF</td>
<td>$N = 108$ BD subtype: BD I</td>
<td>Depression was a significant negative predictor of QoL across all domains (and the strongest predictor for Physical, Psychological, and Environmental QoL) after controlling for a variety of clinical and demographic variables. Mania acted as a significant negative predictor for Social QoL only.</td>
</tr>
<tr>
<td>(Gutiérrez-Rojas et al., 2008)</td>
<td>SF-36</td>
<td>$N = 108$ outpatients</td>
<td>Depression was found to act as a negative predictor for both MCS and PCS after controlling for demographic and clinical variables. Mania scores acted as a negative predictor for MCS only.</td>
</tr>
</tbody>
</table>
(Özer, Uluşahin, Batur, Kabakçı, & Can Saka, 2002) Q-LES-Q $N = 100$

Diagnosis: DSM-III

Mood state: Euthymia

Overall QoL was negatively predicted by depression after controlling for mania, psychosis and anxiety symptoms.
Table 7.

Summary of studies investigating correlations between mood and quality of life (QoL) in bipolar disorder (BD)

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Amini &amp; Sharifi, 2012)</td>
<td>WHOQOL-BREF</td>
<td><em>N = 59</em></td>
<td>Negative correlations were observed between depression and WHOQOL BREF domains.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Recently hospitalised for a manic, mixed or psychotic episode.</td>
<td></td>
</tr>
<tr>
<td>(Brissos, Dias, Carita, et al., 2008)</td>
<td>WHOQOL-BREF</td>
<td><em>N = 30</em></td>
<td>Depression was a significant negative correlate of Physical QoL.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Euthymia</td>
<td></td>
</tr>
<tr>
<td>(Cooke et al., 1996)</td>
<td>SF-20</td>
<td><em>N = 68</em></td>
<td>Significant negative correlations were observed between depression and Social Functioning, Mental Health, and Overall Health Perception.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-III</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Euthymia</td>
<td></td>
</tr>
<tr>
<td>(Depp et al., 2006)</td>
<td>QWB SF-36</td>
<td><em>N = 54</em> older adults (age 45-85)</td>
<td>A negative correlation was observed between the SF-36 MCS summary score and mania. Negative correlations were observed between depression and QoL as measured by the QWB, SF-36 PCS, and SF-36 MCS.</td>
</tr>
<tr>
<td>Reference</td>
<td>Measure</td>
<td>Setting/Participants</td>
<td>Diagnosis</td>
</tr>
<tr>
<td>--------------------</td>
<td>------------------</td>
<td>----------------------</td>
<td>------------</td>
</tr>
<tr>
<td>(Depp et al., 2009)</td>
<td>QWB SF-36</td>
<td>$N = 30$ older adults (age 45-85)</td>
<td>DSM-IV</td>
</tr>
<tr>
<td>(Gazalle et al., 2006)</td>
<td>WHOQOL-BREF</td>
<td>$N = 60$ outpatients</td>
<td>DSM-IV</td>
</tr>
<tr>
<td>(Goossens et al., 2008)</td>
<td>WHOQOL-BREF</td>
<td>$N = 157$</td>
<td>DSM-IV-TR</td>
</tr>
<tr>
<td>Study</td>
<td>QoL Instrument</td>
<td>BD Sample</td>
<td>Findings</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>----------------</td>
<td>-----------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>(Hayhurst, Palmer, Abbott, Johnson, &amp; Scott, 2006)</td>
<td>EQ-5D; EQ-VAS</td>
<td>$N = 221$</td>
<td>Diagnosis: DSM-IV</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mood state: Participants were recently or still in an episode of illness (excluding severe mania).</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Significant correlations were observed between QoL and depression. QoL as measured by the EQ-5D, but not EQ-VAS, correlated significantly with mania.</td>
</tr>
<tr>
<td>(Leidy, Palmer, Murray, Robb, &amp; Revicki, 1998)</td>
<td>QLDS; SF-36; MHI-17</td>
<td>$N = 62$</td>
<td>Diagnosis: DSM-IV</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mood state: Depression ($n = 28$) &amp; euthymia ($n = 34$)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Across mood states, both the QLDS and MHI-17 showed significant negative correlations with depression. For euthymic participants, depression correlated negatively with Vitality, Social Function, Role Limitations (Emotional) and Mental Health. For depressed participants, depression scores correlated negatively with Role Limitations (Physical), Social Function, and Mental Health. QoL showed a significant negative correlation with depression.</td>
</tr>
<tr>
<td>(Özer et al., 2002)</td>
<td>Q-LES-Q</td>
<td>$N = 100$</td>
<td>Diagnosis: DSM-III</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Depression showed a significant negative correlation with all QoL domains.</td>
</tr>
<tr>
<td>(Yatham et al., 2004)</td>
<td>SF-36</td>
<td>$N = 920$</td>
<td>Diagnosis: DSM-IV</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mood state: Current or recent depression (with residual symptoms)</td>
</tr>
</tbody>
</table>
Table 8.

Summary of studies investigating the association between functioning and quality of life (QoL) in bipolar disorder (BD)

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Amini &amp; Sharifi, 2012)</td>
<td>WHOQOL-BREF</td>
<td>$N = 59$</td>
<td>No WHOQOL-BREF domains were found to correlate with functioning.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mood state: Recently hospitalised for a manic, mixed or psychotic episode.</td>
</tr>
<tr>
<td>(Caldirola et al., 2014)</td>
<td>WHOQOL-BREF</td>
<td>$N = 28$</td>
<td>No WHOQOL-BREF domains were found to correlate with functioning.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>BD subtypes: BD I &amp; II</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mood state: Depression; current inpatients</td>
</tr>
<tr>
<td>(Cooke et al., 1996)</td>
<td>SF-20</td>
<td>$N = 68$</td>
<td>The SF-20 subscales Social Functioning, Role Functioning, Mental Health and Overall Health perception correlated positively with functioning.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Diagnosis: DSM-III</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mood state: Euthymia</td>
</tr>
</tbody>
</table>
Table 8. (cont)

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Depp et al., 2006)</td>
<td>QWB</td>
<td>$N = 54$ older adults (age 45-85)</td>
<td>Positive correlations were found between QoL (QWB and SF-36 PCS summary score) and functioning.</td>
</tr>
<tr>
<td></td>
<td>SF-36</td>
<td>BD subtype: BD I</td>
<td>Diagnosis: DSM-IV</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
<td>Mood state: Depression ($n = 14$), (hypo)mania ($n = 11$), mixed ($n = 13$), euthymia ($n = 12$), &amp; unspecified ($n = 4$).</td>
</tr>
<tr>
<td>(Depp et al., 2009)</td>
<td>QWB</td>
<td>$N = 30$ older adults (age 45-85)</td>
<td>Neither the QWB nor SF-36 MCS and PCS summary scores correlated with functioning.</td>
</tr>
<tr>
<td></td>
<td>SF-36</td>
<td>BD subtypes: BD I ($n = 28$) &amp; II ($n = 2$)</td>
<td>Diagnosis: DSM-IV</td>
</tr>
<tr>
<td>(Gazalle et al., 2007)</td>
<td>WHOQOL-BREF</td>
<td>$N = 120$</td>
<td>Within the subset of participants in a manic episode, Psychological QoL was found to correlate negatively with functioning.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
<td>Diagnosis: DSM-IV</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Mania ($n = 40$), depression ($n = 40$), &amp; euthymia ($n = 40$).</td>
<td></td>
</tr>
<tr>
<td>(Goldberg &amp; Harrow, 2005)</td>
<td>Semi-structured life satisfaction interview</td>
<td>$N = 35$</td>
<td>No significant correlations were observed between social functioning and QoL at baseline (inpatient stay) or 2, 4.5, and 7-8 year follow-up.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>BD subtype: BD I</td>
<td>Diagnosis: DSM-III</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mood state: Mania; inpatient at time of baseline assessment</td>
<td></td>
</tr>
<tr>
<td>Reference</td>
<td>Measure</td>
<td>N</td>
<td>BD subtype</td>
</tr>
<tr>
<td>----------------------------</td>
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<td>------------</td>
</tr>
<tr>
<td>(Guilera et al., 2014)</td>
<td>EQ-5D</td>
<td>291</td>
<td>BD I</td>
</tr>
<tr>
<td>(MacQueen et al., 2000)</td>
<td>Medical Outcomes Questionnaire (Wells et al., 1989)</td>
<td>64</td>
<td></td>
</tr>
<tr>
<td>(Özer et al., 2002)</td>
<td>Q-LES-Q</td>
<td>100</td>
<td></td>
</tr>
<tr>
<td>(Russo et al., 1997)</td>
<td>Quality of Life Interview (Lehman, 1988)</td>
<td>138</td>
<td></td>
</tr>
<tr>
<td>(Thomas, Nisha, &amp; Varghese, 2016)</td>
<td>WHOQOL-BREF</td>
<td>84</td>
<td></td>
</tr>
<tr>
<td>(Van Rheenen &amp; Rossell, 2014)</td>
<td>QoL.BD</td>
<td>51</td>
<td>BD I (n = 39) &amp; BD II (n = 12)</td>
</tr>
</tbody>
</table>
### Summary of studies investigating the impact of psychoeducation on QoL in BD

<table>
<thead>
<tr>
<th>Study</th>
<th>QoL Instrument</th>
<th>BD Sample</th>
<th>Intervention</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Cardoso et al., 2014)</td>
<td>SF-36</td>
<td>$N = 61$ young people (aged 18-29)</td>
<td>Details: Participants were randomized to six week of one hour adjunctive clinician-led individual psychoeducation ($n = 32$) or TAU ($n = 29$).</td>
<td>Participants in the psychoeducation group significantly improved in Vitality, Physical Functioning, Social Functioning, Mental Health and Role Limitations (Emotional) immediately post-intervention. These improvements remained at six month follow-up, however Role Limitations (Physical) worsened at this time point. There was no difference between QoL improvements immediately post-intervention or at six-month follow-up between the intervention and TAU group.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
<td>Assessments: Post intervention and six-month follow-up.</td>
<td></td>
</tr>
<tr>
<td>(Castle et al., 2007)</td>
<td>WHOQOL-BREF</td>
<td>$N = 18$ BD subtypes: BD I &amp; II</td>
<td>Details: Participants were randomly assigned to 12 weeks of one and half hour adjunctive, group-based clinician-led psychoeducation (with three monthly booster sessions; $n = 9$) or TAU plus weekly phone calls ($n = 9$).</td>
<td>There was an interaction between treatment and change on the Social subscale, such that the intervention group demonstrated significant improvement while the TAU group scores remained close to baseline.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Diagnosis: DSM-IV</td>
<td>Assessments: Six-month follow-up.</td>
<td></td>
</tr>
<tr>
<td>Study Reference</td>
<td>WHOQOL-BREF</td>
<td>N</td>
<td>Diagnosis</td>
<td>BD Type</td>
</tr>
<tr>
<td>-----------------</td>
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<td>-----------</td>
<td>---------</td>
</tr>
<tr>
<td>(De Barros et al., 2013)</td>
<td>WHOQOL-BREF</td>
<td>55</td>
<td>DSM-IV-TR</td>
<td>BD I &amp; II</td>
</tr>
<tr>
<td>(Doğan &amp; Sabanciogullari, 2003)</td>
<td>WHOQOL-BREF</td>
<td>26</td>
<td>DSM-IV</td>
<td></td>
</tr>
<tr>
<td>(Javadpour et al., 2013)</td>
<td>WHOQOL-BREF</td>
<td>108</td>
<td>Derived from hospital records.</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>QoL Instrument</td>
<td>BD Sample</td>
<td>Intervention</td>
<td>Findings</td>
</tr>
<tr>
<td>------------------------------</td>
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<td>--------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>(Lauder et al., 2014)</td>
<td>Global QoL</td>
<td>$N = 156$</td>
<td>Details: Participants were randomized to receive either Mood Swings (MS; $n = 59$) or Mood Swings Plus (MS-Plus; $n = 71$). Both interventions consisted of five fortnightly online 30-40 minute psychoeducation modules, with booster modules at 3, 6 and 12 months, as well as access to moderated small group ($n = 6$) online participant discussion boards. MS-Plus contains additional online interactive cognitive behavioural therapy based tools.</td>
<td>There were no between-group differences in Global QoL at 3, 6, or 12 months. Both MS and MS-Plus demonstrated significant improvements from baseline; for MS-Plus differences emerged at 3 months and persisted at 6, but were not evident at 12 months. By contrast, MS showed improved QoL from baseline at the 12 month assessment only.</td>
</tr>
<tr>
<td>(Michalak, Yatham, Wan, &amp; Lam, 2005)</td>
<td>Q-LES-Q</td>
<td>$N = 57$</td>
<td>Details: Participants had participated in eight weekly one and half hour sessions of clinician-led group psychoeducation. Data was obtained via retrospective chart review of results.</td>
<td>Significant improvement from baseline was observed in the Physical Health and General Activities domains, as well as the Satisfaction with Medication and Overall Life Satisfaction items.</td>
</tr>
</tbody>
</table>

BD Sample: BD Type: BD I & II Diagnosis: DSM-IV-TR

Assessments: Assessments were completed post intervention (3 months) and at 6 and 12 month follow-ups.

BD Sample: BD Type: BD I or II Diagnosis: Derived from hospital records.

Mood state: Euthymia or mild mood symptoms
<table>
<thead>
<tr>
<th>(Smith et al., 2011) WHOQOL-BREF</th>
<th>N = 50</th>
<th>BD subtypes: BD I (n = 43), II (n = 6) &amp; NOS (n = 1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis: DSM-IV</td>
<td></td>
<td>Details: Participants were randomised to either eight fortnightly online adjunctive psychoeducation modules (Beating Bipolar) plus access to an online moderated participant discussion forum (n = 24) or TAU (n = 26).</td>
</tr>
<tr>
<td>Mood State: Euthymia</td>
<td></td>
<td>Assessment: Outcome was assessed six-months post-intervention.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>There were no significant differences between intervention and TAU groups in QoL scores on any domain at follow-up.</td>
</tr>
</tbody>
</table>
Table 10.

Summary of qualitative investigations of quality of life (QoL) in bipolar disorder (BD)

<table>
<thead>
<tr>
<th>Study</th>
<th>Sample</th>
<th>Interview</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Crowe et al., 2012)</td>
<td>(N = 21) individuals with BD. Diagnosis: Recorded clinical diagnosis</td>
<td>Individual in-person interviews were conducted by asking a series of open ended-questions on how the diagnosis and experience of BD impacted an individual’s life, relationships, school/work, and sense of self.</td>
<td>Themes identified included: a) response to the symptoms, b) other’s response to the symptoms, and c) feeling out of control.</td>
</tr>
<tr>
<td>(Lim, Nathan, O'Brien-Malone, &amp; Williams, 2004)</td>
<td>(N = 18) individuals with BD-I Diagnosis: Recorded clinical DSM-IV diagnosis</td>
<td>Interviews were conducted via small ((n = 2-4)) in person focus-group discussions. Participants were asked open ended questions on what it was like to have BD, what sort of problems they experienced, and how they managed such issues.</td>
<td>Themes identified included: a) BD patient’s view of themselves, b) BD patient’s view of their lives, c) BD patient’s view of their place in the community, and d) BD patient’s views of the future.</td>
</tr>
<tr>
<td>(Michalak, Yatham, Kolesar, &amp; Lam, 2006)</td>
<td>Individuals with BD ((n = 52)), their caregivers ((n = 5)) and healthcare professionals ((n = 12)). Diagnosis: Self-reported.</td>
<td>Individual interviews lasting between 20 minutes and one and a half hours were conducted in person or via telephone. Participants with BD were asked “What do you need to have good quality of life?” Interviews with caregivers asked respondents to describe what their family member needed for good QoL, and interviews with healthcare providers asked them to describe their experiences with patients with BD.</td>
<td>Themes identified included: a) routine, b) independence, c) stigma and disclosure, d) identity, e) social support, and f) spirituality.</td>
</tr>
<tr>
<td>(Rusner, Carlsson, Brunt, &amp; Nyström, 2010)</td>
<td>(N = 10) individuals with BD Diagnosis: Self-reported. Mood state: Severe symptoms of depression or mania excluded</td>
<td>Individual in-person interviews lasting between 50 and 80 minutes were conducted. Participants were asked open-ended questions on the conditions needed for a good life with BD.</td>
<td>Themes identified included: a) turning the course of life, b) protecting oneself from running out of energy, c) being needed, d) being oneself through reliable others, and e) personal landmarks for navigating through life.</td>
</tr>
</tbody>
</table>
APPENDIX F: CHAPTER 5 SUPPLEMENTARY TABLE

Supplementary Table 1.

*Measurement instruments used to assess quality of life (QoL) in the bipolar disorder (BD) literature (listed in order of number of times observed)*

<table>
<thead>
<tr>
<th>Measure Name</th>
<th>Abbreviation</th>
<th>Times Observed</th>
<th>Respondent</th>
<th>Generic or Disorder-Specific</th>
</tr>
</thead>
<tbody>
<tr>
<td>36-Item Short Form Health Survey (Ware and Sherbourne, 1992)</td>
<td>SF-36</td>
<td>67</td>
<td>Self-report</td>
<td>Generic</td>
</tr>
<tr>
<td>The World Health Organization Quality of Life Assessment (Brief) (The WHOQOL Group, 1998a)</td>
<td>WHOQOL-BREF</td>
<td>52</td>
<td>Self-report</td>
<td>Generic</td>
</tr>
<tr>
<td>Quality of Life Enjoyment and Satisfaction Questionnaire (Endicott et al., 1993)</td>
<td>Q-LES-Q</td>
<td>39</td>
<td>Self-report</td>
<td>Generic</td>
</tr>
<tr>
<td>12-Item Short Form Health Survey (Ware et al., 1996)</td>
<td>SF-12</td>
<td>22</td>
<td>Self-report</td>
<td>Generic</td>
</tr>
</tbody>
</table>
Supplementary Table 1. (cont)

<table>
<thead>
<tr>
<th>Measure Name</th>
<th>Abbreviation</th>
<th>Times Observed</th>
<th>Respondent</th>
<th>Generic or Disorder-Specific</th>
</tr>
</thead>
<tbody>
<tr>
<td>EuroQoL Five Dimensions (Balestroni and Berolotti, 2012)</td>
<td>EQ-5D</td>
<td>21</td>
<td>Self-report</td>
<td>Generic</td>
</tr>
<tr>
<td>Quality of Life Enjoyment and Satisfaction Questionnaire (Short Form; Endicott et al., 1993)</td>
<td>Q-LES-Q SF</td>
<td>13</td>
<td>Self-report</td>
<td>Generic</td>
</tr>
<tr>
<td>EuroQoL Five Dimensions Visual Analogue Scale (Balestroni and Berolotti, 2012)</td>
<td>EQ-5D VAS</td>
<td>10</td>
<td>Self-report</td>
<td>Generic</td>
</tr>
<tr>
<td>Quality of Life Scale (Heinrichs et al., 1984)</td>
<td>QLS</td>
<td>7</td>
<td>Clinician-rated</td>
<td>Schizophrenia-specific</td>
</tr>
<tr>
<td>The Range of Impaired Functioning Tool (Leon et al., 1999)</td>
<td>Life-RIFT</td>
<td>6</td>
<td>Clinician-rated</td>
<td>Affective disorders-specific</td>
</tr>
</tbody>
</table>

290
<table>
<thead>
<tr>
<th>Instrument</th>
<th>Abbreviation</th>
<th>Questions</th>
<th>Administration</th>
<th>Specificity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality of Life Interview (Lehman, 1988)</td>
<td>QoLI</td>
<td>5</td>
<td>Self-reported</td>
<td>Severe, chronic mentally illness-specific</td>
</tr>
<tr>
<td>Questionnaire for Measuring Health-Related Quality of Life in Children</td>
<td>KINDL-R</td>
<td>4</td>
<td>Self-report or parent</td>
<td>Child/adolescent specific (ages 4-17)</td>
</tr>
<tr>
<td>and Adolescents-Revised (Ravens-Sieberer, 2001)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Streamlined Longitudinal Interview Clinical Evaluation from the</td>
<td>SLICE/LIFE</td>
<td>4</td>
<td>Clinician-rated</td>
<td>Psychiatric disorders-specific</td>
</tr>
<tr>
<td>Longitudinal Interval Follow-up Evaluation (Keller et al., 1987)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-Item Short Form Health Survey (Wells et al., 1989)</td>
<td>SF-20</td>
<td>4</td>
<td>Self-Report</td>
<td>Generic</td>
</tr>
<tr>
<td>Quality of Life in Bipolar Disorder Scale (Michalak and Murray, 2010)</td>
<td>QoL.BD</td>
<td>4</td>
<td>Self-report</td>
<td>BD-specific</td>
</tr>
<tr>
<td>Mental Health Index</td>
<td>MHI-17</td>
<td>4</td>
<td>Self-report</td>
<td>Generic</td>
</tr>
<tr>
<td>Measure Name</td>
<td>Abbreviation</td>
<td>Times Observed</td>
<td>Respondent</td>
<td>Generic or Disorder-Specific</td>
</tr>
<tr>
<td>-----------------------------------------------------------------------------</td>
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<td>----------------------------</td>
<td>------------------------------</td>
</tr>
<tr>
<td>Quality of Well-Being Scale (Kaplan et al., 1984)</td>
<td>QWB</td>
<td>3</td>
<td>Clinician-rated, weighted by preference ratings (social judgement of each possible score)</td>
<td>Generic</td>
</tr>
<tr>
<td>Brief Quality of Life in Bipolar Disorder Scale (Michalak and Murray, 2010)</td>
<td>BQoL.BD</td>
<td>3</td>
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<tr>
<td>Instrument</td>
<td>Abbreviation</td>
<td>Form</td>
<td>Reporting</td>
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<td>--------------</td>
<td>------</td>
<td>-----------</td>
<td>-------------------------------</td>
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<tr>
<td>Quality of Life Scale (Burckhardt et al., 1989)</td>
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<td>Child Health Questionnaire Parental Form 50 (Landgraf et al., 1999)</td>
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<td>Quality of Life Index (Ferrans and Powers, 1985)</td>
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Supplementary Table 1. (cont)

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<th>Measure Name</th>
<th>Measure Name</th>
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<th>Generic or Disorder-Specific</th>
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<td>Respondent</td>
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<td>Satisfaction With Life Scale (Diener et al., 1985)</td>
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<td>(Ritsner et al., 2005)</td>
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<td>(Weissman, 1999)</td>
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<td>Medical Outcomes Questionnaire</td>
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<tr>
<td>(Wells et al., 1989)</td>
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<td>Tolerability and Quality of Life Questionnaire</td>
<td>TOOL</td>
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<td>Self-report</td>
<td>Patients treated with antipsychotic medication-specific</td>
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<td>(DiBonaventura et al., 2012)</td>
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<td>Quality of Life Self-Assessment</td>
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<td>(Brownell, 2000)</td>
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Supplementary Table 1. (cont)

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<th>Measure Name</th>
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<th>Respondent</th>
<th>Generic or Disorder-Specific</th>
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APPENDIX G: Chapter 6 Supplementary Tables

Supplementary Table 1.

*Unconditional growth model results for depression (MADRS) and mania (YMRS)*

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<td>2.34**</td>
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<td>Linear slope</td>
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<td>-.03**</td>
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<tr>
<td>Variance</td>
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<tr>
<td>Within individuals</td>
<td>37.95**</td>
<td>7.90**</td>
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<td>Between individuals (intercept)</td>
<td>24.10**</td>
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<td>Between individuals (slope)</td>
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*Note: *p < .05, **p < .001

b Parameter was not calculated
Supplementary Table 2.

*Growth model results for depression (MADRS) and mania (YMRS) with Level 2 predictors (mean-centred age, sex, and BD diagnosis)*

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<tr>
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<tr>
<td>Linear slope</td>
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<td>-.09</td>
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<tr>
<td>BD-I</td>
<td>-4.5 (p = .05)</td>
<td>-1.08</td>
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<tr>
<td>BD-II</td>
<td>-1.46</td>
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<tr>
<td>BD-NOS</td>
<td>0(^b)</td>
<td>0(^b)</td>
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<tr>
<td>Age</td>
<td>.02</td>
<td>-.0001</td>
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<tr>
<td>Sex (male)</td>
<td>-3.01*</td>
<td>.16</td>
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<tr>
<td>Interaction (slope) effects</td>
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<tr>
<td>BD-I</td>
<td>.19</td>
<td>.07</td>
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<tr>
<td>BD-II</td>
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<td>.07</td>
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<tr>
<td>BD-NOS</td>
<td>0(^b)</td>
<td>0(^b)</td>
</tr>
<tr>
<td>Age</td>
<td>.0003</td>
<td>-.001</td>
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<tr>
<td>Sex (male)</td>
<td>.09*</td>
<td>-.002</td>
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<td>Variance</td>
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<tr>
<td>Within person</td>
<td>36.98**</td>
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<td>Between-person (intercept)</td>
<td>18.76**</td>
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*Note:  *p < .05, **p < .001

\(^b\) Parameter was not calculated, \(\theta^b\) Parameter is set to zero because it is re
Supplementary Table 3.

*Growth models for SF-36 subscales*

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<th>General Health</th>
<th>Vitality</th>
<th>Social Functioning</th>
<th>Role Limitations (Emotional)</th>
<th>Mental Health</th>
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<tr>
<td>Linear Slope</td>
<td>-.03</td>
<td>.13</td>
<td>.02</td>
<td>.11*</td>
<td>.26**</td>
<td>.68**</td>
<td>1.01**</td>
<td>.48**</td>
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<td>Quadratic Slope</td>
<td><em>b</em></td>
<td><em>b</em></td>
<td><em>b</em></td>
<td><em>b</em></td>
<td>-.008*</td>
<td>-.01*</td>
<td>-.007*</td>
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<tr>
<td>Variance (Intercept)</td>
<td>346.13**</td>
<td>794.78**</td>
<td>348.48**</td>
<td>374.61**</td>
<td>199.69**</td>
<td>411.52**</td>
<td>725.28**</td>
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<tr>
<td>Variance (Slope)</td>
<td><em>b</em></td>
<td><em>b</em></td>
<td><em>b</em></td>
<td>.08*</td>
<td>.12*</td>
<td>.09</td>
<td>.25*</td>
<td>.08*</td>
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*Note:*  *p < .05, **p < .001

*b* Parameter was not estimated