Published in final edited form as:
Int J Soc Psychiatry. 2016 November ; 62(7): 635–644. doi:10.1177/0020764016666572.

Patients' Perceptions of Barriers to Self-Managing Bipolar Disorder: A Qualitative Study

Carol Blixen, PhD [Adjunct Associate Professor of Psychiatry],
Case Western Reserve University and Senior Scholar, Center for Health Care Research and Policy, MetroHealth Medical Center, Cleveland, Ohio

Adam T. Perzynski, PhD [Assistant Professor of Medicine],
Center for Health Care Research and Policy, Case Western Reserve University, MetroHealth Medical Center, Cleveland, Ohio

Ashley Bukach, BS [Data and Regulatory Coordinator],
Department of Psychiatry, Case Western Reserve University, Cleveland, Ohio

Molly Howland, BS, and
School of Medicine, Case Western Reserve University, Cleveland, Ohio

Martha Sajatovic, MD [Professor of Psychiatry]
Neurology and Biostatistics & Epidemiology, Case Western Reserve University School of Medicine and Neurological Institute, University Hospitals Case Medical Center, Cleveland, Ohio

Abstract

Background—Self-management of Bipolar Disorder (BD) is challenging for many individuals**.**

Material—Interviews were used to assess perceived barriers to disease self-management among 21 high-risk patients with BD. Content analysis, with an emphasis on dominant themes, was used to analyze the data.

Results—Three major domains of barriers emerged: Individual barriers (psychological, knowledge, behavioral, and physical health); Family/ Community level barriers (lack of support and resources); and Provider/ Healthcare System (inadequate communication and access to care).

Conclusions—Care approaches providing social and peer support, optimizing communication with providers, and integrating medical and psychiatric care, may improve self-management of BD in this vulnerable population.

Keywords

bipolar disorder; barriers; self-management

Address Correspondence to: Carol Blixen, PhD, Department of Psychiatry, Case Western Reserve University, Cleveland, Ohio. Tel: 1-216-283-4134; cxb28@cwru.edu.

Conflict of Interest: Dr. Sajatovic has research grants from Pfizer, Merck, Janssen, Reuter Foundation, Woodruff Foundation, Reinberger Foundation, National Institute of Health (NIH), and the Centers for Disease Control and Prevention (CDC). Dr. Sajatovic is a consultant to Bracket, Prophase, Otsuka, Pfizer and Sunovion and has received royalties from Springer Press, Johns Hopkins University Press, Oxford Press, UpTo Date, and Lexicomp. None of the other authors declare conflict of interest.

Introduction

Bipolar disorder (BD) is a chronic mental illness associated with reduced quality of life, decreased functioning, high rates of suicide and high financial costs (Murray & Lopez, 1997; Zaretsky et al., 2007). Prevalence in the U.S. may be as high as 3.7% for BD spectrum disorders (American Psychiatric Association, 2002; Hirschfeld et al., 2002). A cornerstone of treatment for individuals with BD is mood stabilizing medications such as lithium, anticonvulsants, and atypical antipsychotic medication (American Psychiatric Association, 2002; Goodwin & Young, 2003; Keck et al, 2004; Yatham et al., 2005); yet roughly half of individuals with BD are non-adherent with medication (Lingham & Scott, 2002; Perlick et al., 2004; Sajatovic et al., 2006, 2007). Concurrent with the use of medications, chronic disease self-management programs (CDSM, can empower patients and improve health outcomes by emphasizing the central role of the individual in managing their mental and physical health while collaborating with health care professionals and systems. (Lorig, 2015; Lorig et al., 2015; Janney et al., 2014). Evidence based skills shown to be effective in BD and amenable to chronic disease self-management include: psychoeducation, monitoring moods, social functioning, sleep hygiene, setting goals and relapse plans, and adopting healthy lifestyle plans (Janney et al., 2014). However, self-management is challenging for many individuals with BD; there are numerous barriers that can impede progress and success.

Few studies have specifically addressed patients' perceptions of barriers to self-management of BD; most have focused on risk factors for poor adherence (Lingham & Scott, 2002; Perlick et al., 2004; Sajatovic et al., 2006, 2007). In this qualitative analysis, perceived barriers to self-management among high-risk patients with BD was assessed as part of a large, on-going U.S. National Institutes of Mental Health (NIMH)-funded, randomized controlled trial (RCT). This RCT is testing a novel customized adherence enhancement (CAE) intervention intended to promote BD medication adherence versus an educational control (EDU) in poorly adherent individuals with BD. Our findings can enrich our understanding of the processes that impact the outcomes of this RCT (Ezzy, 2002), and may help clinicians and researchers integrate the consideration of these factors into effective care delivery practices.

Methods

Sample and Setting

Participants (N=21) from the RCT were recruited at baseline for the present analysis. For qualitative research, this sample size is within the recommended number of 5-25 individuals who have all experienced the same phenomena (Polkinghorne, 1989). Non-adherence was assessed by the Tablets Routine Questionnaire (TRQ), as the percentage of days with missed doses in the past week for each prescribed foundational oral medication for the treatment of bipolar disorder. For individuals who were on one or more foundational medication, an average was calculated in order to gather information on the full bipolar disorder treatment regimen. Higher TRQ scores are a reflection of worse medication adherence (Scott & Pope, 2002). In addition, a sampling grid designed to ensure variability in gender, age, race/ethnicity, and randomization group, was used in the recruitment of the medication non-adherent participants. The study was conducted in the Department of Psychiatry of a Midwestern urban hospital in the U.S., and was approved by the local Institutional Review Board. All participants provided written informed consent.

The mean age of the sample was 47.29 years (SD=11.06), 15 (71.4%) were women, and the mean level of education was 12.10 years (SD=2.31). Only three (14.3%) were married and 18 (85.7%) were disabled or unemployed. Thirteen (61.9%), identified themselves as African-American, 5 (23.8%) as Caucasian, 1 (4.8%) as Hispanic, and 3 (14.3%) as other. Seventeen (81.0%) had Type I BD and 3 (14.3%) had type II BD. The average age of onset was 22.05 (SD=10.31), and the average number of psychiatric hospitalizations was 4.15 (SD=3.47). We have limited data on comorbid physical health conditions for the 21 participants in this qualitative study. This type of information was not collected until approximately six months after the study had started, when many of them had completed their participation. However, co-morbidities reported for the whole sample in the RCT (n=160) revealed the leading conditions to be hypertension 59 (45.7%), arthritis 73 (45.6%), and high cholesterol 39 (38.0%).

Study Design

In this cross-sectional qualitative study, a thematic analytical approach was used to develop a deeper understanding of the perceived barriers to optimal self-management of BD (Strauss, 1987). In this approach researchers move their analysis from a broad reading of the data towards discovering patterns and developing themes.

Qualitative Data Collection and Analysis

Individual face-to-face semi-structured interviews, conducted as part of the baseline assessment in the RCT, were used to collect narrative data on self-management barriers. The goal of using this type of interview was to explore a topic more openly, and to allow interviewees to express their opinions and ideas in their own words. Semi-structured interviews are an appropriate strategy for learning the vocabulary, and discovering the thinking patterns, of the target audience as well as for discovering unanticipated findings and exploring hidden meanings (Marshall & Rossman, 2006). Therefore, respondents were given as much latitude as possible to describe the strategies they used to manage their chronic disease. A topic guide was used to focus the discussion on main topics, and specific topic-related questions. For example, under the topic, “barriers to managing BD,” the following question was asked: *“What sort of things get in the way, or prevent you from managing/ taking care of your BD?”* Follow-up questions such as *“Would you explain further,” and “Would you give me an example?”* were used to facilitate respondent communication. Interviews, which lasted approximately an hour, were audiotaped and transcribed verbatim.

In qualitative research, data collection, coding, and analysis occur simultaneously. Emerging insights can be incorporated into later stages of data generation, enhancing the comprehensiveness of the results (Strauss, 1987). We used a thematic content analysis approach to data analysis, encompassing open, axial, and sequential coding, and the constant comparative method to generate constructs (themes) and elaborate the relationship among constructs (Strauss, 1987). A coding dictionary that included mutually exclusive code definitions was then constructed. Coding structure was reviewed after a preliminary analysis of a sub- sample of transcripts, and the dictionary was refined through comparison, categorization and discussion of each code's properties and dimensions (Strauss, 1987). Significant statements and themes attached to the codes enabled identification/ characterization of perceived barriers to self-management of BD. Reduction of data in this manner enabled us to write a composite description that represented the essence of the phenomenon (perceptions of *"how"* and *"why"*) individuals with BD have problems with self-managing. To ensure qualitative rigor throughout the inquiry process, an audit trail was developed which documented all research discussions, meetings, and activities. In addition, two qualitatively trained investigators (CB, AP) independently coded each transcript to ensure consistency and transparency of the coding; discrepancies were resolved by discussion

Results

Analysis of the data generated 3 major domains of barriers to disease self-management among patients with BD: (1) personal level barriers, (2) family and community level barriers, and (3) provider and health care system level barriers.

Personal Level Barriers

In Table 1, themes and illustrative quotations emerging from the discussion of individual level barriers to self-management are shown. We classified these themes into the 4 categories that reflected the personal barriers that our respondents faced in trying to self-manage their BD: 1) psychological, 2) knowledge, 3) behavioral, and 4) physical health.

Psychological Barriers

Stigma and Isolation—As noted in Table 1, having BD was stigmatizing, causing respondents to feel perceived as different from others, resulting in a loss of self and social isolation:

> "I feel different from other people. Sometime I feel God gave me a bad hand. If I can't think like most people, or you know, do stuff like other people, it gets to me."

Respondent #2004;

> "I like to play chess, but I don't go nowhere to play chess. Normally, I sit with the pieces by myself." Respondent #2012

Taking medications for BD was also perceived as stigmatizing, because everyone would then know they had a mental illness:

> "It took a long time for me to take the medicine because I didn't want to be classified as having a mental illness because I thought I'd be ostracized….. If my friends knew

that I was taking medicine because I was bipolar, they'll say I am crazy." Respondent #2006

Knowledge Barriers

Diagnosis and causes

Diagnosis and causes—There was a paucity of knowledge about BD, ranging from the diagnosis itself to causes of the disease:

> "I had a long time problem trying to understand it because I thought bipolar was two people in one and this evil side and this good side would come in and out.

" Respondent #2006

> "…I still don't understand what constitutes it. To understand it is the first issue. And since I don't understand what symptoms are, I gotta first know 'em before I can say I'm

aware of 'em." Respondent #2052

While some described the cause of their BD as a "chemical imbalance of the brain" or "geneti*c,"* many other causes were cited which ranged from traumatic childhoods*:*

> "I've had a few tragedies, you know, coming up in childhood and stuff, but I don't know if that had something to do with it." Respondent #2009

to being born of alcoholic parents as well as their own alcohol and drug use::

> "I thought because me being a child alcoholic that has something to do with my parents drinking when I was born." *Respondent #2006*

> "It has something to do with my brain, you know. I know I did a lot of damage to myself. …drugs and alcohol play a part in damaging my brain." Respondent #2005

Most respondents described their symptoms of BD as mood swings, manic behavior and/or depression," but one respondent described his symptoms as something called the HALT:

> "But then when I get home, sometime I get real lonely and get that H-A-L- T--where you get hungry, angry, lonely and tired. ….it's like I'm shutting down, and I don't know

when I'm coming out of it." Respondent #2015

Behavioral Barriers

Attitudes—All the respondents agreed that BD was a very serious illness:

> "It's basically one of those illnesses, like cancer or AIDS or something like that. So, it's very serious, like heart attacks or those illnesses that can take your life."

Respondent #2020

However, negative or ambivalent attitudes about medications prescribed for their BD posed barriers to self-management. These included complaints about side effects, which ranged from dry mouth, inability to concentrate, drowsiness, weight gain, to out-of-body experiences:

> "..it's almost like an out-of-body experience. Like even just looking into the world, like walking down the street, it would seem so far away. And it would seem like it

> took extra effort to pick up my legs and to move… it was a very uncomfortable and edgy feeling. And I couldn't handle it." Respondent #2016

Frustration with keeping up a medication routine and skipping medications on days when they were feeling good were also common attitudes:

> "A lot of times I stop taking my medication, because I get tired of just the routine of taking medication. I'll just get up one morning and just say 'I ain't taking it.' Then a few days go by where I haven't took it and then I just start lookin for some drugs." Respondent #2012

> "Sometimes you feel you don't need to take it maybe because you feel fine or something, so the good days could be skip days. "Respondent #2005

For some, being in a relationship meant that they avoided taking medications while others felt that they didn't need to take them:

> "If I start a relationship, I stop taking medication because I don't want them to know what I got (BD)." Respondent #2007

> "I don't see myself being one of those people who need it (medication). So, I have a messed up way of thinking." Respondent. #2020

Lifestyle Issues—One of the major barriers to self-management was making irrational decisions which led to a spiral of negative consequences and despair*:*

> "I make irrational decisions mainly when I'm manic. I make crazy, bad decisions, and then I have consequences. I got arrested because I had warrants on me from 2012 for being argumentative and irritable in public places. And when the cops approached me, I would be yelling and screaming. And then I got jail for eight days and lost my job…. #2013

One respondent described her sudden decision to move out of state with her 3 children because she looked on-line and saw:

> "… these big beautiful houses they have in Georgia, that you can get for less price that you can get here. The problem was I didn't have enough money and no support. I didn't have a car and everybody would tell me not to go to Georgia without having transportation. But I went anyway, sold everything and dragged my three kids with me, uprooted them. I was manic, I was excited and then I came back to reality, and moved back here, and became very depressed after that. Respondent #2015

Limited finances, lack of transportation, and drug and alcohol use were also cited as barriers to self-management of BD:

> "I have no social activities. I have no money to socialize, even Bingo costs money." Respondent #2002

> "I have a lot of problems going to get meds and seeing my doctor. A lot of times I don't have bus fare." Respondent #2012

> “I'm a recovering addict, and I sometimes have my back slides. I'm somebody who experimented with a lot of things and just got it down to just two, smoking marijuana or doing cocaine or crack. I'm weaning myself – slowly but surely.” Respondent #205

Physical Health Barriers

As noted in Table 1 and below, respondents also cited co-morbid physical illnesses as barriers to management of their mental illness:

> “… I have diabetes, chronic arthritis, and chronic asthma. I have a history of pulmonary embolisms and deep vein thrombosis. Did I miss any? Oh, I also have high blood pressure and asthma.” Respondent #2093

> “I was diagnosed with diabetes type one thirteen years ago. I take insulin and that interacts with bipolar and causes mood swings too. It's even more dangerous to have type one interacting with bipolar than type two because you go from low to high very quickly.” Respondent #2013

In summary, respondents in the study cited many personal barriers to self-management of BD which included perceived stigma and isolation, lack of knowledge about the disease itself, and their own negative attitudes towards medications which ranged from denial of their need for them, to feelings of being controlled and dependent. Other personal barriers included their own chaotic lifestyles and comorbid physical diseases which also complicated management of their BD.

Family and Community Level Barriers

Table 2 shows themes, descriptive codes, and illustrative quotations emerging from the discussion of family and community level barriers. Two key barrier categories were: 1) limited understanding of BD, and 2) limited community resources.

Limited Understanding of BD

Lack of support: In addition to their feeling isolated and alone, respondents felt an overwhelming lack of support from family and the community in which they lived:

> “Well, they try, but they don't really know. They think they know and a lot of them just don't think there's anything wrong with me. Like the lady I stay with, she try to understand, but she really don't understand .” Respondent #2012

> “Well my husband, he has a mental illness too. Schizophrenic… …paranoia. I mean, he might understand but he basically don't like to talk about certain things anyways, so I don't know if he understands.” Respondent#2005

Estrangement: Having BD sometimes led to estrangement from family:

> Yep, that's what my family does, they avoid me. And they say it's because I live on the west side, and they live all the way out on the east side. They got a car. I don't. I compare my situation to my friends and their relationship with their families and

> I'm like well, her cousins come over and visit her. You know, it's like no matter where I live if you're concerned, then show it!" Respondent #2007
>
> "I don't have family in the United States. It's just me. The last few years really, my communications with them went from bad to worse." Respondent #2013

Stressful relationships: Friction, misunderstandings and, sometimes abuse, added additional barriers to self-managing their BD:

> "And like even with your family, you can tend to get more stressed, get angry at each other and get frustrated …#2005
>
> "I live with my boyfriend and it's been an on and off twenty year abusive relationship. And as my mind gets a little bit clearer, he's not liking it. He's so used to keeping me, like in his control, you know. He's been physical with me and with my dog, cause when he goes at me, my dog goes at him. And he don't like that. I've put him in prison before for domestic violence." Respondent #2016.

Negative attitudes about medications for BD: Because of misinformation and beliefs about BD, family members and even community support groups, often gave respondents incorrect advice about taking medications for their BD:

> "My family is always telling me "I don't think you need to take the medication, I think you need to call the doctor." Respondent #2011
>
> "… and people telling me "Girl you don't need that medicine, just all you need to do is cut the stress in your life, you don't need the medicine. You looked zooted out. You
>
> know, I can tell you're on medicine. And that makes me say "Okay, I don't want it no- I don't need it no more." But I know I do." Respondent #2007
>
> "I used to go to this one AA meeting, and they were saying no drugs or alcohol whatsoever and they tried to implicate that you shouldn't even take mental health drug and stuff because they felt that the effect of them got you high, which is not true." Respondent. #2006

Limited Community Resources—Unstable living situations, homelessness, and limited income, often led to living in shelters where self-managing BD was especially difficult and led to a spiral of despair:

> "I stay with a friend, but she don't want me there, because she wants an intimate relationship. And I don't want an intimate relationship with her. So, basically, I don't have a home." Respondent #2012
>
> "The problem is a lot of housing programs I do not qualify for, because I'm not a permanent resident or an American citizen for the last seven years, which is a requirement. So I have to go back down to the shelter. It's been very hard for me to accept it. And that's triggering my depression." Respondent #2013

> “When you have a limited income, it's hard to find housing. It's hard to find programs where you can go to be able to get some type of help. They don't give you any avenues of resources. They'll tell you ‘well, go down to the welfare building.’ Welfare building cannot help you….it's even more frustrating when you get down there and you have to deal with the social workers, supervisors, the people down there, the people waiting in the lobby. It's crazy and it's another thing, more stress added on to you.” Respondent #2011

In summary, family and community issues such as lack of social support, limited understanding of BD, misinformation about medication, stressful relationships, and limited income and housing options, posed what respondents perceived as insurmountable barriers to self-management of BD.

Provider and Healthcare System Level Barriers

Table 3 shows themes, descriptive codes, and illustrative quotations emerging from the discussion of provider and healthcare system level barriers. Two key categories of barriers emerged from the data: 1) patient/provider relationships and 2) access to care.

Patient/provider relationships

Inadequate communication: For respondents, the major barrier to having a good patient/provider relationship was the inability of their provider to communicate with them. Many times respondents didn't understand what their providers told them during visits because of the use of unfamiliar words or medical jargon:

> “I'm developmentally delayed, and I don't comprehend things as well as most people. If you don't break it down to something in basically layman's terms that I can understand, I'm not gonna understand what they say…” Respondent #2020

The emphasis on medication-prescribing during the visit, instead of listening, was also seen as a barrier to effective communication:

> “I'm looking at her and she's looking at me and it's making me feel like I'm really crazy or I don't know what I'm saying. It's hard to get them to understand and they just give you you pills, and bye bye! I don't want your drugs. I just want you to hear me, what I'm telling you!” Respondent #2004

Another reported aspect of poor provider communication skills was provider body language that made them feel as though they were *“just another patient”*:

> “She really didn't say much. She kinda just sat there… no rapport whatsoever. It wasn't that I didn't understand what she was saying, but her body language! A lot of times people don't realize your body language will speak louder than what your verbal words say. When I see that your body language is speaking to me, as if you're like, ‘oK’ here we go with another hard luck person with a hundred problems.” Respondent #2011

Access to care

Appointment issues: As noted in Table 3, getting an appointment with a mental health provider was a long and frustrating process, and infrequent scheduled appointments left too much time for respondents to remember what they wanted to report or talk about:

> “I've seen him maybe twice over the last six months. By the time I get around to seeing him, I can't remember. But I know there's something important I want to talk to him about, but we're already on another issue, then I can't frame what the question's gonna be or why I'm asking the question.” Respondent #2052

Turnover in providers: Most of the respondents received their care from resident physician trainees who often rotated off the service after a period of time. Turnover in providers left respondents feeling frustrated and often prevented the formation of a therapeutic relationship. For those who had made progress in managing their BD, the loss of the provider was especially discouraging:

> “….at L.S. you never can tell who you're gonna get. It's like a box of chocolates… I could have somebody one week and somebody the next week. …I always want the same person. I'll wait three months to get an appointment, and then that person is no longer there. So, there's a turnover. And I don't get to build up a relationship.” Respondent #2093

> “Well I wish she had stayed. She left there and went over to B. She was, as far as I'm concerned, the very best therapist that I had. I was making leaps and bounds with her and being able to be myself, which is rare. I have a new one. His name's Q.I. They canceled the last meeting. I'm tryin to get back on track to where I see him.” Respondent #2052

In summary, respondents cited inadequate communication with their provider as a major barrier to forming a therapeutic relationship. Communication problems were compounded by difficulties getting an appointment, and the subsequent rapid turnover in providers.

Discussion

In this well-characterized sample of poorly-adherent people with BD, qualitative analysis identified a number of barriers to self-management that have important implications as to how best to help and empower high-risk individuals. First, participants with BD identified barriers to self-management that spanned individual, family/ community, and provider/ healthcare system domains. This is consistent with McLeroy's (1988) social ecological model of health behavior. This model posits that behavior, actions, and events, are influenced by individual, interpersonal, organizational, community and policy factors.

Second, the internalized stigma associated with having a mental illness was clearly articulated by some participants. Internalized stigma, or self-stigma, occurs when individuals accept society's assessment and incorporate it into their sense of self (Corrigan et al., 2005; Ellison et al., 2013; Latalova et al., 2013). In a meta-analysis of internalized stigma in people living with mental illness, Livingston and Boyd (2010) found a striking negative relationship between internalized stigma and psychosocial variables (hope, self-esteem, empowerment), medication adherence, and a positive relationship with psychiatric symptom severity. In addition to internalized stigma, or perhaps because of it, isolation and a loss of self were common themes among participants. Charmaz (1983) describes this loss of self as a form of suffering felt by those living with a chronic illness who *"observe their former self-images crumbling away without the simultaneous development of equally valued ones."* This author concludes that this loss of self results in *"restricted lives, social isolation, and feeling that one's illness has become a major source of identity."*

Third, while social support is known to be helpful for chronic illness self-management (Gallant, 2003; Strom & Egede, 2012), in the present study there appeared to be a marked absence of social support from families and communities. This included negative attitudes towards psychotropic medications and limited resources such as income and housing resources. Medication adherence in BD treatment has been shown to be related to a number of factors, among them psychosocial support, number of comorbid illnesses, and attitudes toward medications (Lingham & Scott, 2002; Perlick et al., 2004; Sajatovic et al., 2007).

Fourth, communication is crucial to building a therapeutic clinician-patient relationship and delivering high-quality care (Arora, 2003; Fong Ha & Longnecker, 2010; Roter, 1983; Stewart, 1995), yet there were those respondents who felt that they couldn't understand what their provider said, or they were viewed impersonally, *"as just another patient.*" Ineffective provider communication and resultant dissatisfaction is not unique to the participants in our study and patient surveys have consistently shown a desire for better communication with their clinicians (Duffy et al., 2004).

An additional finding from this qualitative analysis was that reported comorbid physical illnesses complicated self-management of BD. Physical illnesses are more prevalent in people with serious mental illness (SMI) than in the general population (DeHert et al., 2011), but there is a significant lack of awareness of the physical health and health care access problems for people with SMI. Mental health treatments in the U.S. are often delivered separately from clinical settings for primary, or other, medical specialty care. Most of the respondents in this study received their psychiatric care from Community Mental Health Centers (CMHC) which generally provide an array of mental health services; however, care is often not integrated with primary care or other specialty care. In addition, medical settings may be poorly equipped to assess and manage individuals with more severe psychiatric symptoms. A recent systematic review of mortality in mental disorders (Walker et al., 2015) noted that approximately two thirds of deaths in people with mental disorders are due to causes like heart disease and diabetes. Care of chronic medical conditions in those with mental illness requires an approach that promotes healthy behaviors, and coordinates care between mental health and medical systems.

It is possible that changing elements in the healthcare climate such as the addition of primary care services to CMHC infrastructures, increased use of electronic health records that facilitate communication between primary and specialty care providers, and between providers and patients, may help to minimize the barriers to physical and mental health integrated care delivery. Further, many experts believe that the increased presence of medical homes, a model that seeks to facilitate partnerships among the patient, his or her primary care physician, and the patient's family, can solve many of the problems related to concurrent care of people with both physical and mental illnesses (Bodenheimer, 2010). Another element to incorporate into the healthcare system may be the use of peer educators. Peer support, provided by individuals who have a serious mental illness such as BD, can teach and model self-management, help normalize the illness experience, promote hope for recovery, and increase feelings of empowerment and self-esteem (Repper & Carter, 2011; Schon, 2015). Peers may also help in reducing the feelings of stigma associated with BD, provide social support for individuals who feel isolated, and improve outcomes. Indeed, a recent evaluation of peer support services for individuals with serious mental illness (Chinman et al., 2014), found that compared with professional staff, peers were better able to reduce inpatient use and improve a range of recovery outcomes.

While our findings on overall barriers to disease self-management among patients with BD have implications for informing care, there are some limitations. Patients with BD who receive care in other treatment settings, or those who have less severe or disabling illness, may have different experiences in managing this chronic illness, and different types of encounters with providers and healthcare systems. At the same time, the focus on poorly adherent patients facilitated an understanding on barriers to self-management among those who are most in need for intervention. The small convenience sample and the conduct of the study in a single urban area in the U.S. may limit transferability of the study findings. In addition, our inability to obtain only limited information on comorbid physical health conditions for our 21 participants, may indicate that this randomly chosen sample may not be representative of the entire data set. These limitations are offset, to some extent, by the use of rigorous qualitative research methods described in this study (Strauss, 1988). The self-report method is direct, versatile, and yields information that would be difficult, if not impossible, to gather by other means.

Conclusion

Our findings indicate that poorly adherent patients with BD had internalized the sense of stigma associated with having a mental illness. Additionally, they had inadequate knowledge about the causes and management of their mental disorder, little or no social support from family and community, stressful relationships, family estrangement, multiple comorbid conditions, alcohol and substance abuse, and chaotic lifestyles. All these factors posed inumerable barriers to self-management for the study respondents. Care approaches that provide social and peer support, locate resources, optimize communication with providers, and integrate medical and psychiatric care, may improve self-management and reduce health complications in this vulnerable population.

Additional areas of future research should further explore the topic of adherence enhancement in individuals with BD as it relates to specific barriers. Our qualitative data illustrates that adherence barriers are not uniform, and it is likely that a one-size-fits-all approach will not satisfy the needs of many with this chronic mental illness. Targeted, or personalized, approaches that address specific challenges to adherence are likely to yield benefits that can help diverse individuals in a variety of settings.

Acknowledgments

Research reported in this publication was supported by the National Institute of Mental Health of the National Institutes of Health under Award Number R01MH093321. Support was also received from the Clinical and Translational Science of Cleveland, UL1TR000439 from the National Center for Advancing Translational Sciences (NCATS) component of the National Institutes of Health and NIH roadmap for Medical Research. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

References

American Psychiatric Association. Practice guideline for the treatment of patients with bipolar disorder (revision). Am J Psychiatry. 2002; 159:1–50.

Arora N. Interacting with cancer patients: the significance of physicians' communication behavior. Soc Sci Med. 2003; 57(5):791–806. [PubMed: 12850107]

Bodenheimer T, Pham Hoangmai H. Primary care: Current problems and proposed solutions. Health Affairs. 2010; 29(5):799–805. [PubMed: 20439864]

Charmaz K. Loss of self: A fundamental form of suffering in the chronically ill. Sociology of Health and Illness. 1983; 5(2):168–195. [PubMed: 10261981]

Chinman M, Preethy G, Dougherty R, et al. Peer support services for individuals with serious mental illness: Assessing the evidence. Psychiatric Serv. 2014; 65(4):429–441.

Corrigan PW, Kerr A, Knudsen L. The stigma of mental illness: Explanatory models and methods for change. Applied and Preventive Psychology. 2005; 11(3):179–90.

DeHert M, Correl CU, Cohen D, et al. Physical illness in patients with severe mental disorders. I. Prevalence, impact of medications and disparities in health care. World Psychiatry. 2011; 10:52–77. [PubMed: 21379357]

Duffy FD, Gordon GH, Whelan G, et al. Assessing competence in communication and interpersonal skills: the Kalamazoo II Report. Acad Med. 2004; 79(6):495–507. [PubMed: 15165967]

Ellison N, Mason O, Scior K. Bipolar disorder and stigma: A systematic review of the literature. Journal of Affective Disorders. 2013; 151:805–820. [PubMed: 24135506]

Fong Ha J, Longnecker N. Doctor-patient communication: a review. Ochsner J. 2010; 10(1):38–43. [PubMed: 21603354]

Gallant M. The influence of social support on chronic illness self-management: a review and directions for research. Health Educ Behav. 2003; 30(2):170–195. [PubMed: 12693522]

Goodwin GM, Young AH. The British Association for Psychopharmacology guidelines for treatment of bipolar disorder: a summary. J Psychopharmacol. 2003; 17:3–6.

Hirschfeld RMA, Calabrese JR, Weissman M. Lifetime prevalence of bipolar I and II disorders in the United States. Presented at: 155th Annual Meeting of the American Psychiatric Association; May 18-23, 2002; Philadelphia, PA.

Janney C, Bauer M, Kilbourne A. Self-management and bipolar disorder-A clinician' guide to the literature 2011-2014. Curr Psychiatry Rep. 2014; 16:485.doi: 10.1007/s11920-014-04885-5 [PubMed: 25123130]

Keck PE, Perlis RH, Otto MW, et al. The Expert Consensus Guidelines: Treatment of Bipolar Disorder. Postgraduate Medicine Report: Special Report. 2004 Dec.:1–120.

Latalova K, Ociskova M, Prasko J, et al. Self-stigmatization in patients with bipolar disorder. Neuro Endocrinol Lett. 2013; 34(4):265–72. [PubMed: 23803872]

Lingam R, Scott J. Treatment non-adherence in affective disorders. Acta Psychiatr Scand. 2002; 105:164–72. [PubMed: 11939969]

Livingston JD, Boyd JE. Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. Social Science & Medicine. 2010; 71(12): 2150–61. [PubMed: 21051128]

Lorig K. Chronic disease self-management program: insights from the eye of the storm. Front Public Health. 2015; 253(4):1–3. DOI: 10.2289/fpubh.2014.00253

Lorig K, Ritter P, Pifer C, Werner P. Effectiveness of the chronic disease self-management program for persons with a serious mental illness: A translation study. Community Ment Health J. 2015; 50:96–103.

Marshall C, Rossman G. Designing Qualitative Research. 4th. Thousand Oaks, CA: Sage; 2006.

McLeroy K, Bibeau D, Steckler A, Glanz K. An ecological perspective on health promotion programs. Health Educ Q. 1988; 15(4):351–377. [PubMed: 3068205]

Murray CJ, Lopez AD. Global mortality, disability, and the contribution of risk factors: Global Burden of Disease Study. Lancet. 1997; 349:1436–42. [PubMed: 9164317]

Perlick DA, Rosenheck RA, Kaczynski R, et al. Medication non-adherence in bipolar disorder: a patient-centered review of research findings. Clinical Approaches in Bipolar Disorders. 2004; 3:56–64.

Polkinghorne DE. Phenomenological research methods. In: Valle RS, Halling S, editorsExistential-Phenomenological Perspectives in Psychology. New York, NY: Plenum Press; 1989. 41–60. 1433

Repper J, Carter T. A review of the literature on peer support in mental health services. Journal of Mental Health. 2011; 20:392–411. [PubMed: 21770786]

Roter DL. Physician/patient communication: transmission of information and patient effects. Md State Med J. 1983; 32(4):260–265. [PubMed: 6865482]

Sajatovic M, Valenstein M, Blow FC, et al. Treatment adherence with antipsychotic medications in bipolar disorder. Bipolar Disord. 2006; 8:232–41. [PubMed: 16696824]

Sajatovic M, Valenstein M, Blow F, et al. Treatment adherence with lithium and anticonvulsant medications among patients with bipolar disorder. Psychiatr Serv. 2007; 58:855–63. [PubMed: 17535948]

Scott J, Pope M. Self-reported adherence to treatment with mood stabilizers, plasma levels, and psychiatric hospitalizations. Am J Psychiatry. 2010; 159:1927–1929.

Schon UK. The power of identification: Peer support in recovery from mental illness. Scandinavian Journal of Disability research. 2015; 12:83–90.

Stewart MA. Effective physician-patient communication and health outcomes: A review. CMAJ. 1995; 152(9):1423–1433. [PubMed: 7728691]

Strauss AL. Qualitative analysis for social scientists. Cambridge University Press; New York, NY: 1987.

Strom J, Egede L. The impact of social support on outcomes in adult patients with type 2 diabetes: a systematic review. Curr Diab Rep. 2012; 2(6):769–778.

Walker ER, McGhee RE, Druss BG. Mortality in mental disorders and global disease burden implications. JAMA Psychiatry. 2015; 72(4):334–341. [PubMed: 25671328]

Yatham LN, Kennedy SH, O'Donovan C, et al. Canadian Network for Mood and Anxiety Treatments (CANMAT) guidelines for the management of patients with bipolar disorder: consensus and controversies. Bipolar Disord. 2005; 7(Suppl 3):5–69.

Zaretsky AE, Rizvi S, Parikh SV. How well do psychosocial interventions work in bipolar disorder? Canadian Journal of Psychiatry. 2007; 52:14–21. [PubMed: 17444074]

Table 1

Personal Level Barriers to Disease Self-Management Among Poorly Adherent Patients With Bipolar Disorder (BD) (n =21)

Themes and Categories	Illustrative Quotations from Respondents
Psychological Barriers *Stigma and isolation*	*"It's kinda weird. People look at you differently. When you say, well, I have bipolar disorder, it's like you're crazy or something. Stay away from her." Respondent #2015* *"..I isolate a lot. I try to stay away from people; basically just stay in my room. I just lock my doors and stay in the house all the time." Respondent #2052*
Knowledge Barriers *Diagnosis & causes*	*"I have no understanding of Bipolar Disorder. Once I understand what it is that I have and why I'm what I am, then maybe I'll understand why I sometimes respond or do things the way I do." Respondent #2052* *"I would like to know what causes it, but I don't. I just figured I was just born like this." Respondent #2012*
Behavioral Barriers *Attitudes & lifestyle issues*	*"I don't like being controlled by my medication, and being so dependent upon it. I just try to do it on my own. I don't want to be stuck on medicine all the rest of my life." Respondent #2009* *"Bipolar is a serious disease because I make irrational, crazy decisions, mainly when I'm manic. Then I have to face the consequences." Respondent #2003*
Physical Health Barriers	*"But being bipolar and dealing with having HIV is sort of like a tough issue because I'm dealing with two things!" Respondent #2005*

Table 2

Family and Community Barriers to Disease Self-Management Among Poorly Adherent Patients with Bipolar Disorder (BD) (n =21)

Themes and Categories	Illustrative Quotations from Respondents
Limited Understanding of BD	*“My father thinks I should just get over it, that it's just in my head. Like I'm making it out to be more than what it is. My father just don't get it and I don't think he ever will. He's just set in his ways and he thinks I'm just stupid and just do these things.” Respondent #2016* *“You have people that tell you, “Oh you don't need that (medications), you just need God.” But you know, I know I need them. I know that I need it, that's the one thing I know.” Respondent #2008*
Limited Community Resources	*“Right now I stay with a friend. I'm homeless. I been try in to get some help with subsidized housing, but I can't seem to get no help, unless I stay at this shelter, S.G. And I know if I go down to S.G. and stay, I'll wind up us in drugs, cause it's a lot of drugs down there.” Respondent #2012*

Table 3

Provider and Healthcare System Level Barriers to Disease Self-Management Among Poorly Adherent Patients with Bipolar Disorder (n =21)

Themes and Categories	Illustrative Quotations from Respondents
Patient/ Provider Relationships	*"That's fine and well, but it would be nice if I understood what is all go in on, so I can at least appreciate the visit, half hour though it may be…I: …then I can at least understand or know which direction I'm go in, or at least I'll have a work in knowledge of why you're asking the questions you are asking me, or whatever. When I see my therapist again, I'm gonna ask him to explain to me what the hell bipolar is—nobody ever told me." Respondent #2052* *"The same questions every time. It's just a standard group of questions. Do I hear voices? Can I read other people's minds? Sometime I want to tell what's goin on. Like, if my brother, sister dies, my past. I'll get upset about that and I want to vent. I wanna get that out. It's like, I go in just to get a prescription for meds." Respondent #2093*
Access to Care	*"It's been over a year. They state you have to have a referral. Well, if that's the case I'm still waiting almost two years for that same referral for someone to call me. Hey look, what does it take? Me to hurt myself or someone else or to really have a bad, you know, reaction for myself, in order to get some help." I need to speak to somebody. I got a lot of issues." #2089* *"…but every six months they give you a new one (therapist) anyway. So you don't really have a chance to have a close relationship. So, personally I try not to discuss anything with them that I feel is very personal to me." Respondent #2006*