

## Bipolar disorder and quality of life: A patient-centered perspective

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### Abstract

**Objectives:** Several quantitative studies have now examined the relationship between quality of life (QoL) and bipolar disorder (BD) and have generally indicated that QoL is markedly impaired in patients with BD. However, little qualitative research has been conducted to better describe patients' own experiences of how BD impacts upon life quality. We report here on a series of in-depth qualitative interviews we conducted as part of the item generation phase for a disease-specific scale to assess QoL in BD. **Methods:** We conducted 52 interviews with people with BD (n = 35), their caregivers (n = 5) and healthcare professionals (n = 12) identified by both convenience and purposive sampling. Clinical characteristics of the affected sample ranged widely between individuals who had been clinically stable for several years through to inpatients who were recovering from a severe episode of depression or mania. Interviews were tape recorded, transcribed verbatim and analyzed thematically. **Results:** Although several interwoven themes emerged from the data, we chose to focus on 6 for the purposes of this paper: routine, independence, stigma and disclosure, identity, social support and spirituality. When asked to prioritize the areas they thought were most important in determining QoL, the majority of participants ranked social support as most important, followed by mental health. **Conclusions:** Findings indicate that there is a complex, multifaceted relationship between BD and QoL. Most of the affected individuals we interviewed reported that BD had a profoundly negative effect upon their life quality, particularly in the areas of education, vocation, financial functioning, and social and intimate relationships. However, some people also reported that having BD opened up new doors of opportunity.

**Key words:** Bipolar disorder (BD), Quality of life (QoL), Qualitative

### Introduction

Patient outcome in bipolar disorder (BD), formerly known as manic-depression, has traditionally been determined by the assessment of objectively measured clinical information, such as rates of relapse, hospitalization, or degree of symptom reduction. However, many treatment studies are now including objective *and* subjective measures of well-being, with one recent area of research focusing upon patients' perceptions of their quality of life (QoL). Quality of life is a broad and potentially complex concept, but essentially refers to an individual's well-being in a spectrum

of life domains, such as occupational, emotional, social and physical functioning. Although a relatively large body of research has addressed the relationship between QoL and unipolar major depressive disorder (MDD) (for example, [1–4]), research into QoL in BD has been slow on the uptake, despite expert opinion that improving functioning and QoL is a key treatment goal in this patient population [5, 6]. Three reviews of this nascent body of literature have now been performed [7–9], all which have concluded that QoL is markedly impaired in patients with BD, even in comparison to patients with chronic medical conditions or other severe, enduring psychiatric

disorders. However, to our knowledge, all of these studies have used quantitative, rather than qualitative, research methods to assess patients' perceptions of their life quality. In a recent literature review, [9] we concluded that an important step forward in this field of research would be made with the development of a disease-specific measure of QoL for BD, and further noted the importance of maximizing the relevance and validity of the scale through thorough consultation with patients, their families and their healthcare providers. We subsequently began to develop such a measure, the Quality of Life in Bipolar Disorder (QoL.BD), and have performed a comprehensive series of qualitative interviews in order to generate the scale's items. This paper reports in more detail on this qualitative dataset, providing an in-depth examination of the views of people with BD, their caregivers and their healthcare teams on the impact of the disorder upon life quality.

### Patients and methods

We used a combination of convenience and purposive sampling to identify potential participants. In the first phase of recruitment we sent a standard letter of invitation to the Canadian Mental Health Association, the Mood Disorders Association and regional mental health teams in British Columbia, Canada. In the United States, we sent the recruitment letter to 95 randomly selected branches of the Depression and Bipolar Support Alliance. The advertisement stated the purpose of the study and asked for people with BD, their caregivers, healthcare providers or advocates to contact us if they would be willing to conduct a qualitative interview about their perceptions of QoL in BD. To be eligible to participate, affected individuals had to be 18 years or older and fluent in English; no limitations were placed on the type of BD they had been diagnosed with (i.e., type I or II, bipolar spectrum disorders were all acceptable). Demographic and diagnostic details were recorded on a standardized report form at the onset of each interview, but no confirmation of diagnosis was made. Affected individuals were also asked to indicate how they felt 'right now' on a visual analogue scale (VAS) ranging from -5 to +5, where -5 represented 'the most depressed or down you have ever felt' and +5

indicated 'the most hypo/manic or high you have ever felt'.

Approximately two-thirds of the participants we interviewed were identified in this manner. Most of this initial sample consisted of outpatients with BD, although a number of representatives from advocacy groups or support groups were also interviewed at this time, as well as several family members of people with BD. In the second stage of recruitment, we used purposive sampling to obtain a more heterogeneous group. Examination of the clinical characteristics of our initial convenience sample indicated that we had interviewed a number of people who were mildly/moderately depressed or functioning relatively well, but few individuals who were severely depressed or hypomanic, or people who were functioning exceptionally well. To rectify this we actively recruited patients with BD from the UBC hospital in and outpatient departments. For these patients, diagnoses of BD had been made on the basis of all available medical information, which included a clinical interview by a board-certified psychiatrist. We focused upon recruiting patients with severe depression or hypomania, including a number of inpatients who were in partial remission from an episode of mania (we did not attempt to interview any patients who were acutely manic). We also interviewed several individuals with BD who appeared to be functioning exceptionally well with the disorder (i.e., had been euthymic for at least 2 years and performing well occupationally or vocationally). At this time we also purposefully recruited a wider range of healthcare professionals (psychiatrists, nurses, occupational therapists, social workers and psychologists) both locally and internationally who had a specific interest in the treatment of BD, or an extensive history of working with this patient population. Several internationally recognised experts in BD research were interviewed, as well as people who worked in healthcare professions and had a diagnosis of BD.

The interviews were conducted both in-person and by telephone, and lasted between 20 min and 1.5 h. The majority (n = 45) were conducted by the first author, with the remainder being performed under supervision by a research assistant (n = 7). The interviews were begun and finished according to a standard script, but were otherwise left

unstructured, as we wished to give participants the freedom to describe their own experiences. At the beginning of the interview, affected individuals were asked the question ‘What do you need to have good quality of life?’ The interviewer then recorded the list of initial topic areas identified by the respondent (for example, social support, occupation, good family relationships). When this initial list was exhausted, participants were asked to describe in more detail whether, in their own experience, their BD had impacted upon each of these areas. Participants often thought of additional areas for discussion as the interview progressed. At the end of the interview, respondents were reminded of their entire list of topic areas and asked to list in rank order the three areas that they thought were most important in determining their QoL. The caregiver interviews followed a similar format, except that we asked respondents to describe the experience of their family member with BD from their own perspective. Interviews with representatives from advocacy groups or healthcare professions were also similar, except that we asked respondents to try to limit their responses to their experiences with patients diagnosed with BD, not other psychiatric conditions. Interviewing was discontinued once no additional information appeared to be forthcoming. All of the interviews were tape recorded, transcribed verbatim and categorized by the first author using standard qualitative research methods [10] which included the following steps:

- (i) the transcripts were initially read through (without coding) in order to gain an overview of the main issues and themes raised by participants
- (ii) the transcripts were read again several times, with all pertinent references to QoL being highlighted and detailed memos being made concerning emerging themes
- (iii) the number of participants describing a particular theme, and the frequency with which themes were mentioned, was recorded, as were instances where opposing viewpoints were apparent
- (iv) emergent themes were selected on the basis of how many participants mentioned them, and how frequently they were mentioned

We decided to perform the analysis manually rather than via computer-assisted qualitative data

analysis software in order to avoid ‘alienation from the data’ [11]. We felt that it was important to develop an intimate knowledge of the data both for the purposes of this qualitative paper and for the development of the QoL.BD. Indeed, through the lengthy process of conducting, transcribing and analyzing the interviews the first author became highly familiar with the dataset and emergent patterns and themes. Informant feedback was used to protect against researcher bias; a draft report on the findings of the study was sent to ten previously interviewed participants, who provided feedback and were re-interviewed to check the validity of the results [12]. The study was approved by the Ethics Committee of the University of British Columbia, and all participants signed consent forms prior to participation.

In total, 52 interviews were conducted, 29 in person and 23 by telephone. Clinical and demographic details for the sample of people affected by BD ( $n=35$ ) are presented in Table 1. For the healthcare professional sample ( $n=13$ ), we interviewed four psychiatrists, four nurses, one social worker, two psychologists and one occupational therapist. For the caregiver sample, we interviewed five individuals, three mothers who spoke on behalf of their sons, one woman who spoke about her brother, and the partner of a man with BD.

## Results

The data presented here is categorized into six main themes: routine, independence, stigma and disclosure, identity, social support and spirituality. There was some cross-over between themes, and there were other themes and sub-themes that emerged that we do not have the space to discuss here. For the purposes of this paper, we chose to discuss themes that were frequently (discussed by at least one third of the sample) brought up by participants, but had not received much attention in the available quantitative bipolar literature. Although many participants commented at some point upon the relationship between side effects of medications and QoL, and upon QoL and work, vocation and education, we decided to report these results separately (for example [13]). Furthermore, we were unable to report in detail here on the relationship between QoL and physical functioning,

**Table 1.** Clinical characteristics of affected sample (n = 35)

Clinical characteristic	N	%
<i>Gender</i>		
Female	23	64
Male	12	36
<i>Age</i>	43 ± 11	Range 21–68
<i>Diagnosis</i>		
Bipolar disorder type I	22	63
Bipolar disorder type II	10	28
Bipolar spectrum	1	3
Missing data	2	6
<i>Age at first episode of hypomania (n = 31)</i>	30 ± 12	Range 6–58
<i>Years with illness (n = 30)</i>	24 ± 11	Range 0.3–43
<i>Number of previous episodes Depression (n = 35)</i>		
0–2	3	9
3–5	5	14
6–10	5	14
Many	21	60
Missing data	1	3
<i>Mania (n = 24)</i>		
0–2	8	33
3–5	6	25
6–10	0	0
Many	9	38
Missing data	1	4
<i>Hypomania (n = 12)</i>		
0–2	2	17
3–5	1	8
6–10	2	17
Many	6	50
Missing data	1	8
<i>Number of hospitalizations</i>		
0	7	20
1–2	14	40
3–5	5	14
6–10	5	14
11–20	2	6
> 20	1	3
Missing data	1	3
<i>Current episode</i>		
No current episode	13	37
Depression	13	37
Mania	4	11
Hypomania	4	11
Mixed	1	3
<i>Visual analogue scale (VAS) score</i>		
+3 to +5	2	6
+1 to +2	7	20
0	9	26
–1 to –2	11	31
–3 to –5	4	11
Missing data	2	6

physical environment, healthcare team, leisure activities or sexuality, although all of these topic areas were discussed in some detail by participants, and will be incorporated into the item generation phase for the QoL.BD.

### **Routine: ‘Order in the chaos’**

Approximately one third of respondents discussed the concept of routine or structure in daily life, although dichotomous viewpoints were evident. Approximately half of this group were of the opinion that routine was an important factor in maintaining mental health. In the words of one person, good QoL was in part determined by:

Having a routine, you know? I think that one reason I went into teaching is because, you know, it starts at 7:30 and it ends about 3:30, 4:30 every day and that works really well for me.

Prior to this, after finishing her undergraduate degree, she was:

determined not to have another episode but I ended up having one anyway about a year ago, because my, my schedule got off, I was working two jobs and, and I would go to bed at 1:00 in the morning one night and 10:00 the next night, and I didn’t have a routine.

Although several respondents reported that they maintained routine via their occupation, other participants found structure in childcare (*Having like a routine where you get up every morning, you have a purpose, luckily my son’s five and a half so I have to get him to school, so I have to get up*) social and leisure activities, spiritual pursuits or even caring for their pets. The importance of physiological routine was also mentioned by several interviewees, in particular, regular sleep, diet (*I mean, not just breakfast, it does make a difference to eat on time, especially if you’re taking medication*) and exercise cycles. In one notable interview, a woman with a history of severe depressive episodes described moving from her family residence into a group home after a 3-month hospitalization. Although being placed in a group home was

associated with significant feelings of loss of respect and dignity, she describes having done *really well under the structure* as the residents were *expected to get up in the morning and go to sleep at night, which was a big thing for me, big change... If anything improved my health and my mood, that was the one main thing.* The same respondent talked about the importance of structure in social contact, where, after finishing a course of study, she went into a *downward spiral after my course finished, simply because I was, I was interacting with people on a daily basis in going there.*

The other half of this sample however, clearly found highly structured environments difficult to cope with. Two of the caregivers for adolescents with BD we interviewed described the problems their children experienced in being able to follow a routine at school. Another participant described that being in a *nine to five, routinized work schedule* was difficult as she did not have *control over my own work days and work times.* Instead, she preferred a work environment that was flexible, where she could *monitor my health and work more when I'm feeling up to it and less when I need to rest or when I'm, you know, having a hard time with whatever.* A PhD student in her 20's reported similarly valuing the flexibility of her academic schedule, stating: *I worry about how my quality of life is going to change once I'm no longer a student and I enter into the workforce and have to be at a place at a certain time every day, and doing something at a certain time every day.* Another participant talked of her need for lack of structure in her leisure activities, describing how she was:

more wary of being in situations where people will notice the difference of my mood from week to week or month to month. And having to explain... why I'm choosing not to be in a situation. Or making commitments, having to be at a certain place at a certain time on an on-going basis. I'm choosing more and more to be in places on a one-off basis.

#### **Independence: 'Or rather, not being independent, but not being dependent'**

Nearly half of the people we interviewed mentioned the concepts of independence, autonomy

or self-sufficiency, with comments typically being centered around three main areas: independence from the family, financial independence and autonomy from the healthcare system. Many participants described their experiences of having to establish, or regain, their feelings of independence within the family. For most respondents, this process occurred in the context of establishing independence from their parents, or, in the words of one psychiatrist, in terms of defining *what is appropriate separation from your parents, vs. listening to your parents' advice, especially when potentially ill.* All of the experts in adolescent BD we interviewed indicated that this was a core issue in younger adults. However, gaining independence from parents was also a central issue for many older respondents with BD. In the words of one woman with BD type I:

there's a sense of control that's been taken away. And I know from my personal perspective I felt I was being taken care of a lot when I was in my 20's... I had a period where I went back and lived with my parents as an adult and I think they felt a responsibility to make sure that I was taken care of. And I'm grateful for it but from the other side of things it also makes it harder to maintain my sense of self.

Another respondent commented of her family *they babied me a lot, and that hurts your self-esteem.* Several participants mentioned that attempts to assert their independence were made more difficult, in their view, by their family's 'over-vigilance' for recurrence of symptoms. One registered nurse described the case of a teenage girl who had been struggling:

to know herself and to know her illness well enough to differentiate between being happy, and silly and giddy, which is normal for a 16-year-old girl, and being hypomanic. And every time she's at home and she gets goofy her mother says 'Are you getting manic?' And that immediately starts a fight.

Other participants, however, reported that their social support network was vital in terms of helping them identify early warning signs of relapse.

Most of the caregivers of people with BD we interviewed expressed concerns about the ability of their relative to establish independence safely, particularly in terms of managing their own medications and finances, although it is worth noting that this small sample of respondents were providing care for people who were severely affected by BD. It also worth noting that issues relating to independence did not pertain solely to parental relationships – several participants also discussed the impact of having a diagnosis of BD upon their feelings of autonomy within their intimate relationships, with one respondent noting that she felt as though she was being *looked after a lot* financially and emotionally, and that she was ... *somewhat handicapped. And that um... my partner is necessary in order for me to function. Not because I want him in my life, but because he needs to be in my life*".

Financial independence was sought from both the family and the from welfare system. One healthcare professional stated that a primary concern for young people with BD was: *obtaining enough money in the future so that they're not a burden to anybody*. In the words of a 47-year-old man who relied upon his family for financial support: *At my age you should be able to be completely self-supporting and not have to look to somebody else. But because of this, I have to look to somebody else and I don't like that feeling very much*. Several participants talked about the effects of being on welfare or long-term disability because of their BD, in particular in relation to financial hardship, feelings of dependency and perceived stigma. According to one woman: *I think that's a big part of what I recognize now as quality of life is feeling I can take care of myself without being heavily dependent on a long-term basis on either the welfare system or my Dad, unless I'm choosing to do so for a specific reason*. Independence or autonomy from the healthcare system was referred to by several people, and was often couched in terms of a desire to be a proactive, respected participant in the healthcare process, to be empowered to *manage my own illness* and not be *dependent on the medical profession*. One advocate who also had a diagnosis of BD, on talking about control in healthcare decisions, described *people having*

*things done to them as opposed to done with. And it... it... you wouldn't see a podiatrist doing that. Or somebody with a back problem having that happen to them*.

### **Stigma and disclosure: 'It's a horrible secret to have to keep'**

Over half of the sample talked about their perceptions of stigma associated with BD, and/or about disclosure of their diagnosis to others. Almost all of these respondents described having experienced marginalization or stereotyping in relation to their BD at some point in their lives, particularly in occupational settings. Several people commented that they felt that there was more stigma associated with being diagnosed with a mood disorder compared to a physical disorder (*I will hide the bipolar more than I hide the brain injury. 'Oh, you hit your head, you have a head injury' – that seems a lot easier for them to hear and for me to say*). Furthermore, three participants were of the opinion that BD was associated with more stigma than unipolar depression. As one 30-year-old woman diagnosed with BD type II put it:

I think they forget about the depressed part and they just... focus on the mania and they don't really recognize what it is but... I guess they just think about what they see on t.v... they just assume ...that you're crazy and you're nuts and you're psycho and you're dangerous. They just assume ...that you're going to hurt other people and you know, the likelihood is that you're going to hurt yourself, if anything.

Several respondents believed that stigma in the workplace had resulted in their being dismissed from positions, demoted, or had had other serious ramifications in terms of their career. In the words of one woman on her return to the workplace:

...other people were off with back injuries, stubbed their big toe, whatever, but when I came back for being on, well you know, I'd say it was depression or whatever, no one wanted to talk about it and I felt further alienated and everything else. So quality of life

would be for me just being accepted for the fact that, yeah, I have, I suffer from depression and I'm okay person, I'm not a bad person, I have a mood disorder and, yeah, my mood might change from time to time, but I'm basically [name] still.

Only a minority of respondents reported that they had not experienced any noticeable stigma in the workplace, or described their employers as being particularly supportive. One woman described her return to work following an episode of mania in the following way:

I think for the first year I sort of sensed that there might be some change in the people I worked with but not really, I think that it was more of an internal perception if anything. You know that first year that you go back to work after having a manic episode you feel that people are watching... I think the difference for me was that many of the people I worked with for 20 some odd years... Plus a lot of the people that I deal with are fairly educated people.

This concept of education affecting levels of stigma was raised by other participants, some of whom (*I find I generally get an alright response... but I associate very much with academics and very educated people*) but not all of whom (*...those people were more understanding than actually the educated people were, which is kind of ironic*) believed that higher education was associated with reduced stigma. Many respondents discussed stigma in the healthcare system. Several made comments similar to that of a woman with BD type I who had been a senior healthcare professional: *Some of the health professionals I have found are the greatest problem.* In contrast, many people also described having exceptional relationships with their psychiatrist or other healthcare worker that were based on respect, dignity and partnership.

Discussion of stigma was usually interwoven with peoples' descriptions of whether and how they disclosed their diagnosis to others. At one extreme, we spoke to participants who had chosen not to disclose their diagnosis to anyone outside of their healthcare team. At the other extreme, some people were very open about their diagnosis, or even de-

scribed going through a process of *telling too many people*. Reasons for choosing not to disclose centered around negative past experiences, usually in terms of people treating the individual differently after hearing that they had a diagnosis of BD. This was exemplified by one woman who said:

If I go into a situation where people don't know that I have a mental illness I have a better chance of being seen as an equal. I have jobs where people sometimes know that I have a mental illness, sometimes don't. If I'm having a bad day then I'm just having a bad day. If people know that I have a mental illness and I'm having a bad day they may think that I'm getting sick again.

Choosing not to divulge had negative consequences for some people *You know, I don't have any new friends and if I do, they're very surface friends and... I feel like I can't share anything and then I feel guilty because you can't be a true friend to somebody and kind of lie to them* but not for others *Now I'm quite comfortable with saying 'Well, I'm the bipolar princess' but ... I'm strategic to when I say it.*

Most participants described a strategy of judicial disclosure, often making complex decisions about when, how and to whom to disclose, particularly in the workplace. For example, one woman noted that *I've done some childcare recently and I won't disclose to them that I have a mental illness.*

#### **Identity: 'my self-esteem's been built up enough where it [the BD] doesn't define me anymore'**

Another recurrent theme related to how a diagnosis of BD can affect a person's subjective feelings about themselves, in particular in relation to self-identity. This was often the case regardless of the life stage the individual was at, although several participants noted that they thought being diagnosed during adolescence, when most teenagers are still *figuring out who they are* could have particular ramifications. One 31-year-old male respondent with a history of severe BD type I with psychosis described the effect of being hospitalized for mania in the following way:

when you end up in the hospital with a full-blown mania and you think that you're a king and you're screaming at the top of your lungs... trying to eat your hospital bed and, and... you don't know how to deal with it or, or how to be. You don't know how to become yourself again. You don't know what happened to you. It's like your identity has been changed. It's like somebody hands you a different driver's license and you're like, 'Well who is this person?'

In the words of another woman:

there's been a loss of identity. You know, if you can imagine if you're 50-years-old, you know, you've lost your career, you're going through the empty nest syndrome, you know, all this stuff, right? And you're trying to figure out what you're going to do with your life, and in depression that terrible despair and hopelessness, and you forget about who you are and what you do, and where to start.

These feelings of identity loss were often tied in with loss of self-esteem, which in the words of one caregiver describing her daughter had been *shot to hell in a handbasket*. For some people, part of restoring their sense of self-worth and identity appeared to be related to a process of accepting their diagnosis: *like, it doesn't all come at once, it's not like this little, just acceptance thing that happens, it, a whole bunch of different things happen at different times like physical acceptance of it, and the spiritual and emotional, and acceptance of the past and all the fears and things that go with it; it's quite a complex process*. For others, it also appeared to be important to realize that their BD represented just one part of them: *I guess in a nutshell it's not letting the illness overshadow and become your life*.

### **Social support 'people who don't try to fix me, they're not judging me, they're just accepting'**

Participants described how BD can affect social relationships in a number of complex ways, both negatively and positively. Many interviewees believed they had lost relationships as a direct

result of their BD, usually friendships or intimate relationships, although some people also talked about irrevocable damage that had occurred to relationships with family members. In the words of one woman: *I found that you just, you can't be honest with people in general unless you really, really, really, really trust them. And even when you do, you lose a lot of friends because they don't understand*. Participants reported that most of the social damage they associated with their BD had occurred during hypomanic or manic episodes, rather than during episodes of depression. For example, in the words of one 21-year-old man with BD type I:

the social aspect would be the acting out behaviour, the grandiosity, and just the self inflation, you know the thinking, you know, saying inappropriate things would make me lose all my friends. And talking too fast, you know, all these things, acting weird, you know, all the odd behaviour. My friends would ditch me of course, and at the end I'd be all alone, and nobody really understood what I was going through so, yeah, in the end I only had like one friend left.

Specifically, participants talked about irritability and inappropriate or volatile behaviour when hypo/manic causing interpersonal problems: *[you] don't interfere with other people as much when you're depressed as you do when you're manic, you're not talking an awful lot, being inappropriate... I think it's a lot easier for people to be around me when I'm depressed than when I'm up*. In addition, several people talked about how others would find their unpredictability or lack of consistency difficult to deal with: *I think I was going up and down very rapidly for quite an extended period of time... I'd go out with people a couple of times and I don't think they'd get the same person more than twice, and I think that would be very disconcerting*. In comparison, a smaller number of participants described forging closer relationships with people, particularly family members, as a consequence of their BD (as one 50-year male said *My relationship with my brother has deepened because he has been willing to put down his life and take me to the hospital...and so there's this sense of trust there*). Intimate relationships were also

described as being profoundly impacted by BD, again both negatively and positively, with some of the negative consequences of the disorder being related to sexual symptoms of BD (such as hypersexuality when hypo/manic or lowered libido when depressed), or side-effects of medication upon sexual functioning.

One sub-theme that emerged revolved around change in social networks. A 21-year-old participant described how his symptoms of BD had influenced his social network as a teenager: *[I was] maybe overly energetic. Although at times... that kind of also gained me a couple of friends that were, that kind of thought that was interesting. It kind of attracted me to a crowd that was like, you know, more the street crowd.* However, several people we interviewed talked about coming to a realization with time that certain types of social networks were not conducive to good mental health, and about their decision to actively make changes in the social groups they associated with. One healthcare professional with extensive experience working with youths with BD reported that *...changing peers – I would have to say the majority of them do make some alterations, and they do stay away from the more questionable crowds.* He also described *one young lady who used to go to church and then sort of drifted away, and then when she got ill, when she started to recover she reestablished a contact with the church and got more involved with the youth of the church and the young people there who seem to be more accepting.*

According to a 44-year-old woman with BD type II:

as I've gotten healthier with my illness and healthier with managing it I've had healthier and healthier friendships... like when I was sick I sort of had like attracts like? You know, when you're messed up you have messed up friends? And then as you get better you have positive people, and people who are doing good things with their life and have positive relations with, respectful relations with their spouses, and don't have addictions, and that kind of thing.

She goes on to describe how her need for social support also changed with time:

Before it was important just to sort of survive, you know, to have people who would phone me, or that I could go places with, or that would get me out of the house or, and then when I was hypomanic, you know, people that I could, just, sort of, they'd put up with all that. But now it's more for happiness, and developing close relationships, and enjoying time together, and love, and support, and it's more kind of normal I guess instead of just always feeling like I'm just on the edge of coping and I sort of need people around.

Finally, other people talked about the importance of support groups in their social network: *in the past 2 years I have joined a support group for people with bipolar, and two of my best friends have bipolar.*

#### **Spirituality: 'It was hard to just have a sort of steady nice relationship with religious and spiritual life'**

Just over one third of the people we interviewed discussed the relationship between BD and spirituality, in particular, their struggle to disentangle 'real' spiritual experience from hyper-religiosity, a symptom of BD, when hypo/manic. As one man put it:

So my dilemma is how do I know when my... transcendence is real, or when is it part of my disease? So I have a tendency to try to avoid transcendence all together, right? Or try to avoid church, or try to avoid, you know, fellowship or whatever you want to call it, because I get confused whether I'm getting, you know, overly emotional due to my disorder or whether this is a normal religious experience, because I can't differentiate the two.

Or, in the words of one Christian woman:

I became very hype-religious and, you know, spent lots of time reading the bible, and singing songs, and praying. And, you know, that's good and it's bad at the same time because, see I felt close to the Lord but it was also a false close... like, you know, you, I mean, like

right now if I spent a lot of time reading the bible and praying I would feel close to the Lord too, but I wouldn't think that God was talking to me 24/7.

One 41-year-old diagnosed with BD type I described her problems expressing her spirituality after an episode of mania *Because anytime you talk about spirituality then you're deemed as having a psychotic episode. And... and that's horrific because now I'm afraid to say anything.* However, it should be noted that hyper-religiosity during mania was not universally viewed as a distorted or unproductive state; one high-functioning euthymic woman reported: *the experiences [when manic] allowed me more insight into spirituality.*

In addition to making the interpretation of spiritual experiences more difficult for some individuals, BD also had an impact upon some people's social involvement in their religious community. For example, *it makes it difficult to maintain a steady relationship in a spiritual community. So, you know, participating and then being depressed and not being there at all, and then being manic and coming back and sort of doing all these kind of slightly embarrassing things and then being sort of mortified.* In comparison, most of the people who talked about the effects of depression upon spirituality reported that their faith (or need for faith) was increased when they were low. For example, *depression makes me lean on my Lord more or when I was depressed religion and spirituality was this, like it sort of held out this promise of God, if, you know, if actually religion and spirituality could do what it was supposed to do then maybe I'd be better. Like there was this kind of dependency?* However, in contrast a man with a severe history of BD type I said *I've gone to church in many different states and I think... I feel accepted by God, no matter where I've been in my life.*

### Results of prioritization exercise

At the end of each interview, we asked all participants to produce a list, in rank order, of the 3 things they considered to be most important in determining their QoL. The frequency results (i.e., number of times each theme was mentioned) of the prioritization exercise are produced in Table 2, which shows that social support, physical health

and mental health (tied), financial health and independence (tied), basic needs and vocation were most frequently cited as being important to having good QoL. Social support was overwhelming (60% of participants) ranked as being the most important contributing factor to good quality of life, with mental health being ranked in second place, followed by financial status, vocation and independence.

### Discussion

Although several quantitative studies have now examined QoL in BD, little qualitative research has been conducted to help elucidate the relationship between this complex psychiatric condition and its impact upon life quality. Existing quantitative research has tended to indicate that QoL is markedly impaired in patients with BD. For example, in a recent large study of health-related quality of life (HRQOL) in patients with bipolar depression, Yatham and colleagues reported on SF-36 scores in patients with BD type I (n = 920) who were either currently depressed, or had experienced a recent episode of depression [14]. SF-36 scores were remarkably low in the role-physical, vitality, social functioning, role-emotional and mental health sub-scales compared to both general population norms and previously reported scores for patients with unipolar depression. Other research has indicated that QoL is also impaired in interepisode or clinically euthymic patients with BD [15–17]. Our exploratory qualitative analysis with patients with BD, their caregivers and healthcare teams provides some support for this body of literature. The majority of the affected individuals we interviewed described how BD had had a profound effect upon their life quality, often having serious and enduring effects on their ability to have good education, meaningful vocation, financial independence and healthy social and intimate relationships. Having said this, we also interviewed a number of people who were functioning exceptionally well despite their diagnosis; a minority of people even espoused the view that their condition had opened up new doors of opportunity for them, for example, in terms of positively changing their career paths or social networks. On the whole, however, even these individuals described having undergone several

years of hardship and adjustment before getting themselves ‘back on track’.

A number of themes emerged from the data, many of which confirmed findings from existing research. For several respondents, establishing routine was an important part of maintaining good QoL. Bipolar disorder, perhaps more than any other psychiatric condition, is characterised by uncertainty and lack of stability (as one expert in BD research put it *there’s uncertainty about relationships, uncertainty about employment, there’s uncertainty about money, and there’s uncertainty about when their next episode of illness might be. So there’s a kind of constant fear that something will go wrong*). Some of the people we interviewed appeared to respond to this pervasive uncertainty by creating as much structure and routine in their environment as possible. Routine in sleep, diet, exercise, work schedules, social contact, spiritual activities and leisure pursuits were cited as being important for good mental health. Other respondents, however, viewed routine as constrictive and unhelpful; these participants valued the ability to retain flexibility in their schedules to respond to fluctuations in their mental state. We were curious to know whether there was a difference in illness severity between these two groups of respondents, but examination of their clinical characteristics (VAS scores, number of previous episodes, current episode) did not reveal any systematic between-group differences. There is quantitative evidence, however, to suggest that stabilizing circadian rhythms in patients with BD can have a positive effect on outcome. For example, one element of Interpersonal and Social Rhythm Therapy (IPSRT) [18, 19] focuses upon stabilizing circadian zeitgebers, such as sleep-wake cycles and social zeitgebers (personal relationships and social demands or tasks that can help entrain biological rhythms) in patients with BD. Although early studies of IPSRT produced equivocal results, [20, 21] more recent reports [22, 23] have indicated that the intervention is associated with reductions in depressive symptomatology and prolonged euthymia in patients with BD.

There were connections between the theme of routine and other themes that emerged from the data, such as spirituality, stigma and disclosure and social support. Three respondents described how they had been ostracized from their spiritual

community as a consequence of their symptoms of BD. Not only did this result in a loss of social support, it also resulted in a loss of social routine in that they were no longer regularly attending religious services. Mitchell et al. (2003) previously examined spiritual beliefs in patients with BD (n = 81), reporting that the majority of their sample held strong religious or spiritual beliefs, and saw a link between their spirituality and management of their disorder [24]. Another respondent described her decision not to participate in structured leisure activities (such as weekly night classes) for fear of having to explain why she was forced to miss some classes, indicating a potential link between the themes of routine, social support,

**Table 2.** Frequency results of prioritization exercise (total count = 92).

QoL priority	N	%
Social support	30	33
Social support broadly	10	11
Family	8	9
Friends	6	7
Intimate relationships	6	7
Physical health	9	10
Physical health broadly	3	3
Medications	3	3
Side effects	1	1
Illness management skills	1	1
Sleep	1	1
Mental health	9	10
Mental health broadly	6	7
Managing stress	2	2
Self esteem	1	1
Finances	8	9
Independence	8	9
Independence broadly	6	7
Independence from healthcare system	1	1
Mobility	1	1
Basic needs	7	8
Basic needs broadly	3	3
Housing	2	2
Physical surroundings	2	2
Vocation	6	6
Employment/career	5	5
Purpose	1	1
Healthcare team	3	3
Education	2	2
Leisure/fun	2	2
Self-motivation/personal goals	2	2
Lack of stigma	2	2
Acceptance of diagnosis	1	1
Routine	2	2
Spirituality	1	1

leisure and stigma. The qualitative data we gathered in this study provided us with some insight into the complex nature of peoples' perceptions of their QoL. Several of the themes we chose to discuss here (for example, stigma and identity) are not frequently examined in relation to QoL; yet, they appear to have a significant impact upon peoples' ability to live their lives to the fullest. Our results highlight the importance of keeping in mind that QoL is often a complicated and multifaceted concept that is probably more than the sum of its parts.

The majority of the people we interviewed also talked at some point about the relationship between social support and QoL. Social support came in a variety of guises. Some people described the importance of their intimate relationships and ties with family members, whilst others referred to broader notions of support, encompassing friends, colleagues at work, their wider community and their pets. Similar terminology was used to define good social support regardless of its source, however, with participants describing needing people who 'understand you and they don't judge you, and accept you for who you are'. In contrast, many participants talked about the negative effects of stigma upon their daily lives. These findings replicate what little quantitative data there is concerning stigma and BD, where people with BD ( $n = 186$ ) in the United Kingdom were shown to have a strong awareness of stigma, and a possible relationship between stigma and self-esteem was indicated [25]. Improving self-esteem and coping with stigma are both incorporated into a cognitive-behavioural therapy (CBT) manual developed by Lam and colleagues [26], as well as other manual-based psychosocial interventions for BD. When asked to prioritize the things they thought were most important in determining QoL in BD, participants overwhelmingly ranked social support in first place, followed by mental health, financial status, vocation and independence. This leads to the question of whether there is a dichotomy between our current primary goal for treatment as clinicians (reduced rates of relapse, or the reduction of symptoms of BD) and patients' primary concerns. Whilst the respondents in this study did report that mental health is an important factor in determining their QoL, they rated their social support networks as being of greater importance.

In a recent review article, Colom and Vieta (6) stated that: *A very important change of paradigm in the treatment of bipolar disorders started a few years ago, when crucial findings on the impact of bipolar disorders on quality of life and social, cognitive and occupational functioning suggested that therapy targets should be changed from symptomatic recovery to functional recovery* [6]. Whilst we second this statement, we would take it one step further to suggest that restoration of QoL (which encompasses more than functional status) should be one future goal for treatment. In order to reach this goal, we need to develop a clearer understanding of what constitutes good QoL in the eyes of people with BD, a better understanding of what their individual goals for treatment are, and to develop valid and reliable scales to assess QoL in BD.

There are several limitations to our study. As with all qualitative research, statistically valid generalizations cannot be made on the basis of the data, nor can causal relationships be established. There was some selection bias in our methodology, although we attempted to interview people from a wide geographic spread across North America, we were unable to interview people who were not English speakers, so our results have little generalizability to other cultures. Also, we interviewed more women than men, so there may be some gender bias in our results. Nevertheless, the data we gathered has provided us with some important insights into the complex ways in which BD can impact upon life quality, or peoples' ability to *love, work and play*.

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