Family Care giving in Bipolar disorder: Experiences of Stigma

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Background: Stigma is a serious impediment to the well-being of those who experience it. Many family- caregivers are challenged by the stereotypes and prejudice that result from misconceptions about bipolar disorder.
Objective: The purpose of this study was to explore the stigma experienced by family caregivers of patients with bipolar disorder.
Methods: This was a qualitative and phenomenological study. In this study, we selected the family caregivers of patients with bipolar disorder in a psychiatric hospital (Iran) using purposive sampling in 2011. By reaching data saturation, the number of participant was 12. Data were gathered through in-depth interviews and analyzed by the "Collaizi" method .
Result: Stigma was a pervasive concern to almost all participants. Family caregivers of patients with Bipolar disorders reported feelings and experiences of stigma and were most affected by them. Analysis of the interviews revealed 3 themes: Negative judgment, Shame, Stigmatization and Social Isolation.
Conclusion: For a person with bipolar disorder, this illness is associated with the following problems: worse recovery, difficulty accessing health services, receiving poor treatment and support, and difficulty gaining community acceptance. Rejection of people with mental illness might also affect their family caregivers at various levels.

Key words: *Family caregiver, Bipolar disorder, Stigma, Phenomenology*

Accshiring to the centers for disease control and prevention (CDC) findings, psychological diseases have been the most influential diseases and 450 million people are suffering from them worldwide (1).Bipolar disorder is a chronic, relapsing and remitting illness, characterized by separate periods of mania (elated mood, disinherited behavior, excessive activity, inflated self-esteem, decreased need for sleep) and depression (low mood, profound loss of interest, changes in sleep and appetite, low self-worth, suicidal ideas and plans) (2).The estimated lifetime prevalence of bipolar spectrum disorders is approximately 2% to 4% (3-5). Bipolar disorder is one of the world's 10 most disabling conditions, and it affects people across nationality, race, and socioeconomic status (6). Even patients receiving optimal medication are likely to have multiple recurrences and have trouble keeping their jobs, maintaining relationships, and getting along with significant others (6).

People with serious mental illness are challenged doubly. On the one hand, they struggle with the symptoms and disabilities that result from the

disease and on the other, they are challenged by the stereotypes and prejudice that result from misconceptions about mental illness. Therefore, people with mental illness are deprived of many opportunities that define a good quality of life: good jobs, safe housing, satisfactory health care, and affiliation with diverse groups of people (7). Stigmatization of individuals diagnosed as having serious mental illnesses has been observed across the world, and the family members who help care for them report feeling stigmatized due to their association with the loved one with mental illness (8-10). Empirically, 43% to 92% of the caregivers of people with mental illness report feeling stigmatized (11). 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 (12).

Across the world, the stigma of mental illness is associated with immense suffering related to various

factors: stress and psychiatric morbidity, problems in relationships, restrictions on social participation and limitations in employment and educational opportunities (13).Stigma may also interfere with help seeking because they want to avoid being labeled as mentally ill and being associated with mental health care (13).On the systemic level, stigma seems to be related to unfavorable policies, i.e., regarding type of treatment, access to and funding for treatment eligibility for social assistance or the right to refuse treatment. At the community level, stigma may become apparent in responses to individuals with a mental illness and to their families, and also responses of different organizations: social service agencies, health care providers, employers, and school officials. At the individual level, stigma may prohibit people from seeking the treatment they need and might create profound changes in their identity and might also change the way in which they are perceived by others. There is no doubt that reducing stigma is a daunting and complex process (14).

On the theoretical level, stigmatization involves a separation of individuals from "us" who are labeled as different and who are believed to possess negative traits. Such a separation may result in negative emotional reactions, discrimination, and loss of status for the stigmatized persons (15).

The experiences of family members of people with mental illness include stigmatized social interactions, high levels of stress, and ongoing caregiver burden. Descriptions of the stigmatized interactions of patients with others appear regularly in the mental health practice literature. Family members of people with mental illness report that the social stigma of mental illness extends to them. They describe feelings of being isolated, ignored, blamed, and criticized by the family, friends, neighbors, colleagues, and even mental health providers. Interventions targeting family support empirically demonstrate outcomes that exceed those of many psychotropic medications, but stigma may result in the delayed implementation of such interventions. Family members of individuals with a mental illness report emotional, relationship, financial, health, and time stressors (16).Although research has gone a long way in understanding the impact of the disease, it has only recently begun to explain stigma in bipolar disorder. Much work yet needs to be done to fully understand the breadth and scope of prejudice against people with bipolar disorder.

Angermeyer and Dietrich (2006) found that people from Non-Western cultures tend to attribute the cause of mental illness more frequently to the afflicted individual (17). It is possible that discrimination against the mentally ill differs in an Islamic culture where mental illnesses and other ailments are, to some extent, considered to be due to the will of God, rather than the evil forces, bad behavior, or other personally devaluate-ing factors. According to the Holy Koran, people with a mental

disorder should be treated with respect, and this might result in a less stigmatizing attitude. Such a perception of causality would also reasonably apply to the individual and might be a factor that reduces self-blame. However, this perception also includes that one must bear one's predicament and wait for the mercy of God! Allah is your patron, and he is the best of helpers (18).

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 the society (19). Similarly, research focused on the perceptions of the bipolar disorder diagnosis among 15 hospitalized individuals and revealed themes related to the struggle to accept their diagnosis (20). Finally, a qualitative study of 32 individuals managing bipolar disorder well revealed how stigma was perceived as being salient to maintaining and regaining wellness (21).

To understand the origins of the stigma of mental illness, we need to study it within its socio-cultural context, meanings and consequences. It may also be relevant to examine the inherent conceptions, experiences and implications of psychological problems associated with stigma to address related problems in mental-health care (22).

The purpose of this study was to explore the nature and meaning of stigma for family caregivers of patients with bipolar disorder in Iran.

Material and Methods

Phenomenology was served as the methodological framework for this study. The aim of phenomenological research is to examine the meaning of life through the interpretation of the individual's lived experiences (23). A major concern of phenomenological research is to capture the totality of the human experience, with an emphasis on the meaning that social behavior has for the individual. Phenomenology is the study of lived experience in which the researcher is discovery oriented. The researcher is on a quest to know answers to the following questions. "What is this every day experience like? What is its meaning? How is it experienced by the individual?" Through reflection, a deeper knowing of the essence of an experience emerges (24). Lopez and Willis (2004) asserted that the phenomenological approach and nursing are a good fit because phenomenology seeks to understand the uniqueness of individuals and experiences (25). Investigators seeking to develop knowledge that embraces ideals of holistic nursing are challenged by trying to understand human experiences in health and illness and identify caring needs of nurses and patients who come together in temporary health care settings.

The interactions inherent in holistic nurse–patient transactions may be explored through phenomenological inquiry (26). The aim of this study was to understand the experience of stigma as it is related to giving care to a person with bipolar disorder. Phenomenology provides the tools for deeply exploring human experience in order to understand the actual lived experience of a phenomenon by examining persons' accounts of their experiences .

Participants and Setting
Twelve family members of persons with the diagnosis of bipolar disorder participated in the study (Table 1). They were recruited from Farshchian Psychiatry Hospital in Hamedan/Iran from July to September, 2011.

Data Collection
The interviews were conducted in Persian. The interview guide was composed of broad questions which provided the participants with the freedom to express their opinions and experiences. The initial questions began with queries about the participants' well-being, such as "Tell me about your family member's illness." This approach helped the participants and the researcher to establish rapport with one another, and facilitate communication. When the rapport developed between the interviewee and the interviewer, the questions proceeded to increasingly focus on the experience of stigma for bipolar disorder .

Face-to-face conversations were conducted with the family members of the persons with the diagnosis of bipolar disorder as per the DSM-IV-TR criteria. Each conversational session lasted 45-70 minutes and usually two separate sessions were conducted for each participant in the clinic of Farshchian hospital .

Data Analysis
Each transcribed interview about the stigma experienced by the family caregivers of patients with bipolar disorder was analyzed by means of Colaizzi's phenomenological method as described by Beck (23, 24).The steps are as follows:
1. Read and re-read all transcriptions to obtain a feeling for them
2. Extract significant statements and phrases from the transcripts, pertinent to the research phenomenon
3. Formulate meanings from the significant statements
4. Organize the formulated meanings into a cluster of themes
5. Integrate the results to date into an exhaustive description of the phenomenon
6. Validate the exhaustive description by returning to the research participants
7. If required, incorporate any new or relevant data obtained from participation validation
Table 2 demonstrates the summary of Colaizzi's method of analysis.

Rigor
To ensure rigor in the research findings, trustworthiness was established in accordance with the standard criteria for qualitative research, credibility, dependability, conformability, and transferability (28).

To enhance credibility, we selected the participants who were the family-members people diagnosed with BD, in line with the accepted criteria. The interviews were conducted in a relaxed atmosphere facilitated by the first author's knowledge of the research area. The rich content of the interviews and the saturation reached, ensured that a satisfactory description was obtained of the caregivers views of the condition of the person with BD and stigma. The analysis was made by moving carefully back and forth between the data and the various steps in the analysis, and the analysis was discussed by the authors and agreement was reached at every step. Dependability was increased through discussion about similarities and differences in consistency and content over time and by having two main guiding questions to ensure that the same domains were dealt with in all the interviews. Numerous quotations from participants are presented to shed light on their experiences of living with a family member with BD. Clear descriptions of the selection, context, and the characteristics of the participants as well as the process of data collection and analysis facilitated the conformability and transferability of the findings.

Ethical Considerations
All participants were informed about the purpose and the method of the study. They were informed that participation in the study was voluntary, and they could refuse to participate or withdraw from the study at any time without any personal consequences. The participants were reassured that their responses will be kept confidential and their identities will not be revealed in research reports or publications. Finally, the participants who agreed to take part in the study were asked to provide written consent.

Result

The formulated meanings were then clustered around three themes. Table 3 demonstrates the examples of how formulated meanings were grouped into themes. The themes that emerged from the analysis of the formulated meaning were: Negative Judgment, Shame, Stigmatization and Social Isolation.

Negative Judgment:
The theme of negative judgment emerged from the anticipated and actualized reactions that participants encountered from friends and family, authority figures in medical services in the police, and in the society in general. Some of the participants reported that they often find it difficult to tell people about the illness of their relatives. The reasons for the participants not to disclose the illness of their relatives varied greatly in our sample. Some of the participants did not disclose the mental illness of their relatives because of the perceived negative reactions from friends and family members .

Examples of statements related to negative judgment of others are as follows:

A brother said, "They see one bipolar disorder person or a murderer and they think they are alike. They only see violence and murder and they don't see the reality".

A mother also said, "People do not have enough knowledge about the disease, so they think people with Bipolar disorder are dangerous…. when people are ill they are seen as dependent or screwed up or a basket case. They think we are different and dangerous, and we need to be made a fool of and they".

One participant says: "During my daughter's illness, my friends and family offered little understanding or support when I was feeling fragile. "People's judgments were really hard for me to accept and take, "he says, (Father).

Shame:

Shame is a social experience and is rooted in exchanges between people. It may grow out of experiences of public humiliation and may result from experiences of being devalued. Shame may also come from experiences of rejection. The shame and discrimination associated with bipolar disorder is the legacy of an era when the bipolar disorder patient was locked away in insane asylums, sometimes for the rest of his or her life .

Examples of statements being coded as shame-related are as follows:

A mother said, "Although the neighbors understand and accept the fact that (K) has a bipolar disorder, I still feel ashamed to have such a mentally ill daughter. They [neighbors] are very helpful even though I feel ashamed that my daughter is sick ."

Another mother said, "My son was fine earlier, but recently he gets upset when people call him names like 'mad' .People around our house don't talk to him. They laugh upon seeing him".

A father also said, "My son has suffered from bipolar disorder for ten years. He is a shame to my family. My wife and I suffered a lot in taking care of him, and to avoid being labeled as different, we don't meet with our friends, relatives or neighbors. My son is hopeless and my life is helpless. We have to endure this burden endlessly. Our worry is that when we die there will be no one to take care of him".

Many people do not want to have an official record that identifies them as having bipolar disorder. They fear that if others might find out, they would treat them differently and judge them based on these problems .

Stigmatization and Social Isolation:

In the statements gathered in this research, Social Isolation in providing care to patients with bipolar disorders referred to social strain, which involves the stigma about bipolar disorder and the feeling of shame or embarrassment of caregivers for having relatives with bipolar disorders.

A sister said, "I rarely discuss or talk with anyone about my sister. I am afraid of the neighbors' gossip and do not want anybody to know about us".

For most family caregivers, the diagnosis of bipolar disorder resulted in a reduction of social contacts. Relatives, too, observed how friends of the patients gradually stayed away, did not visit them in the hospital, or how they shied away from speaking with their friend because there was ''nothing to talk about.

One participant (spouse) emphasized that the loss of friendships and socio-economic status can affect people's lives long after their symptoms are treated and they are able to resume their daily activities. She said, "Friends and family see you as a bipolar person or a potentially bipolar person ".

After institutionalization, some family caregivers reported to have become a topic of conversation among friends and neighbors in an unwanted way. For them, it was a painful additional burden. Also, many reported that their social network was reduced when many ceased to get in touch, and this led to social withdrawal in the family as well.

A daughter of one the patients stated that her father was admitted to the Psychiatric Department, and it was hurtful for her to find others gossiping about her family. One wife said "their friends just vanished. When important people abandon you, it really gets to you and undermines your identity. And then; just silence. I was left sitting alone with the children, who were terrified".

Discussion

In this study, we used qualitative methods to examine how stigma is understood and experienced by family members of patients with bipolar disorder.

The experience of stigma for a family caregiver of a bipolar patient was illuminated in the themes of Negative Judgment, Shame, Stigmatization and Social Isolation. The experience of family caregivers was grounded in a changed temporal world.

Table 1: Demographic data: informants

Caregivers	N (%)	Mean of Age (Year)	Mean of Duration care (month)
Brother	1(8.3)	29	23
Daughter	2(16.7)	22	43.5
Father	2 (16.7)	51.5	30
Spouse	2(16.7)	42.5	26
Mother	3(25)	41.7	25.5
Sister	2(16.7)	21.5	44
Patient sex			
Female	7(58.3)	28.7	49.6
Male	5(48.2)	31.4	39.5

Table 2: Summary of Colaizzi's Method of Analysis

Steps in Analysis	Purpose
1. Reading and rereading descriptions	To acquire general feeling for experience
2. Extracting significant statements	To generate information pertaining directly to phenomenon studied
3. Formulating meanings	To illuminate meanings hidden in various contexts of the phenomenon
4. Categorizing into clusters of themes and validating with original text	To identify experiences common to all informants
5. Describing	To generate a prototype of a theoretical model
6. Returning to participants	To validate the findings
7. Incorporating any changes based on the informants' feedback	To present theoretical model that comprehensively reflects the universal features of phenomenon

Table 3: Examples of Theme Clusters and the Associated Formulated Meanings

Theme	Subthemes	Formulated Meanings
Stigmatization and Social Isolation	Lack of support	A. Family members disagreeing about the management of the mentally ill relative's affairs. B. Little attention from health care professionals. C. Financial strain increased.
	Fear and avoidance	A. patients are dangerous and unpredictable. B. Avoiding from interaction and Talking with patients.
	being labeled and ridicule	A. Feel that mental illness is embarrassing. B. Use of emotionally-charged negative terms same as Crazy

Link and Phelan (2001) conceptualize stigma as being comprised of five interacting components: labeling, stereotyping, separation, status loss, and discrimination that are produced and perpetuated by power differentials in the society (15). The literature also articulates three intersecting levels through which stigma may be manifested and experienced: structural, social, and self.

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 (29). Caregivers of people with bipolar disorder face different challenges than caregivers of people with other illnesses. Among others, these challenges may be affected by culturally and socially determined attitudes to the illness and thereby may have important effects on the level of the burden experienced. Manic episodes of the illness are very disruptive to daily life, work and family relationships. Great demands may be placed on family members to be involved in caregiving. These demands may persist even during remission, when oftentimes residual symptoms are still present (30).Structural stigma was reflected in the participants' narratives about the policies and informal practices of our social institutions (e.g., school, work, and healthcare) that made them feel excluded and devalued members of the 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 and their relatives were frequently exposed to self-perceived stigma in health care and employment settings (31).

Caregivers whose relatives display a more severe type of bipolar disorder perceive higher levels of stigma. However, stigma experiences are less stressful for caregivers who are surrounded by supportive family and friends. Also, caregivers who perceive fewer stigmas may be more likely to seek social support (10). The family stigma process negatively impacts individuals in numerous ways. Family members may avoid social situations and spend energy and resources on hiding the secret. Besides, they may experience discrimination within employment and/or housing situations. Providing psychiatrists with skills to identify and address the impact of blame, shame, and contamination on individuals with mental illness and their family members should be included as a training objective (32).

Researchers explored whether family members experienced discrimination similar to people with mental illness. Studies demonstrated that between a quarter and a half of family members believe that they should hide their relationship with a family member with mental illness in order to avoid bringing shame to the family (33–35).

Stigmatization and Social Isolation was a prevalent experience among our study participants who spoke about negative media representations of a mental illness and having to contend with social relationships that were strained by the lack of knowledge and negative attitudes about bipolar disorder. Suto (2011) found that individuals with bipolar disorder and their family members were frequently exposed to social isolation, stigma and shame in social relationship and employment settings (12).

In the literature, there is a wealth of studies on stereotyping while the body of research on discrimination is far less extensive. In addition, those studies addressing discrimination focus their attention on the producers of rejection and exclusion rather than on the effects of discrimination on the ''stigmatized'' (15).However, according to our findings, more family caregiver stigmatization experiences are made in direct personal contact with others. Raguramet (2004) described that positive symptoms; namely, hallucinatory behavior, delusions and suspicions were found to be very distressing to family members (36). Of other relevant variables, socially unacceptable behavior created more stigma than attribution of a supernatural cause. These findings were similar to those of Srinivasan and Thara (2001) who verified that families living with patients suffering from chronic schizophrenia rarely subscribed to the idea of a supernatural cause (37).

Conclusion

The behaviors of a person with bipolar disorder may further isolate the family, diminish its reputation and jeopardize relationships with friends and neighbors.
Stigma toward bipolar disorder is ubiquitous and has insidious consequences for the affected individuals and their families. Stigma reduction initiatives should target individuals living with bipolar disorder; their families, workplaces, and the healthcare industry taking into account the experiences and impacts of bipolar disorder stigma to improve social support, course of illness, and quality of life.

Acknowledgements

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