Outcomes of Parental Mental Illness on Children

A Qualitative Study from Iran

Fatemeh Oskouie, PhD, MSc, BSN; Reza Zeighami, MSN, BSN; and Soodabeh Joolae, PhD, MSc, BS
C

hildren of parents with mental illness are a substantial, yet marginalized group. Although extensive empirical evidence shows their risks for adverse outcomes, there has been little focus on such children’s personal experiences (Foster, 2006). Without properly understanding the needs of children of parents diagnosed with a mental illness from their own perspectives, it is not possible for nurses and other health care providers to successfully incorporate these children in their care plans (Aldridge & Becker, 1999).

Mental disorders are considered common problems throughout society (Fudge & Mason, 2004; Garley, Gallop, Johnston, & Pipitone, 1997; Orel, Groves, & Shannon, 2003). According to the World Health Organization (2001), 25% of the world’s population experiences some kind of mental disorder. Similarly, the prevalence of mental disorders in Iran is reported to be approximately 20% (Fallahi, Maddah, Shamlu, Abedi, & Babai, 2002; Zoladl, Sharif, Ghoranipur, Kazemnejad, & Ashkani, 2006). Furthermore, mental disorders not only burden the patients themselves but also affect the entire community (Keltner, Schwecke, & Boström, 2007).

Indeed, within families in which someone has a mental disorder, only the patient is considered the person who needs help, and the rest of the family members—especially the children—are excluded from the treatment process (Handley, Farrell, Josephs, Hanke, & Hazelton, 2001). Moreover, children of parents with mental illness are vulnerable to many problems that have rarely been considered by health care systems, and it is believed that providing care for these children is generally ignored within those systems (Maybery & Reupert, 2006). Studies have shown that relatively little is known about the specifics of how these children live with parents diagnosed with a mental illness (Gladstone, Boydell, & McKeever, 2006). Therefore, this group of children is commonly known as an “invisible population” (Fudge & Mason, 2004, p. 1).

Statistics show that one third of men and two thirds of women with mental illness in the United States, and half of the patients with mental disorders in the United Kingdom, have children (Montgomery, 2005). In Australia, 1 million children have at least one parent with a mental disorder, and at least 30% of patients diagnosed with mental illness are women who have children younger than 18 (Maybery, Reupert, Patrick, Goodyear, & Crase, 2005). Similarly, in Iran, research shows that 45.9% of women and 43.9% of men with mental disorders have children (Malakouti et al., 2003). In general, it has been documented that 25% of adults with mental disorders live in the same household as their children (Fudge, Falkov, Kowalenko, & Robinson, 2004).

ABSTRACT

Children of parents with mental illness are a substantial, yet marginalized group. This study, as part of a more extensive research project, used grounded theory to explore the outcomes of parental mental illness on their children. Seventeen informants were interviewed at a mental hospital in the city of Qazvin, Iran. The participants were selected using purposeful and theoretical sampling. Interviews were analyzed using Strauss and Corbin’s method. It was revealed that parental mental illness leads to five major outcomes that involve communication, mental, educational, economic, and extra roles factors. As such, it is suggested that these children should be considered within health care plans and that policy makers, nurses, and other health care providers use these findings for preventive and educational purposes.
Because little research has focused on the child's point of view, not much is known about children's conceptualization and perception of their parents' mental illness (Tsang, Tam, Chan, & Chang, 2003); therefore, practitioners who work with patients with mental illness must be aware of these children's experiences. This issue is even more important for nurses, as they interact directly with patients and their families more frequently and thus have a unique role in supporting these children (Rose, Mallinson, & Walton-Moss, 2002). Considering the community-based nature of mental health nursing, it is possible to observe the natural interactions and the effects of psychiatric interventions within the family (Ward-Griffin, Schofield, Vos, & Coatsworth-Puspoky, 2005). Understanding children's perspectives about the effects of their parent's illness is important, as children's needs tend to change based on these perspectives.

Research on this invisible population is an initial and important step in providing holistic family care; therefore, this qualitative study, conducted in Iran, sought to address such children's experiences and needs. This article presents the outcomes of parents' mental illness on children, as well as how these outcomes relate to other factors. The theoretical model used to study the mental health needs of such children will be detailed in a separate paper.

**METHOD**

This report was part of a larger study that served as the corresponding author's doctoral dissertation (Zeighami, 2011). The larger study focused on the mental health needs of children of a parent with mental illness to explore how such children's mental health needs originate and develop. Grounded theory allows researchers to explain a phenomenon from within the social situation itself, identify the inherent processes operating therein, and analyze simultaneously (Bagheri-Nesami, Rafi, & Oskouie, 2010). The analytical process is systematic and ends when additional data no longer generate new insights (i.e., category saturation). Consequently, using grounded theory helps researchers summarize knowledge, connect the phenomenon to the related discipline, and provide the means to predict—and eventually control—the phenomenon (Strauss & Corbin, 1998).

**Sample**

Purposeful and theoretical sampling was used in this study. The participants were 17 to 26 years old and the children of parents with mental illness who had a history of hospitalization. Inclusion criteria for the children were living with their parents and not having a history of mental illness. Participants were recruited from patients of a mental hospital in the city of Qazvin, Iran, based on these inclusion criteria.

During data collection, some issues the children pointed out regarding their experiences living with a parent with mental illness were related to their own marriages, interaction with the healthy parent, and interaction with practitioners. Therefore, to carry out theoretical sampling, the researcher (R.Z.) interviewed the healthy parents, spouses of married children, nurses, psychologists, and counselors. Overall, 17 participants—the children of parents with mental illness (n = 10), their families (1 spouse of a married child, and 2 healthy parents), and health care practitioners (2 nurses with a master's degree in mental health nursing, 1 clinical psychologist, and 1 psychological counselor)—were interviewed.

Study approval was obtained from the ethics committee of the faculty of nursing and midwifery at the participating university in Iran. Before interviews were arranged, the study's purpose and method were fully explained to each participant individually. Participants were assured that they could withdraw from the study at any time. Moreover, every attempt was made to ensure the privacy of participants during the interview. Written informed consent was obtained from all participants, and all data were treated as confidential.

**Data Collection**

Data—collected from September 2008 to February 2010—were generated through semi-structured interviews using a topic guide and observation. The interviews with the children and their families were held at the hospital and those of practitioners at their workplaces. Each interview lasted 45 to 100 minutes with a mean of 60 minutes, based on the participant's tolerance and interaction. All interviews were digitally recorded and transcribed verbatim no more than 24 hours after the interview, and memos were written by the main interviewer (R.Z.) for each one.

The interview guide was based on an initial literature review and consisted of open-ended questions to allow the respondents to explain their own experiences. After a warm-up conversation with each participant, data collection initiated with open-ended and over-arching prompts:

- “Please tell me about your parent's illness.”
- “Can you explain your parent's illness?”
- “What does your parent's illness mean to you?”
- “Can you explain what happened in your parent's most recent mental health episode?”
- “Does the illness have the same phase in each episode?”
- “What do you want, wish, or desire when an episode occurs?”
• “Who helps you?”
• “If someone wants to help, what is your request?”

Some of these same questions were used when interviewing the other participants (i.e., spouses, healthy parents, health care practitioners), whereas other questions were posed based on participants’ experiences and role. For example, “Can you explain your husband’s illness?” (spouse); “What does your son need when his father has a mental health episode?” (healthy parent); and “From your experience, what is the most important need of children of parents with mental illness?” and “Do you feel you can help children of parents with mental illness?” (health care practitioner). Questions after those were based on the participants’ responses and emerging theory. Data collection was terminated when redundancy occurred, and no new data were obtained in the last three interviews.

Observations were made during the interviews to understand the contextual conditions and explain the variations of children’s behavior in each context. The theoretical sampling was based on emerging questions during data analysis.

Data Analysis

Each interview was analyzed and coded before starting the next interview. Data collection, analysis, and interpretation were carried out simultaneously. Data were analyzed using Strauss and Corbin’s (1998) method of constant comparison, and emerging themes were identified. For the purpose of open coding, the transcripts were examined word by word and line by line, and codes were assigned to recurrent themes, reflecting the respondents’ own words. Codes with similar meaning were grouped and categorized by making comparisons to determine the properties of each concept. Categories were related to their subcategories and linked at the level of their properties and dimensions, a process called axial coding. At this stage, integration and refinement of the theory occurred by selective coding.

Trustworthiness

Factors such as trustworthiness, credibility, dependability, transferability, and confirmability are suggested as criteria for qualitative research (Flick, 2006). Credibility was enhanced by prolonged engagement. The process of data collection and analysis lasted 17 months. Data and method triangulation, use of maximum variation sampling, observation, and published literature review confirm the study’s credibility (Polit & Beck, 2010). Dependability was confirmed by the audit and review of the study process by two experts. Transferability can be judged by readers examining the original context, participant characteristics, data collection and analysis, and appropriated quotations described in the Method and Results sections. Once the description of the phenomenon was complete, it was rechecked by 8 participants. Therefore, the confirmability of the current study was established according to Guba and Lincoln’s (1989) definition in which the achievement of credibility, transferability, and dependability was defined as the establishment of confirmability.

RESULTS

Participants

The study sample included children of patients with mental illness, other family members, and mental health care workers. The children and family subgroup consisted of 13 people, including 6 daughters, 4 sons, 1 daughter-in-law, and 2 healthy mothers. The parents diagnosed with mental illness included 4 fathers and 6 mothers, 5 of whom had mood disorders, 4 with schizophrenia, and 1 with obsessive-compulsive disorder. All patients had a history of hospitalization in the mental hospital (mean = 12 times, range = 3 to 50 times). Children ranged in age from 17 to 26 (mean age = 22). The health care participants included a senior lecturer with clinical expertise and those with a master’s degree in their related field. The mean professional experience among these participants was 13.75 years (range = 5 to 20 years).

Outcomes

Our findings indicated parental mental illness leads to five major outcomes that involve communication, mental, educational, economic, and extra roles factors.

Communication Factors. Parental mental illness was found to disturb their children’s communication with others and prevent them from speaking the truth about their parent’s condition. One of these children pointed out:

My mother’s illness destroys our whole future. I don’t allow my friends to come to our home, because after several times they may ask where your mother is. I can’t explain the situation. It is too hard.

One of the healthy parent participants said:

My son told me that “I wish my father had another disease and didn’t suffer from mental illness. Father’s illness is very bad for me. I am ashamed to speak about it and to communicate with others.”

One of the mental health practitioners, referring to the children’s experiences, explained:

The other aspect of family problems is the social aspect. It seems hard and...their social relationship will be destroyed. They are not invited to relatives’ ceremonies. I even see them in hospital with their social interactions being disturbed.

Another contribution to low levels of communication is the child’s sense of shyness due to the parent’s illness. According to a participant:

I have tried to hide the problem and I told nobody. I avoid entering...
deep relation with others due to fear of explaining my situation. I accept my friends’ invitation to their home but never invite them. My sister and brothers are also like me.

Another reason for decreased communication is related to the community as a whole, as it tends to label these children. A participant explained her experience:

Everybody looks at us in a different way, for example, some people say that “They have mad mother or bad mother.” We cannot accept this and suffer from the viewpoint made by the community about my mother and my family because we are a family with high level of social class.

This was also noted among the health care workers. One practitioner stated:

Labeling is so important. The presence of a mental patient in the family is considered as a great crisis especially because of social stigma. This is the reason why they feel isolated and unsupported. People say “We do not want to go to their home,” and this leads to isolation and therefore the experience of stress. We may not perceive this stress.

Mental Factors. When a parent is diagnosed with mental illness, the children may also experience mental health problems, the most common being anxiety, low self-esteem, and hopelessness. One of the top concerns causing children’s anxiety was worrying about developing mental illness themselves. One married child whose mother was diagnosed with a mental illness revealed:

We have decided to talk to a counselor, about our child. I’m worrying about illness incidence in my child; therefore we want, before having a child, to consult with a specialist.

Another type of anxiety in these children is the possibility of the illness returning and having to face the consequences of another episode. Said one child:

I am anxious about recurrence of the disease. It causes me to be anxious. I am always worried about recurrence of illness. I’m worrying what I can do if he becomes ill when I have my final exam in school. When he is normal everything is good. We have [a] good time, he is not angry; he doesn’t show aggressive and paranoid behaviors. But [on] good days I worry about bad days that may come.

Practitioners also acknowledged this anxiety:

All members of the family have stress and are worried about the repetition of this story [illness returning and its consequences].

Feelings of shyness and loneliness due to the parent’s illness may also lead to low self-esteem for these children. According to one child, her low self-esteem, a result of her mother’s illness, caused her to accept things she heard without argument:

I had high morale before mother’s illness but now I do not so. I had much fun but now nothing is good. I lost my self-esteem. Everything I hear, I believe.

One of the practitioners described the experience in the following statement:

The results of the illness make these children to believe that [their] parent has problems so this is why the society has marked them with undesirable titles. Labeling, stigma, and inappropriate community feedback decrease the children’s self-esteem significantly.

Frequent recurrence of the parent’s symptoms and lack of necessary support to meet their own needs may lead to feeling of hopelessness about the future. One child’s description of hopelessness is stated in the following:

When I was sleeping outdoors, a person suggested me a job and I didn’t ask what kind of job it was. I accepted the job offer immediately. I didn’t ask what job it was and where the workplace was; in fact, the disease caused me to run away. My father’s illness causes me to be without any goal in my life. When I want to attain my goal, illness ruptures it. This is the reason of my hopelessness.

Another child described the situation as:

[The] future has lost its meaning for me. Every good thing is disrupted before it is over. Mother’s illness has spread a dark shadow on my life.

Educational Factors. The presence of a parent with mental illness at home can also lead to interruptions in their children’s education, as they cannot properly concentrate on their school assignments. One child said:

This issue [parent’s mental illness] makes me unable to read. When his illness returns I go to my cave. I would not like to talk to anyone.

Another child recalled his time as a student while dealing with his mother’s illness:

When I was a student and when my mother was ill I said to myself that our bad days begin and we cannot study and that I may fail. Today my sister also has this situation.

This problem involves both younger and older children. One child, a college student at the time of the study, expressed:

I am [a] student. Part of my mind is in permanent challenge with university and another part with home. I cannot go on. The family needs to have a mother. I cannot fill her empty position. I cannot do her roles because I have many tasks in the university.
When I do mother’s work, I cannot study properly.

In addition to this problem, little educational opportunities are available for these children. Having a parent with mental illness actually limits the child’s educational opportunities because a significant part of the family income is spent on treating the illness and its consequences. One of the practitioners said:

These children are deprived of educational opportunities. They cannot continue their studies and go to school. Parental illness causes study abandonment in children.

**Economic Factors.** The presence of a person with mental illness in the family causes economic difficulties for other members. Considering the chronic and recurring nature of mental illness, the family is always being challenged financially. One of the participant’s stated:

I want to help, but I cannot do it always. Sometimes we cannot deal with hospital expenses. It is so expensive. Nobody helps the family.

One of the practitioners described such economic challenges:

Their income is being spent more on treatment of the parent rather than the child’s holistic promotion. This problem, especially in chronic cases, is of great significance. Most income is spent on illness, and little remains for the children’s needs. Frequent hospitalizations and the cost of drug therapy affect the whole family’s economics.

**Extra Roles Factors.** Every parent has specific roles in the family, but having a mental illness causes temporary or constant inability to follow through with these roles. Therefore, other members of the family, especially the children, are required to fulfill these roles. Because children are performing extra roles in addition to their own duties, problems ensue. One participant’s explained:

I work at home…that is problematic. I wish she was healthy and could help me. I do not like her to be depending on me. I must prepare food. Home responsibilities limit my time. I abandoned my job because of her disease. I do all the work. She does nothing.

A young man revealed his experiences as:

When she was hospitalized, we shared her duties at home. Everybody did part of the work. This was problematic when we were younger.

Apart from fulfilling the daily roles of parents, children must sometimes also take care of the ill parent and serve as caregiver. One child stated:

When she is at home I must manage her drugs…. I must watchdog the correct timing of her pills…I have to perform caring duties.

**DISCUSSION**

A family is considered to be a system in which any change in one of its members may affect the others (Rose et al., 2002). Our findings showed that the presence of a parent with mental illness in the family may lead to many alterations in its system, such as changes in family structure and interpersonal relationships. These changes create both obvious and subtle effects on the family (Cooklin, 2006). Our participants, similar to other children of parents with mental illness, described that once a parent is diagnosed with a mental disorder, considerable disturbances may occur in the family, with many consequences (Maybery, Ling, Szakacs, & Reupert, 2005). Therefore, parents diagnosed with mental illness will undoubtedly affect their children (Manning & Gregoire, 2006).

**Communication Factors**

The findings described above are indicative of disturbances in communication with others and may lead to withdrawal and isolation. Both the children themselves and society as a whole play a role in creating this situation. Similar to the findings of Focht-Birkerts and Beardslee (2000), our findings show that lack of communication with others may cause these children to be unable to express their feelings, concerns, and challenges. This may also lead to a decrease in the likelihood of social support for these individuals. Our participants highlighted that one major reason for lack of communication is feeling shy because of their parent’s illness. As a result, children hide their parent’s disease from others, and in most cases, no one—not even friends and other people close to them—knows anything about the illness and its effects on children, so such individuals obviously cannot meet these children’s needs. This issue is common during periods of identity attainment, especially in adolescence, a challenge that has been observed in other studies conducted in this field (Aldridge & Becker, 1999; Stevenson, 2002).

The community adds to this isolation by labeling these children. According to our study, one of the most common reasons that children develop this isolating behavior is lack of information about mental illness in the society. Therefore, improving public mental health education may reduce society’s inappropriate and subjective notions about mental illness. This approach was considered in other studies (Devlin & O’Brien, 1999; Maybery, Ling, et al., 2005).

**Mental Factors**

The participants of the current study identified that their own mental health problems are one of the most burdensome outcomes of parental mental illness. In this study, such mental health issues included anxiety, low self-esteem, and hopelessness. Other studies have found the most frequent feelings these children experienced were guilt (Focht-Birkerts & Beardslee, 2000), helplessness (Stevenson, 2002), psychiatric disability (Riebschleger, 2004), and negative experiences (Foster, 2006).
Fear of developing the parent’s mental illness was found to be the predominant cause of anxiety and worry. This is of particular importance, as the literature has frequently acknowledged the risk of intergenerational genetic inheritance of mental illness (Weissman et al., 2005); however, little research has focused on the subjective construct of such transmission (Foster, 2006). The participants of the current study also expressed fear of transmitting their own negative behaviors to their children. The anxiety of living with a parent with mental illness is too great in that some children explained they do not want to marry or have children out of fear of making their own child live with such anxiety. In one case, toxic inheritances (i.e., stories given to children from family members or others that can turn out to be lies or distortions) were used to determine this type of anxiety (Goodall, 2005).

Participants also experienced anxiety about relapse and recurrence of symptoms. Because the signs and symptoms of mental illness are not always predictable, anxiety related to these fears always overshadows their lives. This issue is especially dramatic during critical periods such as final examinations or other important life events, and thus children’s minds are always preoccupied (Cogan, Riddell, & Mayes, 2005; Riebschleger, 2004). Our participants pointed out that the children’s shyness and loneliness decrease their self-esteem, especially when comparing themselves with healthy peer groups. Such negative experiences are similar to the findings from other studies (Cogan et al., 2005; Foster, 2006). However, Aldridge and Becker (2003) posed contradictory findings, noting that some children of parents with mental illness described positive experiences. Thus, therapists working with children of parents with mental illness should understand that self-esteem is a dynamic concept.

Our findings highlighted that lack of support to meet these children’s needs, as well as the frequent recurrence of their parents’ disorder, gradually shape the hopelessness these children experience. Problems related to the disease, hospitalization, and relapse difficulties have synergistic effects; therefore, children picture their future as uncertain and undesirable. This continuous instability replaces hope with hopelessness. Although the findings of other studies have shown that hope is a coping strategy with parents’ mental illness (Pölkki, Ervast, & Huupponen, 2004), the current study’s participants’ hope quickly turned to hopelessness. This pathological process must be acknowledged in health system policies and programs for children of parents with mental illness.

**Educational Factors**

Due to the problems associated with their parent’s mental illness, such children have little opportunities for education. As stated above, living with a parent with mental illness causes financial strain for the family, as much money is spent on treatment. The educational effects of this are not just limited to primary school students but also involve older children attending university. Fudge and Mason (2004), studying the disruptive effects of having a parent diagnosed with a mental illness, reported that children suggested needing a flexible education plan adapted to their situation.

**Economic Factors**

All study participants emphasized the economic impact of their parent’s illness. Not surprisingly, economic difficulties have been reported in almost all previous studies focusing on children of a parent with mental illness in any culture (Foster, McAllister, & O’Brien, 2005). Regarding the chronic nature of mental disorders and the constant risk of relapse, children are continuously challenged with this problem—and the problems will be even greater if social support is insufficient.

**Extra Roles Factors**

Regarding family roles, our findings indicated that parental mental illness may temporarily or permanently prevent parents from fulfilling their roles, disrupting the entire family’s functioning. These roles are transferred to other members, usually the children, meaning they must perform extra responsibilities. Children must care for their younger siblings in addition to...
doing daily tasks and chores around the home. Sometimes these children must care for their ill parent. These extra roles create even more physical and psychological burnout in children already coping with a stressful situation. The caregiving role is especially emotional for children living with a parent with mental illness; they feel if they choose not to accept this responsibility, the family will face even greater burden. Dunn (1993) described this concept as “guilt and loyalty.”

LIMITATIONS
As our findings are subjective in nature, their application in other contexts should be cautioned. For generalization purposes, similarity between contexts must be considered. Some children refused participation in the study, leading to further limitations. Although the data were saturated, a greater number of participants could increase the depth of the data.

IMPLICATIONS AND CONCLUSION
The findings of our study highlight the issues surrounding living with a parent with mental illness and emphasize the need for programs that assess the whole family, even when just one family member is ill. Such programs have benefits for both the parent with mental illness and the children; in addition, they reduce the costs to the health care system (Michalopoulos, Magnus, Carter, & Vos, 2004). Implementing such programs can improve medication adherence and reduce symptom relapse (Reupert, Green, & Maybery, 2008); in addition, by having the child interact with the parent, such programs can reduce the child’s burden and eventually improve their functioning (Miklowitz, George, Richards, Simonneau, & Suddath, 2003). Although the findings of the current study may be seen as a preconceived concept, it should be noted that this is the first study conducted on this issue among Iranian children. Therefore, it is necessary to include information about this invisible population in Iranian nursing education.

REFERENCES
tient management of bipolar disorder. Archives of General Psychiatry, 60, 904-912.


Dr. Oskouie is Associate Professor, Mr. Zeighami is a PhD candidate, and Dr. Joolaee is Assistant Professor, Center for Nursing Care Research, School of Nursing and Midwifery, Tehran University of Medical Sciences, Tehran, Iran. Mr. Zeighami is also Senior Lecturer, Qazvin University of Medical Sciences, Qazvin, Iran.

The authors disclose that they have no significant financial interests in any product or class of products discussed directly or indirectly in this activity. This study was supported by a grant from the Center for Nursing Care Research, Faculty of Nursing and Midwifery, Tehran University of Medical Sciences and Health Services. The authors thank the participants who shared their experiences for the study.

Address correspondence to Reza Zeighami, MSN, BSN, PhD candidate, School of Nursing and Midwifery, Tehran University of Medical Sciences, Bahonar Avenue, Qazvin, Iran; e-mail: behsare@gmail.com.

Received: December 30, 2010
Accepted: July 18, 2011
Posted: August 17, 2011
doi:10.3928/02793695-20110802-06