

Research Paper: Participation of People With Schizophrenia in Everyday Life: Family's Perspective



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ABSTRACT

Objectives: People with chronic mental health condition like schizophrenia experience a lot of changes in their lives, in addition to their symptoms. The present study used a thematic analysis to explore the participation of people with schizophrenia in daily life from family's perspective. It has uncovered some of the contributing factors in the everyday life participation of this group.

Methods: Semi-structured interviews were held with 8 family members of patients with schizophrenia. All the interviews were recorded and transcribed verbatim. The data were then analyzed in 6 phases of thematic analysis.

Results: Three main themes and 10 subthemes were extracted from the interviews. The main themes included impaired function, family types, and treatment dimensions. The subthemes identified within the family circumstance theme were supportive family, pitying family, ignored family, and confused family.

Discussion: According to the findings, besides the effects of the disease and its treatment on the performance of people with schizophrenia, the family also has a substantial role in the participation of their ill member in daily life activities. Considering the identified effects of families on patients' participation and their needs, designing family-based interventions and training programs can facilitate the participation of patients with schizophrenia in everyday life.

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Highlights

- Social participation in patients with schizophrenia have undergone several changes along with the disease symptoms.
- Treatments have positive and negative effects on patient's social participation.
- Families have crucial role in the participation of their ill member in daily life activities.

Plain Language Summary

People with chronic mental health condition like schizophrenia experience a lot of changes in their lives, in addition to their symptoms. The present study tried to explore the aspects of the participation of patients with schizophrenia in daily life and uncover some of the contributing factors in the social participation of this group. In order to find information about this matter, we conducted some interviews with patients' families and ask them about how their ill members behave in their daily life.

What we found from the interviews shows that disease is the main reason interrupting daily functions. In addition, treatments are double-edged swords in patients' lives. Treatment can improve patients' participation while its side effects can hinder participation. Similarly, the way that families treat their ill member can be both facilitator and obstructer to his/her participation. Supportive families help their ill member to participate in a more active way in their lives. On the other hand, pitiful families deprived them of the opportunity to participate in daily life. Furthermore, there are some unmet needs among families. Needs such as having access to sufficient and useful information about the nature of the patient's disease and effective way to communicate with the ill member. In conclusion, considering the role of families and their needs, we can facilitate the participation of patients with schizophrenia in everyday life through educating families.

1. Introduction

Schizophrenia is a psychiatric disorder associated with cognitive and social difficulties in addition to its symptoms [1]. These difficulties can result in many changes in the patients' level of participation in everyday life, for example, their occupational patterns turn towards passive and less structured activities. Furthermore, since the environment often does not facilitate their participation, most of their activities are performed in isolation and they simply aim to meet their immediate needs or escape from the reality.

Besides their limited daily activities and habits, patients with schizophrenia rarely interact with others and prefer to merely observe or escape the environment. They also feel indifferent about many of their activities' outcomes and consider them worthless [2]. Moreover, research suggests that patients with schizophrenia spend less time on their social life, leisure activities and occupational roles and enjoy less from pleasant situations [3]. The environment affects the participation of patients with schizophrenia in everyday life.

Law stated that the social environment, and especially individual's social attitudes and available social support, are essential in facilitating their participation in everyday life [4]. When a person performs an activity in a social environment, it is often interpreted as meaningful and worthwhile, which suggests the significant role of the environment in facilitating or hindering the meaningfulness of activities [3].

In developing countries like Iran, where the traditional family structure is still the norm and providing social support to groups with special needs is poorly-developed yet, families have to bear the heavy burden of taking care of psychiatric patients. Thus, families as a social environment have the most contact with patients diagnosed with schizophrenia. They not only feel the impact of living with mentally ill person but inevitably exert profound effects on the disease process and the outcomes of the treatment, too.

Many studies showed the impact of disease on families by investigating caregiver burden in psychiatric disorders [5-9]. Nevertheless, there is also evidence that families who provide proper support to their patients and have specific expectations from them, can facilitate

their participation in everyday activities [4] and improve treatment outcomes by increasing their adherence to the medication [10]. Because higher patients' participation in everyday life is one of the main goals of occupational therapy [11], we tried to identify the contributing factors in their participation. The present study explored the participation of people with schizophrenia in daily life from the family's perspective to understand some of these contributing factors.

2. Methods

Qualitative methods provide a useful tool to understand how patients and their families live with the physical and social consequences of a chronic disease or disability [12]. These tools can also provide evidence-based research on the most pertinent issues of the patients, rather than the researchers [13]. We used semantic thematic analysis method to answer our research questions [14].

Study participants

The purposive sampling method was used to select the study participants, in cooperation with a Psychiatric Hospital in Tehran, Iran. The participants were selected from the family members of patients diagnosed with schizophrenia, who lived with the patients.

Data collection

The participants were informed about the research over the phone and invited for an interview if they agreed to participate in the study. The participants provided a signed consent form. The researcher then held individual semi-structured interviews with each participant and recorded their discussions. The data collection process continued till saturation was reached and no new codes were extracted from the interviews. The interview guide questions included, but were not limited to, the following: What are the patient's activities after waking up in the morning? How does he do these activities? What efforts have you made to change the patient's level of participation in everyday life and what were the outcomes?

Data analysis

The data analysis was performed after the first interview was transcribed. We used the 6 phases of thematic analysis described by Braun and Clarke: "familiarizing with data, generating initial code, searching for themes, reviewing themes, defining and naming themes, and producing the report" [14]. The researcher read the interview texts several times and marked the statements that

struck her as important and took notes of the initial ideas for an in-depth understanding. Then, a title was assigned to each marked statement and written on the right hand corner of the text. This step was repeated several times until all of the important statements were coded.

A list of the codes extracted from each participant's interview was then prepared and a cluster of the similar codes was formed into potential themes observed in the lists. The themes extracted from each participant's interview were then tabulated. A list of all main themes and subthemes was then prepared from integrating the tables. This integrated table contained a comprehensive list of themes, subthemes, participants' code, and relevant quotations pertaining to each theme. Ongoing analysis in this phase led to generating clear definition of each theme and naming them. The full content of the table was then discussed in an expert panel (with 3 qualitative research experts) and then the main themes and subthemes were agreed on by the researcher and her colleagues.

3. Results

Eight interviews were conducted for the data collection. Three of the interviews were performed concurrently with both parents, in which one parent was the main interviewee and the other completed his/her statements as desired. One female interviewee had a parent with schizophrenia. The rest of the interviews were conducted with the patients' mothers. Interviews lasted between 32 and 80 minutes. The analysis of participants' experiences led to the emergence of three main themes and 10 subthemes. Table 1 presents these themes and subthemes.

Impaired function

Part of participants' experiences described the changes in their patients' daily functions after the onset of the disease. These changes were explained in 4 subthemes: fluctuating participation, purposeless behaviors, incompetence in functional roles, as well as avoidance and conflict in relationships.

Fluctuating participation

According to the families' explanations, the patients lacked desire or motivation to take part in their environment and were apathetic and unwilling to assume any responsibilities most of the times.

"He has no motivation to continue his job or improve his life. He shows no interest in exercise, swimming or hanging out with friends. He lives in apathy". said participant

Table 1. Themes and subthemes

Themes	Subthemes
Impaired functions	Fluctuating participation
	Purposeless behaviors
	Incompetence in functional roles
	Avoidance and conflict in relationships
Family type	Supportive family
	Pitying family
	Ignored family
	Confused family
Treatment dimension	Limiting treatment
	Beneficial treatment

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number 7. However, the patients occasionally showed interest in active participation in the environment and performing tasks that they were not willing to do before.

“Sometimes he cooperates, and sometimes he is not interested in any interactions, not even a simple one. Occasionally, he interacts very well, cooperates and consults. Overall, it’s a fluctuating matter”. Said participant number 3.

Purposeless behaviors

Purposeless behaviors were linked with the onset of schizophrenia, in which, according to their families, lacked positive effects and particular purposes. “He just keeps walking around the house, from the right to the left and vice versa, until he gets tired and falls asleep”. Said participant number 5.

These purposeless behaviors were sometimes obsessive and related to symptoms like hallucination. “He constantly walks around the house and watches us out, checking every room to see if we were there, then he continues walking around the house, looking over his shoulder. I assume he might be looking for someone or something”. Said participant number 2.

Incompetence in functional roles

According to the families, when the patients did actually participate in daily functions, the quality of their activities were not at the same level as before and fell below the standards. “Even now that she is sick, she takes

care of many of the house chores like cooking, but she is so bad at that!” Said participant number 2.

The ill family member could not properly perform his daily functions and their impaired performances sometimes even lead to losing their roles. “He worked in a packaging unit for a few days, until they realized he can’t focus, and he got fired, because he packed the ice-creams upside down”. Said participant number 6.

Another participant described her father’s role in the family as follows: “My father has no impact in our lives. I have never been able to discuss things with him or rely on him. I always wanted a father and he was not the one. We don’t only need him to be in peace, I want a real father ... a mother wants an actual son”. Said participant number 4.

Avoidance and conflict in relationships

Impaired relationships were a major implication of the disease that affected the familial lives. Some of the families reported that the patients had no desire to establish relationships with anyone or simply failed at it.

“It’s been 14 years since he has been out of the house. He just opens the window, looks at the street and then shuts the window. He even ignores us. Therefore, we somehow avoid him”. Said participant number 1.

Incompatibility in relationships sometimes results in conflicts between the patient and the family members.

“Her brother cannot stand her, they argue constantly, which sometimes turns into an actual fight. Sometimes she attacks and hits me”. Said participant number 2.

Family circumstance

This theme is related to the family. The two first sub-themes are related to the family roles in the patient's participation in everyday life, and the two last themes determine the needs and ambiguities of the family with regards to their ill member.

Supportive family

The efforts made within the families have a positive role in making the patient more active. The family members used strategies to encourage the ill member to perform different tasks and to facilitate continuation of the activities he had already begun. Some families tried to involve their ill member in different activities through financial and emotional support.

“If I were certain about him performing a career, I would rent or even buy him a shop, so that he could stand on his own feet”. Said participant number 3.

Another strategy of these families was to encourage and accept even the poor performances of the patient. “We all encourage him when he does something. We tell him ‘well done, thank you’. Whatever it is, whether he has only washed some dishes, swept the house or cooked, we appreciate his effort, no matter good or bad”. Said participant number 5.

Pitying family

In contrast to the previous subtheme, the family's attitude and manner towards the patient can also negatively affect their level of participation in daily life activities. Most of the families were pitiful about their ill member and gave them excessive support. These supports prevented the ill member from the opportunity to participate in daily life and even self-care activities.

“His father shaves his beard. He can do it himself if desired and does it sometimes. But his father insists to do it, to help him feel relaxed. He also knows how to cook, but he won't bother, because he knows we'll cook for him”. Said participant number 1.

Many families believed that they were supporting their ill member by giving them fewer responsibilities and assumed they were fulfilling parental roles. “His father is a construction laborer. My son asked me to persuade

his father to take him to work with him. But his father refused to do so, because he took pity on him”. Said participant number 6.

Ignored family

The results show that families need to receive attention from the members of the medical team involved in their patient's treatment and expect their own needs and problems be attended to as well as the needs and problems of their patient's. “I wish my father's psychiatrists realized that he has a family who also needs to be treated... none of my father's psychiatrists neither asked me, nor my mother or brother if we were alright or have any problems”. Said participant number 4.

The participant number 5 said that: “Recently, I think I should be hospitalized myself, I have lost all of my energy and control... I am always arguing with my daughter. I feel more disturbed than her”

Confused family

Most of the families revealed that they had no access to sufficient and useful information about the nature of their patient's disease. “We have parented him for several years and still don't know what his problem is. I would love to get some help with this, so that I understand what his disease is and how we can better help him”. Said participant number 1.

Some of the families said that their lack of knowledge was accompanied with feelings of guilt and they believed that they could have facilitated their patient's treatment if they knew more about the disease. “Perhaps we could have treated him much better, if we had known what his disease was from the beginning. We didn't even know what were the purpose of his medications and why there were so many of them. The doctor didn't tell me what his problem was. He just gave me this prescription when I explained his conditions and how he behaved those days”. Said participant number 3.

The families also expected to learn about an effective communication with the ill member of their family. They tried to obtain sufficient information on this subject in order to be effective in their patient's process of treatment and recovery. “I want to know what I have to do for my daughter and how I can treat her better, so that I won't have to face bigger problems. It is the counselor's job to explain me how I should behave, so that I won't trigger her or make her more nervous. That was all I wanted

from my counselor, and nothing more". Said participant number 5.

Treatment dimensions

The next two subthemes demonstrate the families opinion about the treatment. The results showed that the treatments had a diverse limiting and facilitating effect on patients' performance.

Limiting treatment

According to the families, the treatment side-effects were among the barriers to the patient's participation in everyday life. Sleeping disorders caused by antipsychotic medications or attention deficit caused by electroconvulsive therapy are some of the examples of the side-effects, mentioned by the families. "Medications made him bedbound and inactive. He cannot get up to go to work at a certain time every day". Said participant number 3.

Beneficial treatment

On the other hand, the regular intake of medications and other treatments had also positive effects on the patients' participation in daily activities, in addition to reducing their symptoms.

"I took her to the doctor and he was hospitalized for two months and they treated him with electroconvulsive therapy. He has calmed down and has become more active, ever since. He washes up at least a couple of dishes and does a bit of shopping if forced to". said participant number 5.

The other participant noted that the regular medication intake controlled patients' sleep cycle and facilitated their performance in daytime activities.

"My father follows a more regular sleep schedule, since taking his medications. He no longer stays up all night. He goes to bed with my mother and wakes up in the morning to go to work". Said participant number 4.

4. Discussion

The present study explored the families' description about the participation of their member with schizophrenia in daily life functions. The results suggest that schizophrenia symptoms and its treatment make several changes in the patient's daily life functions. Gard et al. [15] and Strauss and Gold [16] argued that patients with schizophrenia are less involved in purposeful activities

such as food preparation or academic and vocational tasks compared to the healthy people. Furthermore, evidence shows a strong relationship between the negative symptoms of schizophrenia and poor performances in these patients, which is mainly associated with a lack of motivation [9, 17].

The negative symptoms emerged as fluctuation in participation and inadequacy in performing functional roles among the studied patients. Moreover, poor social performance and impaired social competence are among the problems experienced by patients with schizophrenia [18, 19]. Based on the families' reports in this study, some patients are rarely willing to interact with others and even with their family members.

This avoidance has forced families to even dedicate a separate physical space to the patient. And when the patient establishes a relationship with people, it often ends in tensions due to the incompatibility of the patients and the social environment. In addition to the negative symptoms of the disease, impaired executive functions also exert adverse effects on the patient's everyday life functions and attention deficit is common in patients with schizophrenia [20]. This study showed that failure in vocational and academic activities and Instrumental Activities of Daily Living (IADL) such as financial management are among the conditions that are disturbed due to impaired cognitive functions.

The families' attitudes and behaviors towards the patient can play an important role in their participation in everyday life. Family support can be considered both as positive and negative factors in determining a schizophrenic patient's participation in daily life. Families who adapt expectations and commitments, facilitate engagement and encourage their re-engagement into the world can facilitate patients' participation [21]. The extended and close knit family structures of the traditional societies can emotionally and financially protect the patients against the disease pressures [22] and family warmth protects the patient throughout the disease course [23].

According to the studied families, family support can encourage the initiation or maintenance of participation in daily activities. Snowden discussed that the constructive involvement of the family in the treatment of psychiatric patients can mitigate the symptoms of the disease, prevent crises, improve social adjustment, and ultimately diminish the patients' need for treatment [24].

The inefficiency of the ongoing services and social support provided by the health system, as well as cultural

issues, highlight the role of Iranian families. This condition makes families assume a greater responsibility toward their ill member and seek to abate the effects of the disease on the patient's life through different strategies.

In contrast, the present study identified excessive family support as an inhibiting factor to participation in everyday life. This level of support may be caused by the expectations from the family members in countries with such cultural backgrounds like Iran. In such cultures, the family is expected not to leave the patient alone and to constantly care for him/her during the disease course [25].

In Asian countries, families' over-involvement in the process of treatment sometimes leads to over-responsibility in them and they end up making decisions for the patients without their participation [26]. In addition, families as the main caregivers shoulder the greatest burden in the patients' process of rehabilitation. Thus, it is necessary for both the patient and the family to receive rehabilitation services [27]. Nevertheless, counseling services and practical help for the caregivers appear to be mostly neglected [28]. In the present study, the long-term responsibility of caring for patients with schizophrenia and the physical and mental pressure exerted on these families have increased their need for healthcare services.

According to the previous studies, the families of the patients with schizophrenia have greater educational needs compared to the caregivers of patients with other psychotic disorders, thus medical team members should focus more on caregiver's needs. The most important needs of these families include information about the disease, available medical treatments and their side-effects, learning about strategies that can improve coping with the patient's disease-related behaviors and strategies for patient management [29] and having knowledge of the disease's warning signs, and the best responses to them [28]. The interviewed families also wished to receive information about the ways of better interacting with their patients.

The results also specify that undergoing treatments act as a two-way pathway. The reduction of positive symptoms, enhance the quality of life [30] and improve psychosocial performance in patients with schizophrenia [31]. Also, their side-effects adversely affect the patient's life [32, 33]. The participants reported side-effects such as oversleeping or memory problems due to electroconvulsive therapy, which diminish the opportunity of the patient's participation in daily activities.

5. Conclusion

Given the chronic nature of schizophrenia, patients require ongoing care services. The cultural context of developing countries such as Iran and the lack of accessibility to adequate social support lead to the direct and long-term involvement of the family in the process of rehabilitation. According to the results, in addition to the effects of the disease and its treatment on the performance of these patients, the family has also a substantial role in the participation of their ill member in daily life activities. Considering the family's effect on the patient's participation and the needs discussed by the families interviewed in the present study, designing family-based interventions and training programs for the process of treatment seems necessary. Occupational therapists, as members of rehabilitation teams, who facilitate the participation of patients in daily life activities, can benefit from such family-based interventions.

Ethical Considerations

Compliance with ethical guidelines

Ethical approval was obtained from IUMS Ethics Committee under the code of 24671-32-02-93. Additionally, all research participants have completed consent forms and we have used numbers instead of their names whenever we refer to their quotes.

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Conflict of Interest

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