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THE EXPERIENCES OF CAREGIVERS OF CHRONIC PSYCHIATRIC PATIENTS IN THE COVID-19 PANDEMIC: QUALITATIVE STUDY

COVID-19 PANDEMİSİNDE KRONİK PSİKİYATRİ HASTASINA BAKIM VERENLERİN DENEYİMLERİ: NİTEL BİR ÇALIŞMA

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ABSTRACT

Aim: This study was designed to determine the difficulties, needs and experiences of caregivers of chronic psychiatric patients in the COVID-19 pandemic.
Material and Method: One of the qualitative research methods, was a case study. Individual interviews were conducted with 15 relatives of patients who benefited from the Community Mental Health Centers. A Personal Information Form and A Semi-Structured Interview Form were used as data collection tools. Conventional content analysis was used to analyze the data.
Findings: The average age of the participants in the study is 50.73 ± 10.32; 10/15 are female, 12/15 are married, 14/15 are in a nuclear family structure, 7/15 are primary school graduates, 7/15 of them do not work and 5/15 are siblings of the patient. 6/15 of the patients have a diagnosis of schizophrenia, the average duration of the disease is 17.07 ± 9.95 and the average time to receive support from the Community Mental Health Center is 3.33 ± 1.54. The difficulties experienced by the patient during the pandemic period, 7/15 is not being able to manage patients' drug treatment and 7/15 experiencing disease recurrence. The caretakers during the pandemic period experienced 11/15 need for treatment for patients and 9/15 need for communication with the patients. In relation to how caretakers managed the pandemic, 10/15 were asking for support from the Community Mental Health Center and 5/15 were unable to cope.
Conclusion: It is seen that caregivers are faced with many difficulties. This reveals the need for effective community mental health services and telepsychiatry.

Keywords: COVID-19, community mental health center, caregiver

ÖZET

Amaç: Bu çalışma, COVID-19 pandemisinde kronik psikiyatri hastalarına bakım verenlerin yaşadıkları zorlukları, ihtiyaçları ve deneyimlerini belirlemek amacıyla tasarlanmıştır.
Gereç ve Yöntem: Araştırmada nitel araştırma yöntemlerinden, durum çalışması kullanıldı. Toplum Ruh Sağlığı Merkezlerinden yararlanan 15 bakım verici ile bireysel görüşmeler yapıldı. Veri toplama aracı olarak "Kişisel Bilgi Formu" ve "Yarı Yapılandırılmış Görüşme Formu" kullanıldı. Verilerin analizinde betimsel analiz yöntemi kullanıldı.
Bulgular: Araştırmada katılımcıların yaş ortalaması 50.73±10.32 olup; 10/15'i kadın, 12/15'i evli, 14/15'i çekirdek aile yapısında, 7/15'i ilkokul mezunu, 7/15'i çalışmıyor, 5/15'u hastanın kardeşidir. Hastaların 6/15'i şizofreni tanısına sahip, hastalık süresi ortalama 17.07±9.95 ve Toplum Ruh Sağlığı Merkezi'nden destek alma süresi ortalama 3.33±1.54'dür. Pandemi döneminde hasta ile ilgili yaşanılan zorluklar sorusunda 7/15'u "ilaç tedavisini yönetmede güçlük ve 7/15'u "hastalık nüksü"; pandemi döneminde ihtiyaçlar sorusunda 11/15'i "hastanın tedavisi" ve 9/15'i "hasta ile iletişim"; sorunlarla nasıl başettiniz sorusunda 10/15'i "Toplum Ruh Sağlığı Merkezi'nden destek isteme" ve 5/15'i "başedememe" temaları öne çıkan temalar olarak belirtilmiştir.
Sonuç: Bakım verenlerin birçok zorlukla karşı karşıya kaldığı görülmektedir. Bu, etkili toplum ruh sağlığı hizmetlerine ve telepsikiyatriye olan ihtiyacı ortaya koymaktadır.

Anahtar Kelimeler: COVID-19, toplum ruh sağlığı merkezi, bakım verici

INTRODUCTION

The COVID-19 pandemic has affected individuals physically, psychologically, socially, and economically (Arpaci et al., 2020; Druss, 2020; World Health Organization, 2021a). Compared to the general population, poor, vulnerable, and disadvantaged groups have been more influenced by this process. Individuals with chronic mental illness are also among the risky individuals in the COVID-19 pandemic (Druss, 2020; Hamada & Fan, 2020). Current social distancing strategies increase feelings of social isolation and loneliness, anxiety and substance use, and the risk of exacerbation of chronic mental illness symptoms (Brown et al., 2020; Çelik-İnce, 2020).

Chronic mental illnesses cause deteriorations in various areas of functionality such as personal care, social relations, professional life, and leisure activities. Persistent symptoms that do not fully recover despite treatment influence the functionality of individuals at different levels, increasing disability and making them dependent. Individuals need help to increase their functionality and quality of life. In this context, Community Mental Health Centers (CMHCs) provide treatment and care services to individuals with mental illness in a setting where they feel safe, ensure that individuals reintegrate into society and that their families can support the patient by coping with this disease.

In CMHCs, the difficulties that can be experienced are assessed through constant interaction with patients and their families. Moreover, providing information about diseases, treatment methods, and course of diseases in the mental social treatments offered ensures active participation in treatment for patients and families. The length of hospitalization of patients in psychiatry clinics is also shortened with CMHCs providing outpatient treatment services (Bag, 2020). Thus, relapses are prevented and social functionality and quality of life are increased (Ensari et al., 2013; Arslan et al., 2015; Özdemir et al., 2017; Söğütlü et al., 2017).

Most individuals with chronic mental illness live with their families. Individuals who take responsibility for the care of the patient in the family provide basic support to patients due to age-related problems, disability, dependence, mental health problems, and chronic diseases. Caregivers relieve the increasing pressure on health and social care systems during the COVID-19 process. Every change experienced for any reason affects the patient and the patient's family. Maintaining regular contact with patients and providing a sense of social connection during the COVID-19 process can be crucial to preventing recurrence of symptoms and possible hospitalization. However, the psychosocial support provided to patients and their families in CMHCs has been limited due to the COVID-19 pandemic. For this reason, it is important to determine the experiences and needs of caregivers objectively and perform individual interventions (Çelik-İnce, 2020). There are few studies on the effect of COVID-19 on caregivers (Holmes et al., 2020). Although caregivers are considered 'essential care partners', they remain 'invisible' throughout the COVID-19 pandemic (Phillips et al., 2020). This study provided in-depth data on the difficulties, needs, and experiences of caregivers of chronic psychiatric patients during the COVID-19 pandemic.

METHODS

Research Type

Phenomenological design, one of the qualitative research types, was used in the research. Phenomenology helps us to understand the meaning of people's lived experience.

Universe and Sample

The universe of the research consisted of individuals giving care to the patients who had received support from Community Mental Health Centers in the city center of Istanbul. Snowball sampling technique, one of the purposeful sampling methods, was used to sample the research. The sample of the study consisted of 15 caregivers who were aged over 18, who had been living with the patient and were their primary relatives (mother, father, sibling, child, and spouse), who had not been diagnosed with mental illness, who volunteered to participate in the study and were willing to share their experiences. Each participant (F1, F2, …, F10 and M1, M2, M3, M4, M5) was coded.

Data Collection

Personal Information Form and Semi-Structured Interview Form were used to collect data. Face-to-face interviews were conducted with 15 caregivers who were invited to the community mental health center or participated in the research by telephone. Prior to the interviews, the participants were informed about the research, and their consent was taken for their participation in the study and voice-recording during the interview. Study data were collected from February 8 to April 20, 2021. The interviews took approximately half an hour.

Personal Information Form: The form consists of 10 questions about age, gender, marital status, family structure, education level, employment status, closeness to the patient, diagnosis of the patient's illness, duration of illness, and duration of attendance to CMHC.

Semi-Structured Interview Form: The form includes five open-ended questions to elucidate the caregivers' experiences (Table I).

Table 1. Interview Questions

1.	Can you explain a day caring a patient?
2.	What were the difficulties you experienced regarding the care and treatment process of your patient during the pandemic period?
3.	Has there been a change in the course of your patient's illness during the pandemic period?
4.	What were your needs during the pandemic period?
5.	How did you cope with these changes?

Data Analysis

Conventional content analysis proposed by Graneheim and Lundman was used to analyze the data. 14 After each interview, its contents were documented by the research team immediately. Then, the data were read several times to gain a general understanding of the participants' statements in line with the study objectives. After that, the research team extracted meaning units or initial codes, which were eventually merged and categorized according to similarities and differences. MAXqda2 software 10.0 R250412 was used for data analysis. In the end, the final codes, including their defining properties and their relationships with each other, were reviewed in order to reach a consensus regarding the central, unifying themes emerging from the data.

Ethical Dimension

Permission numbered 2021/13 was obtained from the Ethics Committee of a university. Before the interviews, the aim of the research was explained to the participants and their informed consent for participation in the research was taken. Furthermore, the participants were informed that the interviews would be recorded, that the confidentiality of the information would be paid attention to, and that the codes would be used instead of names.

FINDINGS

The mean age of the participants was 50.73±10.32. Of the participants, 10 out of 15 were female; 12 out of 15 were married; 14 out of 15 had a nuclear family; 10 out of 15 were primary school graduates; 7 out of 15 were unemployed; 5 out of 15 were siblings of the patient. 8 patients out of 15 were diagnosed with schizophrenia; the mean duration of illness was 17.07±9.95; the mean duration of receiving support from the Community Mental Health Center was 3.33±1.54 (Table II).

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Table 2. Demographic Characteristics of the Participants

Participant number	Age	Gender	Marital Status	Family structure	Education Level	Employment Status	Closeness to the patient	Diagnosis of the patient	Diagnosis period of the patient (years)	Duration of attendance at TRSM (years)
F-1	50	Female	Married	Nuclear	Primary school	I am not working	Spouse	Schizophrenia	30	2
F-2	49	Female	Married	Nuclear	Primary school	Work at Work (Part-time or full-time)	Mother	Bipolar Affective Disorder	20	4
F-3	43	Female	Married	Nuclear	College	Work at Work (Part-time or full-time)	Sibling	Schizophrenia	16	2
F-4	52	Female	Married	Nuclear	Primary school	I am not working	Sibling	Schizoaffective Disorder	21	2
F-5	49	Female	Married	Nuclear	Primary school	I am not working	Spouse	Bipolar Affective Disorder	5	1
F-6	29	Female	Single	Nuclear	College	Working at Home (Part time or full time)	Child	Schizophrenia	16	5
M-1	60	Male	Married	Nuclear	Primary school	Work at Work (Part-time or full-time)	Father	Schizophrenia	9	3
F-7	71	Female	Married	Nuclear	Primary school	I am not working	Mother	Schizophrenia	19	5
F-8	45	Female	Married	Nuclear	High school	I am not working	Sibling	Schizoaffective Disorder	29	5
M-2	55	Male	Divorced	Nuclear	Primary school	Work at Work (Part-time or full-time)	Father	Bipolar Affective Disorder	7	5
F-9	58	Female	Married	Nuclear	Primary school	I am not working	Spouse	Bipolar Affective Disorder	38	4
M-3	55	Male	Married	Extended	Primary	Work at Work	Spouse	Bipolar	3	1

					school	(Part-time or full-time)		Affective Disorder		
M-4	50	Male	Married	Nuclear	High school	Work at Work (Part-time or full-time)	Sibling	Schizophrenia	21	5
M-5	35	Male	Single	Nuclear	High school	Work at Work (Part-time or full-time)	Sibling	Schizophrenia	9	2
F-10	60	Female	Married	Nuclear	Primary school	I am not working	Mother	Schizophrenia	13	4

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In the study, 3 themes and 15 sub-themes were identified (Table III).

Table 3. Theme and Sub-Themes of the Research

Themes	Sub-themes
Difficulties	• Unable to manage the drug treatment • Recurrences of the illness • Hospitalizations • Anger • Self-harm • Unable to explain COVID-19
Needs	• The treatment process • Communication with the patient • Psychological support • Nothing
Coping	• Asked support from CMHC • Could not cope • Patience • Inculcated themselves • Hospitalized their patient

Difficulties

When the participants were asked about the difficulties they experienced regarding the care and treatment process of their patients, 7 out of 15 stated that they were unable to manage the drug treatment; 7 out of 15 expressed recurrences of the illness; 3 out of 15 expressed hospitalizations; 3 out of 15 expressed anger; 1 out of 15 expressed self-harm; 1 out of 15 stated that they were unable to explain COVID-19.

• We did not know how to manage the treatment process; we did not know how to get the injections and where to get the drugs. He/she discontinued medication; he/she said nothing would happen to him/her. We could not prevent it.

• He/she became very introverted at home, gained weight, started to hear voices again; the symptoms increased; we had to be hospitalized. The sounds he/she was hearing did not decrease. This was the most challenging for us. Turns out, that was his/her place.

• He/she got very angry; he/she took it out on me when he/she could not go out; it was very tiring.

• We could not explain COVID and why he/she should stay at home; it was very difficult to protect. When he/she was hospitalized, he/she was very afraid of being COVID infected.

• He/she had a suicide attempt, jumped off a bridge. He/she broke his/her arms and legs, returned from the dead.

Needs

During the pandemic period, 11 out of 15 caregivers answered that the patient needed the treatment process; 9 out of 15 answered that they needed communication with the patient; 3 out of 15 answered that they needed psychological support; 1 out of 15 answered that they needed nothing.

• We could not persuade him/her to take a bath and take drugs. I was so tired; I wanted to take a breath

• He/she blames us if we talk; we cried a lot; we struggled a lot; his/her obsessions increased; his/her insomnia and anger got worsened; I had to calm him/her down. He/she kept saying “I would have euthanasia. Why is it not legal in Turkey?”. It was very difficult; we, including him/her, could not sleep at all. We were mentally depressed as well. Believe me, they should hospitalize me too.

• He/she was always quiet. He/she had never left his/her room before the pandemic; he/she did not leave during the pandemic either. Therefore, we did not need anything.

Coping

When the participants were asked how they coped with these changes, 10 out of 15 said that they asked support from CMHC; 5 out of 15 said that they could not cope; 2 out of 15 stated that they were patient; 2 out of 15 that they inculcated themselves; 1 out of 15 stated that they hospitalized their patient.

- It was difficult; I was patient. I trusted the doctors and nurses.

- I said “God, I trust you”; I inculcated that it will be okay; I prayed.

- I could not cope; I could not help either. He/she threw him/herself off the bridge.

- We hospitalized him/her; he/she didn’t listen to us. CMHC has become our everything. It lightened our burden; we would have been ruined without CMHC; it helped us breathe.

- How can I cope? He/she does not understand. If I say something, he/she blames me. We called CMHC constantly. Fortunately, the nurse at CMHC called and convinced him/her. I was relieved too. It made us understand the illness; we are no longer ashamed of it; the illness makes him/her suffer.

DISCUSSION

CMHCs are defined as units where individuals with mental illness are treated and followed up, where rehabilitation, psychological training, various psychosocial treatments are provided, which increase these individuals’ skills in living in society, which works together with psychiatry clinics and follow-up patients with home visits when necessary. Various measures have been taken by the Ministry of Health to conduct mental health services during the pandemic process. Since the first day of the COVID-19 pandemic, CMHCs have tried maintaining their services with minimum personnel and generally through phone calls. Mobile teamwork, which is one of the most important practices of CMHCs, is planned for some groups (those with physical disabilities, individuals aged greater than 65, those who refuse treatment, those who do not go out of the house due to social isolation, patients who are severely devastated due to their illness, etc.) for whom distance or onsite support cannot be provided (Ministry of Health, 2020). Due to these measures, the support provided by CMHCs to individuals with mental illness and their families has been limited. CMHCs must observe the experiences, difficulties, and resources that are important for individuals with mental illness and their families and combine these observations in the psychosocial practices they provide.

Difficulties

Participants mostly stated inability to manage drug treatment and recurrence of illness as difficulties. The current evidence suggests that some of the measures taken to control the pandemic has a disproportionate impact on the most vulnerable individuals. For individuals with mental illness, especially disease recurrence, disruption of services, isolation, exacerbation of symptoms in response to pandemic-related information and behavior are among the possible risks (Holmes et al., 2020; Gillard et al., 2021; Murphy et al., 2021). One of the most important findings of this research was the expression of self-harming behavior. Individuals with mental illness may be more affected by the emotional reactions caused by the COVID-19 pandemic. Because of their high susceptibility to stress compared to the general population, the pandemic may cause a recurrence of the mental illnesses, worsening, and an increase in the suicide rate in patients (Hamada & Fan, 2020; Moutier, 2021; Yao et al., 2020). Murat & Anıl-Yağcıoğlu (2021) conducted a retrospective study in a CMHC during the COVID-19 pandemic and determined (1) psychiatric hospitalization, (2) admission to the emergency room for psychiatric reasons, (3) discontinuation of antipsychotics (not using oral formulations for one week or delaying the next antipsychotic injection for two weeks), (4) new-onset suicidal thoughts or suicide attempts, and (5) non-suicidal self-harm or violent behavior in individuals with serious mental illness. Boldrini et al. (2020) reported that the rate of those who reported suicidal ideation during the COVID-19 pandemic increased by 35% compared to the 2018-2019 control period in Italy. Therefore, it is of great importance to develop policies and strategies to prevent suicide. In mental health disorders, the risk of infection, including pneumonia, is high (Seminog & Goldacre, 2013). Therefore, the COVID-19 pandemic should be assessed more carefully in those with mental illness. The risk of transmission of COVID-19 is quite high, especially for patients with self-care problems, lack of insight, and impaired cognitive functions and who have difficulty in fulfilling the rules of general hygiene and protection from infections. Caregivers also gave feedback on the fact that they could not explain COVID-19 and its limitations to the individual with mental illness. During the COVID-19 process, patients should be informed why isolation is necessary for their health, family, close environment, and the entire society. Since this one-time instruction will not be enough, and it needs to be discussed and explained again to reinforce it from time to time (Psychiatric Association of Turkey, 2020).

Needs

Most of the participants stated that they had needs related to the treatment process the patient and communication with the patient. It was determined that individuals with mental illness and caregivers need training on issues such as drug management, coping with stress, communicating with the ill individual, and problem-solving and that inadequate knowledge on the reasons and treatment of illness is an important obstacle against the continuation of the treatment. In the study by Yönder-Ertem (2020), it was stated that the families of patients who had received service from CMHC had problems with the illness and family functions, intra-family communication skills, roles, and behavior control and that it is important to plan and provide counseling for these problems. It was reported that the loss of access to mental health support during the COVID-19 quarantine may increase vulnerability (Holmes et al., 2020). Gallagher and Wetherell (2020) stated that COVID-19 had a negative impact on the mental health of family caregivers and significantly contributed to loneliness and depressive symptoms. Most of the caregivers stated that they needed financial or moral support (Arguvanlı & Taşçı, 2013).

Coping

The vast majority of the participants stated that they asked for support by reaching CMHCs by phone for the difficulties they experienced and that the patients could struggle with the difficulties they experienced by making the CMHC team (especially psychiatric nurses) talk to the patients on the phone. In a recent survey which was published by Carers UK and provides insight into some of the new challenges and concerns faced by caregivers at the beginning of the pandemic, it was reported that 70% of 5,047 caregivers had provided care more due to the viral outbreak (Carers UK, 2020; RTE, 2020). This increases the burden experienced by the caregiver. As in this study, caregivers requested especially telepsychiatric support from CMHCs during the restrictions. The importance of telepsychiatric support was demonstrated in many studies (Kopelovich et al., 2021). WHO (2020b) reported that there were major disruptions in basic mental health services and that 70% of countries have been implementing telemedicine approaches in response to the challenges of providing face-to-face mental health services. Furthermore, CMHC experiences during the COVID-19 process emphasize that telepsychiatry and online psychological support programs are an effective patient management tools (Dubey et al., 2020; Shore et al., 2020; Mutlu & Anıl-Yağcıoğlu, 2021) and that there is a need for improving telepsychiatry (Bajraktarov et al., 2020; Carpiniello et al., 2020).

CONCLUSION

In this research, important information was obtained about how the COVID-19 pandemic has affected individuals with mental illness and their caregivers. CMHC teams should decide the medical and psychiatric risks for patients and their families, their care needs, their urgent or basic needs, and changes that should be made in care if needed and should intervene, especially in times of crisis. This study also revealed the importance of telepsychiatric and online psychological support programs.

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Conflict of Interest

The authors certify that there is no conflict of interest with any financial organization regarding the material discussed in the manuscript.

Authorship Contributions

Design of Study: *Burcu Ceylan, Selda Polat;* ***Analysis and Collection of Data:*** *Selda Polat, Burcu Ceylan;* ***Preparation of Manuscript:*** *Burcu Ceylan, Selda Polat*

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