



Care Bermuda, families of the patients with chronic mental disorders in Iran surrounded by psychosocial problems and needs: a qualitative study

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Background: A mental disorder is characterized by a clinically significant impairment of cognition, emotion regulation, or behavior. As a result of the shift in care from medical centers and hospitals to home care, we now see a change in the treatment of patients with chronic mental disorders. Consequently, families have become the main support system in the progressive care of these patients, leading to psychological and social problems. The current qualitative study investigated the social and psychological health needs and problems of family caregivers of patients with chronic mental disorders in Iran's cultural and social context.

Methods: This was a content analysis qualitative study. The study was conducted in three psychiatric hospitals in Farabi, Noor, Modares. Purposive sampling was done and continued until data saturation. Semi-structured, face-to-face, and individual interviews were conducted with 49 participants (15 family caregivers of patients with CMD and 34 members of the mental health care team). Data analysis was done using the conventional content analysis method.

Results: Eight hundred seventy-five primary codes were obtained, which were classified into 10 subcategories and 3 main categories of 'health challenges of caregiver', 'confused concept of care' and "the need for a coherent support system.

Conclusion: In Iranian society, after the patient is discharged from the hospital or care center, family members will change their role to the most important caregivers of these patients. The psychological and social health of these caregivers is destroyed because of the problems they have in providing care for their patients and their needs, which are not met.

Keywords: chronic mental disorders, family caregivers, psychosocial needs, psychosocial problems, qualitative study

Introduction

Mental health is currently considered one of the main components of public health in societies. Mental health problems are critically increasing in many parts of the world^[1]. A mental disorder is characterized by a clinically significant disturbance in a person's cognition, emotional regulation, or behavior^[2]. According to estimations, about 19% of the world's population suffers from various types of mental disorders. It covers about 31.3% of the general population in Iran^[3]. As one of the main causes of disability^[4].

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HIGHLIGHTS

- The present qualitative study aimed to investigate the social and psychological health needs and problems of family caregivers of patients with chronic mental disorders in the cultural and social context of Iran.
- The improvement of the psychosocial capacities of the caregivers through interventions and efforts to provide continuous health and government support for them, together with the public awareness of mental illness can greatly reduce the psychosocial burden of these caregivers.

Nowadays, along with advancements in providing psychiatric services, we can witness a change in the treatment of patients with chronic mental disorders (CMD) as well as the relocation of the care place from medical centers and hospitals to home care^[5], making families the main support system in the ongoing care of such patients^[4,6]. Bipolar mood disorder, schizophrenia, and depression are recognized as CMD that are associated with high levels of perceived care burden for caregivers^[5]. As a hidden healthcare system, family caregivers are located along the health system and has become an institution where patients with mental disorder live^[7]. Therefore, it is known as the most important source of support in the care, symptom management, and treatment process of these patients^[8–10]. Accordingly, CMD in any member of a family will lead to psychological, social, and responsibility burdens not only for the patient but also for all

family members^[11], which will start from the very onset of the disease and continue throughout life^[12].

One of the common consequences that family members of patients with mental disorders face are being ridiculed by others. Therefore, they try to hide the disease to avoid exposure to the people around them. Most families, generally with the appearance of the disease, suffer from the annoying and humiliating looks of society and the people around them^[13]. Some members of society may consider a patient with a mental disorder as a person who has suffered from magic and a curse^[8]. The families of these patients often suffer from the devastating consequences of stigmatization, and the feeling of shame is the most concrete emotional response to the experience of stigmatization of mental disorders^[14]. The feeling of infamy and social stigma is known as one of the factors affecting the reduction of social interactions^[15]. The negative effect of this label, which is referred to as 'family stigma', is more felt in societies where family cohesion is high (Like Iran)^[16]. In the study of Akbari *et al.* (2018) it was found that in Iran, about 88.5% of families of patients with schizophrenia experience negative attitudes and stigma. Also, about 30% of caregivers of people with major depressive disorder and 50.5% of families with bipolar disorder suffer discrimination and ridicule from the people around them^[17]. These cases are associated with the feeling of embarrassment, dishonor, or disapproval and rejection by others, and the feeling of disconnection from social ties and social isolation^[18]. Family caregivers of CMD patients experience a high percentage of diseases such as depression and anxiety disorders, and it is estimated that the life expectancy of these people is 10 years less than other normal people^[19]. These cases are associated with threats to mental health, decreased family satisfaction with life, and decreased quality of life^[8]. Therefore, in terms of mental, and social health, they are at risk and their ability to cope with and adapt to these conditions is damaged, so in the end, the whole life of these people will be affected by the condition of the disease^[4]. Therefore, these families need to receive psychosocial support^[6]; because when caregivers feel that they are receiving adequate support from professional caregivers in the process of caring for their patients, they accept their role more hopefully and optimistically, which in turn will reduce the risks of caring burden^[20]. In Iran, about 55% of the families of patients with mental disorders reported receiving moderate and lower support. Based on this, it can be said that one of the main responsibilities of the health care system is social and psychological support for these people^[17].

Despite the emphasis on promoting psychosocial health, doing so will be fraught with challenges. For example, the mental health care team has lacked sufficient knowledge regarding the provision of this type of care, and it can be difficult to provide this type of support^[21]. On the other hand, insufficient understanding of the psychosocial problems and needs of family caregivers of CMD patients becomes an obstacle to providing appropriate support to these families^[22]. Therefore, it seems necessary to identify the psychosocial problems and needs of family caregivers of CMD patients. In studies by Berekatain *et al.*^[23] Akbari *et al.*^[17], Iseselo *et al.*^[8], Chen *et al.*^[24], Wirsén *et al.*^[25] to identify the problems and/or needs of families with patients with mental disorder has been addressed, but these researches and similar studies have not comprehensively investigated the psychosocial problems and needs of family caregivers of patients with CMD, and the researcher has not come across a study that can provide extensive knowledge in this field or the study was not conducted

in Iran. Due to the fact that the nature of health and psychosocial experiences are highly dependent on the social, temporal, and spatial conditions of humans and these factors are different in every society, there is a need to use a qualitative approach to identify the dimensions of psychosocial problems and needs of caregivers of patients with CMD in the cultural, social, and economic context of Iran^[3]. So that the members of the mental health team and the health policymakers, using the results of this study, can plan properly to reduce the psychosocial problems and the needs of the family caregivers of CMD patients. As such, the present qualitative study aimed to investigate the social and psychological health needs and problems of family caregivers of patients with CMD in the cultural and social context of Iran.

Methods

This study is part of a larger mixed-method study, approved and carried out in the Faculty of Nursing and Midwifery, Isfahan University of Medical Sciences (with ethics code IR.MUI.NUREMA.REC.1400.107). The content analysis method was used to help the researcher understand the real world as experienced by the study participants. This study was conducted with the approach of conventional qualitative content analysis by inductive method^[26]. In order to achieve a rich understanding of the psychosocial problems and needs of family caregivers with CMD in the cultural and social context of Iran.

First, the files of the patients admitted to the ward were studied, and if they met the inclusion criteria, the families of the patients were contacted, the objectives of the study were explained to them, and if the caregivers of the CMD patients were willing, a visit was made to them in the hospital and the interview took place. In this study, 15 family caregivers of chronic mental patients (diagnosed with schizophrenia, bipolar disorder, and depressive disorder) whose patients were hospitalized in one of the three psychiatric hospitals in Farabi, Noor, Modares at the time of the study and there was sufficient satisfaction and readiness to share their experiences and opinions, they were not diagnosed with a mental illness, and they had cared for a patient with CMD for at least 2 years they entered the study (Table 1). And with 34 members of the mental health care team, including psychiatrists, psychiatric nurses, psychologists, occupational therapists, social psychologists, etc., who were in contact with CMD patients and their families for at least 2 years and consented to participate in this study, were interviewed to better identify the various dimensions of psychosocial problems and the needs of family caregivers of patients with CMD (Table 2). With study participants, semi-structured in-depth individual interviews were conducted. The data collection method was purposive sampling with maximum diversity in terms of age, sex, level of education, and type of mental illness for family caregivers and the type of specialization and responsibility for members of the mental health team until saturation data continued. That is, the data obtained from the interviews were a repetition of the data from the previous interviews. The sampling method was nonprobability and purposeful sampling in the form of achieving representativeness and in the form of maximum difference. This sampling method is used when the goal is to reach a sample that represents a wider group of samples and is as close to it as possible. In this method, the maximum difference in the range of qualities, characteristics, situations, or occurrences of the

Table 1
Information of family caregivers

	Care givers	Number (Percentage), n (%)
Sex of caregivers	Male	7 (46.66)
	Female	8 (53.34)
Age of caregivers (year)	20–30	3 (20)
	31–40	3 (20)
	41–50	2 (13.33)
	51–60	5 (33.34)
	> 60	2 (13.33)
Relationship with the patient	Father	2 (13.33)
	Mather	3 (20)
	Sister	2 (13.33)
	Brother	1 (6.66)
	Spouse	4 (26.68)
	Children	3 (20)
Type of disorder	Schizophrenia	7 (46.66)
	Bipolar mood disorder	6 (40)
	Depression	2 (13/34)
Years of care	2–10	3 (20)
	11–20	8 (53.34)
	21–30	4 (26.66)

phenomenon under study is considered to consider the participants. The purpose of this method is to ensure that as many variables related to the topic are examined as possible and to portray the main themes that have been obtained from different participants. The basis of this sampling method is based on the principle that the difference in the characteristics or important dimensions of the participants should be carefully considered.

Table 2
Information of the health team members

	Health team members	Number (percentage), n (%)
Sex	Male	15 (44.12)
	Female	19 (55.88)
Age (year)	20–30	1 (2.95)
	31–40	15 (44.12)
	41–50	11 (32.35)
	51–60	7 (20.58)
Education rate	Bachelor degree	14 (41.17)
	Master degree	11 (32.35)
	Doctor degree	9 (26.48)
Profession	Psychiatric nurse	15 (44.12)
	Psychiatrist	6 (17.64)
	Psychologist	5 (14.72)
	Social psychiatrist	1 (2.94)
	Hospital assistant	2 (5.88)
	Charity officer	1 (2.94)
	Expert of justice	1 (2.94)
	Responsible for the patient care and rehabilitation center	1 (2.94)
	Responsible for hospital occupational therapy	1 (2.94)
	Social helper	1 (2.94)
Work experience (years)	2–10	9 (26.47)
	11–20	16 (47.06)
	21–30	9 (26.47)

The logic of this method allows extracting all the usual patterns obtained from different people in order to get the best understanding of the phenomenon under study^[27]. Data were collected from October 2021 to February 2022. The interviews were conducted by the first author, who was a PhD student in psychiatric nursing. She had learned qualitative interview methods during her PhD student period and had 8 years of psychiatric training and work experience, and was also interested in the research topic, in three research hospitals. Individual and face-to-face interviews with the participants in the study were conducted in a quiet room in the psychiatric departments of the study hospitals. The objectives of the research were explained to the participants. Semi-structured interviews were conducted. Sample interview questions from the families of CMD patients included: ‘What is your experience of caring for your patient?’ ‘What problems did you encounter in this field?’ ‘What needs do you have that solving them will make you experience fewer problems?’. Examples of questions from mental health care team members include: ‘What problems and challenges are the families of CMD patients facing?’ and ‘What services do these families need most?’. The interviews lasted from 20 to 45 min and averaged about 30 min. Two pilot interviews were initially conducted as an interview guide. Two interviews needed to be repeated, and a total of 53 interviews were conducted with 49 participants. All interviews were audio recorded. In this study, the following ethical issues were fully observed. Before sampling, the objectives of the research were discussed with the participants and if they wished to enter the study, a written informed consent form was obtained from the participants. The interviews were recorded anonymously and assured that the interviews were confidential.

Data analysis in the qualitative stage was performed using the qualitative content analysis method of the Grenheim and Landman method. This is an inductive method that allows categories to flow from the data. Researchers immerse themselves in data to gain new insights. The advantage of the conventional content analysis approach is to obtain direct information from participants without imposing a presuppositional classification or theory^[26]. The stages of content analysis generally include determining the content of the analysis, determining the unit of analysis, initial coding, classification of codes into subcategories, formation of subclasses from subcategories, formation of main classes from subclasses^[28].

The analysis process of each interview was performed immediately after the end of each interview. Following the interview, the researcher immediately listened to the recorded audio and examined whether the interview needed to be repeated or continued. Then, each interview was conducted verbatim and according to the participants. After analysis, each subsequent interview was performed and so on until data saturation. The interview analysis process was performed by the first author and was shared with the research team members for approval and coordination at each stage of the analysis and was discussed until a final consensus was reached. Data management and analysis was performed using MAXQDA20 software version 20.4.0.

Lincoln and Guba criteria were used to confirm the validity and scientific accuracy of the study. In order to increase the credibility of the study, the researcher tried to use prolong engagement in research environments and the member checking by participants to confirm the accuracy of the data and codes extracted. In order to achieve dependability, from the beginning

of the research, all related activities and decisions were discussed with the research team. Also, by clearly, accurately and purposefully describing the research process, and the characteristics of the study participants, it was possible for the readers to follow the research path. In order to be confirmability, the researcher tried to first identify her views on the psychosocial needs of family caregivers of patients with CMD and avoid bias in this area [29,30].

Results

Participants of the study consisted of 15 family caregivers of patients with CMD and 34 members of the mental healthcare team, whose characteristics are listed in Tables 1 and 2. Generally, 1750 min of recorded interviews, 875 primary codes were obtained, which were classified into 10 subcategories and 3 main categories of 'health challenges of caregiver', 'confused concept of care' and 'the need for a coherent support system' (Table 3).

Health challenges of caregiver

Family caregivers of the patients with CMD are, undoubtedly, responsible for the largest and most extensive emotional, social, and physical care of these patients. Accepting the heavy role of caring for these patients and commitment to it can threaten the

health of caregivers. Human health is one of the most important pillars of human life, whose different aspects are intertwined and affect each other.

In the present study, one of the most important problems in terms of health was the poor mental health of family caregivers of CMD patients. This subcategory was divided into two subcategories: psychological complications of patient care and psychosomatic complications of patient care. These caregivers experience problems such as dissatisfaction with life, mental exhaustion, loss of confidence, stress, feelings of being diminished, insecurity, depression, and helplessness which are imposed on them as psychological burdens.

A family caregiver of a patient with schizophrenia disorder said: 'Sometimes we have a strong feeling of helplessness. We have some problems when he (the patient) is at home, and other problems when he is in hospital. There is no peace in our life. There is always commotion in the house. All of us like to escape from this situation. At this age, I'm getting depressed and not inclined to do anything'. (F7)

Additionally, imposing a psychological and social burden on the caregivers of the patients with CMD makes them psychosomatic exhausted.

Table 3
Categories, subcategories, and sub sub category

Category	Sub category	Sub sub category
Health challenges of caregiver	Caregiver mental health problems	Psychological complications of patient care Psychosomatic complications of patient care
	Caregiver social health problems	Experience stigma and social discrimination Forced to hide the disease Condemned to social isolation Lack of understanding and empathy of society with caregivers Society's ignorance of mental illness Traditional structure of society
Confused concept of care	Unsuitable family environment	Inappropriate interaction between the patient's family members Other family members suffering from mental illness Failure to accept the disease from the family The impact of problems caused by the disease on all family members
	Financial problems	Imposing the financial burden of the disease Insufficient income in the family Conflict of performing professional responsibility and continuous care The vicious cycle of economic hardship and disease treatment
	Exhaustion of caregiver	The helplessness of the caregiver to treat the patient Decreased family performance to care for the patient
	Complexity of care	The caregiver's constant preoccupation with caring Facing the caregiver with multiple roles Limitation of the caregiver's normal life routine Failure to accept care from the patient's side
Need for a coherent support system	Weak support from mental health care team	The interaction of the health team and the caregiver Psychological support and empathy of the health team with the caregiver Educational needs of caregivers Improving life skills in caregivers Psychological evaluation and treatment of other family members of the patient Family and patient follow-up after discharge
	Weakness in providing official support from government systems	Lack of financial support for these families poor insurance coverage inadequate legal support for the caregivers difficult admission of the patients in welfare centers lack of job opportunities
	Weakness in providing informal support	The role of NGO The activity of peer support associations

The sister of a patient with depression disorder said: 'I had to bottle up everything that led to a continuous attack of migraine and a nervous stomach as well. I sometimes throw up blood'. (F8)

In terms of social health, the most important problem of caregivers is the issue of social stigma caused by mental illness. The participants believed that when a family member suffers from mental illness, they feel that their family reputation is lost. The negative image envisaged in the mind of people with regard to the patients with mental illness. Because of this image, caregivers of these patients may experience some degrees of scorn and discrimination and try to hide their patients from others. Moreover, they are doomed to be rejected by society and their acquaintances.

In this regard, the mother of a patient with manic disorder said: 'People inconsiderably call these patients mad. We also didn't like our relatives know about it. Even now, they don't know anything'. (F2)

Similarly, a psychiatrist maintained: 'Stigma is a social issue; society does not have a good view of it. People are afraid of these patients, distance themselves from them, do not let them enter their gatherings, ignore them, and even scorn their actions or behaviors'. (D3)

Based on the components of this category, wide-ranging challenges in psychological, social, and physical dimensions are considered as the most important issues reducing the psychosocial health of family caregivers of the patients with chronic disorders.

Confused concept of care

The psychosocial problems and needs of the caregivers of patients with CMD are not limited to a few specific ones; these caregivers experience a variety of issues that are interconnected, intertwined, and interdependent. To solve these problems, other problems should be solved as well. Therefore, being confused about these problems, the caregivers cannot easily find a solution to them. The participants stated that inappropriate relationships between the patient's family members and the tense atmosphere within the family, and the simultaneous involvement of several members of the family with mental illness affect all family members and lead to the accumulation of problems.

A psychiatric nurse said in this regard: 'Because of their family situation, I sometimes personally put myself in the patients' shoes and believe that they are in the right to be mentally ill as they have grown up in an inappropriate family environment and are supposed to tolerate this unsuitable condition'. (N10)

The long and complicated process of caring for chronic mental patients can sometimes prevent the caregivers of these patients from doing their social and professional responsibilities, leading to a conflict between professional responsibilities and the ongoing care of their patients. Moreover, many of these patients are responsible to earn a living which is interrupted when the illness becomes chronic, leading to many financial problems for their families. Given these economic problems, the unemployment of the patient or the caregiver, and the high costs of treatment, the

families fail to meet the medical needs of their patients that may disrupt the treatment process. As such, a vicious cycle is created in the treatment process.

'I think many families have financial problems; many patients are the head of families who have no longer any income as they are hospitalized': said a psychologist. (PS3)

The father of a patient with manic disorder said: 'If we do not have financial problems, we'll have no problem with regard to the treatment of our daughter. My only concern is the treatment costs. I can't deal with these costs alone and with empty pocket'. (F9)

Furthermore, since mental illness is a chronic problem, these caregivers are continuously faced with the symptoms of the disease and the long and intolerable process of care. This leads to the exhaustion and frustration of the caregivers over time. During this time, leaving the patients and being indifferent to them, as well as unwillingness to have a visit at the time of hospitalization or discharge from the hospital are among the implications of the rejection of the patients by the caregivers.

'... The families are tired too. They intend to leave the patient; they are tired of the patient and the treatment process as well' (a psychiatric nurse). (N3)

'God knows how hard it is to live with these patients. I wish they could be given an air injection and we could get rid of them. It is very difficult to take care of them ...' (The mother of a patient with bipolar disorder). (F15)

The participants also talked about the complexities of caring for a patient with a chronic mental disorder. In order to improve and reduce the symptoms of the disease, they have to endure hardships such as constant conflict with annoying symptoms of the disease, constant preoccupation with the care and protection of the patient, and disability of the patient. Another problem is the patient's lack of cooperation in the treatment process, which is due to their lack of insight into the disease, leading to the nonacceptance of the care.

The boy of a schizophrenic patient said: '... It is really difficult to live with these patients, especially patients who, like my father, have schizophrenia and sometimes are under the delusion. One of the symptoms of this illness is suspicion; he is suspicious even of the closest family members. It is really unexplainable; it is not understandable for those who have not experienced similar conditions'. (F3)

The mother of a patient with manic disorder said: 'When she gets better, my daughter no longer takes her medicine. She says: 'I have no problem; I'm not depressed; I don't have any disease.' Our problem is that she does not take her medicines'. (F2)

All of these make the process of caring for a mentally ill person a complicated issue that leads to numerous problems for the caregiver. This, like a confused clutter, causes psychosocial problems which cannot be easily resolved.

The need for a coherent support system

Support is generally accepted as one of the factors which improve the health of people. Because of social stigma, patients with CMD and their caregivers are often neglected and experience discrimination in receiving the related services. Lack of receiving support from the mental healthcare system, government systems, and informal systems, all of which complement each other in one way or the other, is experienced by caregivers.

‘When these patients are stigmatized, they are automatically marginalized, leading to the weakness of their support network. This weak network cannot tolerate the imposed pressures, just like a building whose foundation is not so strong to bear the load of the building. Thus, the building will break down, causing dozens of problems’ (a social psychiatrist). (D7)

Health team members are responsible for the most important communication with patients and their family caregivers. Failure to receive support from the side of these people, for the caregivers of the patients, can cause anxiety and feelings of low value in these people. Things such as the interaction between the health team and the caregiver, the psychological support and empathy of the health team with the caregiver, the educational needs of the caregivers, the improvement of life skills in the caregiver, the psychological evaluation and treatment of other members of the patient’s family, the follow-up of the family and the patient after discharge, examples of the support of the health care system.

The participants talked about the ineffective interaction and insufficient empathy of mental health team members. The caregivers would like to have a better relationship with the patient’s physician and nurses. They believed that the treatment team did not have the necessary empathy with them.

The brother of a patient with depression disorder stated: ‘Families like us, who have a patient with mental disorder, expect the nurses and doctors to understand us. Although they deal with these patients, they understand neither the patients nor their families. They don’t listen to us...’. (F6)

One of the problems of the caregivers expressed by the participants of the study is the lack of their awareness of the nature of the disease, the treatment process, and the life skills deficit. Accordingly, these caregivers need to receive more information and awareness from the treatment team with regard to the disease and its treatment.

‘Many of them have no awareness of the treatment process. Despite the fact that they involve in the treatment of their patient, they don’t know that the treatment is a long process; they have no information about the nature of the illness’ (A psychiatrist nurse). (N9)

Since in the family of patients with CMD, there is a possibility that other family members will be affected by this range of diseases, it is necessary to psychologically evaluate other family members of the patient hospitalized in the psychiatric department and, if necessary, treat other family members of the patient. In this regard, one psychiatric nurse said:

‘... When a counselor and psychiatrist is good, he can see if the family needs medication or not. Many times, pressure comes to the family and they also need medication’. (N11)

The participants in this study were of the opinion that in order to achieve more effective and continuous treatment, the patient and his family should be followed up after discharge from the hospital. A psychiatrist stated:

‘...families, when their patient is discharged, the continuation of treatment should be monitored in a systematic way, which is a part of the structure and always a part of care, and it is necessary. They should not be abandoned after discharge and we should take care of them...’ (D3)

More effective support provided by the government for patients with CMD and their caregivers was also mentioned by many caregivers. Lack of financial support for these families, poor insurance coverage for patients and their families, inadequate legal support for the caregivers, difficult admission of the patients in welfare centers and lack of job opportunities for these patients indicate the insufficient government’s support for the caregivers of these patients.

The head of a charity center said: ‘Although most of these families are supported by the welfare organization, no enough attention is paid to them. They have very poor insurances and the help they receive is really inadequate ...’. (KH)

‘If we can provide day-care centers for these patients, they can go there during the day and return home at night. Doing so, the patients can learn a profession that leads to more income for the family; this also decreases their presence at home’ (A psychiatric nurse). (N6)

The father of a patient with schizophrenic disorder said: ‘My son is now 33 years old. I tried so hard to bring him under the coverage of my own insurance as the cost of his treatment and medicines are high; insurance decreases these costs; but I have not been able to do that yet ...’. (F14)

Limited access to psychiatric services was another problem of the caregivers of the patients with CMD. Many caregivers do not have immediate access to a psychiatrist or psychiatric emergency at the right time, especially when the patient is unwell. This increases not only the stress of the caregivers but also the likelihood of injury to the patient or caregiver.

‘... There is limited number of these centers in society. It is difficult for many families to come and go. In an emergency, the patient becomes aggressive; the family does not know which center to go at that time to solve the problem; thus, they will postpone their visit ...’ (An official of the Rehabilitation Center for Chronic Mental Patients). (MT)

According to the participants, the caregivers frequently experience an ineffective support from the healthcare system. The systematic follow-up of the patient and family after discharge is one of the unmet expectations of the caregivers. Moreover, given the genetic nature of mental illness, assessing the psychological status of other family members of the patient and their treatment is one of the most obvious principles of treatment which play a crucial role in promoting mental and social health of these families. However, it should be noted that these are usually ignored by the healthcare system.

'... Taking care of these patients and their families and follow-up after discharge and supporting the family is cut off after a while. The patients and their family are left alone in the society when they separate themselves from the treatment system. However, follow-ups can effectively reduce the burden of care that family caregivers bear ...' (A psychiatric nurse). (N10)

The father of a patient with schizophrenic disorder said: '... Perhaps through psychologists we can treat our underlying pains; there are too many problems and families need to be supported ...'. (F14)

'Both patients and families need regular counseling. Alongside with the treatment of the patient, the families also should be aware; one-sided treatment is useless ...' (A psychologist). (PS4)

Therefore, based on the findings of this category, the supports, which have a logical agreement and compatibility with each other and, like pieces of a coherent whole, are structurally, continuously and systematically provided to the caregivers, can solve the psychological problems of these caregivers.

The support of nongovernmental organizations (NGOs) and peer associations are the components that are presented as the needs of family caregivers of chronic mental patients and placed in the informal support group.

One of the caregivers said: '... if there is a center like charity centers, which will reach us. At least for one year, it will help us a little financially. At least, for example, one toman. Let them investigate. Let them see how we are. Read our salary slips, help us. It's really hard'. (F15)

Another caregiver said:

'... it really has to be a team; it has to be a group that we feel comfortable with. calm down and come back. I know 4 other people who have experienced my situation. They understand my pain. I really say. there is a celiac association, but we don't have a mental patients' association in Iran' (F8).

In Iran, the challenges and psychosocial needs of family caregivers of the patients with CMD are not limited to a few specific challenges. These challenges range from the psychological and social burdens imposed on the caregiver to the heavy responsibility of continuous and prolonged care of these patients, which is often accompanied by miserable family conditions, unsatisfactory economic situation and insufficient support of health team members, health care system and government. Because of these problems, the caregivers become exhausted and leave the patient. Each of these challenges can negatively affect other factors, thereby decreasing the mental and social health of the caregivers.

Discussion

The aim of this study was to identify the psychosocial problems and needs of family caregivers of the patients with CMD. The caregivers and providers of mental health care expressed their perception and experience of care in three main categories of 'health challenges of caregivers', 'confused concept of care' and 'the need for a coherent support system'. These three categories,

like the three sides of the Bermuda Triangle, surround caregivers, leaving them unattended and unable to easily get rid of their psychosocial problems, like those being lost in the Bermuda Triangle.

The findings of the present study showed that most caregivers who are responsible for the care and treatment of CMD patients at home, suffer from mental and social health problems. According to Ebrahimi *et al.*^[31] the caring for a patient with CMD can reduce the energy of families and thus cause feelings of helplessness and depression in other family members. Sharif *et al.*^[32] states that family caregivers experience a variety of physical, psychological, and social care burdens that can disrupt their psychosocial integration. Rahmani *et al.* (2022) state that families may experience moderate to severe stress in adapting to the needs of patients with severe mental illness. Long-term stress can reduce the family's capacity to effectively face challenges, reduce resilience, and lead to psychological problems in caregivers^[33].

Among other problems that are placed on the list of mental health challenges of caregivers, family caregivers of CMD patients suffer from psychosomatic diseases. Psychosomatic pains are pains that have a psychological origin, that is, pains that are suppressed or suppressed by psychological pressures, and are manifested physically. Physical illnesses and sleep disorders are also among the most common issues faced by families of psychiatric patients. It is estimated that caring for a patient with a mental disorder in the family increases the physical disorders of family members three times more than a normal person^[33].

One of the most important and common experiences of the participants in this study was the experience of stigma followed by the experience of social discrimination in this field. Fernandes *et al.*^[34] believe that social stigma is an obstacle to the resilience of the family of these patients and it seems that the occurrence and impact of these stereotypes cannot be prevented. In fact, overcoming the impact of stigma is more difficult than treating the effects of the disease itself. Because stigma is an obstacle to receiving and seeking treatment, recognition, or acceptance of mental illnesses^[35]. Farzi *et al.* (2020) regarding the relationship between stigma and family functioning state that the most damaging consequences of stigma are when the family accepts the stigma of society and internalizes the negative views of society towards itself. In this case, it is said that the person has an internal or emotional stigma. This leads to a change in identity, the loss of the person's previous personality values and acceptance of the stigmatized point of view, and its consequences include a decrease in self-esteem, depression, guilt, and self-blame, a decrease in the quality of life and a decrease in the feeling of well-being, and physical complaints such as sleep disorder and chronic fatigue. The emotional consequences of the family's experience of public stigma generally include feelings of disrespect, disregard, and discrimination in society. In order to deal with it, families often choose isolation and withdrawal from the community, and by hiding the illness of the family member and delaying the search for the patient's treatment, in their opinion, they prevent the disease from being revealed^[36]. Sharif *et al.*^[32] mention that the social stigma of mental illness can largely be related to the lack of public awareness of the mental illness, and the secrecy and hesitation in disclosing a family member's mental illness can be partially related to the stigma. This issue may be largely related to people's low awareness of mental health, as well as the cultural

nature, which tends to underestimate the abilities and performance level of people with mental disorders.

One of the problems expressed by the participants in this study was that due to the cultural and traditional structure of Iranian society, caregivers are expected to take care of patients with CMD. Meanwhile, some caregivers accept and continue this imposed role only because of the cultural structure of the society. Commitment values, which are an important element in family caregiving in many cultures, may have negative effects on the health of caregivers. Variables related to caregiver burden vary between cultures, and cultural considerations, such as cultural obligations toward caring for chronically mentally ill patients, should be considered when planning interventions to reduce caregiver burden^[37].

Tense family atmosphere and inappropriate relationships within the family were revealed in our study as the most important challenges of the families with CMD. According to Fernandes *et al.*^[34], the pattern of dysfunctional interaction can be found in the family environment of chronically ill patients. Similarly, Liu *et al.*^[38] indicated a change in the family relationships of these patients in China. Additionally, as shown in our study, given the chronic and lifelong nature of mental illness, these patients need comprehensive and continuous care, imposing a great deal of burden on the shoulders of the caregivers. Despite the efforts made by the caregivers to support these patients, the patients do not welcome the care, consider it a nuisance for their well-being, and feel trapped in the prison of the family care. Hence, they try to free themselves from this situation by either running away from the family or being aggressive. These difficult and complex conditions gradually cause the caregivers to become indifferent to the treatment process of their patients, which is sometimes accompanied by patient rejection. The results of the studies by Mui *et al.*^[39] and Ambikile *et al.*^[40] are also in line with our results.

Economic problems were also mentioned by the participants of the study. These problems prevent the family from going through the treatment process properly. Because of the high costs of treatment and medicines, many patients or families may abandon the treatment process. Furthermore, many caregivers and patients with CMD do not have any income, and are also not covered by health or unemployment insurances. Having no adequate knowledge about the nature of chronic mental illness and the inability of patients to work, the families expect the patients to work and have an income. Thus, the unemployment of these patients leads to more tensions and harms within the family, thereby increasing the psychological and social harms of the caregivers. In their studies, von Kardorff *et al.*^[41] and Hegde *et al.*^[10] also refer to the economic problems of these families as one of the main challenges. In this regard, the support provided by the government systems such as increasing the number of rehabilitation centers and care of welfare-dependent patients, adequate insurance coverage for special patients, considering subsidies for them, and job support were among the expectations of caregivers participating in this study. They felt that meeting these needs by the government would make it easier to endure the difficult conditions of caring for the patients with chronic mental disorder. According to Chen *et al.*^[24], and Kumar *et al.*^[42], financial support, free medicines, and health insurance coverage are among the expectations of the families of these patients. Their results are in line with the results of our study.

The participants in this study stated that the long treatment period of these patients and facing periods of relapse and failure to achieve complete recovery in these patients cause caregivers to be disappointed in the complete treatment of the patient and feel helpless in managing the disease. On the other hand, the caregiver facing heavy care duties and enduring the hardships and problems of caring for a chronically mentally ill patient causes a drop in the family's performance in caring for the patient and causes the family to reject the patient or not follow-up on the continuation of the treatment. Karimi Rad *et al.* (2022) state that the problems related to caring and the unpleasant experiences that the family caregivers of patients with mental disorders have acquired in this way have caused apathy, decreased the patience and anger of the caregivers, and disturbed their peace. At times when the recovery slows down and they do not get the positive and desired result from the care provided, they become demotivated and continue the care with difficulty^[43]. Sharif *et al.*^[32] state that family caregivers experience different types of psychological, social, and economic burdens that can disrupt their biological, psychological, and social integration.

Another finding of the study was the need of family caregivers for multifaceted support of the healthcare system in a way that increases their awareness of the nature of chronic mental illness and the treatment process. Having a proper communication with the caregivers, the healthcare system can understand the difficult situation of them and support them psychologically. The patients also should have a strong source of support after being discharged from the hospital. In the studies of Tamizi *et al.*^[44] and von Kardorff *et al.*^[41], the neglected educational need of the caregivers is one of the most important factors, which imposes a burden on the caregivers of the patients with CMD. Similarly, in the studies of Clibbens *et al.*^[45] and Cleary *et al.*^[46], the establishment of proper communication with mental health professionals and access to health care services are among the most important needs of caregivers.

Among the findings of the study was the need to pay more attention of the official government systems in supporting and paying attention to the needs and problems of chronic mental patients and their families. In many developing countries, government support, and other institutions are insufficient and very little, and there is a need for the government to expand social support for family caregivers of patients with CMD, thereby causing reduce the burden of care perceived by families^[47].

Among other things, the findings obtained in this study were the need to receive support from nongovernmental organizations, such as receiving help from charity associations. The people of Iranian society have a great desire to provide charitable assistance, but based on the experience of the participants in this study, this type of public assistance is less directed at the families of chronically mentally ill patients. Perhaps one of the reasons is the lack of information from benefactors about the needs of caregivers and families of patients suffering from CMD, and with proper information, we can benefit from the help of these altruistic people.

On the other hand, in this study, one of the psychosocial needs of the family caregivers of CMD patients was to be in peer groups, which can make them feel understood and heard and have more adaptability. Iseselo *et al.* (2016) state that family caregivers of chronically mentally ill patients tend to peer-oriented social support groups that are designed to improve the quality of life of mentally ill patients. Likewise, these support groups are known to

be useful for taking care of physical and mental problems that have arisen in the caregivers of these patients due to taking care of a patient with a mental disorder^[8].

Based on the main categories of the present study, caring for a patient with a CMD can harm the psychosocial health of family caregivers of these patients. Caring for and paying attention to the sick member of the family is of great significance in the Iranian family. Accordingly, despite the irreparable damages these caregivers have to tolerate, they accept this heavy responsibility because of either compassion and family solidarity or fear of judgment. In this regard, they expect to receive support from other family members, the healthcare system, and the government.

The limitations of this study were the simultaneous conduct of interviews and the corona pandemic. The researchers tried to overcome this limitation to some extent by following health guidelines.

Conclusion

As found in the present study, in the Iranian society, after the patient is discharged from the hospital or care centers, family members will change their role to the most important caregivers of these patients. The psychological and social health of these caregivers is destroyed because of the problems they have in providing care for their patients and their needs, which are not met. The improvement of the psychosocial capacities of the caregivers through interventions and efforts to provide continuous health and government support for them, together with the public awareness of mental illness can greatly reduce the psychosocial burden of these caregivers.

Ethical approval and consent to participation

The study is approved by ethics committee of Isfahan university of Medical Sciences (ethics code IR.MUI.NUREMA.REC.1400.107).

Consent to publication

Written informed consent was obtained from the patient for publication of this study. A copy of the written consent is available for review by the Editor-in-Chief of this journal on request.

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Author contribution

F.L. and J.M.: study design and concept, and literature review and drafting; M.A.: performing the study and drafting; M.A.: performing the study and analysis. All authors read and approved the study.

Conflicts of interest disclosure

There are no conflicts of interest to declare.

Research registration unique identifying number (UIN)

1. Name of the registry:
2. Unique Identifying number or registration ID:
3. Hyperlink to your specific registration (must be publicly accessible and will be checked):

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Data availability statement

All data related to this study are presented in the article.

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