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Chronic Illness 2011 7: 209 originally published online 28 February 2011
DOI: 10.1177/1742395310395959

The online version of this article can be found at:
http://chi.sagepub.com/content/7/3/209
‘It’s something that I manage but it is not who I am’: reflections on internalized stigma in individuals with bipolar disorder

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Abstract
Bipolar disorder (BD) is a complex chronic condition associated with substantial costs, both at a personal and societal level. Growing research indicates that experiences with stigma may play a significant role in contributing to the distress, disability, and poor quality of life (QoL) often experienced in people with BD. Here, we present a sub-set of findings from a qualitative study of self-management strategies utilized by high functioning Canadian individuals with BD. Specifically, we describe a theme relating to participants’ experiences and understandings of internalized stigma. Descriptive qualitative methods were used including purposeful sampling and thematic analysis. High functioning individuals with BD type I or II (N = 32) completed quantitative scales to assess symptoms, functioning and QoL, and participated in an individual interview or focus group to discuss the self-management strategies that they use to maintain or regain wellness. Thematic analysis identified several themes, including one relating to internalized stigma. Within this, four additional themes were identified: stigma expectations and experiences, sense of self/identity, judicious disclosure, and moving beyond internalised stigma. One of the more unique aspects of the study is that it involves a participant sample that is managing well with their illness, which differs from the norm in biomedical research that typically focuses on pathology, problems and dysfunction.

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Introduction

People with mental illness often have to endure negative life experiences due to the symptoms of their condition and face deficits in functioning and quality of life (QoL). In addition, they may also have to struggle with the negative attitudes and behaviours that society, and they themselves, hold regarding mental illness. Stigma is a complex, multifaceted social process that consists of labelling, stereotyping, separation, status loss, and discrimination that co-occur in a power differential. Three levels of stigma identified within the research literature consist of public, structural and internalized stigma. Public stigma refers to the phenomenon of large social groups endorsing stereotypes about mental illness and acting against individuals who are labelled mentally ill. Structural stigma refers to institutional policies and practices—the structures that surround a person—that create inequality by restricting opportunities for people with mental illness. Internalized stigma refers to a subjective process, embedded within a socio-cultural context, which may be 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. The concept of internalized stigma is central to the understanding of the psychological harm that is produced by stigma.

Bipolar disorder (BD) is a complex chronic mental illness characterized by recurrent episodes of depression and elated mood. BD type I is characterized by recurring episodes of depression and mania (a distinct period of abnormally elevated, expansive or irritable mood), while BD type II is characterized by depression and hypomania (the subsyndromal counterpart to mania). Research into BD has historically focused upon the biological and genetic causes of the condition, and pharmacological approaches to its treatment. Research into psychosocial factors in BD has been relatively slow on the uptake compared to corresponding research into other forms of mental illness, such as unipolar depression or schizophrenia. However, it is now recognized that psychosocial factors have a significant impact upon how the condition manifests with a range of psychological, social, and family factors being implicated in the onset and course of BD (for example). Further, there is growing evidence that psychosocial interventions improve outcomes in BD.

Research into the role of one psychosocial factor in particular—stigma—has also been slow on the uptake in relation to mood disorders, but existing studies have revealed that, like other psychiatric illnesses, BD is a profoundly stigmatizing condition and that stigma is a common experience in both people with BD and their caregivers. Research also indicates that internalized stigma can have profound implications for behaviours and outcomes in affected individuals. For example, a study of 200 individuals with either a diagnosis or significant family history of BD found that those with heightened perceptions of stigma described themselves as significantly less willing to have children. Another study of people with BD (N = 264) revealed that those with strong concerns about stigma during the acute phase of their illness exhibited greater impairment in subsequent social and leisure functioning, even after symptom severity, baseline social
adaptation, and sociodemographic characteristics were controlled for. In addition to these quantitative investigations, a small number of qualitative studies have highlighted the potential influence of internalized stigma on subjective experiences. Stigma experiences were described by all participants in a study of depressed individuals with rapid-cycling BD \((N = 19)\). Participants described employing strategies for selectively disclosing their diagnosis, sometimes going to lengths to conceal their diagnosis and the fact that they were taking psychiatric medications. In another qualitative study, Australians with BD (type I) described their struggles with feelings of isolation, rejection, and workplace stigma. Recently diagnosed individuals with BD \((N = 26)\) participating in an Internet-based study described their loss of a sense of self, uncertainty about the future, and stigma as major difficulties that they faced following their diagnosis. Our own qualitative research has revealed that individuals occupying different roles in relation to BD (those who experience BD, care for persons with BD, or are experts in treating BD) all identified stigma and discrimination as factors that can profoundly impact QoL and workplace functioning for people in this population.

In summary, there are preliminary quantitative and qualitative findings indicating that stigma can play an important role in the expression and experience of BD. In this article, we seek to advance this literature by reporting on qualitative findings from a study examining the self-management strategies used by high functioning individuals with BD. Our rationale for focusing upon individuals who are living well with BD was threefold. First, we wanted to diverge from the traditional stance of BD research—which historically has focused on pathology and dysfunction—by adopting a ‘strengths-based’ approach. Second, we were cognisant from our QoL research in this area that some people with BD do learn to live well with this chronic health condition and experience good QoL; we believed that it was important to give voice to the positive well-being strategies found effective by these individuals. Third, focusing on this group holds the potential to provide insights into experiences at a different point in the recovery timeline; people who are functioning well with a chronic illness may, for example, be addressing issues related to social identity and that are situated primarily outside of the medical system. This contrasts with research with severely ill individuals whose experiences are often overwhelmed with symptoms and medication side-effects, and whose lives are immersed within the medical system. Data from the participant sample were analysed to identify five themes regarding ‘wellness’ in BD: (1) taking care of myself; self-management strategies for BD; (2) accepting BD, not being defined by it; (3) social support; (4) focus on personal growth; and (5) stigma. The objective of this article is to focus in depth upon the last of these themes: experiences and understandings of stigma from the perspective of individuals who are functioning well with BD.

Methods
Methodological approach
The study was carried out using descriptive qualitative methods. Qualitative description is a research method based on the general tenets of naturalistic inquiry with the purpose of providing a description and summary of the phenomenon/experience being studied. Design features include purposeful sampling, interviews and/or focus group interviews, and qualitative data analysis strategies (such as content analysis or thematic analysis). As such, qualitative description is a well-suited method for this research which is aimed at exploring and describing the meaning and experience of stigma for participants living...
with BD. Thematic analysis was used as the analytic framework for identifying themes in the current data set. Ethical approval for the study was granted by the UBC Behavioural Research Ethics Board committee.

Recruitment

Guiding factors that determined study sample size included the scope, intent of the study (an in-depth exploration of the experiential nature of living well with BD types I and II), and the literature using descriptive qualitative methods. A review of the research using descriptive qualitative methods revealed frequent sample sizes of between 10 and 20 participants (e.g.,). Although our initial recruitment strategies yielded a sample size commensurate with qualitative description, it did not reflect the experiences of individuals with BD type II. Purposeful sampling was therefore subsequently used to selectively recruit for male participants and individuals with BD type II yielding a final sample size of 32. Participants were recruited by distributing advertisements throughout British Columbia, Canada via a range of methods, including newsletters of local non-profit mental health organizations, newspapers, public lectures and education events, and online resources. The advertisement asked that people with a diagnosis of BD type I or II who felt that they were ‘functioning well’ to contact the research team.

Screening

Potential participants were screened by telephone for inclusion with the MINI International Neuropsychiatric Interview to confirm diagnosis of BD and with the Multidimensional Scale of Independent Functioning (MSIF) to assess functioning across work, residential, and educational domains. The MSIF has been validated for assessing functioning and disability in BD.

Inclusion criteria

Participants were required to be 19 years of age or older, be fluent in English, have a global score of 1 or 2 on the MSIF (‘no’ or ‘very mild’ disability), and not be in an episode of illness that would render participation in a qualitative interview or focus group difficult (e.g., severe depression or florid mania). Individuals who were experiencing a mood episode but were still functioning well remained eligible for participation, as we believed that important insights into self-management strategies for BD would be gained by including those who maintained their functional status despite high symptom burden.

Quantitative methods

Upon consenting to participate in the research, participants were asked to complete several self-report and clinician-administered scales. The primary purpose of this article is to describe the qualitative experiences of participants; therefore, the quantitative data are outlined in Table 1 for the sole purpose of describing the sample. The importance of stigma was not ascertained until the analysis phase of the study; consequently, quantitative scales of internalized stigma were not administered.

Qualitative methods

Following completion of the quantitative assessment scales, participants self-selected either an individual interview or a focus group to discuss the self-management strategies they employed in relation to their BD. Our rationale for allowing participants to choose between an interview or focus group involved recruitment considerations and our approach to data analysis. We believed that
some participants would be more comfortable in one type of interview setting over another. Both the focus groups and individual interviews used the same set of core questions as our aim was to explore the topic in depth and encourage discussion of unique experiences. This contrasts with the aims of some focus group research where the intent is to reach consensus, to identify points of disagreement and to analyse the effects of group dynamics. In this study, the data from each type of interview were analysed according to the individual’s perspectives; the fact that we had a small number of members in each focus group (2, 3, and 4 participants) enabled us to identify individual perspective and comments with relative ease.

Individual interviews were conducted by one of the research team members (EM, psychologist and researcher in...
psychiatry; MS, qualitative researcher in occupational science; SH, clinician and occupational therapist) and lasted between 60 and 90 min. The interviews took place in the participants’ homes, at the university, and/or over the telephone (rural or remote participants). Three focus groups of a similar duration were held at the university and facilitated by the above team members. The research team developed a standardized semi-structured interview guide; all participants were asked the same core set of questions, but interviewers maintained the latitude to ask additional questions where appropriate or required for clarification. Questions pertaining to stigma included: ‘Have you experienced stigma as a result of having BD?’; ‘Does your diagnosis of BD have an impact on how you think about yourself?’; and ‘Do you think there are barriers in the healthcare system that affect your ability to stay well?’ These questions encouraged individuals to tell their own story, thereby contributing insights and experiences that broadened our understanding of managing well with BD and illuminating stigma. All interviews were audio recorded and transcribed verbatim.

As is common in qualitative traditions, data collection and data analysis occurred concurrently, and thematic analysis was used to compare, contrast, and categorize the data into themes (both within and across transcripts). The data were coded, organized, and re-organized several times as categories were developed without reference to any conceptual frameworks, and an exploration of the relationships between and within sub-categories led to the development of an initial coding framework and preliminary themes. The research team met to evaluate the initial coding framework and to synthesize the categories and concepts into themes. Data were then re-coded according to these themes, whereupon coded data segments were again reviewed to determine their fit with each theme. NVivoQSR, a qualitative software program, was used to manage the data and facilitate data analysis. The team held analytic meetings to discuss and monitor coding consistency, and thus address the analytic validity of identified themes. In addition, the team met to ensure that the findings were internally consistent and supported by the data from the participants’ interviews.

Results

Demographic and clinical characteristics for the sample \((N = 32)\) are provided in Table 1. In terms of demographics, approximately two-thirds of the sample were women and most described themselves as Caucasian. In terms of clinical characteristics, three quarters of the sample were diagnosed with BD type I and mean scores on symptom measures indicated sub-threshold levels of manic symptoms and mild to moderate depressive symptoms, although QoL scores were in the normal (i.e., general population) range. It is worthwhile to note that the average participant had a significant clinical history of BD, in terms of episodes and hospital admissions, indicating that, although this sample was currently functioning well, this was not simply a sample of individuals who had experienced a mild course of the disorder.

Stigma arose as one theme from the qualitative data analysis of the larger wellness study. In this article, we focus upon findings specific to participants’ experiences and understandings of stigma. As participants’ stories were analysed, the following four themes relevant to internalized stigma were identified: (1) expectations and experiences; (2) sense of self/identity; (3) judicious disclosure; and (4) moving beyond internalized stigma. Narrative excerpts are provided below to illustrate the four themes from the participants’ perspectives (Table 2).
The first theme, ‘expectations and experiences’, describes the negative social responses that participants either anticipate or encounter as a result of having BD. All participants in the sample mentioned that, at some point during the course of their illness, they had expectations of, or actual experiences with, stigma. Here, expectation implies an assumed response of others to BD, as was implied by Anne: ‘nobody looks twice at you if you have diabetes, but if you have a mental disorder, then you’re crazy.’ Experiences, on the other hand, refer to actual exchanges that participants have had that were considered stigmatizing. To reflect the interwoven manner in which participants discussed stigma expectations and experiences, these two concepts are combined into one theme for the purposes of this article.

In relation to stigma experiences, several participants identified the sensationalistic and inaccurate portrayal of BD by popular media. Sarah explained:

I think there’s sort of cultural or media images of bipolar which totally don’t relate to my reality. Frequently I’ll be watching a TV show and usually it’s about some psychopathic murderer and they are defining him as bipolar...

Sarah also expressed concern with the media having ‘latched onto’ BD as ‘the tag of the day.’ Media images of BD impact the way society views and understands individuals living with the illness—a frustration that Kate expressed, ‘They [the public] think you’re homeless, picking pop cans, in and out of Riverview [a psychiatric hospital] you know, dangerous, violent, running around deranged.’

Participants frequently identified how culture, including ethnic background and familial culture, contributed to their experience of stigma. In particular, participants who identified as British, Asian or Indo-Canadian

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<th>Pseudonym</th>
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Notes: *Female = 1; male = 2.

BD I = 1; BD II = 2.
recognized an increased stigma due to their particular ethnic background. For example, a woman of Chinese descent, Jeannie, who was recently diagnosed with BD spoke about the high level of stigma within her own ethnic group: 'In the Chinese community I would say these mood disorders aren’t really recognised. It’s either you’re crazy or you’re not.’ Two participants referred to an increased sense of shame associated with having a mental illness in the context of their British heritage. For instance, Mary referred to her BD as a ‘closed issue’ and ‘a closeted thing in our family.’

Other participants who did not identify with a particular ethnic group mentioned feelings of stigma within a smaller cultural unit—the family. They spoke about how mental illness was met with silence by people from their parents’ and grandparents’ generations. Indeed, the topic of intergenerational silence regarding family members living with mental illness was mentioned by many participants. For example, Mary said:

When I came out of from the hospital, I stopped by my grandmother’s place and I was just told that my grandmother had the same problem, she will understand. But...then, it was understood that I would never ever mention that issue again.

Other experiences arose from an individual’s current family circumstances. Hannah, who along with her young children, lived with her parents and described the family’s response to her BD diagnosis:

But my family will continue for the rest of their lives to judge me for it [the BD diagnosis]...Once you’ve been diagnosed with an illness people will use that against you for the rest of your life.

**Sense of self/identity**

The ‘sense of self/identity’ theme refers to the effect that BD has on participants’ views or definitions of themselves. Although many of the participants acknowledged that their sense of self/identity has been affected by their BD diagnosis, not all of these effects were negative. More than one quarter of the sample felt that BD has had a negative effect on their self-image, while fewer respondents were either neutral or noted a positive impact of BD on their sense of self/identity.

Although the relationship between BD and participants’ sense of self/identity was not always described in great detail, in certain cases, statements about this relationship were striking in terms of the potential magnitude of impact the diagnosis of BD carried. Lydia stated:

I had a huge amount of internal stigma, and walked around like ‘Oh god, everybody knows,’ you know, and felt like a loser. I went into a huge depression around it, felt like I was inadequate.

Similarly, Olivia described the effect of the diagnosis:

Oh, I have a mental illness! There’s something wrong with me. Now no one will ever want me...feeling very flawed...I don’t want to be categorised...I myself had an idea of what a bipolar person was like...and I’m not like that.

Upon being asked whether or not BD has defined her, Lydia reflected on how she would be perceived by others:

Oh, [it] defined me, yeah. So, I walked around thinking everybody could see, like “oh, I have mental illness”...I think I already had that kind of an internalized stigma or an internalized shame. And so it was just something that escalated it to a big huge like, walking blemish, you know...

Participants also spoke about how their identity was enveloped by BD, with their actions and behaviours being perceived by others as resulting from...
their illness. Anne said:

People look down their nose at me. Attributing any time that I’m happy or any time that I’m sad to being bipolar. And it’s not me...being defined as bipolar, instead of me being defined as having bipolar.

Not all participants expressed a negative experience of their identity being subsumed or tainted by their BD diagnosis. For example, Sarah stated:

What I’m finding is just managing life in general, just being a mom and a teacher and a wife and a homemaker and all that stuff is enough to deal with. So that I don’t think of it in terms of, ‘am I managing this as a bipolar person?’ I just think, ‘am I managing this as a person?’

The ‘people-first’ discourse was also apparent in the following comment made by Charlotte: ‘Getting a label doesn’t mean it defines you, it’s like I am not bipolar. I have bipolar disorder, it’s something that I manage but it is not who I am.’

Some participants interpreted their association with BD as being positive for their identity. For example, a teacher, Sarah, described going through the process of being hospitalized due to BD and then regaining her functioning, reflecting on it in a positive light:

[Y]ou don’t want to admit stuff like [depression] if you’re a teacher because you think you have to be this perfect role model, but it’s not actually a flaw. I think it’s actually a strength if you can go through something like that and come out on the other side...Cause there’s a lot of kids who go through it too, and they need to know that they’re not alone.

Judicious disclosure

The third theme emerging from participants’ narratives refers to the ways in which high functioning individuals with BD have learned to cope with and manage internalized stigma through ‘judicious disclosure.’ Rather than simply hiding or ‘coming out’, the participants describe using an informal process to evaluate the extent to which they should reveal information about their BD. Jeannie differentiated judicious disclosure from ‘coming out’ by saying, ‘I don’t really disclose it to everyone. I don’t advertise that I’m bipolar.’ Similarly, Max recounted his father’s suggestion to, ‘deal with it, acknowledge it, but it doesn’t have to be on your business card.’

Through trial and error, many participants have adopted strategies to assess whether disclosing information about their BD will lead to positive or negative outcomes. For some participants, the nature of the setting is a consideration for whether to reveal information about their illness. They describe differentiating between casual and formal situations when choosing to disclose their illness. Molly explained:

I don’t have many close friends but I’ve got lots of acquaintances, and I’m very open about my episode and talking of bipolar. But in any kind of school or professional setting I’d be pretty loath to talk about it.

In addition to varying disclosure strategies according to setting, participants also spoke about disclosing their BD only in situations where it was necessary or advantageous. For example, Jane felt that her illness was not ‘publicly identifiable’ and explained her reason for not disclosing her BD in the workplace: ‘People in my work life don’t know my diagnosis...because it doesn’t interfere with my work at this time, so it’s not something I feel like I need to talk about.’ Jane elaborated on the value of having the right skills to identify situations where it may be beneficial to disclose:

I definitely get better services by disclosing it. Like, for example, when I first left my
job in the middle of hypomanic episode and... when I talked to the woman at the EI [employment insurance office]... I said, ‘You know it’s, actually to be honest, I’ve just been recently diagnosed with bipolar disorder’... then she could understand my situation with compassion and that helped me get better services... I use it to my advantage.

Another consideration for judicious disclosure that several participants mentioned is whether the person to whom they are considering revealing information is perceived as knowledgeable and understanding. Daria offered a number of insights that contribute to an understanding of judicious and injudicious disclosure. Daria chose to disclose her BD only to people who she knew would receive the information well, such as a close circle of friends or colleagues: ‘You see once people know you and love you and they find that you have it, they’re not going to change their opinion.’

Failure to employ judicious disclosure strategies can lead to angst and worry amongst individuals with BD. Daria explained:

In retrospect I wish I had not told a few people whom I have told. Not being very judicious about who you tell definitely has its pitfalls.

However, some participants explained that disclosure of BD is not always a choice, as symptoms may unavoidably create situations of disclosure. These situations of injudicious or forced disclosure can be experienced as quite negative, as Daria described:

When I’m sick I take pleasure in telling people I’m bipolar... since I’ve been more stable, I’ve not done it as often and I think that’s a good plan because I’m told that that’s not necessarily who I am.

In contrast, Daria identified that positive experiences may also result from this type of injudicious disclosure:

My first coming out of the closet happened rather dramatically with my having a nervous breakdown in school when I was a teacher... It was the best thing that ever happened to me... because now I could be sick in public and not worry about it.

Sarah reflected on positive feelings that were associated with disclosing her BD: ‘It’s been a source of support if they know [about BD] and they’ve just been treating me the same.’ Another participant, Pamela, described disclosure as the gateway to her continued wellness:

I said, “Okay, I got bipolar illness.” And I told people. It has always been a deep dark secret and it was that coming out and telling people where... I allowed myself to realize that I am bipolar.

Similarly, the process of disclosure is perceived by some as being empowering, as Charlotte shared:

I used to worry about stigma coming up and, honestly, whenever I’ve disclosed... it’s been more of an empowering thing because it’s something you’ve come through and become stronger by.

**Moving beyond internalized stigma**

The fourth theme, ‘moving beyond internalized stigma’, describes participants’ reflections on no longer internalizing stigma towards their own mental illness. Several participants made specific reference to having moved beyond internalized stigma. This sentiment was articulated by Olivia who initially felt ‘flawed’, but ‘then I relaxed about it... and now it doesn’t bother me.’

Anne acknowledged that, although she no longer allows her BD diagnosis to tarnish her self-image, stigma still exists...
in society:

When I first got my diagnosis, I felt like I was defective, but it doesn’t really define me anymore. I don’t let it. But as far as society, very few people know [about her diagnosis] because of the stigma attached.

Sarah talked about her progression from diagnosis to her current state:

So, I don’t think of myself as [a] bipolar person anymore. I just think of myself [as someone] who went through something. That was the handy label that they put on it because that’s how [it] helped the professional to treat me and the treatment certainly helped.

Lydia commented that after initial feelings of ‘internal stigma’ she was able to move beyond the labels she had allowed to shape her sense of self:

[I] came to another place. I guess I didn’t really do a flip-side of it, but I have come slowly to an awareness that, you know what? I’m not a freak and I’m not so different from any other people.

On a similar note, Bess discussed her evolution from internalized stigma towards a more positive view of self where she was ‘not ashamed about it ... not anymore’.

Discussion

In this article, we describe the qualitative findings of a study regarding the self-management strategies used by a sample of high functioning individuals with a chronic form of mental illness. Our analysis reveals that participants consider internalized stigma to be a factor that significantly affects their ability to self-manage BD. Indeed, internalized stigma appears to add a layer of complexity for individuals with BD who are seeking to both reclaim their identity and recover their roles in society.

Participants face a constant negotiation between the stereotype-laden social-identity and the self-identity that they choose to adopt. Some qualitative research paints an essentializing and rather bleak picture as to how individuals with BD perceive themselves, for example, ‘bipolar patients view themselves as unstable, defective, and helpless, their lives as disordered, their community as rejecting them, and their future as uncertain and hopeless’. In contrast, our study suggests that people with BD are not always passive and inevitable receptacles of stigma—rather, they describe a range of subjective experiences as they actively manage their illness and mitigate internalized stigma.

Our analysis has uncovered that the subjective experience of stigma has consequences with respect to how individuals understand their sense of self or identity.* Drawing on a symbolic interactionist perspective (e.g.,), identity can be conceptualized as a complex social construction evolving out of various interactions with others in multiple social contexts. People develop their identities within a system of social interactions and negotiations, where meanings about the self are developed and transmitted. Thus, identities are ‘strategic constructions created through interaction, with social and material consequences’. Stigma is one such possible corollary.

Study participants discussed the impact of BD upon their identity, with both positive and negative accounts emerging. An individual’s identity is both personal and social and considered to be ‘an outcome of social symbolic interaction’. One’s personal identity refers to the idiosyncratic and unique attributes that distinguish the person from others; whereas one’s social identity refers to how people see and

*Here, we use the terms ‘self’ and ‘identity’ interchangeably.
define themselves in relation to their membership in a social group or category.\(^5\)\(^7\) Traditionally, researchers\(^5\)\(^9\),\(^6\)\(^1\)-\(^6\)\(^3\) interested in the intersection between acquired illness and identity have theorized the experiences of illness as an unsettling and disturbing disruption.

For some participants, the onset of BD marked a ‘biographical disruption’\(^6\)\(^4\) meaning that the onset of the illness signified a disruption in a person’s life that was identity-altering requiring a re-negotiation of identity and resulting in internalized stigma.\(^6\)\(^1\),\(^6\)\(^2\),\(^6\)\(^4\),\(^6\)\(^5\) Some participants described having an ‘illness identity’ imposed on them—whereby they were reduced to the symptoms and the undesirable characteristics of their illness—despite currently managing well with their BD. Participants’ experiences with the enduring effects of an extrinsically imposed illness identity are consistent with Goffman’s\(^5\)\(^6\) theorizing, and consistent with qualitative research in relation to subjective experiences with schizophrenia.\(^6\)\(^6\) Participants in our study referenced several potential sources that perpetuate stigma experiences and illness identity, including the stereotypical media images of BD, and the shame and embarrassment that are embedded within families and ethnic cultural groups.

For individuals who are managing well with their illness, BD is often a hidden condition, a concealable stigma. Individuals with a concealable stigma often have a choice of whether or not to disclose their illness to others. Consequently, managing the information that they share about their condition, also known as judicious disclosure, becomes a vital strategy to protect against negative reactions of others. As with the participants in other research,\(^2\)\(^3\) our sample provided detailed narratives about the disclosure decision-making process. Participants reported a range of positive (e.g., empowering) and negative (e.g., anxiety-provoking) experiences with the disclosure process. As with the participants in the Schutze\(^6\)\(^6\) study, our participants suggest that the desire to maintain a ‘normal’ life is a partial motive for using judicious disclosure strategies.

Having to face disclosure decisions on a regular basis may create additional stresses and challenges for individuals who have concealable stigmatized conditions. Pachankis\(^6\)\(^7\) proposes that managing the threat of potential discovery of a concealable stigma may result in cognitive (e.g., suspiciousness, preoccupation), affective (e.g., anxiety, demoralization), behavioural (e.g., social avoidance, impaired relationships) and self-evaluative (e.g., diminished self-efficacy, identity ambivalence) consequences. While this model focuses on the negative consequences of concealing a stigma, our participants highlight potential positive features of judicious disclosure. Likewise, Corrigan and Lundin\(^6\)\(^8\) offer a more balanced view of the costs and benefits for individuals who disclose their mental illness. They suggest that the potential benefits of disclosure may include: not having to be concerned about hiding experiences, the ability to be more open, encouraging engagement with people who are supportive or who share similar experiences, and playing a role in combating public stigma. Potential costs of disclosure may include: encountering negative reactions, risks of ostracism, discrimination experiences, and increased anxiety associated with concern of how one is perceived by others.

Increasingly, researchers question the original assumption that chronic illnesses necessarily result in a damaging biographical disruption.\(^6\)\(^2\),\(^6\)\(^5\),\(^6\)\(^9\) The results of this study support the literature that speaks to the risks associated with universalizing experiences of living with a chronic mental illness. Numerous study participants expressed positive accounts of living with BD, thus pointing to possible
transformative processes and highlighting diversity as opposed to homogeneity of experiences. Such findings do not point to either a positive or negative single identity journey. Instead, they point to contextually sensitive, multiple possible iterations of identity struggles and re-negotiations resulting from experiences of living with chronic illness. Several participants described how, upon being diagnosed with BD, they initially incorporated society’s negative attitudes towards mental illness internally, viewing themselves as damaged or flawed. However, a proportion of the sample described a progression from a state of stigma to one in which they no longer endorse and internalize stigma. These participants describe a gradual process of coming to terms with the diagnosis of mental illness, navigating the pitfalls of public stigma, negotiating BD into a holistic sense of self, and integrating the illness experience into a positive social identity—a process that is also reflected in the findings of other qualitative research. In their thorough review, Crocker and Major add insight into the phenomenon of individuals who successfully defend against the negative effects of internalized stigma. They proposed a number of mechanisms by which individuals seek protection from stigma through their stigmatized group membership, such as attributing negative feedback to one’s group membership, comparing themselves to others in similar situations (i.e., in-group comparisons), and selectively devaluing dimensions or attributes to which they or their group fare poorly. Many of these self-protective mechanisms resonate with the experiences of participants of this study, who actively manage their illness as well as the potential damage of internalized stigma. From a clinical perspective, our findings point to the potential importance of exploring understandings of stigma within the context of psychosocial interventions (e.g., psycho education or cognitive behaviour therapy) for chronic mental health conditions such as BD.

Limitations

The limitations of this study involve two related elements of the research design. Stigma is a theme that arose from a larger study that centred on self-management strategies that high functioning people with BD use to maintain or regain wellness. Thus, the interview questions posed to elicit stigma experiences and opinions were embedded in this larger study but did not constitute the primary research focus. A greater depth and breadth of perspectives about stigma may have been revealed by participants if it was the main purpose of the study. Related to this design feature is the recruitment process and subsequent sample that was created. The purposeful sampling that occurred through recruiting participants who were interested in, and capable of, describing their wellness strategies is likely to have missed many individuals who were primarily interested in sharing their views and lived experiences of stigma. Finally, the stigma findings do not reflect the perspectives of individuals with BD who are, by self-definition and quantitative measures, not managing as well with their condition. These insights may be forthcoming when the second phase of the study (in which we are interviewing people who are struggling to manage their BD) is complete. We have also undertaken further qualitative research into understandings of stigma using community-based research methods (see www.crestbd.ca for further details). Despite these limitations, the findings contribute to a growing body of literature that seeks to understand stigma through the lenses of those who experience it.

Conclusions

Consistent with other qualitative studies, our findings reveal that individuals...
who are assigned to a stigmatized group do not necessarily, nor passively, accept the negative consequences of this group membership. Few published studies describe how individuals with BD subjectively experience stigma. Moreover, no studies to date have focused specifically on how individuals who are functioning well with chronic mental illness understand and experience internalized stigma. By exploring stigma in a group of individuals who are well, this study adds new insight into the subjective experience of stigma and extends the qualitative research in this area.

Acknowledgements

We are indebted to the individuals who gave their time to participate in this study. E. Michalak is supported by a Scholar Award from the Michael Smith Foundation for Health Research and a New Investigator award from the Canadian Institutes for Health Research. The study was funded by the BC Medical Services Foundation.

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