

Experiences That Matter in Bipolar Disorder: A Qualitative Study Using the CCC Framework

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Abstract

Background: Bipolar disorder impacts every domain of living, but treatment is often focused only on core diagnostic symptoms. Care and quality of life can be improved by understanding the experience of people with the condition. Direct interviews with affected individuals offers a unique window into the lived experience of bipolar disorder.

Methods: Thirty individuals participated in Experience Group sessions. Researchers conducted individual interviews (n=12) and group sessions (n=18). Audio files were transcribed and NVivo software processed initial thematic analysis. Data was analyzed using the Capability, Comfort, and Calm (CCC) framework of outcomes that matter most to people developed by Teisberg and Wallace (Liu et al. 2017; Teisberg et al. 2020).

Results: Themes identified in the CCC framework included the struggle to maintain identity, employment disruptions, relationship loss, unpredictable nature of bipolar disorder, personal perception of diagnosis, social stigma, identifying appropriate medication, managing dismissive doctors, finding the right psychotherapist and navigating financial burden.

Limitations: Limitations of our study include a small sample size and length of interview time. Researchers also had limited information about participants' diagnoses and comorbidities.

Conclusions: Qualitative data about bipolar disorder helps identify aspects of care and quality of life that are overlooked when focusing only on core diagnostic symptoms. Improved outcomes could be achieved by implementing care based on the lived experiences of people with bipolar disorder.

Background

Bipolar Disorder impacts around 45 million individuals worldwide and impairs multiple domains of functioning, such as psychosocial, neurocognitive, and personality (Gitlin and Miklowitz 2017; James et al. 2018). Suicide among people with bipolar disorder has consistently been shown to be 20- to 30-fold greater than in the general population, and life expectancy is 9 to 20 years shorter (Chesney et al. 2014; Plans et al. 2019). Nonetheless, many individuals with bipolar disorder struggle to receive quality treatment or any care whatsoever. Qualitative research to understand individual's lived experience offers perspective into obstacles to high quality treatment for people with bipolar disorder that may lead to alternative care models and lead to better outcomes.

Qualitative research provides an alternative investigative approach to discern matters most to people with bipolar disorder and their families. In the absence of qualitative input from these individuals and families, clinical teams may not understand what matters to the affected individual. In the case of an inpatient psychiatric facility in the UK, for example, focus groups with patients and families revealed that what mattered most to them was normalcy, which each individual defined differently (Wallang et al. 2018; Andrews et al. 2019). This learning led to the reorienting of outcome measures and care delivery from

primarily focused on individual's safety to recovering quality of life. Designing care based on individuals' needs and goals could improve the treatment experience, treatment engagement and outcomes (Teisberg et al. 2020).

People with bipolar disorder have higher levels of unemployment and impaired performance at work that may lead to people taking less rigorous employment (Marwaha et al. 2013). People with bipolar disorder experience higher disruptions in relationships and lack of meaningful relationships (Kogan et al. 2004; Granek et al. 2016). Although the importance of employment and relationships to well-being is intuitively important, disruptions in these areas affect individuals differently and are difficult to quantify with existing clinical outcome measures.

People with bipolar disorder are often initially misdiagnosed and experience difficulties with medications (Judd et al. 2002, 2003; Hirschfeld et al. 2003; Baldessarini et al. 2007). The misdiagnosis may create confusion and distrust in mental healthcare, but this impact is rarely acknowledged or addressed in treatment. Medication adherence may be as low as 25 percent, and one-third of people with bipolar disorder have somebody in their core social network discouraging medication use (Sajatovic et al. 2011; Jann 2014; Greene et al. 2018). Medications may be effective but patients have difficulty adhering to medication regimens due to side effects, complex regimens, lack of insight, or poor relationships with prescribers (Jawad et al. 2018). (Fornaro et al. 2016). Better understanding the patient's experience of misdiagnosis could strengthen providers' ability to build trust with patients and lead to better outcomes.

Finally, people with bipolar disorder experience dismissive doctors, limited availability of desired and affordable doctors psychotherapists which leads some people to receive suboptimal care (Madden et al. 2020; Wharam et al. 2020). They must also navigate the impact of stigma on their personal and professional lives (Hawke et al. 2013). A recent analysis at our institution of the 5-year longitudinal cost of bipolar disorder to the University of Texas medical plan. BD members without hospitalization were 2 times more expensive than control members (Bipolar=\$52.4 K vs. Control=\$26.8K) and BD members that were hospitalized for the disease were four times more costly (BD_{hosp}=\$107.8 K vs. \$26.8 K).

Hospitalized Bipolar members had similar longitudinal costs when compared to members with other significant medical conditions like cancer and myocardial infarction (Bipolar=\$107.8 K; Cancer=\$105.4 K; Myocardial Infarction=\$103.3 K) (Leung et al. 2021) The high disease cost for employers highlight the need for specialized bipolar disorder centers, improved access to psychiatric care and to understand how best increase health value.

With these considerations in mind, in 2019, the Bipolar Disorder Center at UT Health Austin partnered with investigators at the Value Institute for Health and Care, a joint enterprise between the University of Texas at Austin's Dell Medical School and McCombs School of Business, to conduct a qualitative study with people diagnosed with bipolar disorder. The study aimed to gain a better understanding of the lived experience of those individuals with bipolar disorder to develop a comprehensive list of outcomes that matter most to this population and to identify the gaps in care that prevent them from achieving those

outcomes. We wondered whether information obtained through qualitative interviews might identify different aspects of bipolar disorder than standard symptoms measures.

Method

This study was IRB approved by the Office of Research Support and Compliance at the University of Texas at Austin.

Study Participants and Demographics

Participants who were 18 years and older with a diagnosis of bipolar disorder were recruited with assistance from staff and providers at the Bipolar Disorder Center, as well as through outreach to organizations in Central Texas that provide support and services to people diagnosed with bipolar disorder. Each person who participated received a grocery store gift card.

Thirty individuals were enrolled in the study. We conducted individual interviews (n = 12) and group sessions (n = 18) with these individuals. Of the 30 individuals who participated, 24 were diagnosed with bipolar disorder, while six were parents of adults living with bipolar disorder. Parents were interviewed separately from their affected child. Among participants with bipolar disorder, 16 were women and eight were men. The oldest person to participate in the research was 58. The youngest was 20. Because the sample size of parents studied is small, results from those conversations are incorporated only when they informed and illuminated insights from the affective individuals, rather than as standalone conclusions.

Study Design and Data Collection

To meet study aims, researchers conducted qualitative individual and group interviews using a methodology known as Experience Group (EG) sessions (Teisberg et al. 2020; Guzik et al. 2021). This methodology is designed to help investigators understand both the clinical and daily lived experiences of people with a shared set of health needs, i.e. bipolar disorder in this study. Researchers developed semi-structured discussion guides with open-ended questions to allow the participants to self-select issues (both clinical and non-clinical) that are most important to them. During the session, facilitators encouraged discussion around topics such as participants' daily experience living with their condition, challenges they face, hopes, fears, and goals. While insights related to clinical experiences inevitably come up in these conversations, the focus on the person's daily lived experience aids researchers in understanding both the successes and obstacles faced by these individuals in situations outside health care settings.

Experience Groups methods aim to include people whose medical and/or social circumstances are as shared and similar as possible (Teisberg et al. 2020; Guzik et al. 2021). We facilitated a total of five groups, each consisting of 3–5 people for this project. Groups were stratified by age (18–34 and 35 and up). Sessions lasted 90–120 minutes. All groups and interviews took place in person (prior to the COVID-

19 pandemic), either in a non-clinical conference room at Dell Medical School or private conference rooms at local public libraries.

Discussion guides for individual interviews followed the same principles as the group sessions: semi-structured with open-ended questioning to allow participants to select experiences and stories important and relevant to their lives concerning their health condition. Researchers conducted individual interviews with those who were unable or uncomfortable to meet in a larger group setting. All interviews and group sessions were audio-recorded and transcribed verbatim, although one session was manually recorded through note-taking.

Analysis

The two researchers who facilitated the interviews debriefed after each session for 30–60 minutes to discuss significant themes observed. Researchers took notes during both sessions and debriefs. After the audio files were transcribed, researchers conducted an initial thematic analysis of the data using NVivo, a computer-assisted qualitative data analysis software tool. Following the initial coding, researchers further analyzed the data using the Capability, Comfort, and Calm framework of outcomes that matter most developed by Teisberg and Wallace (Wallace and Teisberg 2016, 2017; Liu et al. 2017; Teisberg et al. 2020). Capability outcomes relate to the ability to function and do things that are important to the individual. Comfort outcomes reduce the physical, mental, and emotional suffering caused by a medical condition. Calm refers to outcomes that relate to the experience of receiving health care. See Table 1.

Table 1
The CCC Framework with Interventions

Intervention	
Capability	
<i>Struggle to maintain identity</i>	Screen and treat personality disorder Support social and professional functioning
<i>Disruptions to employment</i>	Cognitive remediation Reduce polypharmacy to improve cognition Treat residual depressive symptoms Employment services
<i>Loss of relationships</i>	Family focused therapy Caregiver support
<i>Unpredictable nature of disorder</i>	Access to care, medicine and social support services
Comfort	
<i>Perception of unscientific diagnosis</i>	Robust psychoeducation More time with providers
<i>Social stigma</i>	Group psychotherapy
<i>Finding the right medication</i>	Medication collaborative decision making
Calm	
<i>Dismissive doctors</i>	Improve time and communication
<i>Finding a psychotherapist</i>	Support to navigate psychotherapy Offer therapy resources in clinic
<i>Financial burden</i>	Navigators assist navigate insurance and resources

Results

Capability – Ability to support identity through work and relationships

Struggle to maintain identity

...When I said [bipolar is] confusing, what I meant is it's confusing in that I really don't know who I am. I question every conversation in every social environment that I've been in. Did I say too much? Was I talking too fast? Was I really me? ... I don't really get to just be. It's always judging.

A bipolar diagnosis affects identity from the internal experience of emotions and thoughts, as well as the external perception of the community. Participants often had difficulty differentiating thoughts and behaviors that were attributed to bipolar disorder from those that were attributed to neurotypical emotions and cognitions. For example, some participants described pursuing relationship or career goals during a manic episode, but having those goals dissipate with resolution of the manic episode. Another participant shared a story in which she surprised her daughter with cake and balloons and her daughter immediately questioned if this was a symptom of mania. Some participants discussed how they enjoyed mania and that treatment made them feel "boring." Several participants shared the experience of others assuming they were "crazy" or dangerous based solely on the diagnosis of bipolar disorder.

Disruptions to employment

I've literally been fired from every job that was fire-able.

Almost all participants described disruptions in school and/or work. These disruptions not only happened during mood episodes, but also during periods of euthymia. Participants attributed employment difficulties to medication side effects on energy and cognition and the interference of monthly physician or weekly psychotherapy appointments. Some participants described having to take employment as skill levels below what they were qualified for or capable to perform. However, one participant used his experience with bipolar to develop a career, namely by becoming a peer support specialist.

Loss of relationships

... I lost everything. I lost my family. It was my nuclear family, my mom, that reported me to CPS < Child Protective Services>. I had lost that support system as well. I lost my husband, I lost my kids. Then with the divorce, I lost his family. I didn't have any friends. I just hit rock bottom.

Many participants reported difficulty with relationships, often attributed to behavior during mood episodes. Participants spoke of difficulty maintaining social networks of friends, romantic partners, and family. One participant perceived his symptoms would always be a barrier to maintaining social networks, and another participant shared his fear that he would be unable to start a family. Participants who had intact support emphasized the importance of family support to their well-being.

Unpredictable nature of bipolar disorder

"...out of the blue, all of a sudden after 15 years of really great stability, everything just changed really. I don't know why."

Participants struggled with the unpredictability of bipolar disorder and routinely talked about "stability." Stability to some participants meant emotional stability, which leads to stable behavior, work and

relationships. Other participants expressed that stability would be feeling “normal” and the absence of thinking about stability at all. Most participants believed stability arises from medication and psychotherapy, but more than one participant refused medication as they felt it worsened their quality of life.

Comfort – Reducing physical and mental suffering

Perception of diagnosis as indeterminate and unscientific

“Well something else is that it's not cancer. Or this is part of why it's hard to accept a bipolar

diagnosis because there's not a blood test. There's not a physical marker for ‘this is what it means to have bipolar disorder. You look at the symptoms, and then that determines whether or not you have it.”

Many participants found the nature of psychiatric diagnosis and the inconsistency of diagnosis among providers distressing and disconcerting. Many participants had been evaluated by multiple providers and received different diagnoses and treatment recommendations. Participants talked about currently having comorbid diagnoses of anxiety, ADHD, and PTSD. Some expressed frustration that providers did not clearly communicate the diagnostic process or criteria.

Social stigma - Lack of public awareness and education

It's like, "Hey, I have bipolar." And they want to get away from you. I'm not dangerous, but there's just the negative stigma attached to it.

Most participants experienced stigma in social and professional settings. Participants felt stigma impaired obtaining jobs and perceived that employers worried about disruptions to work. Some participants shared that family members refused to accept a bipolar disorder diagnosis of their loved one since they were not “crazy” or violent. Some participants expressed a wish for more public awareness about mental health conditions such as bipolar disorder to reduce the stigma.

The trials of medication

"These meds are making me sick. It's making this, and this, and this, and this happen. ...And so, I just stopped taking the medication because I thought I was going to die.”

Many participants with bipolar disorder discussed antidepressant medication, typically prescribed prior to a bipolar diagnosis, worsening depression, or inducing mania. Participants experienced multiple medications trials due to ineffectiveness or side effects. Participants shared learning to accept side effects as preferable to mood episodes. Common side effects cited were impaired cognition, blunted emotions, and avolition. Some participants expressed that it could take months to find the medication regimen that was right for them. The potential side effects and unpredictability of medication regimens had both physical and emotional consequences and left many participants feeling an overall lack of support.

Calm – Healing and consistent providers

Dismissive doctors

I was confused about the diagnosis...how that related to me, how they [providers] could just give me medicine without offering any path to recovery. And then angry that they would do that.

Participants often felt that providers dismissed concerns about diagnosis and treatment. Some participants wanted more robust explanation and support at the initial time of diagnosis. Many participants noted that short appointment times limited the ability to address all concerns. Participants experienced limited choices or loss of providers due to insurance or lack of psychiatrists in the community. This lack of support and consistency made it difficult for many participants to find a long-term provider they could trust, a challenging proposition for a condition in which the care offered by providers is highly variable.

Finding the right psychotherapist

They're like, 'Yep, you're bipolar. Here's medicines and a list of counseling services you can call.' It's like six pages long, and all heavily waitlisted. And so, that was incredibly frustrating to call all of those numbers and get voicemails, and leave messages, and then weeks and months later get calls back.

Many participants found the process of finding an available psychotherapist difficult and confusing. Participants reported limited choices due to insurance and inadequate guidance from providers. The majority had an interest in psychotherapy and believed that therapy would be beneficial to their well-being. For those under-insured and/or lacking the time and resources necessary to find a therapist, securing regular care felt like a seemingly insurmountable obstacle.

Financial Burden

I don't think I can get my medications or therapy unless I am gainfully employed. I think I'm just going to be basically working to pay for my medications and my medical health treatment. That's why I think there's no hope for me in this country.

The cost burden impaired treatment by restricting access to psychiatrists, psychotherapists, or medications. Some participants reported that they could not afford tolerable and effective medication due to lack of insurance or high out-of-pocket cost. Participants shared both positive and negative experiences with services funded by local and federal agencies that provide care to vulnerable populations, including individuals without insurance, poor-quality insurance, or financial hardships. Participants also shared difficulty navigating the disability system, which would be helpful to access care and address psychosocial stressors and avoid homelessness.

Discussion

The results of this study highlight areas of need as identified by people with bipolar disorder that should be addressed to optimize care. Bipolar disorder poses challenges to every facet of an individual's life, physical, psychological, as well as interpersonal and professional. However, research and clinical practice commonly measure success only by mood symptoms or hospitalizations, rather than by broader psychosocial measures (Malhi et al. 2017, 2018). We propose addressing unmet needs in several ways; again using the Capability, Comfort, and Calm model as an organizing framework (Liu et al. 2017; Wallace and Teisberg 2017; Teisberg et al. 2020).

Improving capability through better social support, assistance with maintaining employment, and focus on identity

Participants in our study reported the importance of social support for quality of life but also noted they faced difficulty forming and maintaining relationships. Caregiver distress affects outcomes, and previous research has shown that providers can bolster social support and improve outcomes by adding family-focused therapy (Miklowitz et al. 2003; Perlick et al. 2004). This highlights the importance of viewing the person in the context of the social system to optimize functioning and the benefit—to both the individual and their support system—of including family psychoeducation and psychotherapy in care models.

Participants in our study shared the experience of unemployment, underemployment, and cognitive impairment, which may be due to medication side effects, residual depressive symptoms, or direct neurocognitive decline associated with bipolar disorder (Kim et al. 2018). Cognitive remediation has been extensively studied and validated for schizophrenia. Recently, there has been increased interest in cognitive remediation for bipolar disorder (Vieta et al. 2013; Kim et al. 2018), although more research is required to establish its effectiveness. Other interventions include more aggressive treatment of depressive symptoms or pharmacotherapy targeting cognitive impairments (Gitlin and Miklowitz 2017). Employment services can effectively enable patients to return to work (Drake et al. 2013). Case managers, peer support specialists and social workers could support employment services, such as navigating human resources and accommodation requests.

Our data suggest that individuals with bipolar disorder struggle with identity, namely differentiating 'normal' emotions and thoughts with emerging illness. This finding is consistent with other qualitative research (Inder et al. 2008). Participants talked about common comorbidities such as attention deficit hyperactivity disorder (ADHD), anxiety, and post-traumatic stress disorder (PTSD), but not personality disorders. Stigma around personality disorders may have decreased the comfort of our participants to discuss this topic. Alternatively participants may not have received a personality disorder diagnosis because providers feel uncomfortable or unwilling to discuss it with patients despite a personality disorder diagnosis in the medical record. Stigma can be addressed with psychoeducation for patients and families, as well as advocating for public awareness campaigns. In addition, providers require training to increase comfort with diagnosis and decrease their own sense of stigma.

Psychotherapy for bipolar disorder typically focuses on recognizing and managing symptoms and social functioning (Geddes and Miklowitz 2013). Yanos et al proposed that psychotherapy may address identity by challenging the person's association of a psychiatric diagnosis with incompetency and inadequacy (Yanos et al. 2010). Fortunately, multiple effective treatments for co-morbid personality disorders exist and should be incorporated in the treatment of bipolar disorder (Bateman et al. 2015). Robust bipolar specific psychotherapy that can address identity and maladaptive behaviors, rather than be restricted to limited models of personality that may not apply in such a dynamic illness, could be a useful advance in the management of bipolar disorder.

Improving comfort through a better understanding of bipolar disorder diagnosis, addressing stigma and providing relief of symptoms

Our results indicate that people who receive a diagnosis of bipolar disorder may have mixed experiences of relief in having an answer and disappointment in a diagnosis with increased burden and social stigma. The treatment team should help the person and their family with processing and psychoeducation or provide psychotherapy of the bipolar disorder diagnosis.

Medications for bipolar disorder can be intolerable or ineffective. A lack of consistent practices for the appropriate treatment of bipolar disorder may explain the experience that participants felt providers offered different treatments; psychopharmacology should be consistently re-evaluated through evidence-based research. Addressing the emotions, side effects, and perceived effectiveness of treatment through collaborative decision-making with the affected individual promotes better adherence and satisfaction to medication treatment (Fisher et al. 2016).

Improving calm through better accessibility to strong provider relationships and coordinated care

The experience of provider relationships might be considered as important as well-chosen medication in bipolar disorder treatment. People have long valued and recognized the importance of accessibility of care, such as geography and psychotherapy or social services, relationships with providers, and cost of care (Björkman et al. 1995). Participants in our study confirmed the importance of strong provider relationships to their well-being. Participants identified communication and adequate time spent with providers as things that contributed to a positive relationship. However, they also described an inability to see preferred providers due to insurance, cost, or availability barriers. Other qualitative research has similarly shown that insurance restrictions may limit access to care and that people will space appointments, see providers with whom they have a weaker relationship, and take less medication than prescribed to save money (Madden et al. 2020; Leung et al. 2021). Improved access to care may be through support obtaining insurance.

Compared to other medical settings, people accessing mental health services are more likely to view these services as a pathway to resources outside the health care system, such as housing, education, and employment (Easter et al. 2016). Providers and treatment teams need to consider that people may have

this expectation for help with other resources. It is also useful to consider that race and geography create disparities in access to mental health care (Kim et al. 2017). Providers and treatment teams should have knowledge about social service resources and familiarity with navigating insurance, as offering this assistance may improve outcomes related to psychotherapy and medication.

Limitations

Limitations of our study include a small sample size and length of interview time. The study was open to participants with any bipolar disorder diagnosis, although experience between bipolar disorder subtypes (e.g., 1 or 2) may differ. Participants lived in the same state but in different cities; each city has unique resources and challenges. Our recruitment methods were biased to people seeking treatment in a bipolar disorder treatment program. It may have been biased toward participants who wanted to share that they are overly satisfied or dissatisfied. Participants all spoke English as a primary language, limiting the ability to generalize data to people who primarily speak other languages.

Conclusion

This study frames the discussion and analysis of lived experience with bipolar disorder using the Capability, Comfort, and Calm framework. These outcomes can be used as criteria for the design of care services, which might provide a more comprehensive and unique approach compared to the typical fractured and inconsistent care delivery for bipolar disorder. Implementing change may be as simple as reviewing social history, for example employment status, more routinely or the addition of questionnaires or measures. Larger, designed studies are needed to further test this approach to care design.

Declarations

- Ethics approval and consent to participate: This study was IRB approved by the Office of Research Support and Compliance at the University of Texas at Austin. All participants gave consent to participate in the study.
- Consent for publication: All authors have given consent for publication.
- Availability of data and material: All data is confidentially stored and de-identified data may be available for publisher's review.
- Competing interests: S.S.M Sunovion Pharmaceuticals (Chair DSMB), Meadows Mental Health Policy Institute (Senior Fellow). No other authors have interests that might be perceived to influence the results and/or discussion reported in this paper.
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