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# Personal and Societal Construction of Illness Among Individuals With Rapid-Cycling Bipolar Disorder: A Life-Trajectory Perspective

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Objective: Bipolar disorder is a chronic mental illness associated with substantial impairment in quality of life and function. Although there has been tremendous growth in understanding bipolar disorder with respect to treatments, very little study has focused on the viewpoint of affected individuals. The purpose of this study was to examine the subjective experience of illness among 19 men and women with rapid cycling bipolar disorder receiving treatment at an academic psychiatry clinic. Methods: Personal constructs of illness with respect to life-trajectory and societal reaction to the individual, specifically the issue of stigma, were evaluated using a semistructured, open-ended anthropological interview. Results: Participants perceived bipolar disorder as a disease with biologic underpinnings. Stigma was a major issue for all individuals. In common with individuals without serious mental illness, individuals with bipolar disorder work at mastering developmental tasks appropriate for their life stage. At times, younger individuals appeared to have difficulty separating their own identity from the effects of illness. For older individuals with bipolar disorder, life was perceived to be disrupted by bipolar disorder, with early plans and dreams often "derailed." Conclusion: Although bipolar disorder may severely alter an individual's planned life trajectory, accomplishment of life goals can at least partially offset the sense of loss that is often seen in bipolar illness. (Am J Geriatr Psychiatry 2008; 16:718-726)

**Key Words:** Bipolar disorder, stigma, rapid cycling, life course, aging, subjective experience

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Bipolar disorder (BPD) is a serious and chronic mental illness that is associated with substantial impairment in quality of life and functional outcomes, high rates of suicide, and high financial costs. Classic, Type I BPD occurs in 0.4%–1.6% of the U.S. population, affecting somewhere in the order of 1 to 3.5 million individuals. Some individuals develop rapid-cycling BPD (RCBPD), a variant of illness in which mood episodes occur four or more times over the course of a year. RCBPD is known to be particularly refractory to standard medication treatments and may have a relatively poor prognosis.

Individuals with BPD, particularly those with RCBPD, often experience severe, negative psychosocial consequences of their illness that may profoundly affect interpersonal relationships, occupational functioning, self-esteem, and sense of self.<sup>3,4</sup> Although there is growing evidence that environmental and lifestyle features can have an impact on severity and course of illness, 5,6 it is likely that as individuals age their experience of illness may be affected by psychological developmental processes as well. There are a number of lifespan developmental theories that address psychosocial aspects of the aging process and that may be helpful in understanding individual coping with BPD across the lifespan.<sup>7–10</sup> How individuals perceive illness is affected by their own personal explanations of illness and concept of personal identity, as well as societal constructions of bipolar illness. Serious mental illnesses such as BPD tend to be highly stigmatizing, with affected individuals frequently marginalized and discriminated against by society at large.

Although there has been tremendous growth in understanding of BPD with respect to treatments and treatment outcomes, very little study has been devoted to understanding individual subjective experience of BPD and how this experience affects personal life domains. The theory, methods, and empirical findings of the social and behavioral science literatures have not traditionally been well integrated into clinical research. However, these approaches may inform our understanding of how individual characteristics affect treatment outcomes and may provide a complementary way to identify effective health interventions.

The purpose of our study was to analyze the subjective experience of illness among men and women with RCBPD to determine if this experience is affected by and, in turn, affects the developmental process. Personal constructs of illness with respect to life-trajectory and societal reaction to the individual, specifically the issue of stigma, were evaluated among older and younger individuals with BPD.

#### **METHODS**

This was a cross-sectional, exploratory study to evaluate illness experience in individuals with RCBPD receiving treatment at a specialty tertiary care academic psychiatry clinic. This analysis is part of a larger study evaluating illness behavior and treatment adherence in BPD (K-23 MH065599, PI Sajatovic), which enrolled individuals with an index depressive episode. As per the requirements of the larger study individuals were prescribed treatment with mood stabilizing medication or maintenance antipsychotic medication for at least 6 months and all had illness duration of at least 2 years but not more than 20 years. Individuals with BPD were enrolled following either self-referral in response to posted study advertisement or referral from clinic staff. Following confirmation of diagnostic/clinical status using the Mini-International Neuropsychiatric Interview (MINI) illness experience was evaluated with: 1) a semistructured, open-ended anthropological interview (SEMI); 2) quantitative rating scales, and 3) observation of the individual's appearance and behavior during the course of the interview. This study was approved by the local institutional review board and included consent for audiotaping. Any potential identifying features of the interviews, such as names of providers, friends, or residence location were changed during transcribing to preserve participant confidentiality.

The Subjective Experience of Medication Interview (SEMI) is a qualitative, semistructured assessment of subjective experience of mental illness, <sup>13</sup> which requires approximately 60–120 minutes to administer. Illness experience domains assessed include illness attitudes, attributions and behaviors, social relations, treatment history and medication experience, self-medication, quality of life, stigma, culture/ethnicity, and health care logistics. The SEMI has been modified for use in populations with BPD. The SEMI was conducted by research staff trained in its use by the investigators, and monitored via random reviews of

tape-recorded interviews/transcripts by another member of the research team. SEMI transcripts were also regularly reviewed for accuracy with audiotapes by a research staff member who did not originally transcribe the interview. SEMI data interpretation/coding is done by regular, multiple-rater (2–5 raters) consensus rating of specific domains, some of which were based upon predetermined themes taken directly from SEMI questions, and additional themes that emerged from the data/participant responses. Multirater consensus coding is conducted on a regular and ongoing basis by the research team to continue to refine coding accuracy. Degree of concordance among raters for SEMI theme coding was  $\kappa = 0.52$ –1.0, with a median of 0.77.

In addition to the SEMI, selected quantitative measures of domains of illness were performed, including the Hamilton Depression Rating Scale (HAM-D),<sup>14</sup> the Clinical Global Impression (CGI),<sup>15</sup> and the Insight and Treatment Attitudes Questionnaire (ITAQ).<sup>16</sup>

#### **Data Analysis**

The SEMI was transcribed from the audiotapes in its entirety. Following completion of the transcription, a brief narrative summation of the interview was completed to include features of the interview which the interviewer felt were important and which would not be apparent on the basis of content alone (for example, the fact that a participant might have appeared anxious, or preferred to sit in a corner of the room). Narrative statements made by subjects in response to specific SEMI questions included articulation of individual explanatory models of illness, effect on life trajectory, and perception of stigma in relation to a variety of personal features such as social relations and occupational role, ethnicity, medication and treatment, self-presentation, and popular perception. Narrative data from the SEMI was coded by other members of the research team into discrete themes, and evaluated across participants for each thematic domain. There were an initial set of predetermined themes based upon specific SEMI questions (for example, "Does anybody act differently toward you because of your illness?") to begin to assess the theme of stigma. Additionally, participant responses that expanded on these or other themes were analyzed in the context or setting in which the individual experienced them. In some instances data on a particular theme, such as stigma, were obtained at other points during the interview instead of, or in addition to, a specific query regarding societal reaction toward illness. This exploratory study initially utilized grounded theory to elicit themes, <sup>14</sup> and then examined the themes to determine relationship to established developmental models, specifically Erik Erikson's theory on adult psychosocial development. <sup>9,10</sup>

#### RESULTS

## **Quantitative Findings**

Mean age was 41.1 years (SD: 13.2, range: 20-62). All were white/non-Hispanic, except one participant who was African American, and the sample was nearly evenly split between women (N=10) and men (N=9). Mean age of illness onset was  $18 \pm 5.6$  years (range: 11-25 years) for individuals currently in their 20s or 30s compared to mean age of onset of  $37.5 \pm 8.6$  years (range: 22-46) for individuals in their 40s, 50s, and beyond (p <0.0001, df = 18, t = 2.1).

All individuals were in the depressed phase of illness (mean HAM-D: 19.8 ± 4.7). Global illness severity for all participants reflected relatively severe global psychopathology (mean CGI: 4.37.76). ITAQ scores for this group of participants were all quite high, with a mean group score of 21.3  $\pm$  1.6. This is consistent with high levels of insight into mental disorder diagnosis and acknowledgment of current diagnosis as well as attitudes consistent with perceived need for current and future medication treatment for mental disorder. Scores on the quantitative measures generally agreed with qualitative findings in that depressive themes were very prominent in the interviews, and the high scores on the ITAQ, which implicitly assumes a biomedical explanation for bipolar disorder, supported the explanation of illness cause and origins identified by the participants.

#### **Qualitative Findings**

Explanatory Model of Illness. Table 1 provides representative quotes that demonstrate participant opinions of domains of illness experience. Participants in

Sample interview question:	Explanatory Model "What do you think caused your illness?"	Stigma "Does anybody act differently towards you because of your illness?"	Effects on Life Trajectory "How might your life script have been different if you did not have bipolar disorder?"
Representative quotes	Cause of illness:  "I see it as a brain malfunction"  - 43-year old woman  "It was very much genetic"  - 32-year-old man	Perception of stigma:  "I think people do treat me differently because I have an illness. I think they see me as weaker and I think that they're afraid to give me as much responsibility and often times don't give me as much credit as I deserve."  - 27-year-old woman	Effects on personality:  "I probably would have been a totally different person, so I can't even answer that I am bipolar, that's all I am."  - 20-year-old man "I think it's made me a stronger person"  - 48-year-old woman
	Effects of stress on illness:  "I have this belief that stress sometimes brings out an illness. Maybe you have a predisposition just like you have a predisposition to diabetes or varicose veins, and you if don't get those variable things that cause, that would impact on them, you won't get the disease."  - 62-year-old woman	Effects of stigma on social relations:  "You close up and isolate yourself, you hide the disease so you try to look presentable when you're out, talk presentably, seem interested, you don't want to go to social things because you don't know if you can hide it anymore."  - 51-year-old woman "I would hide my medications if I know other people are visiting"  - 43-year-old woman "The social impact of the illness as a general rule, it can either make or break friendships. It can make people encourage you and be supportive or they can totally leave you alone"  - 58-year-old man	Effects on occupational/life role achievements:  "I think that having a profession is so associated with having a life, and I don't have a profession now."  - 53-year-old woman  "I think I would have been a better mother and I think I'd still be working. That kinda hits everything!  - 51-year-old woman

this specialty academic medical center clinic overwhelmingly supported the biomedical theoretical construction of bipolar illness. This did not differ between older and younger participants, or between men and women. Participants were informed regarding biological explanations of BPD, using sources such as medical texts and the Internet to obtain the most recent and relevant information regarding their illness. Nevertheless, many participants appeared to struggle to digest the meaning of available biological information. A number of participants "customized" information within the context of their explanatory model of illness, for example noting that medications acted like "taking vitamins" for chemicals that were

missing in the brain. Others noted the effects of stress on illness symptoms and outcomes, with the majority of individuals ( $N=14/19,\,74\%$ ) perceiving stress to have a negative effect on their quality of life, and some individuals believing that stress was a trigger that precipitated their illness.

Some comments reflected the incorporation of cultural interpretations of personality deficits that often configure American explanatory models of illness. <sup>15</sup> A 62-year-old woman described the origin of her illness, "Something I inherited, I think. Because, now looking back, I think my mom had the same thing I have, but I did not understand it at the time. I just thought she was a mean person."

Stigma. All participants voiced the opinion that having BPD was stigmatizing on multiple levels. Most individuals with BPD perceived negative social effects of stigma and were selective regarding who they shared information with concerning their diagnosis. Information regarding illness was generally only carefully shared with close friends, understanding family members, and individuals important in employment such as work supervisors or human resources staff at the individual's place of employment. Some individuals deliberately concealed information from family or friends regarding their illness such as hiding their medications or giving vague or inaccurate information about the purpose of their medications. One 24-year old woman told others, "I ha[ve] ulcers, that is why I take medications." Some individuals contrasted stigma experienced in relation to their mental disorder versus lack of stigma that was typically experienced in relation to medical disorders. A 51-year-old woman noted, "They do not visit you in the hospital. They do not send over food, come and visit you when you come home. I guess I just realized and missed it when my brother-in-law was in a car accident and in the hospital and all the attention. When you are in psychiatric lock-up you do not get that."

Although this sample of patients in an academic medical center were predominantly white, a 61-year-old African American woman noted that there were some associations between stigma and culture: "African Americans are the one race of people that do not embrace medical mental illness. That is a no-no for us. And that is why a lot of people probably do not get the help they need because they're so in denial about it. That is just to our race that is like a curse almost. They're not going to admit that, period."

In cases where information regarding BPD is shared with supportive others, there was a perceived benefit with respect to coping with illness. Young people in particular noted that individuals who themselves have mental illness may be particularly supportive. Additionally, younger individuals were more likely than older individuals to find support and make contact with other individuals with BPD over the Internet. In contrast, some older individuals were less appreciative of support or peer group. A 51-year-old woman stated, "I do not have any friends with mental illness. I was going to a support group

for a while and I stopped going because I thought it was depressing."

Some older individuals noted that stigma regarding BPD has decreased somewhat in recent years, although has not by any means disappeared. These older individuals contrasted fears of negative reactions from previous generations with what they perceived as slightly less stigma from current generations. A 53-year-old woman discussed how her own parents might have handled or did handle her illness: "My father died before I was diagnosed. . . .It would have been horrible for him. I mean, he would not have accepted it and would have seen it as personal weakness, and pull yourself up by the boot straps."

Effect on Life Trajectory. Participants perceived BPD as having a profound effect on life trajectory. Among older participants, bipolar illness was perceived as having the effect of "derailing" life plans and life trajectory. Additionally, older individuals expressed concern over the cumulative toll that illness has had on their lives, and the potential life achievements that were never realized because of having bipolar disorder. A 61-year-old woman said, "You know people do not even have a clue as to how it keeps you from being the person that you should be, that you w[ere] meant to be. You understand?"

Some younger individuals with BPD had a difficult time articulating effects of BPD on their life trajectory due to an inability to separate individual identity from identity as an individual with BPD. Having bipolar illness may thus become the defining identity for some young persons with bipolar illness and inhibit them from accomplishing goals common to young adults such as establishing personal, sexual, and occupational identity. In spite of the burdens and challenges, young adults with BPD hope to achieve developmental milestones, similar to what might be expected among young adults without mental illness. However, trying to accomplish these age-appropriate goals can be enormously difficult for young individuals with BPD.

In addition to the predominantly negative effects of illness, some individuals noted positive changes in themselves as a result of having BPD, including being more sensitive to others who are suffering, becoming a stronger person, or gaining insight into the need to slow down in life, stop being "a workaholic," and spend more quality time with loved ones.

Within the context of discussing the life-changing effects of BPD, a number of individuals articulated the importance of enriching other's lives as a positive coping method in dealing with the cumulative and devastating effects of BPD. This was especially true of older women with BPD in their roles as parents and grandparents. A 53-year-old woman noted: "What makes me enjoy myself most is giving pleasure to other people...enriching somebody else's life." A 51-year-old woman said, "My purpose right now is to be a good mother and to give my children as much as I can in love and stability and instruction." Other positive coping mechanisms especially evident in older adults who appeared to have had relative success in living with BPD included continuing educational enrichment such as attending classes/going back to school and creative pursuits from which they derived satisfaction and self-esteem.

#### **DISCUSSION**

This analysis evaluated individual understanding or exploratory model of illness, perceived stigma, and the effects of bipolar illness on life/developmental trajectory. There are a number of studies 16-18 that have addressed the issue of aging in bipolar disorder, primarily from a biological or health resources perspective. However, few studies have addressed the issue of perceived experience of bipolar illness either in mixed populations or across the lifespan, in spite of the fact that it has been suggested that individuals affected by illness are those who are most likely to provide important insights into health research.<sup>19</sup> As suggested by Russell and Browne,<sup>20</sup> although qualitative research does not have the statistical power nor generalizability of quantitative research, qualitative methods can provide detailed information on a number of important clinical topics such as how individuals with bipolar disorder can stay well. Thus the expertise of people who have successfully dealt with bipolar illness is particularly likely to provide new insights for practice.<sup>20</sup>

Perceived etiology of illness is important to both internally and externally generated stigma as it might be anticipated that self-blame and perhaps some of the devastating and intense effects of stigma could be minimized among those who do not believe

that illness is due to any inherent character flaw or defect. Individuals with BPD in this study, receiving care in an academic specialty clinic, consistently endorsed a biological construct of illness. As this was a well-educated, insured American population, this explanatory model of illness may be not entirely representative of a wider population of individuals with BPD. Consistent with a biological explanation, individuals in this sample perceived BPD as a disease with genetic underpinnings, although most individuals recognized the negative effects of stress on illness manifestation and outcome.

All individuals in this sample were depressed to a clinically significant degree, as evidenced by their relatively high scores on depression and psychopathology rating scales. Studies of bipolar illness outcomes suggest that depression has been reported to be the most common, pervasive, and disabling longterm symptom of BPD.<sup>21–23</sup> For the group evaluated here, faith in the biomedical model was not necessarily supported by positive results of treatment on an immediate and personal level as most had enduring depressive symptoms. Most, however, felt hopeful about the future and anticipated further improvement and improved quality of life. Written sources of information such as books and the Internet, as well as psychoeducation from physicians and other medical providers, were perceived as beneficial and clearly an important component of positive treatment attitudes. Other researchers have reported the positive long-term benefits of psychoeducation in the treatment of BPD.<sup>24,25</sup>

In spite of the fact that individuals in this group endorsed a biological, nonself-blaming explanatory model of illness, effects of perceived stigma were strong and individuals were often selective in sharing information regarding their illness with friends, acquaintances, coworkers, and even family members. Although membership in a stigmatized group is often assumed to have negative consequences, 26,27 individuals with BPD may find ways of coping with stigma that are positive and constructive, such as forming supportive relationships with other individuals with BPD, and delineating a clear difference between society's negative representations of the mentally ill and their own personal, "no-fault" construction of illness.<sup>27</sup> It is possible that attendance at biomedically oriented specialty clinic may facilitate acceptance of the "no-fault" model of illness and rejection of societal stigmatization. However, it is also possible that individuals who reject societal stigma and are biomedically oriented may also be more likely to gravitate toward a specialty academic clinic. With respect to perceived stigma from a lifespan approach, older participants in particular noted that societal stigma regarding mental illness may be decreasing in recent years. <sup>28–30</sup>

Subjective experience of illness is affected by the perceived burden of illness on the life of the individual and perceived effects of bipolar illness on an individual's life trajectory. Lim<sup>11</sup> recently reported a detailed analysis of how 18 individuals with BPD, aged 28-58 years, viewed the effects of BPD upon their lives. These participants viewed their lives as being characterized by loss and deficits, and were keenly aware of how different they were from others. They described being isolated from the community around them and rejected by their families. They did not believe that they had the ability to manage their illness or lives and had a low sense of self-efficacy, which negatively affected their view of the future. In contrast, a recent report by Russell and Browne<sup>20</sup> of 100 individuals with BPD noted that active strategies to "stay well" could be successful for long periods of time and included acceptance of diagnosis, mindfulness, education, identification of relapse triggers and signals, sleep and stress management, appropriate lifestyle changes, treatment, use of support, and a "stay-well" plan.

This sample contrasted younger individuals in their 20s and 30s and older individuals in their 40s, 50s, and beyond, and found differences in perceived effects of BPD on life trajectory. Although all individuals noted some negative effects, such as in the report by Lim,11 others, such as in the report by Russell and Brown, <sup>20</sup> were able to develop strategies that offset some of the most devastating consequences of illness. As noted earlier, a potentially useful way of comparing and contrasting these differences across the age continuum is Erikson's model of psychosocial development, which identifies crucial steps in the development of the individual's relations with the social world. The model, which is applicable in most cultural settings, spans the full life spectrum from infancy to old age and delineates specific developmental tasks for each psychosocial development stage. The stages of relevance with respect to examining individuals with BPD in this analysis include adolescence (teenage years), early adulthood (20s and 30s), middle-aged (40s to 50s), and later life (age 60 and beyond). Erikson's model proposes that although the stages of psychosocial development are universal to the human life cycle, the distinct ways that an individual navigates these phases are a product of personality, culture, and life events or circumstances. The presence of bipolar illness, typically first occurring in early adulthood, has immediate and profound consequences on the life of the affected individual.

In this sample, younger individuals had illness that generally first manifested in childhood/adolescence or young adulthood, whereas older individuals had illness with onset in early to later adulthood. In common with individuals without serious mental illness, individuals with BPD work at mastering developmental tasks appropriate for their life stage. Erikson proposed that the main developmental tasks of late adolescence and young adulthood are the establishment of a personal identity and the ability to form positive intimate/personal relationships. In this group, some younger individuals appeared to have difficulty separating their own identity from the effects of an illness with onset in childhood or adolescence. Younger individuals with BPD who are still struggling with the issue of self-identity may be particularly vulnerable to the damaging effects of stigma.

The question of life "trajectory" may be a problematic concept for young adults who are on the threshold of many major life tasks, and there may be a shortened concept of a "before" and "after" BPD. For younger patients with BPD learning about BPD appears to be critical in helping them establish their own identity in the face of often extremely disabling symptoms. Formation of intimate relationships is often overshadowed by looming bipolar symptoms, in particular depression. Some young individuals with BPD may preferentially seek intimate relationships with other young people with mental illness, perceiving these as more supportive and accepting.

For older individuals with BPD, life is perceived to be disrupted by BPD, with early plans and dreams often "derailed." In common with the sample identified by Lim and colleagues, 11 there is often a constant struggle for stability and normality in their lives. However, in spite of the burden of recurrent depression and mania, individuals can successfully

accomplish important life goals such as forming and continuing important personal relationships and maintaining employment. Erikson proposed that the main developmental tasks of later adulthood are generativity and integration—that is, concern with guiding the next generation, and the acceptance of one's life and the people who have become significant to it. Consistent with Erikson's model, older individuals in this sample who were able to progress from one developmental stage to another derived satisfaction and self-esteem from their adult life accomplishments. With respect to stigma response across the lifespan, damaging effects of stigma may be potentially minimized among older adults who successfully accomplished key life/developmental goals.

In contrast to the sample identified by Lim and colleagues, 11 sense of self-efficacy appeared to be relatively strong in the population studied here. Although this analysis is limited by providing only a cross-sectional rather than a longitudinal perspective on subjective experience, participants in this analysis indicated that learning to live with BPD and accomplish life goals in spite of illness burden may take effort and time. Although some individuals appear to, through trial and error, develop effective methods of coping with BPD, it is also possible that the life/developmental stage of the individual at time of illness onset may be a key predictor of later-life illness and stigma coping.

Although our study offers some insights into how individuals with BPD may experience and cope with their illness, there are some important limitations. The small size of the sample may limit extrapolation

of the data in larger populations. Additionally, because this was a well-educated, financially secure population treated in an academic mental health setting, it is possible that populations that are more culturally diverse, receive care in other settings, or are more socioeconomically disadvantaged may have different subjective experiences and possibly differing coping mechanisms. This study excluded older adults with illness for more than 20 years, and their views may be different compared to later-onset individuals who had a chance to establish family, financial, and other supports. Finally, individuals with rapid-cycling illness and those who are depressed may experience and cope with their disorder differently compared to those whose illness is nonrapid cycling or those who are euthymic or experiencing manic symptoms.

BPD is a severe and persistent mental illness that has profound effects on the lives of affected individuals. Personal constructs of illness that do not place blame on the individual may be supported by psychoeducational approaches as well as support from significant others and from positive interactions with other individuals with BPD. Positive coping mechanisms may provide some protection against negative societal reaction and stigma. Lastly, BPD may severely alter an individual's planned "life trajectory"; however, over time, accomplishment of life goals can at least partially offset the sense of loss that is often seen in bipolar illness.

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