Original Article

Mental health needs of the children of parents with mental illness

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Abstract

Context: There is considerable empirical evidence about the psychosocial vulnerability of children of parents with mental illness (COPMI). Nonetheless, these children's experiences and needs have still known poorly.

Aims: This study was conducted to explore the mental health needs of COPMI.

Settings and Design: The grounded theory approach was deployed.

Material and Methods: Semi-structured interviews were held with 17 participants who had been recruited purposively and theoretically from a psychiatric teaching hospital located in Qazvin, Iran 2008–2010.

Statistical Analysis Used: The data were analyzed using Strauss and Corbin method (1998).

Results: After relating the main concepts of the study, the "COPMI need theory" was formulated. This theory explains children's needs, changes of needs in the cycle of parents' illness, the process of fulfilling the needs, and outcomes-driven from need fulfillment.

Conclusions: Based on findings, recommendations were provided to mental health professionals who for dealing with families and children of patients with mental disorders.

Keywords: Children, Family, Grounded theory, Mental disorder, Parents

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INTRODUCTION

The global prevalence of mental disorders has been reported to be 20 cases per every 100 people.[1] It is estimated that in Australia, one of every five people experiences serious mental problems.[2] Moreover, about half of American people experience some forms of mental disorders during their lives[3] so much so that 40 million people are affected by mental illnesses each year.[4] In Europe, mental disorders have been also estimated to affect about 27% of the total population.[5] In general, it is estimated that 25% of the global population suffer from mental problems.[6] The prevalence of these disorders in Iran is also about 20% from which one percent of these patients need inpatient hospital care.[7]

Statistics show that in the United States, one-third of male and two-third of female patients who suffer from mental disorders have children. Moreover, half of the people with mental health condition in England have children.[8] Studies conducted in Iran have also revealed that 45.9% of female and 43.9% of male patients who are suffering from mental disorders have children.[9] In general, 25%

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of adults who suffer from mental problems have children who live with them.[10]

In families with mentally ill members, children are very vulnerable.[11] They deal with different problems which are usually taken for granted. Therefore, they have been described as the "invisible population" at risk for mental problems.[12] Although many studies have highlighted their greater vulnerability to mental disorders, cognitive impairments, interpersonal communication problems, psychosocial dysfunction, and impaired adaptive function,[13] it is believed that providing care to these children is an area which is usually overlooked in healthcare systems.[14]

Till date, among the long-term effects of parents' illness on their children, the social and vocational problems have been mostly discussed.[15] Although most of these children's problems are reported to result from chronic effects of their parents' illness,[16] issues such as unemployment and low quality of life also influence their problems.

In families with mentally-ill members, only the ill member has considered in need for receiving help and other members, particularly children, are usually omitted from the process of treatment.[17] Those parents who are afflicted by mental disorders affect children need's fulfillment, cause communication, mental, educational, and economic problems. Moreover, parent's mental disorders are associated with some new problems which aggravate the problem of unmet basic needs.

Despite the importance of the problems which are experienced by children of parents with mental illness (COPMI), there is limited knowledge concerning these children's conceptualization of their parent's illness.[18] Those healthcare professionals who are working with people with a mental health condition have to be aware of these children's needs. Such awareness is of an added importance to nurses because of their direct and frequent contacts with patients and family members.[19,20]

According to the lack of knowledge about these children specific requirements and the significant effects of their unmet needs on their own and their community's health, this study was made to explore the mental health needs of COPMI.

MATERIAL AND METHODS

The grounded theory approach was used in this study. The main focus of this approach is on the process of individuals' mutual interactions as well as human behaviors and social regulations.[18] This 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.

Sampling

Sampling was done purposively and theoretically and was continued until reaching the point of saturation. After saturation in the 14th interview, three additional interviews conducted. Accordingly, the children of patients with mental disorders were approached. They were included in the study if they lived with their parents, had no history of mental illness, and their parents had a history of hospitalization in psychiatric wards. Participants were recruited among mental hospital patients located in the city of Qazvin, Iran. Patients were treated in mental health services with multidisciplinary team approach. Team members were included by psychiatrist, psychiatric nurse, psychologist, social worker, and counselor. The team was led by psychiatrist. Although other members had some challenges especially in defining their dominion.[21]

Participants and interview questions were determined based on the findings of previous interviews. In other words, we shifted from purposive sampling to theoretical sampling based on the study findings. If the preliminary findings of a grounded theory highlight the necessity for sampling from other individuals who have more information, they can be also included in the study. We also included healthy parents, nurses, psychologists, consultants, and the spouses of the participating children in the present study.

Data collection

The study data were collected through holding semi-structured interviews as well as writing memos and filed notes. Thus, an interview guide containing several open-ended, broad questions was developed to help the interviewer maintain the continuity of the interview process. The process of each interview was regulated according to the corresponding interviewee's responses to the interview questions. For instance, once it was identified that parents' mental illness has a cyclical nature, the interview guide was revised to include questions about the characteristics of each phase of the cycle such as, "please tell me about your parents illness" "Can you explain what happened in your parent most recent episode?"

The interviews were arranged based on the participants' preferences. Family members were interviewed in hospital settings while interviews with the participating healthcare professionals were held in their workplace. The interviews ranged in length from 45 to 100 min with a mean of 60. All interviews were recorded digitally and transcribed and typed

immediately (within the first 24 h) to maintain the integrity of the data and prevent probable biases. While transcribing the interviews, we also wrote memos for each interview.

Before conducting each interview, we met the corresponding interviewee and explained the aim and the methods of the study. All interview transcripts and audio files were labeled with numerical codes to protect the participants' anonymity. After obtaining informed consent, the study participants' demographic characteristics were documented. These data were collected solely for describing the study participants. We also attempted to protect the participants' privacy during the interviews.

This research was conducted by permission 920443- 870429 issued from the Ethics Committee of Nursing and Midwifery Faculty of Iran University of Medical Sciences, Tehran, Iran. To respect the participant's rights, both separate and private meeting with each participant was arranged before the actual interview. Participants were also assured to have the right to withdraw from the study at any time. Moreover, every attempt was made to ensure the privacy of participants during the interviews. Written informed consent was obtained from all participants and all data were kept confidential.

Data analysis

We analyzed the data simultaneously with data collection and using the constant comparative analysis method proposed by Strauss and Corbin (1998).[22] The analysis and coding of each interview were done before conducting the next one. Therefore, the flow of the next interview was determined by the data obtained from and the concepts generated in previous interviews. Memo writing was also initiated after the first interview. Primarily, the memos were categorized based on the interviews; however, we gradually started to categorize ideas and hypotheses according to their titles and the generated concepts.

During the open coding of each interview, its transcript was read several times and coded by using the participants' own words (*in-vivo* codes) or our own wordings (connotative codes). In the process of axial coding, codes with similar conceptual meanings were placed in categories. The codes and the categories of each interview were compared with the next interview to identify their interrelationships and properties. Then, categories with similar conceptual meanings and properties were combined and organized around axes to form larger categories. The categories were continuously compared, revised, reorganized, and re-categorized during data analysis. Finally, in the selective coding phase, the core category of the study was identified by focusing on the interviews, categories, memos, and relevant literature. To prevent biases, we attempted to put aside our personal ideas and viewpoints and close focus, with openness, on participants' unique experiences.

Trustworthiness

Factors such as credibility, dependability, confirmability, and transferability have been recognized as the criteria for the evaluation of qualitative studies.[20] Prolonged engagement increases data credibility. In the present study, the process of data collection and analysis lasted for 17 months. A confidence-based relationship with participants is crucial to obtain high-quality data from them. Given our considerable experience in dealing with the families of people with a mental health condition, we were able to build confidence in our relationships with the study participants. We also used a member checking technique to ensure the congruence of the findings with the participants' experiences. Moreover, we attempted to provide detailed explanations about the study method to help the audiences follow the flow of the study. Besides, many techniques were employed to obtain factual data which included recruiting key informants, collecting data through interviews, field notes, and memo writing, collecting and analyzing the data simultaneously, analyzing the data collaboratively and simultaneously by all authors, comparing the data and the generated categories constantly in terms of their similarities and differences, allocating adequate time to perform the interviews, returning the generated codes to the participants, and using their viewpoints in the more abstract phases of the study.

RESULTS

Two sets of participants were included in the study. The first set consisted of 13 patients' family members (six daughters, four sons, one daughter-in-law, and two healthy mothers) while the second set comprised four healthcare professionals. The mentally-ill parents of the participants included by four fathers and six mothers among whom, five suffered from mood disorders, four from schizophrenia, and one from obsessive disorders. They had a history of hospitalization between 3 and 50 times up to 13 times on an average. The mean of children's age was 22 years with a range of 17–26. All four participating healthcare professionals were university faculty members. On average, their work experience was 13.75 years with a range of 5–20.

The core category

The core category of the study was "Need evolution in the cycle of parents' illness." This core category consisted

four main categories including "cycle of parent's illness," "outcomes of parent's illness," "Children need," and "Seeking support." The outcomes of parent's illness have been published previously[18-20,23] and the "Seeking support" category will be published in future attempt. Here, we explain two remaining categories, i.e. "Cycle of parent's illness" and "Children's need."

The cycle of parent's illness

As far as family members were concerned, the mental illness of parents had cyclical and recurring nature. Depending on the afflicting mental illness, the cycle may be repeated even every 6 months.

"It is like a cycle. We need to follow this trend every 6 months (the participant draw a circle in the air by the movement of fingers)."

The study findings revealed that parent's illness had five phases all of them being repeated in each cycle. The phases were "preillness," "illness," "hospitalization," "borderline," and "normal" which are explained as below, respectively.

The preillness phase

Mental illness did not appear suddenly; rather, it began gradually so much so that family members could notice its onset. Although the early manifestations of mental illness which help families suspect its onset were very different, they mostly included changes in patients' behaviors and interactions with others. Sometimes, the manifestations of illness were mild. The length of this phase ranged within a few days to 1 month – mostly 1–2 weeks. One of the participating children noted,

Before the onset of the illness, she becomes sleepless and stares at one point. Then, sleeplessness status becomes more severe. Then, we notice that she is becoming ill. It doesn't take too long; rather, she is in this state for 1–2 weeks and then, the symptoms appear.

The illness phase

In this phase, patients showed the signs and the symptoms of the acute phase of their illness which hospitalization was finally required. Like the previous phase, the length of this phase also varied from several days to 1 month though in most cases, it was about 1–2 weeks.

The same symptoms (of the previous phase) continue; however, after the onset of his illness, the signs become more severe and he avoids taking his medications. Recurrence takes several days to happen and we take him to doctor 1–2 weeks afterward.

The hospitalization phase

When the signs and the symptoms of parents' illness became severe, family members were feeling compelled to take them to the doctor regarding possible hospitalization. Therefore, patients were hospitalized and treated at the hospital. The length of this phase was 1 month, on average.

After receiving medications for 1 month, she gets so much better than the first and the last days of her hospital stay are never comparable in terms of the severity of manifestations.

The borderline phase

In this phase, patient's manifestations subsided, partial recovery was achieved, and patients were discharged from hospital while some manifestations still persist. The participating family members entitled this phase as the "borderline" phase. The length of this phase was also 1–2 weeks.

After returning home, he is bored and in a borderline state and doesn't talk at all. He continues to think with himself until getting normal gradually.

The normal phase

After the borderline phase, patients regained a healthy status and started their normal life. This condition continues until illness recurrence.

Well, (in this phase) she is fine and likes to stay home and work constantly. However, she did not like to shoulder any responsibility before (this phase).

Children's needs

Parents' mental illness creates some certain types of needs for children which will be changed in different phases of the illness.

The needs of the preillness phase

In this phase, COPMI needed to confabulate. They needed someone intimated to understand them and their conditions, and to whom, they could talk about their problems.

My mother needs help and hence, she cannot help me. Well, I need a companion. I mean a companion to whom I can talk about the future. The best type of help to me in this phase is somebody who talks with me about my problems.

The needs of the illness phase

Like the previous phase, children also needed consolation and sympathy about the problems of their parents' illness in this phase as well.

In her illness, I become depressed not because of myself but for the sake of my mother. Therefore, I need someone to sit and talk with

me, throw me in another mood, and avoid remembering my past. In this phase, my only need is to confabulate with someone and also to vent my frustrations to some degrees.

Another need of this phase was to transfer patients to the hospital and quick hospitalize. One of the participants noted,

It greatly depends on the time of hospitalization. Once noticing that his illness is staring, I use thousands of tricks to take him to hospital.

The needs of the hospitalization phase

In this phase, COPMI did not like to be alone because loneliness was painful to experience during their parent's hospitalization period. A female participant said,

Well, at that time, I like not to be alone. It is very hard when we are alone. We like someone to be with us to boost our morale. Therefore, we go to my grandmother or uncle's home to avoid being alone. Our morale is damaged seriously when we are alone. However, when somebody comes to our home, greets us, and consoles us, our morale is boosted considerably.

The needs of the borderline and the normal phases

When the ill parent was discharged from hospital and returned home, the most burning need of children was a need for guidance. They usually suffered from some shortages. Hence, they needed education and guidance to their alleviation. Their first educational need was to know how to deal with their newly-discharged parents. In other words, the children of these patients needed to receive educations and guidance about how to deal and interact with their newly-discharged parents. One of the participants referred to the need for education about dealing with his parent in the borderline phase as below,

We need to know how to deal with him and how to treat him. (Therefore,) Education is an important prerequisite. They should educate us about how to treat him to prevent conflicts.

Healthcare professional participants also confirmed these needs. One of them said,

Like other people, mental patient's children need to learn some mental health skills because these children, particularly adolescents, usually aggravate their parent's symptoms unintentionally. On the other hand, parents also need to learn some skills to be able to manage their illness.

Another educational need for children in these two phases was a need for education about patient's illness and patient care.

I like to know more about the starting point of the illness. For instance, I want to know why it becomes acute suddenly and then, find solutions to the causes. I also need information about medications and his illness. I want to know whether it is better to take medications for life or not.

Information about legal issues was another educational need of the mental patients' children. One of the healthcare professional participants said,

Their other need is the need for information about legal issues because they, particularly the family members of psychotic patients, usually are involved in lawsuits. Therefore, they need to have information about the legal aspects of mental illness to manage their patients more effectively.

Presenting the theory

During data analysis, the first generated category was "cycle of parent's illness." We recognized that each of this cycle phases had a certain meaning to the participants which were making differentiation from other phases. Then, it was identified that children's needs in each phase are different from their needs in other phases. All categories were arranged around the axis of "need evolution" and then, the theory of "COPMI need" was formulated.

The study findings revealed that parent's mental illness have several consequences for children including communication, mental, educational, economic, marital problems and other extra roles[23] as well as positive outcomes.[18] Negative consequences of parents' mental illness cause some sort of requirements among children. These requirements are influenced by their age, gender, and the availability of mental health care services. Children's needs change during different phases of parent's mental illness. In the first three phases, children mainly need companionship. For instance, in the pre-illness phase – that family members notice that the afflicted parent is developing signs and symptoms – children need to confabulate with someone. In the illness phase, the acute signs and symptoms appear and children need someone to help them transfer their afflicted parent to the hospital and sympathize with them. During the hospitalization of parent, children suffer from loneliness and do not want to be alone. In the borderline phase, parent achieves partial recovery discharged from hospital and returns home though some of the signs and symptoms of illness are still exist. During normal life phase, signs and the symptoms are totally disappear. The main need of children in these two latter phases is about receiving some guidance, i.e., they need to receive educations about the afflicting illness, the associated legal issues, and how to care for and interact with their newly-recovered parent. Children need those persons

who are trustworthy, knowledgeable, and skillful and can support them to meet such needs. These individuals may be chosen from their own healthy parent, siblings, relatives, neighbors, or healthcare professionals. If unmet, unfulfilled aforementioned needs can make the children psychosocially vulnerable. Obviously, children whose needs are fulfilled feel being supported and valued experience calmness and will have normal development and psychological balance. They will be more serious about their attempts for improving their ill parent's recovery. Therefore, it can be concluded that parent's mental illness is a "cause" which is associated with the phenomenon of "need evolution" in the context of those factors which affects needs. The status of mental health services is considered as the mediating factor of this phenomenon. Children's main strategy for fulfilling their needs is "seeking support." The outcome of this process is either calmness or vulnerability.

DISCUSSION

Family is considered as a system in which any change in one of its members may affect the others.[2] Our findings indicated that parent's mental illness has a cyclical and recurring nature for family members.

During their parent's mental illness, children go through five phases of "pre-illness, illness, hospitalization, borderline, and normal." These phases recur in each cycle of parent's illness which means that each phase has certain unique attributes. Consequently, healthcare professionals need to become aware of the attributes and the incidences of each phase to develop and implement appropriate care and treatment measures. However, it seems that most healthcare professionals do not recognize these five phases and instead simply divide mental illness into two main phases of acute illness or hospitalization and recovery or discharge. Gavois *et al*. also conducted a study on all family members of people with a mental health condition and described two main phases of crisis and recovery for the illness.[24] Illness phase can be equated with "crisis phase" which has already reported by Gavois *et al*.

Irrespective of their parent's mental illness, the children of mental patients have the same needs as the children of healthy parents. These needs are called in different theories as children's basic needs. However, parent's mental illness prevents or hinders the complete fulfillment of these needs. Besides these needs, parent's mental illness creates certain type of needs for children. These newly-developed needs of children change across the phases of parents' illness. The findings on the nature of children's needs and their changes according to parent's mental illness phases are uniquely achieved by this study and have not been reported by previous studies.

In the pre-illness phase, mental patient's children need to confabulate with someone. In this situation, they like to have companions who understand their conditions and talk with them about their problems. Talking about the problem has a refining effect and gives the sense of calmness. The previous study has showed that talking with others among children is their coping mechanism for their parent's illness.[10] This mechanism is very important because these children usually feel ashamed of their parent's illness, are reluctant to establish close relationships with others, and have no intimate friends or companions.[25] The need to help for transferring their parents to the hospital is important so that some patients may face a lack of insight about their illness and thus may not be collaborative. Consequently, their family members may be compelled to resort different strategies for taking them to hospital. Gavois *et al*. noted that family members of mentally ill patients perceive the onset or the recurrence of their ill relative as a major crisis, so they need healthcare professional's support to immediately be present and overcome such crisis.[24] Therefore, we can equate their concept of "being present" with the concept of "need for help to transfer patient" driven from the current study.

Once an ill parent is hospitalized, the most annoying problem for children is loneliness. A hence their main need is not being alone in this phase. Loneliness is a painful experience at the time of parent's hospitalization and which needs coping strategies. The effect of loneliness on children is so much strong that 30%–37% of children experience behavioral or emotional problems during their parent's hospitalization.[26]

When a parent with mental illness returns home, children need guidance. They have a great desire for receiving information about the unknowns. This finding has admitted by previous studies.[27] This fact implies that healthcare systems have been unable to effectively deliver patient education. In other words, such need highlights the weakness of healthcare systems in the area of care delivery to mental patients and their families. Children's first educational need is to know about how to deal with their newly-discharged parents. They tend to receive education, guidance, and counseling about dealing and interacting with these patients. Children's need for education is so strong that the most important recommendation of the previous study was to assess their needs and to provide appropriate educations for them. Another educational need of children is information about their parents' mental illness and also

about patient care. Children need educations about mental illness, its manifestations, and treatments, particularly about medications. Legal issues are another educational need among these children. The family members of mental patients are usually confronted with legal problems whose management needs having credible information about legal rules and regulations.

Nurses are one of the most important professional sources in this regard. First, nurses are always easily accessible and second, they are easier to communicate with. In accordance with nurse's constant presence in healthcare settings, children have easier and better access to them and may be willing to ask their help. Nurses with good communication skills can considerably help to fulfill the needs of mental patient's children. Due to other mental health professional's shortage in some Iranian mental health settings, nurses need to carry the heavy load of mental care provision, which may cause their burnout and inability to provide adequate support. Psychologists are another source of support according to our participants the reason behind such preference is their general educations. Physicians are usually considered as another source of need fulfillment because of their previous familiarity with patients. Some of our participants also referred to their peers as well. However mostly participants, were reluctant to talk about their problems with even they had been trying to hide their parent's mental illness from their friends. According to Reupert and Maybery, hiding parent's mental illness form friends is one of the most the common strategies used by children in different cultures.[28]

Successful needs fulfillment among COPMI is associated with outcomes which encourage their healthy physical, psychosocial, and spiritual growth and development. Such a healthy growth and development enables children to attempt harder to enhance their parent's recovery consequently, fulfilling children's need would be beneficial to children, patients, families, and communities. Lack of need fulfillments may result their greater social vulnerability and gives them senses of defenselessness, loneliness, insecurity, and tension. These negative consequences might have negative effects on different groups of communities.

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

CONCLUSION

To the best of our knowledge, this was the first study in Iran into the exploration of the needs of COPMI. Findings of this study are novel in the mental health care context in Iran. The comparison between these findings and findings of studies conducted in other countries also revealed the novelty of some of our findings. For instance, the five phases of mental illness as perceived by the participating family members is a novel finding which had not been reported earlier. Moreover, the most important finding of this study was the core category of 'Need evolution in the cycle of parent's illness'. Some study findings advanced the previous knowledge about the positive outcomes of mental illness as well as the effects of children's age and parent's gender on children's needs. Other study findings support the findings of previous studies regarding mentally-ill parent's children.

Theories which are developed by using the grounded theory approach usually embrace many hypotheses which can be tested in other studies.[29]

Conflicts of interest

The authors disclose that they have no significant financial interests in any product or class of products discussed directly or indirectly in this activity.

Author contribution

All authors contributed to this research.

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