

Stigma Shrinks My Bubble: A Qualitative Study of Understandings and Experiences of Stigma and Bipolar Disorder

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Abstract

Purpose: This qualitative study contributes to the stigma and bipolar disorder literature focused on understanding structural, social, and self-stigma experiences from the perspectives of individuals living with bipolar disorder and their family members.

Methods: Community-based participatory research principles guided our engagement of individuals with bipolar disorder and community partners in the initiation, development, implementation, and reporting of this study. We collected data through focus groups with individuals living with bipolar disorder (3 groups) and family members (2 groups) during an annual bipolar disorder community engagement event. Thematic analysis was conducted as an iterative process and aided by several research team meetings.

Results: Three core themes emerged: (1) explicit and implicit exclusionary practices linked to structural stigma; (2) social stigma (e.g., *If my child had leukaemia you would all be bringing me lasagna*) and; (3) the burden of self-stigma (e.g., *What's wrong with me?*). These findings address issues arising in work, school, social, and health care settings that shape stigma phenomena.

Conclusion: Parallels between the present findings and stigma experiences regarding other types of mental illnesses suggest considerable overlap. Individuals with bipolar disorder expressed hope for change that included (a) working with health care professionals who use a psychosocial rehabilitation approach and (b) implementing personal strategies for unloading the burden of self-stigma in their lives.

Implications: The conceptualization of stigma as self, social, and structural resonated well with the experiences and understandings of study participants. This conceptualization offers a bridge for communication between people with bipolar disorder, their families, and health care practitioners, and may be a useful framework for guiding efforts to reduce stigma. Community-based participatory research principles and lived experiences are crucial elements in stigma reduction endeavors.

Keywords: community-based participatory research, psychosocial factors, mental health, focus groups, bipolar disorder

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** The Collaborative REsearch Team to study psychosocial issues in Bipolar Disorder (CREST.BD, www.crestbd.ca) is a team of researchers, health care providers, and community members dedicated to developing knowledge on bipolar disorder. The international team includes representatives from a variety of health disciplines, including psychology, psychiatry, occupational therapy, nursing, genetic counselling, and mental health advocacy. A guiding principle of CREST.BD is to foster and promote 'Community-Based Participatory Research', whereby individuals with bipolar disorder, their family members and health care providers are active participants in research and knowledge exchange.

Introduction

Bipolar disorder is a mental illness estimated to affect two to three percent of the adult population in Canada and the United States (National Institute of Mental Health, 2011; Schaffer, Cairney, Cheung, Veldhuizen & Levitt, 2006). Like other chronic health conditions, bipolar disorder is associated with primary and secondary disabling effects for those who live with the condition. Research has concentrated predominantly on the primary effects of bipolar disorder, which comprise negative consequences attributable directly to the symptoms and course of the condition. These can include functional impairments that result from episodes of mania, hypomania, depression, or psychosis (Kleinman *et al.*, 2003). Far less research has examined the secondary effects, or collateral consequences, of living with bipolar disorder: that is, the adverse effects associated with the social response to the condition. One of the most insidious secondary effects of bipolar disorder is stigma.

Stigma is a dynamic, multifaceted social process that has been consistently implicated as a key contributor to poor outcomes for many people who live with stigmatized health conditions, such as mental illnesses (Hinshaw, 2007; Livingston & Boyd, 2010). Link and Phelan (2001) conceptualize stigma as being comprised of five interacting components — labelling, stereotyping, separation, status loss, and discrimination — that are produced and perpetuated by power differentials in society. The literature also articulates three intersecting levels through which stigma may be manifested and experienced: structural, social, and self. First, structural stigma refers to the policies and practices of institutions (and their professional representatives), in positions of power, that systematically restrict the rights and opportunities for people with mental illnesses (Corrigan, Markowitz & Watson, 2004; Herek, 2007; Livingston & Boyd, 2010). Second, social stigma refers to *the phenomenon of large social groups endorsing stereotypes about and acting against a stigmatized group* (Corrigan, Kerr & Knudsen, 2005, p. 179). Accordingly, collective representations are constructed about particular social groups whose members possess undesirable features (Crocker, 2003). Third, self-stigma refers to the internalization of societal attitudes and discriminatory practices (see Crocker, 2003; Major & O'Brien, 2005). With respect to mental illnesses, stigma has been defined as a subjective process that is *characterized by negative feelings (about self), maladaptive behaviour, identity transformation, or stereotype endorsement resulting from an individual's experiences, perceptions, or anticipation of negative social reactions on the basis of their mental illness* (Livingston & Boyd, 2010, p. 2151). These levels provide a useful heuristic for understanding stigma,

but they overlap and intersect rather than unfold in isolation.

A large body of literature exists in relation to stigma and mental illnesses, with the findings synthesised in several review articles (Angermeyer & Dietrich, 2006; Heflinger & Hinshaw, 2010; Hinshaw & Stier, 2008; Livingston & Boyd, 2010; Peterson, 2005; Read, Haslam, Sayce, & Davies, 2006; Schachter *et al.*, 2008; Schulze, 2007; Wahl, 1999; Wahl & Aroesty-Cohen, 2010). Problematically, research in this area has tended to focus on the perceptions and experiences of people with mental illnesses in general, as opposed to specific types of mental illnesses. Evidence exists that both social and self-stigma may vary considerably across different forms of mental disorder (e.g., Crisp, Gelder, Rix, Meltzer & Rowlands, 2000; Dinos, Stevens, Serfaty, Weich & King, 2004; see review in Hinshaw, 2007). A small body of qualitative research has, however, begun to document stigma experiences specifically among people with bipolar disorder. In one study that examined psychosocial issues faced by 18 people with bipolar disorder, stigma was identified as a factor that negatively affected how they viewed themselves and their place in society (Lim, Nathan, O'Brien-Malone & Williams, 2004). Similarly, research focused on the perceptions of the bipolar disorder diagnosis among 15 hospitalized individuals, revealed themes related to the struggle to accept their diagnosis (Pollack & Aponte, 2001). Finally, a qualitative study of 32 individuals managing well with bipolar disorder revealed how stigma was perceived as being salient to maintaining and regaining wellness (Michalak *et al.*, 2011).

We sought to further develop the body of literature on stigma and bipolar disorder that accesses personal experiences and opinions and reflects how the three levels of stigma are experienced. Our overall objective was to describe qualitative research findings, informed by community-based participatory research methods, exploring the understandings and experiences of stigma from the perspectives of people with bipolar disorder and their family members.

Methods

Community-based Participatory Research Approach

Acknowledging the complexities of researching psychosocial issues in bipolar disorder and the limited multidisciplinary research available, we established the Collaborative REsearch Team to study psychosocial issues in Bipolar Disorder (CREST.BD) in 2007. CREST.BD is a team of researchers, health care providers and community members dedicated to developing knowledge about psychosocial factors in bipolar disorder

through community-based participatory research methods.

Community-based participatory research is an orientation in which scientific inquiry is conducted in partnership with community members (e.g., individuals living with bipolar disorder and their family members) with the aims of engaging community members, building research capacity, and influencing social change (Roche, 2008). It is based on the premise that collaborating with those who have direct involvement and personal knowledge about the issue under study will yield findings of relevance to community members, facilitating positive impacts on health and well-being (Fredland, 2010). Thus, substantial community input is sought throughout the entire research process (Chen, Diaz, Lucas, & Rosenthal, 2010; Israel, Schulz, Parker, & Becker, 1998). As a guiding principle of CREST.BD, community-based participatory research provides an innovative approach that places the knowledge and expertise of community members at the core. Accordingly, research is a process of creating knowledge of direct relevance to community members with the aims of bridging the gap between theory, research, and practice (Israel *et al.*, 1998).

Through active engagement and consultation with stakeholders, the topic of 'stigma' was identified as a research priority for CREST.BD. Thus, we embedded a study within a full-day CREST.BD community engagement event to answer the question: *How do individuals living with bipolar disorder and their family members understand and experience stigma?* The research group, which included one team member who lives with bipolar disorder, decided upon the questions and the order in which they were asked. Qualitative methods were used, as they are well-suited to elicit in-depth information from the perspective of participants (Salvatori, Tremblay & Tryssenaar, 2003). Ethics approval for this research was granted by the University of British Columbia Behavioural Research Ethics Board and participants provided written, informed consent.

Participants

Participants attending the community engagement event were invited to participate in focus groups on the topic of stigma. The event included brief presentations by CREST.BD team members, information about community services and ongoing research, and opportunities for networking and contributing to CREST.BD's research direction, web site development and knowledge translation. Advertising for the event was widespread and used a variety of strategies (e.g., CREST.BD newsletters, networking, and Craigslist). Research participants included (a) 28 individuals who self-reported as having been diagnosed with bipolar

disorder type I or II and (b) 16 family members or supporters of people diagnosed with bipolar disorder. The sample included 13 men, 30 women, and one transgendered individual; their median age was 50 years. Demographic data revealed the following self-identification: Caucasian 29; Asian 4; First Nations 1; Indo-Canadian 1; Other 7; missing data 2. All participants had a minimum educational attainment of a high school diploma, with 25 participants attaining university or college degrees, or additional education. Participants' incomes levels varied, with the majority (n=24) earning less than \$25,000 annually.

Data Collection

Three focus groups were held with people diagnosed with bipolar disorder (n=28) and two were conducted with family members of people with bipolar disorder (n=16). Focus groups were used to encourage dialogue among participants and offer safety to those who may have found individual interviews more intimidating. Each focus group occurred prior to the main events of the day and was facilitated by two CREST.BD members. The focus groups were digitally recorded and lasted approximately 90 minutes. The facilitator asked the following open-ended questions (modified according to group membership): *What does stigma mean to you? Can you tell us about your experiences of stigma? What are the effects of stigma on your life? How might we reduce stigma? What ways of reducing stigma have worked for you personally?* These questions encouraged individuals to tell their own stories. The audio recordings were transcribed verbatim by CREST.BD community members and a professional transcriptionist.

Data Management and Analysis

The qualitative data were analysed by several research team members, including people living with bipolar disorder, using thematic analysis (Braun & Clarke, 2006). Thematic analysis is a form of pattern recognition and involves the identification of themes through careful reading and re-reading of the transcripts (Fereday & Muir-Cochrane, 2006). Through an iterative process, the data were coded, organised, and re-organised several times as categories were created and as relations between and within sub-categories led to the development of preliminary themes. The research team met to discuss the emerging patterns, leading to the selection of a coding framework whereby stigma was conceptualised as manifesting at structural, social, and individual levels. The same research team then independently coded the data, informed by this coding framework. To address the analytic validity of the identified themes, regular analytic team meetings were held to discuss and monitor coding consistency (Morse & Richards,

2002). In addition, the team met to ensure consistency, confirmability and credibility of the findings (Smith, 1996). Emergent themes are supported by direct quotes from focus group participants to enable readers to evaluate the interpretations.

Results

The three levels of stigma (structural, social, and self) were used as a conceptual framework. Because people's lived experiences are not compartmentalised, the findings sometimes intersect, spanning multiple levels.

Restricted Zones: Explicit and Implicit Exclusionary Practices Linked to Structural Stigma

People with bipolar disorder and their families recounted discrimination experiences at work and school that resulted in views of these locations as sites of exclusion and missed opportunities. Participants attributed different types of exclusion to the misinformation and beliefs that others have about bipolar disorder and its implications for expected work and school capabilities. Restrictions on the options that individuals have in society, which arise from the power of institutions, are understood in the literature as *structural stigma*. Restrictions as formal practices were exemplified by a participant's comment that the British Columbia Law Society requires its members to disclose any major psychiatric conditions. Informal practices created restrictions for participants in diverse circumstances, including those that were least expected: in the context of health care services. One participant said: *I've had psychiatrists who won't see me because I'm bipolar!* Family members described being discouraged from calling hospitals and having their opinions (and experiences of the person living with bipolar disorder) excluded from discharge plan discussions. A father of sons with bipolar disorder elaborated:

It's probably health professionals not understanding the place of a parent or an advocate, just completely misunderstanding the role. Partly they put up the privacy act issues and partly they just feel like, I would say the arrogance of being gate keepers of all knowledge, of all medicine. And you know patience runs out. You just say 'come on, I know this person way better than you. Wouldn't you please just listen?' So, incredible exasperation.

The perceived lack of compassion and understanding within the mental health system ranged from general practitioners' ignorance about the condition to some professionals' authoritative, non client-centred stance toward people with bipolar disorder. A

participant with bipolar disorder offered a description consistent with theoretical notions of structural stigma: *devaluing, loss of respect or having people be condescending...and mostly this is used against me by authorities in judgments.*

Despite a general acceptance of consumer roles in mental health services, the extent to which staff accepted people in peer support roles remained variable. People with bipolar disorder who were employed to support others living with mental conditions experienced subtle but significant exclusionary practices at work. One participant described expressions of stigma between consumer support workers and staff.

They [peer support workers] were not allowed into the staff room and I felt like that was just such a physical expression of stigma. They were accompanied to use the photocopier; it was just ridiculous. And they totally had gotten used to it and taken it for granted at this point. Like the back of the bus kind of thing, ridiculous! And they are horribly underpaid.

The reality of consumers being a part of — but apart from — the mental health team was manifested in different ways, such as not being given a key to the staff bathroom.

Structural stigma in competitive employment was most often discussed in the context of fearing unwanted disclosure and job loss, reduced career advancement, and education concerns. Participants worried about the consequences of disclosing bipolar disorder at work including the risk of being fired. Understandably, being fired was associated with feeling devalued and rejected. Whether being fired resulted from overt discrimination or unsatisfactory job performance, the material and emotional consequences were serious.

I lost my work because I became sick and I couldn't do my job anymore... That is a huge impact on your quality of life if you lose your job and you're like, 'am I going to find something else if my illness is going to prevent me from holding down a job?'... Jumping through all the hoops, even in terms of applying for benefits. All very difficult to do especially when you're sick, right? And feeling like you're in limbo and you don't know how your life is going to go on.

Disclosure of bipolar disorder was an issue some students faced. Sometimes they were encouraged to conceal their diagnosis, for example, on graduate school applications. Other students recounted experiences during which unwelcome disclosure was initiated by people in positions of authority.

I was in university at the time taking music; I was 18. I left halfway through the course for about two weeks, for my first psychiatric stage. I came back and I remember

my instructor in front of the class, she starts getting into a thing about how a lot of composers have mental illness. Then she decided to tell everyone that that's why I was in the hospital. That was it. No one wanted to talk to me after that, so I ended up dropping out for the first time.

Social Stigma: If My Child Had Leukaemia, You Would All Be Bringing Me Lasagna

All participants discussed the inaccurate and misleading representation of individuals living with bipolar disorder in the media, where the focus has been on the sensational events rather than successful lives (Wahl, 1999). Participants described how negative images reinforce bipolar disorder stereotypes through language and in films.

It seems okay for there to be this stereotype of negative connotations with mental illness, whereas it is not acceptable anymore to out and out slur racist jargon or to put other people down based on their specialties. It's okay to make fun of somebody who's bipolar or schizophrenic. It's really sad, the movies about mad people. Deranged and everything; that just perpetuates the myth.

Quality of life for people with bipolar disorder, as well as and their families, was compromised by everyday (mis)understandings of the condition. Social stigma affected interactions at a community level; it was felt keenly within family relationships, where acceptance is expected. One mother whose child has bipolar disorder said:

I've always said to family, 'You know what? If my child had leukaemia, you would all be bringing me lasagna. But now he has bipolar disorder, you are not showing up.' So for me that's where the stigma is present for us.

Several family members raised the issue of bipolar disorder within their extended family to garner acceptance and support for the affected individual. Despite some positive outcomes, family responses were often disappointing, as evidenced by one participant's efforts to help his relatives accept their son's diagnosis.

His parents kind of abdicated simply because they saw the addiction issues. As a result, this young man, he has lived on the street, he's just been all over [and despite having] very well-meaning wonderful parents, he's suffered a lot. Because unfortunately they just have not even today come to the place of just saying, 'okay, he's mentally ill. Let's deal with that, let's target that.'

The impact of social stigma on quality of life also occurred in more subtle ways. When describing the meaning of stigma, one participant stated, *I feel stigma shrinks my bubble. So I have a less-than experience to a certain*

extent. Adults with bipolar disorder were excluded from family party invitations and their relationships with siblings were negatively affected. Stigma became an obstacle to maintaining friendships.

I lost friends when I became ill. People were withdrawing from me and kind of cutting me out of their life. And that was really confusing to me, that it was happening, because I thought these were good friends. That's one of the ways in which stigma has moved against me.

What's Wrong With Me? The Burden of Self-Stigma

Participants described affective and cognitive elements of internalized stigma. They identified shame, self-blame, self-doubt, self-judgment, and self-loathing as part of their daily experience of living with bipolar disorder. Internalised negative attitudes influenced activities, relationships, and decisions, thereby affecting quality of life. The shame of having bipolar disorder was coupled with negative feelings such as self-loathing and depression, which one participant identified as a vicious cycle. This participant explained: *I didn't really have that much stigma with other people so it's mostly with myself. Judging myself and being uncomfortable with myself and thinking 'am I weird?' or 'what's wrong with me?'*

Self-stigma affected the choices people made and limited their potential to engage in customary life activities. For example, parents described anticipating judgment and discomfort from their relatives, prompting avoidance of social situations. The influence of negative self-assessments on everyday life was captured by one participant who described being ... *shy and shamed because I don't want to show my [disability] bus pass to the driver.* Clearly, not using the bus constrains community mobility and leads to greater social exclusion. Another impact of self-stigma was the self-limiting belief that important life goals, typical of those of others at their age and stage of life, cannot be achieved. One participant living with bipolar disorder explained:

I thought I was a bad person because I couldn't do what other people do. I couldn't make money and I couldn't do all sorts of different things and because of those things, I thought I would self-exclude from having relationships, from trying to advance my career.

Self-stigma places the blame on the individual with bipolar disorder, leaving little room for acknowledging the roles of societal misinformation or structural barriers. Participants described a *fear of the unknown* that drives societal stigma and adds to their own lack of understanding. At times misunderstandings about bipolar disorder contested the very notion of its legitimacy as an illness. One participant explained that *there's also a sense of blame that it's not a real illness. It's a moral property or a values issue.*

The dire picture provided by participants' health care providers also contributed to self-stigma. Despite the knowledge expected of health care practitioners, these professionals sometimes perpetuated misunderstanding.

You get all this information about your illness and it's brutal and it's so discouraging. Then you kind of feel like, 'oh, this is how it's going to be?'...It's really hard to overcome this, the stigma you initially internalize.

Although recognising the impact of self-stigma, participants identified the importance of taking responsibility for themselves and learning more about living with bipolar disorder from credible sources. Messages of hope emerged as people found they could take control of their thoughts and feelings, thereby mitigating negative self-judgments. Elements of recovery and resilience can be understood as the fading of 'what's wrong with me?' and the emerging of a revised identity.

Bipolar is a part of who I am, a big part, but it's not all. I have a million other things going on. And I just want to see where life takes me and be out there in the world, as I am.

Participants' talk of recovery revealed the hope they have to overcome self-stigma. Their sense of hope was aided by working with health care professionals who had a psychosocial rehabilitation orientation and were client-centred. Participants identified the importance of being open about bipolar disorder and noted that appropriate disclosure becomes easier throughout the lifespan. Also described was the necessity of self-management strategies, such as connecting with others for support, to cope with the burden of self-stigma. Although positive public role models with bipolar disorder may reduce self-stigma, ultimately, the answer to self-stigma is that *change has to come from within*. A life lived without the burden of self-stigma can reduce the sense of limitation clearly identified by our participants, and free the self to see *a bigger reality out there*.

Discussion

Our study used community-based participatory research and qualitative methods to examine how stigma is understood and experienced by people who live with bipolar disorder and their family members. For participants, stigma manifested in both subtle and explicit ways; it was commonly perceived to be an impediment to maintaining quality of life and to resuming conventional life. Although these findings do not purport to be generalisable, overall participants' narratives reaffirmed previous findings from

other qualitative research involving people who have other mental illnesses (Dinos, *et al.*, 2004; Knight, Wykes & Hayward, 2003; Schulze & Angermeyer, 2003). Thus, although disorder-specific structural and social stigma may well exist (Crisp *et al.*, 2000), people with different types of mental conditions also may share similar perspectives and experiences related to stigma.

The inductive and deductive analytic approach adopted in the current study enabled us to discover themes from the data while also situating the results in the familiar framework of structural, social, and self-stigma. Structural stigma was reflected in participants' narratives about the policies and informal practices of our social institutions (e.g., school, work, and health-care) that made them feel like excluded and devalued members of society. This theme has also been echoed in several other studies. For instance, a qualitative study by Gonzalez and colleagues (2007) found that people with schizophrenia (n=18) and their relatives (n=26) were frequently exposed to self-perceived stigma in health care and employment settings. Federally-funded national organisations that work against stigma at all levels operate in Canada (Mental Health Commission of Canada, 2011), the UK (Time to Change, 2011) and New Zealand (Like Minds, Like Mine, 2011). Time to Change, for example, directs its campaigns at the entire population and works with the police, the judiciary and at other structural levels to combat discrimination. Strategies for addressing structural stigma such as legislative reform are detailed in recent publications (Corrigan, Roe, & Tsang, 2011; Hinshaw, 2007).

Social stigma was a prevalent experience among our study participants who spoke about negative media representations of mental illness and having to contend with social relationships that were strained by the lack of knowledge and negative attitudes about bipolar disorder. As the title of this paper suggests, the social and structural manifestations of *stigma shrinks my bubble* occur through decreased opportunities for individuals to participate in important domains of conventional life.

Self-stigma was represented in the participants' choice of words, such as *discouraging, self-excluded, shamed, blame, uncomfortable, and judging myself*. For some, these negative, self-limiting thoughts had a crippling effect on their desire to pursue social relationships and life goals. Conversely, self-stigma was also perceived as being within the control of the individual, and therefore amenable to change. Participants identified several strategies, such as finding support from others, which helped in coping with self-stigma. These strategies complement other recommended approaches for overcoming self-stigma: engaging in treatment (e.g., cognitive behavioural therapy), learning to manage

disclosure, and participating in activities that foster personal empowerment (Corrigan *et al.*, 2011; Hinshaw, 2007).

Although our data on stigma among people with bipolar disorder and their family members resonate with findings of other studies, we believe that the community-based participatory research approach used to examine this topic reflects a progressive, principled style of knowledge production serving the needs of the community of persons with bipolar disorder, including affected individuals, families, researchers, and service providers. Engaging people who live with bipolar disorder throughout the entire research process — including research design, focus group facilitation, data analysis, and interpretation — grounded the data in the lived experience of bipolar disorder, thereby enhancing the credibility of the results. We also contend that examining stigma from the perspective of both family members and people who live with bipolar disorder strengthens the validity of our findings.

In our continued research on bipolar disorder stigma, CREST.BD is using a novel theatrical performance that incorporates a performer's lived experience with stigma. In this study the knowledge and attitudes of research participants, both those individuals living with bipolar disorder and healthcare providers, are measured pre- and post-exposure to the theatre event. Future self-stigma research that builds on the findings reported here will occur as part of a study that aims to determine, quantitatively, the self-management

strategies most useful for maintaining wellness in people with bipolar disorder.

Limitations

There are three major limitations to consider in interpreting these findings. First, although our focus group method encouraged dialogue, interaction, and openness, it may not have been well-suited for people who were uncomfortable sharing personal information in a group setting. Second, well-educated participants were over-represented in our sample. As they do not reflect the ethnic, cultural, and economic diversity that typifies this part of Canada, we recognise that other perspectives were missed. Third, our analysis was focused on themes and patterns that were similar among the study participants. Because we did not contrast different perspectives between family members and people with bipolar disorder, we may have downplayed some of the complexity and idiosyncrasy of the findings.

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