



Poetry as a Framework for Understanding Embodied Experiences of Bipolar Disorder

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Abstract

This paper is about making sense of bipolar disorder. We open with lines from a poem titled "Oasis of Life" by the poet/coauthor of this article which are part of his endeavor to know and tell some of his embodied experience living with bipolar disorder. We then use this poetry as a framework for interpreting stories of others living with/supporting someone living with bipolar disorder as described by three members – two sisters and their mother – from a family where both sisters and their father have bipolar disorder. These family members stories are treated here as an instrumental casestudy and were collected through in-depth private interviews as part of a qualitative study conducted by the first author to better understand needs of adults who have disability and/or mental health issues and who support close family members with disability and/or mental health issues. Our purpose is to bring together poetry and research data in an exploratory way with the poet, or to use Hornstein's term, "expert by experience", sharing in data analysis with the researcher or "expert by training". From our analysis, we provide an early stage illustration of how poetry may be an effective and unifying mechanism for interpretation and communication of complex embodied experience of bipolar disorder.

Keywords: Bipolar disorder; Poetry; Embodied experience; Support; Meaning; Managing well

In the desert of a life aflame
Another year-like day
Drags its tired feet
To reach a frosty mist-valley
And embrace a century-long night
Where...
to fuel my thought-mills,
I will toss around in bed
and count
every foggy star
every single scar
every standing soldier
every fallen angel
and every day in exile

Psychologist and professor of psychology Gail Hornstein argues for the value of studying first-hand accounts of living with mental illness [1]. Consistent with Hornstein's view, an emerging body of academic work is aimed at building understandings of subjective experiences of living with bipolar disorder. Themes evident in the reports of these experiences include confusion, insecurity, isolation and stigma [2-4]. Confusion and insecurity can pervade individual struggles to understand and manage intense and unpredictable manifestations of bipolar [4] while isolation and stigma are the realities of living with bipolar in social contexts characterized by ignorance and fear of mental illness. Given such challenges to understanding bipolar disorder, and mental illness more broadly, living with mental illness may epitomise Michael Polanyi's claim that 'we can know more than we can tell' [5].

The opening lines of this article are part of one poet's endeavor to

both know and tell some of his embodied experience - i.e. thoughts, feelings and moods - living with bipolar disorder. The poet, as co-author of this article, shares lines from a poem titled "Oasis of Life" for how these constitute part of his conscious and unconscious processing of confusion and complexity. As well as representing his individual story of living with bipolar disorder, this poetry is used as a framework for interpreting the experience of members of an instrumental case study family who, as research participants, share stories of living with/supporting someone living with bipolar disorder. Our case family is comprised of two sisters and their mother and both sisters and their father have bipolar disorder. These family member stories were collected through in-depth private interviews as part of a qualitative study, conducted by the first author, to better understand the needs of adults who have disabilities and/or mental health issues and who support close family members who have disabilities and/or mental health issues. Our purpose is to bring together poetry and research in an exploratory way with the poet, or using Hornstein's term, "expert by experience", sharing in data analysis with the researcher or "expert by training". From our analysis, we provide an early stage illustration of how poetry may be an effective and unifying mechanism for interpretation and communication of complex embodied experience of living with bipolar disorder.

We begin by providing an overview of research findings about living with bipolar disorder including a small number of recent

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works targeting experiences of “managing well” with bipolar. We then demonstrate how the process of creating poetry can be a means of achieving goals identified under a managing well framework and further, how the resulting poetry can be used to make sense of efforts by others to manage well with bipolar disorder.

Background

Individuals with bipolar disorder live with intermittent and often unpredictable episodes of depression and mania [6]. The intensity and variability of accompanying moods and feelings make bipolar difficult to understand and explain to others [2,4]. These difficulties are exacerbated by what Hirschfeld discusses as a diagnostic lag wherein although the symptoms of bipolar manifest relatively early in life, obtaining an accurate diagnosis often takes several years [2,7,8]. Strained family relationships frequently surround people with bipolar disorder as family members struggle for understandings [9,10] and individuals with bipolar experience stigma and rejection within a broader social world that continues to desire social distance from people with mental illness [3,11-13].

Consumer/patient advocates point out how stigma and rejection are reinforced by medically-focused views that entail emphases on mental illness as a lifelong and increasingly debilitating disease [14-16]. Resulting approaches target deficits and control of symptoms through interventions which are predominantly pharmacological in nature [16,17]. Since the 1990's, advocates have called attention to the dehumanizing aspects of these approaches and argue instead for recovery models of mental illness which entail a focus on individual empowerment and strength in developing a distinct and positive identity with or without illness symptoms [18-22]. Recovery is conceptualized as a process through which an individual manages illness and achieves success according to his or her definitions of illness and success [15,23].

Amidst this discussion, a small body of qualitative work is surfacing that is aimed at capturing the experiences of “staying well” with bipolar disorder [2,13,24-26]. Jonssen, Wijk, Skarsater and Danielson (2008) interviewed 18 individuals with bipolar about their views of the illness and the future; these authors highlight the importance their participants place on striving to understand their illness [2]. Consistent with an emphasis on efforts to understand one's illness, participants in Russell and Browne's [24] interview study (N=100) about strategies for staying well with bipolar disorder spoke in terms of mindfulness about their illness and paying careful attention to what triggers, as well as to what signals, a manic or depressive episode [24]. Participants from a study by Murray et al. [13] of the experiences of 33 “high functioning” individuals with bipolar elaborate on approaches to being mindful of their illness as they describe the value of reflective practices, such as journaling, as a means of expressing and making sense of their illness experience. A participant in the Murray et al. [13] study was explicit about journaling as a means of “getting everything out” [13]. We elaborate on this line of thinking as we examine poetry as a means for expressing thoughts and feelings. Poetry writing has been used by the second author to bring the struggle of a depressive episode out into the open and to fight depressive entities within. He also uses poetry writing to make sense of manic and mixed episode thoughts and feelings that he characterizes as cryptic, random, racing and reckless. The resulting rhythm and rhyme of the poetry is intended to engage readers through use of images of sadness and rage which are, to some degree, part and parcel of everyone's life. Thus the poetry may serve as bridge between embodied experiences of those with and without bipolar disorder. We further present this poetry for how it can be used to make sense of and

communicate experiences of participants in a research study about living with bipolar disorder.

Methods

Instrumental case study

We use an instrumental case study method to focus on an issue – using poetry to communicate and interpret the experience of bipolar disorder – and we select a bounded case – one family's experience – as an illustration [27]. As such, we offer a “detailed contextual analysis of real life situations” aimed at evolving understandings of the “interrelationship of complex issues” [28]. Our case is defined as experiences of living with bipolar disorder and supporting close family members who have bipolar disorder presented from the perspectives of three members – two sisters and their mother – from a family where both sisters and their father have bipolar disorder.

The case family: context and recruitment

Our case family is selected from a qualitative study carried out by the first author and aimed at building understandings of the needs of adults with disability and mental health issues. For the broader study, private, in-depth interviews were conducted with participants with a range of disability and mental health issues (N=17) and their support providing family members (N=49); a few participants (N=3) occupied both roles, i.e. having a disability and/or mental health issues as well as supporting someone with a disability and/or mental health issue. Effort was taken to collect as many perspectives from within each family as were available and interested in participating. Ethics approval for this study was obtained from the Conjoint Health Research Ethics Board at the first author's University. Each participant provided informed consent before his/her interview began. Included in informed consent, participants accepted that although they are assigned pseudonyms, the small, in-depth nature of this study raises potential that participants be identified in research reports, particularly by readers who know their families. In accepting this risk, participants indicated their involvement in the study is motivated by a desire to have their experiences more widely known and understood.

We select this case family because of the number and complexity of mental health issues members face and the number, depth and types of perspectives on these issues provided by family members. From this family we obtained detailed accounts of understanding and managing bipolar disorder from two sisters who simultaneously grapple with their own bipolar disorder while endeavoring to understand and support the bipolar experience of each other and their father all while being supportive of their mother's efforts to understand and care for everyone in the family.

Within our case family, data were collected from Jade, aged 37; Jade has Bipolar Type 2 and responded to a call for participants distributed through community and university programs that provide resources and education centred on mental health needs. Jade communicated the call for participants to both her sister Sasha, aged 32, who has Bipolar Type 1 and to their mother Carol, aged 60.

Jade lives on her own and attends university full time and works part time while Sasha and Carol each live on their own and work full time. Carol's husband of 39 years/Jade and Sasha's father, Simon also has Type 2 Bipolar Disorder as well as dementia; Simon is undergoing assessments and living in long term care as his behaviors have made it impossible for Carol to manage with him at home. The fifth member of this nuclear family is son/brother Braden, aged 35, who lives in another province with his wife and teenage son.

As prospective participants in the broader study, Jade, Sasha and Carol were pre-screened by email, telephone or in person by the first author to ensure that they met the inclusion criteria. To be included, participants had to be over age 18 and self-report that they, their adult sibling or child have a disability and/or mental health issue. Disability was defined broadly to include physical, intellectual, Autism spectrum, traumatic brain injury and fetal alcohol spectrum disorder. Mental health issues were also defined broadly to include anxiety, depression, obsessive compulsive disorder, bipolar disorder, psychosis and schizophrenia. Siblings and parents could be biological, step, adopted or foster.

Data collection

A semi-structured interview guide was used to support rapport with participants and allow flexibility of the interview structure around predetermined topics [29] of living with and/or supporting someone with bipolar disorder. Jade was interviewed for 2.25 hours in a meeting room at the University, Sasha for 1.5 hours and Carol for 2 hours, each at coffee shops. Interviews were conducted by the first author, digitally recorded and later transcribed. Field notes were taken during interviews.

During interviews, Jade, Sasha and Carol each chronicled her life in terms of successes and challenges living with/supporting a close family member living with bipolar disorder. Our data was thus triangulated as what was shared by each is consistent with, and supported by, what was shared by the others.

Data analysis: Several rounds of analysis were conducted by the coauthors to examine meanings of interview transcript data and poetry, each in light of the other. We followed practices of content analysis beginning with a broad organization of data achieved through repeatedly listening to the interview recordings and reading the transcripts and field notes [30] while repeatedly reading and discussing meanings within the poem "Oasis of Life". Once a familiarity with the data was achieved, a content analysis was conducted through examining what is in the text and "giving it a name" or code. Codes or themes were chosen to "reflect all relevant aspects of the messages and retain, as much as possible, the exact wording used in the statements" [31].

Analysis was begun by first studying passages of text so as to identify themes of responses to particular questions while accounting for the context of the passage within which themes occur. These initial themes were used to guide a next level analysis of words and phrases from the text. This analysis followed the interpretive practices of constant comparison and attempting to uncover patterns [31]. The passage of poetry was selected from the broader poem for how it reflects prominent themes in the interview data.

Findings

Exile, restlessness and exhaustion: Fitting with a bipolar episode, poetry images are of a weary, exiled yet restless figure. This poetry was written during an almost nomadic period of exhaustion, restlessness and separation from others described by the second author. During this time, the second author yearned to relocate to an environment that felt right but this repeatedly collided with his virtually immediate feelings of agitation with each new environment. Similar sentiments of exile are evident in the research data as both sisters and their mother describe each sister's restless yet exhausting quest for understanding of her bipolar disorder and endeavoring to feel understood by and connected to others. Weariness occurs amidst the lengthy, involved pursuit for understandings as well as in attending to the manifestations of bipolar once some understanding of the disorder is achieved.

Time in exile: While the poetry images are of days spent in exile, the older sister Jade discusses having been cut off from others and from typical rhythms of life during a two month hospitalization in her grade twelve year. She says: "I definitely didn't want to be in the hospital. I wanted to be in Grade 12 with the rest of my friends... Um, it was life shattering actually". Indeed, the pull to return to regular life was so strong, Jade expands: "I was a little bit of a rebel, before they transferred me to Hospital B I actually (chuckle) escaped from Hospital A".

Subsequent phases of exile are evident as Jade describes being misdiagnosed with schizophrenia rather than bipolar and how this gave her experience with the stigma with which people with schizophrenia live: "It's a hard, hard cross to bear. Um, a lot of weird comments of people like are you going to come and stab me in the night in the dark?". Jade elaborates noting the difficulty doctors had in distinguishing between symptoms of schizophrenia versus bipolar: "It was so unknown...not until my Dad got sick (chuckle) and they put two and two together and I no longer had schizophrenia".

Jade takes comfort in the connection she feels between her father's illness and her own as well as in what she regards as the relatively lesser stigma of bipolar compared to schizophrenia: "Ah, it's kind of interesting cause the stigma's not as, somehow to me it's not as challenging. It also, um, is kind of nice you know to know that I have a reason, like it's you know it relates to my Dad and you know like we have sort of a way to kind of put it together". Yet life with bipolar brings its own exile. Jade highlights an example from her workplace:

"My manager was nice enough to, um, look on the computer as to what, ah, bipolar was and photocopy it and put it in a binder for everyone to see and state that they should read it because they had a co-worker with this problem (chuckle) so that was a bit disheartening. I went into work and found it in the binder...I was covering for somebody at one of the locations and there it was and so it was very, um, embarrassing, um, humiliating..."

Comparatively, Sasha's sense of exile is conveyed as an experience of darkness and hopelessness as she describes the extremes of a depressive episode as "a deep dark black hole...you just don't see your way out. Getting out of bed, getting dressed was difficult, even seeing Dr. M, I would get anxiety and start throwing up (quavering voice)". A sense of exile is also evident in Sasha's manic episodes when she describes being out of control while convincing others that she was ok: "There was a phase when I was working up north when I just didn't care...spending wildly, not eating, getting no sleep. Yet in the state I was in, I convinced everyone that everything is fine, nothing to worry about".

When she did seek help, Sasha shared some of Jade's frustration with the diagnosis experience. Sasha struggled not only to obtain an accurate mental health diagnosis but to obtain any mental health diagnosis at all in the small community in which she was living: "People at work thought I was faking...in small towns, mental illness is non-existent. They just don't get it. At the hospital, they were looking for something physically wrong".

For her part, Carol's sense of exile takes the form of worry over the consequences of mental illness being poorly understood and how this can impact her daughters and husband. Carol reflects: "If people don't know about these types of illnesses, don't care or want to learn, you can get turned away, chucked in a corner, end up on the street". Carol adds: "We need to clear the stigma, the elephant in the room. There is so much fundraising and awareness going into other illnesses but not mental illnesses...if we could open up about this..."

Carol goes on to speak of how her own identity can be compromised by the mental health support needs by which she is surrounded. She says she is “Struggling over whether I am ready to, or should, retire and be Simon’s full-time caregiver... I am trying to find, keep who I am amidst all of this”.

Managing exhaustion of dragging feet and restlessness of endless days and nights: Demands on energy required to manage a mental illness and potentially fit in/lessen or avoid exile, are captured in poetry images of dragging feet and endless, restless days and nights. Research participants speak of ongoing demands in terms of maintaining oneself and attending to one’s illness.

While Jade is matter of fact with her claim “I know how to maintain myself”, Sasha provides a more elaborate account of the demands of self maintenance:

“Not just the pills... accepting you have the illness is a huge part... it’s not just the medication and therapist and psychiatrist and my family and friends...it is me as well...it’s the encompass of all these things that I have to do and keep in order to keep myself healthy...I have something that is as severe as cancer...I have to attend to this always. It is never going away...once you accept that it is the most difficult part”.

Carol describes her own vigilance in helping Sasha, maintain her health: “Sasha can cycle during the same day...I know the signs...the speeded up speech, the not sleeping the hyperactivity...one thing about Sasha is the spending...that is another thing I worry about because you can end up bankrupt. Uhm, speed with driving...all those things I have become familiar with and learned to notice”.

Carol’s discussion of Jade’s health maintenance centre on efforts Jade herself extends: “Jade knows her limits, Jade gets her sleep and doesn’t overindulge”. Indeed, Carol speaks with admiration of how, even when things are difficult, Jade perseveres:

“Jade has struggled but kept going, putting one foot in front of the other. I’ve told her she’s my hero...she has kept going ahead and ahead...she just doesn’t stop...she’s had a number of troubles...she has arthritis, pain, discomfort... but she keeps coming back, rebounding, perseveres...she might get knocked down but she comes back again”.

Carol sums up her descriptions of her family’s experience with an expression of pride for how her daughters have managed their restless, exhausting symptoms and endeavors to be understood by others; Carol combines her summary with a reassertion of her husband’s place in the family despite the challenges of his illnesses: “The girls have had a lot to contend with yet they’ve managed to become contributing members of society and Simon and I are very proud”.

Discussion

In their interview study of the meaning of living with bipolar, Rusner et al. [32] found participants struggled to understand their illness as it is “intertwined with one’s whole being”. Rusner et al. [32] conclude that metaphors are a valuable means for capturing complexities of the experience of living with bipolar disorder. We endorse this conclusion with our finding that metaphors used in the poetry and research data we examined are vital representations of embodied experiences with bipolar disorder within a social context where mental illness is poorly understood. Jade’s cross to bear, Melanie’s dark hole, and Carol’s elephant in the room reflect bodies weighed down by, immersed in or sitting awkwardly next to, bipolar disorder. These encumbered bodies accord with the poet’s images of dragging feet through endless days and nights while the poets’ restless, exhausted tossing and turning in the

night mirrors Jade and Sasha’s restless movements between hospital and home and struggles to understand and manage their bipolar disorder.

Through this analysis, we make a niche contribution to the growing number of creative, subjective accounts of experiences with mental illness by historical and popular culture figures. We distinguish our work for how we bring together creative and research expression as a new way of drawing out elements of shared experience. We thus address a gap identified by researchers and popular writers committed to understanding mental illness. The resonance we found between the research data and the poetry leaves us advocating for increased efforts that bring together multiple representations of living with bipolar. We conclude that such efforts may support or constitute strategies for mindfulness and self-understanding which researchers have found to be associated with managing well with bipolar.

Limitations

This study is limited to the bringing together of distinct inner worlds of bipolar as expressed by a single poet and three members from one family. As such, we make no claims of generalizability. Instead our contribution is in illuminating depth and connections within a small number of experiences. We believe this constitutes early evidence of the artistic relevance of research data and scientific relevance of poetry. We hope this prompts continued expansion of ways people with bipolar disorder may be understood by others.

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