Renegotiating Identities: Experiences of Loss and Recovery for Women With Bipolar Disorder

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Abstract

Along with major changes in mood, people living with bipolar disorder (BD) often experience recurrent hospital admissions, feelings of failure and hopelessness, social stigma, underemployment, and a loss of independence. In this study we explored the experiences of loss, coping, and recovery in a community sample of women living with BD. Ten women living with BD each participated in a semistructured interview. We used the constant comparative method to analyze the data. We identified three themes from the data – identity bound by the diagnostic label, multidimensional effects of the bipolar disorder identity, and strategies for renegotiating identity. For these women, recovery involved an ongoing process of balancing their sick self with their healthy self. The findings contribute to conceptualizations of loss, coping mechanisms for dealing with loss, and the relevance of loss in recovery for people living at the margins with BD.

Keywords

Bipolar disorder (BD) is an affective disorder characterized by fluctuations in mood that fall at extreme ends of the mood spectrum, ranging from depression to mania (American Psychiatric Association [APA], 2013). Several subtypes of BD are recognized – bipolar I disorder, bipolar II disorder, cyclothymic disorder, substance/medication-induced bipolar and related disorder, bipolar and related disorder because of another medical condition, other specified bipolar and related disorder, and unspecified bipolar and related disorder (APA, 2013). BD is the 7th leading cause of total healthy life years lost because of disability (World Health Organization [WHO], 2008). It affects 2.4% of adults in a lifetime (Merikangas et al., 2011), with diagnosis most common between the ages of 18 and 24 years (Mitchell, Slade, & Andrews, 2004). BD is associated with higher rates of unemployment, substance use, anxiety disorders, and suicide (Mitchell et al., 2004; WHO, 2008).

Loss in the Context of Mental Illness

While historically, loss has been conceptualized as an emotional reaction to grief following the death of a person with whom attachment bonds are shared, contemporary definitions of loss include physical (e.g., destruction of a home in a natural disaster) and internal losses (e.g., reduced self-esteem; Harvey, 2001). Despite this, loss as experienced by people with mental illness has received scant research attention. More is known about the loss experienced by family members of an adult or child with a mental illness because research has predominantly focused on caregivers' perspectives (Stein, Dworsky, Phillips, & Hunt, 2005). Additionally, one comprehensive literature review revealed that, when loss from mental illness was reported in qualitative studies, it was not the main focus of the research (Baker, Procter, & Gibbons, 2009).

Loss is a common theme in recent studies of living with schizophrenia, major depression, and psychosis (Borba et al., 2011; Mauritz & van Meijel, 2009; Wittmann et al., 2010). Loss of

reality is prominent and exemplified during psychotic episodes, as well as by inhibited cognitive function, reduced energy, and loneliness. Loss for people living with BD remains underexplored, despite reported feelings of confusion about their sense of self; negative effects of medications on creativity, energy levels, and ability to maintain a healthy weight; and concern about how they were viewed by other people (Inder et al., 2008; Proudfoot et al., 2009). People living with BD also report difficulties maintaining employment and financial status (Michalak, Yatham, Maxwell, Hale, & Lam, 2007; Proudfoot et al., 2009), instability resulting from major changes in mood and recurrent hospital admissions, feelings of failure and hopelessness, and reductions in control and independence (Lim, Nathan, O'Brien-Malone, & Williams, 2004).

Coping with Mental Illness

Coping strategies facilitate the adjustment process following adverse events, such as major loss (Davidson, Sells, Songster, & O'Connell, 2005; Harvey, 2001). Strategies that aim to assist individuals with the practicalities of a situation are referred to as problem-focused coping (Lazarus & Folkman, 1984). Problem-focused strategies for mental illness include medication adherence, identification of triggers and warning signs of an episode, adoption of new lifestyles to accommodate the illness, and utilizing professional help (Beanlands, McCay, & Landeen, 2006; Mauritz & van Meijel, 2009; Proudfoot et al., 2009). One study of 100 adults with BD identified coping strategies, which included being mindful of limitations following illness onset, understanding personal triggers to mood episodes, identifying and responding to early warning signs, and managing sleep patterns and stress levels (Russell & Browne, 2005). The acquisition of practical skills to manage BD was linked to the participants' ability to cope and is consistent with other research (e.g., Beanlands et al., 2006; Davidson et al., 2005; Proudfoot et al., 2009).

Emotion-focused coping strategies lessen the psychological and emotional impact of a stressor (Lazarus & Folkman, 1984). These strategies include acceptance of the illness (Beanlands et al., 2006; Inder et al., 2008; Mauritz & van Meijel, 2009; Proudfoot et al., 2009; Russell & Browne, 2005) and finding meaning in the illness, such as having hope for a brighter future, being optimistic about psychosis remission, engaging in new activities, and creating new life goals (Harvey, 2001; Macias & Rodican, 1997; Mauritz & van Meijel, 2009; Michalak et al., 2007). These findings support the notion that people who accept their illness are better equipped to manage their symptoms (Proudfoot et al., 2009).

Mental Illness and Recovery

Recovery from mental illness involves a process of moving from experiencing denial, despair, and anguish to rebuilding hope, feeling motivation, and taking responsibility for one's actions (Baxter & Diehl, 1998). Traditionally, recovery was defined as reverting to former functioning. In this approach, the likelihood of recovery for people with a mental illness was considered low (Corrigan & Ralph, 2005). However, recent years have seen a paradigm shift toward defining recovery as a personal process involving the ability to pursue life goals and aspirations regardless of the presence of symptoms (Corrigan & Ralph, 2005; Repper & Perkins, 2012). Studies support the notion that recovery, including from BD, is facilitated by the development of an identity other than as an ill person (Proudfoot et al., 2009).

There is a strong emphasis on the importance of grief work when recovering from mental illness (e.g., Hochman, Fritz, & Lewine, 2005; Wittmann & Keshavan, 2007; Wittmann et al., 2010). Following Freud's (1917/1957) construction of grief as a process to be worked through, grief work refers to the notion of expressing the pain of grief and moving on from the loss. This notion has been applied to loss associated with mental illness (Wittmann & Keshavan, 2007), but

this application is limited because living with mental illness is not the same as bereavement. Furthermore, stage/phase/task theories of grief, underscored by the grief work hypothesis, have been subjected to robust theoretical and empirical critiques for lacking empirical evidence and cultural transferability (Breen & O'Connor, 2007).

Study Rationale

People with BD often lead full lives if the disorder is managed, but might also experience a series of losses because of the effects of the disorder on their lives. Personal loss can have a pervasive effect in someone's life (Baker et al., 2009), yet the relationships between loss, coping, and recovery for people with a mental illness, including BD, remains unclear. To address these gaps, we explored the experiences of loss, coping, and recovery in a community sample of people living with BD. We asked (a) what is the nature, scope, and consequences of losses experienced because of BD, (b) what are the coping mechanisms or strategies of people with BD when dealing with these losses, and (c) how is the concept of loss relevant to the recovery of people affected by BD.

Methods

Participants

We used theoretical sampling to access information-rich cases (Bailey, 2007). We recruited adults living in the community (not in hospitals or psychiatric care) with a diagnosis of any type of BD, who were undergoing therapeutic treatment, were taking medication (if indicated), had consent from their treating health professional to participate, and had the ability and willingness to consent as determined by screening measures. The latter criterion follows from studies in which participants with BD were screened for symptoms of depression and mania (Inder et al., 2008; Lim et al., 2004; Proudfoot et al., 2009).

Community mental health organizations, private psychologists, community newspapers, and local radio advertised the study. Additionally, the first author (a clinical psychologist registrar) delivered presentations about the study to BD support groups and invited participation. Data analysis was concurrent with data collection and sampling ceased when repetition and linking of categories (also called theoretical saturation) became apparent by interviews eight and nine (Strauss & Corbin, 1998). Initially 14 participants were recruited; however, one withdrew before the interview because of an unexpected injury, one did not meet the inclusion criteria (severe depression range; see Materials), and one participant's interview was excluded from analysis because of the presence of mania symptoms, despite the use of the mania screening instrument (see below). Additionally, despite our attempts to recruit a broad sample, only one man was recruited so we decided to exclude his interview from the analysis.

The final sample comprised 10 Australian women ranging in age from 29 to 68 years ($M = 50.00$, $SD = 15.33$). Seven were diagnosed with bipolar I disorder, two with bipolar II disorder, and one with cyclothymia. The time since diagnosis ranged from 3 to 22 years ($M = 10.10$, $SD = 5.53$). The number of hospitalizations ranged from 0 to 10 ($M = 2.30$, $SD = 2.94$). Seven were recruited from community organizations, and one each from a private psychologist, an advertisement, and the snowballing technique. The women had a high education level, including six with a university degree. At the time of the interview four were married, and two each were separated/divorced, in a relationship, and single. Four lived with a spouse, three lived alone, two with a housemate, and one with extended family. Three each were retired, unemployed, or employed on a part-time basis, and one worked full-time.

Participant Screening

The first author screened potential participants for current manic and depressive symptoms. The Altman Self-Rating Mania Scale (ASRM) comprises five items and is used to identify the presence of mania symptoms within the previous 2 weeks (Altman, Hedeker, Peterson, & Davis, 1997). Symptoms are rated on a 5-point scale (0 = not present and 4 = severely present). Users of the ASRM report very good test-retest reliability (.86) with BD samples and congruence with diagnostic tools (e.g., Clinician-Administered Rating Scale for Mania, the Young Mania Self Rating Scale; Altman et al., 1997). Additionally, the use of the ASRM is not based on prior knowledge of the participants' symptoms and thus was the optimal measure in our research. Scores range from 0-20; a cut-off score of 6 or greater indicates the presence of mania. Mania is known to impair judgment and compromises the credibility of responses (Altman et al., 1997), and as a result we planned to exclude any participants scoring 6 or more on this measure. The mean ASRM score for this sample was 2.70 (SD = 1.56) and no participant scored 6 or more.

We used the Beck Depression Inventory (BDI-II) to assess each participant's severity of depressive symptoms within the previous 2 weeks (Beck, Steer, & Brown, 1996). The BDI-II comprises 21 items; each item is rated on a 4-point scale (0 = symptom not present and 3 = symptom severely present). A score of 0-13 indicates minimal depression, 14-19 mild depression, 20-28 moderate depression, and 29-63 severe depression. The BDI-II has sound psychometric properties and is compatible with diagnostic nosology (Dozois, Dobson, & Ahnberg, 1998). We decided to screen out participants within the severe depression range. Participants who scored within the mild or moderate range were included but carefully monitored during the interview using the Subjective Units of Distress Scale (SUDS; Wolpe, 1990), which we describe below. One participant scored within the severe range and was not interviewed. Overall, the mean BDI-II score for this sample was 11.70 (SD = 8.68).

The SUDS (Wolpe, 1990) was used throughout each interview to assess participant distress. If a participant appeared uncomfortable or distressed, or described something as difficult, she was asked to rate her distress, ranging from 0-10 (0 = no distress present and 10 = extreme distress). Participants scoring 5 or above were asked if they wished to take a short break or withdraw from the interview; however, most reported scores between 0 and 2 and no one wished to withdraw or take a break.

Interview Schedule

We developed a semistructured interview schedule. We used the Personal Loss from Mental Illness Scale-PLMI as a starting point for generating the questions but the questions were much broader than the PLMI topics (loss of roles and routine, loss of former relationships, loss of former self, and loss of future; Stein et al., 2005) because we also asked about coping, emotions, recovery, and positive experiences. Example questions included: What is your general experience of having bipolar disorder? What strategies do you use to cope? What does the term recovery mean to you? What positive things have you learned about yourself? What advice might you give to someone else with bipolar disorder? Participants were encouraged to provide examples so that the data reflected their experiences. The first author used the guide flexibly to provide some consistency across interviews while allowing each interview to be tailored to each participant, which facilitated the development of rapport. The interviews ranged from 45 to 84 minutes ($M = 68.62$, $SD = 12.90$).

Procedure

The university's Human Research Ethics Committee approved the study. Potential participants received an information letter, consent forms to allow the first author to contact the participants' psychologist/psychiatrist/general practitioner (a condition of the ethics committee ensuring that

participants had access to support, should it be required, following participation in the study), the ASRM, the BDI-II, and a postage-paid envelope. We asked participants to return these forms within a week. The ASRM and BDI-II were scored against the cut-off scores; only participants who scored below the cut-off range were interviewed. We provided support options to the person with an elevated BDI-II score.

Data Collection and Analysis

We sent an information letter describing the study to each participant's health professional and asked if he or she objected to the interview taking place in a private residence. There were no objections from clinicians and most reported they thought participation would be beneficial for the participant. Each interview was scheduled at a venue and time convenient to the participant and first author. Interviews occurred at the university ($n = 4$), the participant's home ($n = 3$), a public library ($n = 2$), and a community hall ($n = 1$), and were digitally recorded and transcribed verbatim. Participants were offered regular breaks and were asked to contact the first author and their health professional if they felt distressed after the interview. Participants were also provided with community mental health emergency contact numbers as an additional support. All recordings were deleted immediately after transcription and all identifying information was excluded from transcripts.

Data were analyzed using the constant comparative method (CCM; Glaser & Strauss, 1967). CCM is suitable with smaller samples to aid the identification and distinction of categories. In using CCM, researchers explored how individuals attach meaning and value to real life experiences by means of constantly comparing the stories of individuals. CCM typically comprises four processes: (a) identifying and comparing incidents of each category, (b)

integrating categories and their conceptual aspects, (c) identifying themes and their boundaries, and d) writing and proposing themes that are integrated and consistent with the data.

We commenced analysis as soon as practicable to explore the categories emerging from each interview and to inform subsequent sampling (Strauss & Corbin, 1998), using NVivo version 9 (QSR International Pty Ltd, 2010). The first author transcribed, read, and re-read each interview to identify the emerging codes on an interview-by-interview basis (Strauss & Corbin, 1998). She then grouped codes to create a category in NVivo, which represented an overall concept. Subsequent interviews were analyzed with previous codes in mind. To augment the credibility of the analysis, the second and third authors (an experienced qualitative researcher and a clinical psychologist, respectively) reviewed several transcripts and the NVivo file; this is an example of analyst triangulation (Patton, 1999). Where necessary we created new codes and collapsed and refined others, which assisted us in integrating categories and their conceptual aspects into themes. The final process comprised writing summaries of major themes, which was aided by the use of memos about emerging codes and illustrated with data extracts.

Findings

The analysis of the interviews indicated that the changes in identity resulting from being diagnosed and living with BD pervaded the data. In particular, three themes emerged from the data. These were identity bound by the diagnostic label, multidimensional effects of the bipolar disorder identity, and strategies for renegotiating identity.

Identity Bound by the Diagnostic Label

In this section, we describe the development of an identity bound by the BD diagnosis. The diagnosis is underpinned by the biomedical model of illness, which positions the medical practitioner as the expert and emphasizes the necessity of professional interventions for disease

(Breen, Wildy, & Saggers, 2011). There are two subthemes – adopting the patient identity and the independent patient.

Adopting the patient identity. Some participants appeared to adopt an identity centered on being a patient, because this aided their understanding of who they were following diagnosis and it provided direction for their treatment and their role in the treatment process. Often this process involved attempts to establish credibility as a person with BD because mental illnesses are "not really acknowledged the same way that physical illness [is] acknowledged." As a result of these experiences, the participants learned to describe themselves predominantly from a biomedical perspective, stating that they had a "disease," and were "ill," "sick," and a "patient." The adoption of the patient identity, also termed engulfment, whereby a person's identity is consumed by the illness and patient roles (Beanlands et al., 2006), facilitated medication adherence. For example, statements like, "If you have got bipolar you will need medication," "I do not see any alternative. . . . I am happy to take my medication" and "Seroquel has been the answer."

Adopting the patient identity resulted in a loss of power, autonomy, and independence. For some, the patient identity mirrored aspects of a parent-child relationship as evidenced by the use of the term "father-figure psychiatrist." As one participant explained, the patient role meant having little control over her treatment and resulted in feelings of powerlessness. Similarly, another participant described the lack of information about her diagnosis and treatment: "I did not really understand what I had; nobody really told me that I had anything really. They gave me pills to take [but] they did not explain what they were for." These experiences demonstrate that although the patient identity might provide hope for the treatment of BD, it can also result in feelings of helplessness and distress.

The independent patient. The participants' attempts to navigate life with BD led to the development of a paradoxical independent patient role, which emerged from the tensions between the passive patient role and the need for self-determination. For example, medication adherence was challenged by some participants because medication took away their "capacity to think properly" and made them feel "muffled." One participant adhered to medication but resisted relinquishing all control. Instead, she described, "The bad side for me would be to lower my standards, lower my expectations of myself, get around with the Seroquel shufflers and just accept myself in that role." Similarly, another participant described being medicated during a hospital stay but resisting actively ingesting the medication: "I said, 'No I am not going to take them, I do not want the medication.' I would say, 'Well here is my arm, you can inject me, but I am not going to swallow it because I do not want it.'"

The Multidimensional Effects of the Bipolar Disorder Identity

The experience of BD cannot be viewed in a vacuum. Instead, it has ripple effects in all domains of life, including on identity. We outline these ripple effects in four subthemes – diminished roles and relationships, operating on little fuel, loss of control, and the exciting and frightening me.

Diminished roles and relationships. All participants described experiences of relationship loss. Four reported divorcing because of the strains that BD put on their marriages. The remaining participants reported that their romantic relationships were affected by ongoing illness. For instance, one participant stated, "Not being able to have an ordinary relationship with my husband was another loss." Four participants described the effect of BD on their parenting abilities. For instance, one participant described the effect of her illness on her relationship with her daughter:

I am not able to be there for her when I have gone to hospital. I cannot really be a mother for her. That is a loss for me because she is very important to me and to not feel that I can be a parent to her [pause] it is difficult.

The participants recognized the effects of BD on their family and social networks. One participant described difficulties in cultivating long-term friendships – "If you make a friendship when you are in a creative period, those friendships see you as a creative person; they do not see you as a dark person who wallows in self-pity, despair, and depression." Another participant stated that she only saw her friends when she was "well." During long depressive episodes, one participant avoided becoming intimately involved with anyone because she did not want to be a "burden." One participant commented on the effect BD had on others: "I always say that I do not suffer from bipolar; it is my family and friends that suffer from it." Two participants reported that their family and friends were "in denial" about the BD diagnosis and chose to ignore it. For example, one participant described her mother saying, "Well it is not my problem, it is your problem. Why should I have to change my life to fit in your situation?"

Relationships were also affected by the way in which the participants were perceived by their relatives and friends. For instance, some participants faced negative comments such as "you are a lunatic" and "you have been in the loony bin," and statements that they "should never be in charge of children," which resulted in loss of social status and credibility. One participant explained, "You have got this big stamp on your forehead that everyone else sees. . . . All this stuff about equality in our society is just a load of rubbish." Collectively, these relationship changes and breakdowns resulted in feeling "hurt," "separated," and "very lonely."

The loss of credibility led to participants concealing their identity as a person with BD. Four participants described having well and sick identities, with their lives organized accordingly. During episodes of depression, one participant would retreat to her bedroom and tell her friends that she was away. Another participant thought that it was better to socialize with her friends when she was not symptomatic, revealing that her friends, "could see well [me] for birthdays and celebrations, but sick [me] would get her own help; she would look after herself."

Operating on little fuel. Participants described their mood swings as "debilitating" to their day-to-day functioning. Employment was considerably affected by mood changes. The participants thought that their medication affected their memory and cognitive functioning in the workplace. For many, not being able to function as they once did made it "terrible," "difficult," and "hard" to perform in the workplace. Consequently, some participants described being forced to take sick leave because they struggled to perform their duties while "operating on very little fuel." Others reported relinquishing their full-time jobs for less secure positions because of needing recurring time away from work. One participant stated, "I went from full-time [work] to part-time. Now I am casual and I am lucky if I do two shifts a week." Similarly, another participant stated, "I have had to leave work and I have been working there for eight years."

Participants also described the effect of BD on their educational opportunities. One participant explained that she "broke down" during her studies because she lacked concentration and focus and another participant thought that she "lacked confidence" to complete her studies. These two participants reported that studying became difficult because they were no longer deriving pleasure or purpose from it. For example, one participant stated, "I do not really care about studying in the depression; it does not mean anything for me anymore. I do not know why I am doing it." A third participant believed that she could not pursue a PhD because she did not

have "the longevity of thought" and "continuity of endeavor" to complete a doctoral course. Consequently, participants felt a sense of failure: "I was a drop-out" and "I did not complete any of the degrees [I started]."

Loss of control. Participants described a "strange takeover" and loss of control resulting from the sporadic and cyclical mood changes of BD and the inability to prevent them. Some participants were unable to control their behaviors, which were often "out of character" and conflicted with their morals. For instance, one participant stated, "I was a person I did not want to be; I did things I would not normally do." The participants also experienced a loss of control over their thoughts and actions, which in some instances was potentially life-threatening. For example, one participant stated, "In mania my emotion flips and changes very quickly. I might [attempt] suicide in the mania or feel suicidal." Another participant thought that she could not be her "usual jolly self" because she feared others would perceive her as being symptomatic of mania. Consequently, she thought she had become more "serious" and "less spontaneous," and she "think[s] twice" about her actions.

Participants also reported a loss of control in instances where their family, friends or work colleagues engaged in symptom surveillance. For example, one participant stated, "I have actually had friends say, 'Are you symptomatic? You are talking a lot; maybe you have got some mania?'" Another participant reported that her work supervisor "crossed the line":

My boss was really worried that I might have been becoming unwell and, unfortunately, she contacted my psychiatrist before I got there. That was such a breach of confidentiality and just triggered a whole lot of stuff for me. . . . My boss had said I was wearing different clothes, so it is this fear of I cannot look different, I cannot wear different things, I cannot have a lot of money or act in certain ways.

Furthermore, this scrutiny and engagement in self-surveillance created self-doubt and reductions in self-efficacy and self-esteem. For instance, one participant reported, "I have felt less trust in myself, I felt I did not have as much confidence in different things that I did." Similarly, another participant reported, "I lack confidence something terrible." A third participant asserted:

It is very difficult, particularly when you have been episodic many times; after a while you begin to doubt yourself and you lose that kind of tenacity and nerve to do things – I am going to go and work here or I am going to do this degree – you know, everyone needs that sort of leap where they say, maybe I cannot but I am going to do it anyway, and then they do it. But I think maybe for a bipolar person that has fallen down so many times, after a while you start to think maybe I am overreaching.

The exciting and frightening me. The participants described experiencing different facets of themselves during mood changes. Depression was a catalyst for negative self-perceptions and included suicidal ideation, withdrawal, loneliness, self-pity, despair, losing face, and embarrassment, and was experienced as "flat-lining," a "growing emptiness," a "dormant time," and "hibernation." Some participants reported feeling frightened by the changes noted in their personality during depressive episodes and became "dramatic," "quieter and serious," and "weak." One participant stated, "I wore black all the time, petticoats, bad eye make-up and walked around looking miserable." Another explained that depressive episodes diminished her being to "nothing." These experiences of depression were predominantly negative and viewed as an inevitable process of participants' illness.

In contrast to episodes of depression, mania tended to be experienced as "creative," "ecstatic," and "adventurous," a time of having "endless energy," and being "on fire." As a result, some participants were reluctant to relinquish mania experiences. However, the participants recognized that manic episodes were also "scary" and "destructive," and involved "seeing things [and] talking to objects." One participant stated, "I think the mania part was that I would stretch myself until I felt like I was hanging onto a windowsill with my fingertips ready to drop any time." Similarly, another participant stated, "It was steadily getting worse and I felt more and more endangered, very kind of paranoid, and very unsafe even to go to sleep in my parents' house." A third participant reported that episodes of mania damaged her self-image when she experienced a "loss of reputation and loss of identifying with how I really wanted to be, which was probably wholesome [with a] good personality."

Strategies for Renegotiating Identity

Our third theme captures the participants' attempts to reclaim their identity in light of their BD diagnosis. The theme comprises four subthemes. These were acceptance of BD as a new reality, reclaiming control through self-help strategies, connecting and identifying with others, and redefining identity in relation to recovery.

Acceptance of BD as a new reality. Participants reported that a way of coping with loss from BD was to "escape" and "get away" from their lives. Some participants described strategies of leaving (literally or figuratively) through alcohol use, prescription drug use, and/or travel. However, the participants also described accepting BD over time. For example, one participant described, "I have got to choose to live in reality. I can live in psychosis LaLa Land and my experiences are very good with mania [laughter], but at some point, you have to go back to the real world." Accepting BD meant "coming to terms with it" and relinquishing what one cannot

control. Furthermore, participants accepted that BD was "forever" and that it "will never go away." Acceptance brought about a "sense of freedom" and self-discovery.

Reclaiming control through self-help strategies. The participants reported being able to "deal" with BD and taking "responsibility" for its management by engaging in self-help strategies. Three participants learned more about BD through reading, cognitive behavior therapy, mindfulness therapy, and other self-help books. The participants spoke of the importance of being aware of symptom triggers. For example, one participant stated, "[If] I have had some sort of stressor or trigger during the day, I need to talk about it – I call that emotional regulation – it is emotional flossing, like flossing your teeth." Others focused on strategies for symptom management, including "relaxation," "sleep," setting "limitations," "exercise," and maintaining a "positive attitude."

Important practical strategies included reconnecting with the activities and hobbies that defined aspects of their identity. For example, some engaged with "craft," "patchwork," "church," and "sing[ing]." However, engaging in these tasks was difficult at times, which is why many thought it was important to persevere. One participant explained:

Overall, [in] dealing with my losses I have always been a very determined, persistent, tenacious person, so even when I was climbing the great mountain of my disease and people said, "You are not going to do this and you are not going to do that or you should not do this," I was thinking, I am going to do whatever it is I want to do!

The overall reward of self-help strategies was an increased sense of self-control and autonomy. For example, one participant stated, "I have control of bipolar, it does not have control of me." Similarly, another participant thought that it was important to "take charge" of

her life to recover from the losses associated with BD. Attempts to gain control were about trying to "stabilize" and "live well" with BD. This achievement was not only "therapeutic," but it gave participants a sense of "hope." Participants thought they had a new "purpose in life" once they had control of their illness.

Connecting and identifying with others. Participants thought that their partners, family, friends, health professionals, and support groups provided "advice" and "safety." For one participant, the support of her husband gave her strength and made her feel "empowered." Participants also commented on the practical and emotional support they received from friends. For example, one participant stated, "They used to come and do the washing for me, bring me homemade bread, and look after the family." One participant was appreciative of how well a friend understood her needs:

I remember [a friend] saying [about me], "Some days [she] wants to talk, other days she just needs to be quiet." That struck me so much. I will never forget that because I wrote [it] down after – she knows when I need to be quiet and she knows when I need to talk. You know, it is such a wonderful friend that can do that.

Eight participants sought out community support groups; six were attending a support group at the time of the interview. These participants thought that support groups filled the void of "loneliness" and aided the "healing process." Support groups provided a lot of laughter, camaraderie and a sense of connection with "like-minded people." One participant explained, "You feel, I am not an oddity; I am just one of many others who are travelling the same road. That feeling that I am not the only one." Two participants were critical of support groups. For example, one participant stated that support groups "tend to stop progression in a sense; you

become institutionalized" and another participant recalled, "I was 23 and I was going to a support group with fairly chronic people with really difficult experiences, so that was not helpful."

Redefining identity in relation to recovery. The development of a new identity from both the former and the post-diagnosis selves was a key aspect for the participants' recovery process. This ongoing process of negotiation resulted in increased self-acceptance. For example, one participant stated, "I have accepted the fact that I am more unusual, that I have a brain that is exceptionally different; I would not say better than anybody else's, I do not think, but it is different." To cope, participants thought it was important to remember, "Bipolar is what I have, it is not who I am." Developing self-acceptance entailed nourishing positive traits developed since diagnosis such as compassion, empathy, persistence, strength, optimism, courage, and tolerance. Six participants described feeling "lucky" to have learned more about themselves. Furthermore, one participant saw her reimagined self as unique:

> I found a poster in a magazine and I stuck it in my wardrobe. There is a girl with a small hump on her back with a little bit of downy hair; she has got long hair and big eyes. The poster reads, "I am not like other girls" . . . and I think that is how I see myself. I feel that I might be even a subtype of the human species basically – not in a bad way – just that I am different. . . . In wanting to be like everyone else I had missed that there was maybe something special about me. In a way, that is something that can be celebrated.

Discussion

In this study we showed that the women participants' identities were considerably influenced by their BD diagnosis and that living with BD has multidimensional effects on relationships,

employment, education, and sense of self. The women employed a combination of strategies to renegotiate or reimagine aspects of their lost selves in light of BD. The women strove to redefine their identity and acknowledged that this new identity might at times be obscured by sporadic and cyclical mood episodes characteristic of BD. Thus, when individuals are symptomatic, their relationships, roles, and functions might be overshadowed by their sick, or spoiled (Goffman, 1963), self. For this reason, the women described coping from loss as a vacillation, a backward and forward process of accommodating facets of the sick identity while simultaneously preserving aspects of the healthy self. The women described the process of balancing the duality of selves (Wisdom, Bruce, Saedi, Weis, & Green, 2008) as never-ending, meaning that recovery had no end-point but was instead an ongoing process.

This study is innovative in its focus on the multidimensional effects of loss resulting from BD and the range of coping strategies adopted by women with BD in renegotiating their identity. Although identity issues have been reported in other studies of mental illness (e.g., Baker et al., 2009; Beanlands et al., 2006; Inder et al., 2008; Lim et al., 2004; Michalak et al., 2007; Proudfoot et al., 2009; Wisdom et al., 2008; Wittmann & Keshavan, 2007), our findings show that loss of identity occurs intermittently and fluctuates because of mood changes in BD. For the women in our study, the patient identity fills the void resulting from a loss of identity following the diagnosis of a mental illness (Macias & Rodican, 1997) but, as reported previously, mood changes tend to result in helplessness and distress (Beanlands et al., 2006) and there might be a reluctance to relinquish mania experiences (Veseth, Binder, Borg, & Davidson, 2012).

The women's reports of changes in, and losses of, relationships are consistent with previous studies on mental illnesses (e.g., Borba et al., 2011; Lim et al., 2004; Mauritz & van

Meijel, 2009; Wittmann et al., 2010) and BD specifically, where sporadic and cyclical moods affect the ability to initiate and sustain friendships (Inder et al., 2008) and employment (Mauritz & van Meijel, 2009; Michalak et al., 2007; Wittmann & Keshavan, 2007). Loss of social credibility and status is an issue commonly reported by people living with BD (Michalak et al., 2007; Proudfoot et al., 2009) and mental illness more generally (Borba et al., 2011; Lim et al., 2004; Mauritz & van Meijel, 2009; Wittmann et al., 2010). Moreover, the women's experiences align with statistics showing that people with BD are more likely to be divorced or separated compared to the general population (Mitchell et al., 2004). The effect of BD on parent-child relationships has also been noted in the literature (Baker et al., 2009; Borba et al., 2011; Wisdom et al., 2008; Wittmann et al., 2010).

The women's strategies for renegotiating their identities in light of BD are aligned with previous research on coping strategies (Lazarus & Folkman, 1984) and the importance of accepting mental illness in recovery (Beanlands et al., 2006; Macias & Rodican, 1997; Mauritz & van Meijel, 2009; Proudfoot et al., 2009; Russell & Browne, 2005). Attempts to reclaim control and autonomy are consistent with a previous study on coping with BD (Russell & Browne, 2005) and with theories of finding meaning following loss (Harvey, 2001). The renegotiation of identity aligns with studies showing that developing an identity, other than as "a patient" or "ill," is important for rehabilitation and recovery (Proudfoot et al., 2009) and allows people with compromised identies to conceal their diagnosis and "pass" (Goffman, 1963). Furthermore, the identification of positive traits such as compassion and persistence is consistent with Sajatovic et al. (2008), who reported that individuals with BD learned to be strong and wise and to enjoy life despite the illness.

Unlike stage/phase/task models of grief following bereavement, the women's adjustment to living with BD was not a linear process. Instead, participants vacillated in their adjustment because of the sudden and unpredictable changes in mood and their experiences of ongoing losses. Such a process is consistent with Stroebe and Schut's (1999) dual process model of bereavement, which highlights the oscillation between loss and restoration orientations. Notions of recovery from mental illness are conflicting; although the predominant focus is on finding meaning and purpose in life and pursuing and attaining self-determined goals (Repper & Perkins, 2012), the idea that recovery is the attainment of a former state of health persists in some sectors of the community (Corrigan & Ralph, 2005). Our findings support the former focus and challenge the latter by presenting recovery as an ever-evolving and unending process, and thus contribute to a synthesis of loss and recovery frameworks in the context of living with BD.

The findings of this study have important implications for improving intervention and treatment plans for people with BD. First, mental health professionals might want to focus their efforts on how people with BD can access support networks during symptomatic periods when they might not want or be able to rely on their social networks for support. Second, incorporating the assessment of loss into clinical practice might open up opportunities for clients to discuss issues of loss (Wittmann et al., 2010) and strategies for reducing the multidimensional effects of BD. As suggested by previous researchers (Mauritz & van Meijel, 2009; Wittmann & Keshavan, 2007; Wittmann et al., 2010), complicated mourning could develop if losses associated with mental illness are not grieved. Third, clinicians should consider ways to work with BD clients who are struggling with their post-diagnosis identity, and, fourth, clinicians may also wish to consider the role of family psychoeducation given the considerable effects of BD on relationships.

The use of a community-based sample to explore the subjective experiences of community residents with BD is a key strength of the study. Nevertheless, the small sample recruited from a relatively large city reduces the transferability of findings across age, class, education, race, gender, and residential density. Only three types of BD were represented in this sample and the losses associated with each type remain obscured. However, the spectrum of BD means that the types are difficult to distinguish, and the distinction, although clinically relevant, is not typically emphasised in research (e.g., Proudfoot et al., 2009). The participants' use of support groups is likely an artifact of our recruitment strategies and responses from people with BD who are socially isolated with little support might differ. Although participants were informed that their data were confidential, participants might have believed that their treating health professional could access their data and this might have caused a social desirability bias in responses.

We propose two recommendations for future research. First, we recommend that issues of loss in light of length of time since diagnosis be explored to identify the existence of a relationship between losses and time. Second, although it is standard practice to screen out participants who are symptomatic (Inder et al., 2008; Lim et al., 2004; Proudfoot et al., 2009), it would be valuable to explore whether issues of loss are more prominent closer to an episode of mania or depression. This might provide more insight into how people with BD immediately cope with the losses associated with a mood episode.

Conclusion

Overall, BD has a significant impact on an individual's sense of identity that is exacerbated by sporadic and cyclical mood changes. As such, it is important for individuals to preserve aspects of themselves while simultaneously accommodating their illness, so that their identity is not

consumed by it. Although recovery is often a long-term, even lifelong process, those who manage to achieve a balanced self-view appear to adapt to and accommodate the day-to-day struggles. It is important to remember that even though BD can result in a range of losses, individuals can also develop new skills, grow personally, and attain a new identity as described by the women in this study.

Authors' Note

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