Introduction

Bipolar disorder (BD) is a disorder of mood in which, over time, a person experiences one or more manic episodes that are usually accompanied by one or more major depressive episodes [1]. A recent systematic review and meta-analysis determined that its worldwide lifetime prevalence is 1.06%-1.56% [2]. It is considered the most expensive behavioral health care diagnosis, costing more than twice as much as depression [3,4]. Its economic burden includes a 39.1% greater hospitalization rate compared to 4.5% for other behavioral health diagnoses, which results in high out-of-pocket, deductible, and medication costs for both insured and uninsured persons [3].

The behaviors resulting from manic and depressive episodes can have negative and lasting consequences for an individual. Long-term studies of persons with BD report that they experience moderate impairment during 19%-23% of months and severe impairment during 7%-9% of months [5]. BD has a significant negative effect on quality of life in the areas of education, work, financial functioning, social support, and intimate relationships [6-8]. Suicidality is a significant burden of the disorder. A comprehensive review indicated that 31.1% of such persons will attempt suicide [9] and 4% to 19% will complete the act [10]. Medication is recognized as a primary intervention for persons with bipolar disorder, but its behavioral consequences suggest a need for psychosocial interventions as well.

Qualitative research is valuable for highlighting the lived experience of persons with bipolar disorder, and as such it can provide useful implications for intervention. The purpose of this study was to identify common themes among persons with bipolar disorder through a meta-synthesis of qualitative studies of their lived experience.

Methodology

Qualitative meta-synthesis is an approach to analyzing data across qualitative studies; a means of bringing the data together to produce a deeper understanding of the phenomenon. The process is rigorous, as the researcher must specify a question and then search for, select, appraise, summarize, and combine the available qualitative studies to address the question. Meta-synthesis goes beyond the systematic review in that it produces a categorical integration of findings with implications for intervention [11]. The purpose of this meta-synthesis was to better understand the lived experience of persons with bipolar disorder through a comprehensive interpretation of available findings. One meta-synthesis of research on bipolar disorder has previously been published, but it only dealt with the experience of symptoms and diagnosis [12]. Nine studies were reviewed in that meta-synthesis, most of which were conducted in Western countries (Australia, the U.K., and the U.S.). The authors identified nine themes, including struggles with identity; loss of control; disruption, uncertainty and instability; negative impact of symptoms across life and the experience of loss; negative view of the self; positive aspects of mania; struggling with the meaning of diagnosis; stigma; and acceptance and hope.

Inclusion criteria and search

Initial inclusion criteria for the present meta-synthesis involved the following parameters: (a) the studies employed qualitative methods; (b) participants were adults diagnosed with bipolar disorder; (c) the studies focused on their lived experience; and (d) the studies were both published and unpublished. Database searches were completed by a doctoral research assistant and two Master of Social Work students, based on search terms and appropriate Boolean operators provided by a reference librarian using the following keywords: qualitative; lived experience of bipolar disorder; personal experience; personal reflection; and phenomenology. Searches were conducted using the Academic Search Complete, PsycInfo, PubMed, and ProQuest databases. Search criteria did not specify a begin date and extended to October 2014. Through this method 1,753 studies were identified.

Meade and Richardson (1997) [13] developed a three-step process for study selection in meta-synthesis, which allows for a narrowing of search...
results based first on the title, then the abstract, and lastly the entire text. After their reviews the research assistants provided the primary investigator with 93 studies they believed fit the inclusion criteria. Studies were excluded if they were narrowly focused on a specific experience, such as a specific culture or treatment modality, or were solely quantitative in nature. Methodological quality was not a criterion for exclusion. Through this process the original list of studies was narrowed to 75. The full texts of the articles were then examined by the research assistants and principal investigator, and 30 were excluded. The researchers then followed Sandelowski and Barroso’s (2006) [14] recommendation to limit the geographic area to studies conducted in the United States. This yielded a total of 12 studies out of the remaining 45, of which six were published in professional journals and six were unpublished dissertations.

Data extraction and analysis

A data extraction table was adapted from Paterson, Thorne, Canam, and Jillings (2001) [15] in order to organize the relevant information on methodologies, participant demographics, and results of each study (Table 1) [16]. Data extraction was completed by the research students and reviewed for accuracy by the principal investigator. The studies were then analyzed using the methodological framework provided by Noblit and Hare (1988) [17] for meta-synthesis. Those authors suggest making lists and tables of important phrases, metaphors, and other key findings, and then comparing the main ideas. The initial themes were formulated by the research students and reviewed by the principal investigator, and an iterative process ensued by which the researchers discussed and reviewed data categories until they arrived at their final themes.

Results

Table 1 provides summaries of the 12 studies for this meta-synthesis. They were conducted between 1995 and 2014 and represent 234 participants, with 146 females and 88 males. A majority of participants identified as Caucasian or European-American, but other demographic information was reported inconsistently among the studies. The following four themes and sub-themes were identified.

The experience of accepting the diagnosis

The process of receiving a diagnosis of bipolar disorder is fraught with emotion, as it requires a person to come to terms with an adjusted view of the self. The first sub-theme of lengthy uncertainty was evident in the process of diagnosis requiring a long period of time, occurring years after symptoms first appeared [18]. For some, the delay was a function of incorrect diagnosis or not feeling “heard” within the medical field. One woman stated, “It basically took me 5 years and eight doctors to get an accurate diagnosis…ridiculous” [19]. A few studies suggested that denial is often present, accompanied by anger and despair over one’s acceptance of the disorder [20,21]. As one participant indicated, “I chose to ignore it for a long time…I knew there was something wrong but, at the same time, I didn’t want to get diagnosed” [22].

Reflecting a second sub-theme of emotional reactions to the diagnosis all participants expressed that they had experienced a range of strong emotions when receiving the diagnosis of bipolar disorder. Depending on their levels of self-awareness and self-motivation, those emotions ran the gamut from negative to positive. A participant in Pollack’s (1995) [20] study referenced the denial he had seen in others with bipolar disorder: “You’re still going to have the ones that are going to throw them [bipolar-related informational pamphlets] out, because they don’t want your lousy information”. Some participants experienced shock and distress, believing the diagnosis meant they were somehow “different” from other, normal people. One study participant recalled thinking her diagnosis meant she was “nuts. Manic-A manic depressive is somebody’s who’s institutionalized…out of control…somebody that has to be locked up” [23]. Diagnosis could also bring relief and greater self-understanding. One person shared, “I was so happy to have somebody assess me and evaluate me and give a name to how I felt” [19]. Another described the diagnosis as putting a “piece into the puzzle” [18], because it finally helped give her behavior a framework for self-understanding. People who had always felt they were different found solace in the diagnosis’ explanation. They judged their past behaviors less harshly and began to question the validity of their negative self-views [22].

Several studies described a third sub-theme, coming to terms with the diagnosis, as a process or journey. Participants indicated that they went through adjustment stages similar to Kubler-Ross’s stages of grief, including denial, anger, and despair [21]. One person recalled going through “several phases of denial” [23]. Another reported, “So there is just a lot of grieving. Grieving is a really good word for it because you grieve for the life you thought you would have’”[19,22] described a process of moving through different diagnosis-related stages, including denying diagnostic information, protecting the pre-diagnosis identity, using diagnostic information to restructure identity, and, eventually, getting on with life.

Several study participants had come to see positive aspects of having bipolar disorder: “I think it is kind of a positive illness to have. I truly believe that in many ways it has made me more insightful” [19]. Individuals mentioned gaining compassion and developing a richer life, deeper sense of spirituality, and desire to help others with the disorder [22]. Many participants expressed optimism about the effects of intervention on their mood, functional level, and stress level [24]. In Sajatovic’s 2009 [25] study, participants shared their hopes that the medications would “reduce symptoms and balance mood”. Others expressed short-term hopes for managing their lives: “I think my future’s looking up. My goal is not to be in the hospital…I have a good job, I have a good manager, I have my own little house…I want to stay positive” [18].

Negative impact on relationships with others

Relationships were often negatively affected by the diagnosis and its related symptoms as seen in the first sub-theme of social withdrawal, which was described as a way to protect others and prevent being a burden to them [19,22,23,26]. As one participant said, “You end up just going off by yourself to protect them [family] and myself and letting it just pass” [19]. In addition to withdrawing for other people’s protection, participants often noticed strong reactions among partners, friends, and family members to their diagnoses, including fear and anxiety [18,25]. As a result, people with bipolar disorder reported having fewer close friends, mainly due to fear about disclosing their condition [18,19]. One young woman shared “I prefer not to [have friends] actually because I just kind of get screwed over” [18].

People with bipolar disorder often must renegotiate their relationships, a second sub-theme. One woman described “being-in-relationship in a new way,” focusing on only the relationships that nurture her [19]. Another woman mentioned having to decrease the time she spent with some friends because they “didn’t know how to act” after her diagnosis [22]. People with bipolar disorder used a variety of coping strategies; some internal and some external, to help them manage the condition.

Internal strategies

Two sub-themes that emerged in this category of internal coping strategies included vigilance over one’s mood and other self-care practices. Goldberg (2007) [23] and Driscoll (2004) [19] observed that participants practice forms of constant self-monitoring of their feelings in order to control the disorder. This vigilance helps them catch early warning signs of mania or depression: “Yes, it’s on my mind constantly. What are my motives?..I’m always doing a check. Am I being too happy?..Am I...you
| Chapman JR (2002) [22] | Purpose: Explore the sources of challenges to identity and how participants dealt with those challenges | Semi-structured, open-ended Interviews. Analysis used grounded theory methodology | N=12  
Sampling: purposive (participants were referred by clinicians)  
Half had a diagnosis of BDI and half had BDII. All were Caucasian or mixed-Caucasian ethnicity. Median age 40, age range 22-62. Males 25%, females 75%, Married 60%, single 40%  
BDI 50%, BDII 50%  
Several themes surrounding the concept of Identity  
1. Challenges to identity  
a. Symptoms as challenges  
b. Timing of symptoms has different implications  
2. Protecting identity  
a. Discounting information  
b. Strategies for protecting identity  
c. Denial, reinterpreting information, ignoring information, preventing others from seeing symptoms, self-medicating  
3. Restructuring identity  
a. Decisionging whether to use information  
b. Using information to restructure identity  
4. Getting on with life  
a. Self-monitoring  
b. Dealing with issues of control  
c. Reevaluating views of the past  
|  |
| Doherty EF and MacGeorge EL (2013) [26] | Purpose: Explore the types of behaviors from support networks young adults with BD perceive as helpful in coping with the disorder. | Semi-structured Interviews Ethnographic evaluation. | N=30  
Sampling: Purposive at first (contacted clinicians), then convenience (posted flyers on campus and in community). Age range was 18-30, Mean age=23, median age=24  
24 women, 6 men. All had a BD diagnosis. No information on ethnicity provided.  
Eleven types of helpful behavior were identified.  
1. Emotional support (especially helpful in depressive states)  
a. Conversational  
b. Reappraisal of situation  
c. Esteem/encouragement  
d. Expressions of love  
2. Everyday support  
a. Counseling  
b. Activities (helpful in depressive states)  
3. Illness-Management Support  
a. Advice (some identified this as impt before mania) and information  
b. Treatment support (anything that helped treatment adherence)  
c. Vigilance support (checking in, monitoring moods) (some identified this as impt before mania)  
d. Educational support (support provider wants to learn more about BD)  
e. Maintenance support (help with managing day-to-day life/everyday tasks)  
|  |
| Driscoll JW (2004) [19]. The experience of women living with bipolar II disorder (doctoral dissertation). University of Connecticut, United States of America. | Purpose: Explore the phenomenon of the experience of women living with Bipolar II. Provide a voice for women, as the qualitative literature was silent during the time of dissertation | Colaizzi’s (1978) phenomenological method is used to investigate. (Qualitative) | 11 women were interviewed, all diagnosed with Bipolar II Disorder.  
Sampling: purposive (referred by therapists)  
Age range 30-61. All Caucasian  
8 married, 3 divorced  
Four themes emerged: melancholy to mayhem at the flick of a switch, dwelling in the maze: the journey toward diagnosis to treatment, emerging in steadiness: regaining control, and cultivating a new self. The study resulted in increasing understanding and awareness of a woman’s experience of living with bipolar II disorder. The results will help with education, practice, and research in women’s healthcare.  
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| Freedberg RP (2011) [18]. Living with bipolar disorder: a qualitative investigation (doctoral dissertation). Western Michigan University, Kalamazoo, Michigan. | Purpose: Gain a better understanding of the lived experiences of adults diagnosed with bipolar and the how they use cognitively, affectively, and spiritually oriented strategies to cope with life stressors and circumstances. | Qualitative Phenomenological method used to analyze interview transcripts. | Eight English speaking adults age 18 years or older and diagnosed with Bipolar Disorder at least one year or longer.  
Mean age=31.4, median age=31  
Sampling: convenience (recruited through a classified ad)  
7 females, 1 male  
6 Caucasian, 1 African Amer., 1 Other  
Four themes emerged: diagnose brings understanding accompanied by irrevocable change, finding effective treatment is an interminable process, bipolar disorder is the third partner in every relationship, caring for oneself is just as important as receiving formal treatment. A wide variety of coping strategies reported placing importance upon assessment and nurturance of client self-care strategies by mental health professionals.  
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| Pollack, L. E. | 1995 | [20] | Purpose: To examine how people with BD strive to go on despite their illness. | N= 90, pooled data from 3 studies Sampling: purposive (referred by clinicians) Referred by clinicians or volunteered at BD treatment centers (academic medical center Mood Disorders clinic, a community mental health clinic, a private hospital or a state hospital. Mean age was 36.5 with 46 participants being male, and 44 female. 66 were Euro-Americans, 14 were African Americans, 10 identified as Other | No gender difference in the experience of stigma, self medicating through drug abuse, or value of lessened irritability and impulsivity because of medications. Sample of women experienced more fear of weight gain because of medications, had higher quality social relationships, and had lower rates of self medicating through alcohol abuse. | "The Lived Experience of Bipolar Disorder: A Systematic Review and Meta-Synthesis" | J Psychiatry Ment Health 1(2): doi http://dx.doi.org/10.16966/2474-7769.102 | "Sci Forschen Open HUB for Scientific Research" |

| Walsh J, Crooks P, Cooke N, Cummings C | 2006 | [49] | Purpose: To examine gender differences related to adherence to treatment for BD. | Five individuals diagnosed with Bipolar Disorder 2 male, 2 female. 1 Multi-cultural, 1 Afr American, 2 Caucasian. Mean age 39.25 Sampling: convenience (recruited from database of neuropsychology research participants) | Kemp BS | Four themes emerged: feeling fear, feeling challenged, feeling balanced, and feelings towards providers. Results provide illumination of why the sample participants adhere, challenges faced, coping strategies to manage the disorder, and desired communication to providers. | "The Lived Experience of Bipolar Disorder: A Systematic Review and Meta-Synthesis" | J Psychiatry Ment Health 1(2): doi http://dx.doi.org/10.16966/2474-7769.102 | "Sci Forschen Open HUB for Scientific Research" |


| Kemp BS | 2010 | [27] | Purpose: To give voice to individuals diagnosed with bipolar disorder who adhere to their medication regime, through the eyes of a provider also living with the disorder. | Kemp BS | [2010] | Kemp BS | [2010] | Living with bipolar disorder: we adhere to our medication (masters thesis). Gonzaga University. Spokane, Washington. Purpose: To give voice to individuals diagnosed with bipolar disorder who adhere to their medication regime, through the eyes of a provider also living with the disorder. | "The Lived Experience of Bipolar Disorder: A Systematic Review and Meta-Synthesis" | J Psychiatry Ment Health 1(2): doi http://dx.doi.org/10.16966/2474-7769.102 | "Sci Forschen Open HUB for Scientific Research" |


know, overreacting?” [23]. Many people with bipolar disorder stressed the importance of self-care with a variety of practices including regular routines, good nutrition, journaling, mood charting [27]; listening to music, meditating, painting, reading, practicing their faith, and napping [18,22]; exercising [19,27] to communicate needs and maintaining healthy boundaries [18]; and remembering the past in order to stay on track with recovery [27].

The utilization of social support

Support from friends, family, and practitioners represented the primary external coping strategy. According to Pollack (1995) [20], “the existence of a support system that encourages positive efforts toward self-management” represents a significant factor “that influence(s) a person’s ability to select useful self-management strategies”. For one participant [27], “family (mom, spouse, cousin) and support group” helped her observe her moods and “kind of know if I’m becoming a little bit manic or if I am getting depressed”. Another (Driscoll 2004) [19] recommended:

- always have a safety net of people who know you, I mean counseling people and doctors who have met you when you’re well and then when it hits the fan you can go back and they see right off that this isn’t the high functioning girl I know.

Doherty’s (2012) [26] study highlighted the importance of the emotional, everyday, and illness-management support offered by family and friends. One participant recognized that his mother “really emphasized that she and the rest of my family love me unconditionally…I have this idea that, like, nobody cares about me…So I think that that’s something that’s helpful to keep hearing that”. Another shared an example of her friend’s support:

- If she starts to notice I’m not slowing down but not as interested in my job or she, for some reason she can tell before I can that I’ve been off my medication for a while. So she’ll be like, ‘You know you need to be on your meds.’

Discussion

This meta-synthesis identified four themes with a variety of sub-themes that cut across the qualitative research and offer personal, nuanced understandings of the experience of living with a diagnosis of bipolar disorder. The dominant theme emerging from the data was the challenge of accepting the diagnosis. This involved a process of struggle to determine if the diagnosis fit and learning more about the disorder over time, with ambivalence being a key characteristic. On one hand, having a diagnosis explained the problems and symptoms the participants faced and reduced...
some of their self-blame, but at the same time acceptance of such a serious diagnosis was a struggle for what it implied about the future. Participants realized that having a bipolar diagnosis was considered a life-long condition. They had to consider whether their goals for the future were realistic given their current capacities. Some were hopeful and retained their previous personal goals.

The struggle to accept the diagnosis seemed to encapsulate the following themes delineated by Russell and Moss (2013) [12]: struggles with identity; loss of control; disruption, uncertainty and instability; the negative impact of symptoms across life and the experience of loss; negative view of self; struggling with the meaning of the diagnosis; and acceptance and hope. Even though there was only slight overlap between these two meta-syntheses (three studies), the present meta-synthesis lends credence to the process of accepting the diagnosis as a difficult challenge that involves many aspects of the self and life situation, and might involve a stage process. Given this finding, practitioners should encourage and help clients to engage in a process of person-situation reflection [28] as a means of gradually accepting this major change in identity.

Included in the sub-theme of coming to terms with the diagnosis was the ambivalence participants felt about medication use. The quantitative literature has established that non-adherence to medication among persons with bipolar disorder is high [29,30]. One systematic review indicated that 20%-60% of clients are intentionally non-adherent during their course of medication therapy [31]. Another systematic review studying the reasons for this behavior included poor insight about the disorder and doubts about the ongoing need for medication, concurrent substance use, and concerns about current or future adverse effects [32]. Barriers to care and the fact that medication does not produce a sufficient response are other explanations for non-adherence [30,33]. The likelihood that persons with bipolar disorder will eventually experience a relapse-ninety percent (90%), according to Truer and Tohen (2010) [5]-means they should be informed that one of the most common reasons for relapse is the discontinuation of an effective medication regimen.

Despite their ambivalence in other areas, participants in this meta-synthesis were adamant about their need to be aware of warning signs and other triggers that may herald a developing mood episode. They talked about making lifestyle changes, including having a routine schedule and getting proper diet and exercise, to help maintain their mood. Social workers could emphasize the development of self-management techniques, taking a strengths-based approach to help clients find what is helpful in terms of self-care and bolstering their efforts to avoid mood swings. Interventions such as psychoeducation [34,35], family-focused, cognitive-behavioral [36,37] and interpersonal therapies have shown to be effective in addressing these concerns by increasing client awareness and understanding of the disorder and the importance of medication compliance, stable social and sleep rhythms, avoidance of heavy substance use, and relapse prevention planning for ongoing stability [38-40].

The theme that coalesced around negative impacts on relationships confirms the importance of interventions that address the burden on relationships experienced by persons with bipolar disorder. The chronicity of the disorder negatively affects family life, leading to less cohesion and organization, greater conflict, lower rates of intact family, and higher rates of parental tension [41,42]. These features, in turn, increase the risk for the client member’s relapse [43]. This finding of the meta-synthesis is consistent with a large longitudinal study in which 89%, 52%, and 61% of caregivers, respectively, reported moderate or high burden in relation to client problem behaviors, role dysfunction, and disruption in household routines [44]. What also emerged in our meta-synthesis, however, was the sub-theme that persons with the disorder withdraw from relationships at times in order to protect others from the interpersonal impact of the mood swings. Apparently, some people with bipolar disorder try to protect their relationships when they think they might act in ways that are detrimental [19,26,45]. Family interventions can help the client and significant others to share their respective relationship concerns and perhaps experience mutual support during the adjustment process.

The desired goal of participants in this meta-synthesis to develop positive social support, and the opportunity to engage in previous activities of social life, is well supported in the quantitative literature. Deficient social support is associated with more mood symptoms and interruptions to circadian rhythms [46]. Persons who are able to maintain a work, social, and family life experience fewer symptoms are able to develop and maintain a higher quality of social functioning [47]. A systematic review of family interventions, including family education along with communication and problem-solving skills development, concludes that the process is effective in reducing relapse rates for persons with bipolar disorder [37].

Study limitations

While this meta-synthesis makes a contribution to the knowledge of the experiences of people with bipolar disorder, it has several limitations. Because it did not set out to consider varying cultural contexts the study only encapsulates the experiences of participants within the United States. Another limitation is the controversial application of qualitative meta-synthesis itself [48]. Interpreting individuals’ experiences with a secondary lens gives concern to issues of varying possible interpretations of the data. The functioning levels of participants could also be a limitation in that, in attempting to solicit responses, only high functioning persons were included. The majority of participants in the meta-synthesis were women and thus the biological component of gender may also have skewed results. For example, [49] reported that women with bipolar disorder had a better quality of social relationships and lower levels of self-medicating through substance abuse than men. Despite these limitations, this meta-synthesis adds to the current knowledge base of the lived experiences of persons diagnosed with bipolar disorder and provides a variety of implications for individual and family intervention.

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