

## Original Article

# The Disease Management Experiences of Patients with Stroke during the Covid-19 Pandemic: A Qualitative Study

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### **Abstract**

**Background:** The pandemic, COVID-19, has disrupted the delivery of healthcare services. The admissions of patients with stroke to hospitals decreased during the pandemic. There is considerable uncertainty about how patients with stroke manage their illnesses beyond the control of healthcare professionals during the pandemic period.

**Aim:** Our study aimed to determine the experiences of patients with stroke regarding disease management during the pandemic period.

**Methods:** This study had a descriptive qualitative design. The study was conducted with 18 patients with stroke registered in the Stroke Outpatient Clinic of Hospital X. A patient information form and a semi-structured interview form were used, and video-online in-depth interviews were conducted with each patient and recorded. After the interviews, the records were directly transcribed and analyzed. The transcripts were analyzed using thematic content analysis.

**Results:** As a result of our study, five main themes were reached. These themes are; difficulty in access to healthcare, fear, change in the flow of daily life, inability to access sufficient information, and adaptation.

**Conclusion:** As a result of our study, it is seen that patients with stroke have difficulties due to pandemic conditions, and individual and institutional solutions have been developed for these difficulties over time. It is recommended to create accessible health systems, increase online health services, and implement initiatives that support patients with stroke in bio-psycho-social aspects, for all extraordinary conditions that may be experienced.

**Keywords:** Stroke, patients, disease management, pandemics, qualitative research.

## Introduction

Stroke is the second most common cause of death in the World (Feigin et al., 2021; Virani et al., 2021). In addition to rapid diagnosis, initiation of treatment, and care in the hospital during the acute period, long-term follow-ups after stroke are also important (Topcuoglu et al., 2020; Turner et al., 2019).

The pandemic, COVID-19, has disrupted the delivery of healthcare services and changed quality of nursing care for patients with stroke (PwS) (Cadilhac et al., 2022; Chen et al., 2020). The hospital-based reasons for the decrease in admission were a decrease in stroke treatment rates and checks for stroke in hospitals, suspension of all outpatient visits, the use of outpatient clinics for pandemics, and the inability to communicate effectively with patients. Training programs for the management of disease and risk factors for secondary stroke prevention were decreased during the pandemic. The patient-based reasons were the fear and worries of PwS about being infected with the virus and the difficulty in accessing healthcare services (Rinkel et al., 2021; Zhao et al., 2020).

PwS who have to stay home due to extreme measures taken during the pandemic period are likely to experience difficulties because of the increase in their care needs and a decrease in support resources. Individuals with a high risk of secondary stroke should be followed up regularly. However, during the pandemic period, several problems such as the inability to provide effective care to PwS, their disease management at the desired level, and providing the necessary support to patients and their families have emerged as new challenges (Cadilhac et al., 2021; Miller, Stacy & Bakas, 2022; Rinkel et al., 2021; Zhao et al., 2020).

The decrease in interaction with PwS during the pandemic has caused disruptions in the planning and practice of nursing care about secondary prevention. It is unclear how PwS manage their disease during the pandemic period. Our study aimed to determine the experiences of PwS regarding disease management during the pandemic period. Our results will contribute to the improvement of nurses' care plans and practice methods for PwS in terms of extraordinary conditions.

## Methods

**Study design and participants:** This study had a descriptive qualitative design using semi-structured interviews. The study was conducted between November 2020 and October 2021. Study samples were collected from 18 patients who applied to the stroke outpatient clinic of a hospital. The purposive sampling method was used, the target group consisted of patients aged  $\geq 18$  years; patients who used electronic devices such as smartphones, tablets, or computers; who had a stroke, and who volunteered to participate in the study. PwS with any disability in hearing, speech, and cognitive perception were excluded from the study.

**Data collection:** In-depth online interviews were conducted with each patient using a semi-structured interview form (which had been prepared by the researchers). Before starting the in-depth interview, the patient information form was filled out by all participants. In-depth interviews were recorded with a screen recorder, including both video and audio recordings. The interviews lasted an average of 30 min. and continued until data saturation was obtained and no new experience emerged.

**Ethical considerations:** The necessary permissions were received from the Non-Interventional Research Ethics Committee (no:2021/10-38) and the chief physician of X hospital. The verbal consent of the patients participating in the study was obtained at the time of record.

**Data analysis:** Demographic data of PwS were analyzed as numbers and percentages. The recordings were directly transcribed after the culmination of the interviews. Data were analyzed in six steps according to Braun and Clarke's (2006) thematic content analysis using an inductive approach. Firstly, the three researchers read all the transcripts for data familiarization, then partitioned and coded individually by them. Afterward, themes were reviewed, defined, and named. The researchers discussed the results until they agreed and finally.

**Rigor:** The Consolidated Criteria for Reporting Qualitative Research guidelines were used in this study to improve the study's rigor (Tong, Sainsbury & Craig, 2007). To ensure the credibility of the study, all interviews were conducted by the first

researcher who was experienced in qualitative research. All participants were explained that they can freely express their experiences; the interviews were continued until data saturation was obtained. In addition, credibility was established by the interviewer's prolonged engagement with the participants. To achieve transferability, all study stages were explained in detail to the participants. The participants' statements were duly translated into English while preserving the original statements. Additionally, the purposeful sampling method was used in the study. For dependability, the same recording method and interview questions were used in all the interviews. To establish confirmability, the researchers

formed a consensus together, and expert opinions were obtained from the second and fourth researchers who are very experienced in qualitative research. Additionally, before ending the interview, the researcher-moderator summarized the collected data and requested the patients to state their opinions about the accuracy of the information gathered.

### Results

The sociodemographic characteristics of the PwS in the study are given in Table 1. In the interviews, all findings about the experiences of PwS in disease management were divided into five main themes

**Table 1. The Sociodemographic Characteristics of the PwS (n= 18)**

Characteristics		Mean	SD
<b>Age (years)</b> (min-max:46-80)		62.6	11.1
		n	%
<b>Sex</b>	Male	9	50.0
	Female	9	50.0
<b>Education level</b>	Primary education	10	55.6
	High school	3	16.7
	University	3	16.7
	Postgraduate	2	11.0
<b>Marital status</b>	Married	14	77.8
	Single	4	22.2
<b>Employment status</b>	Working	3	16.7
	Not work	15	83.3
<b>Living place</b>	Urban	6	33.3
	Rural	12	66.7
<b>Type of stroke</b>	Ischemic	17	94.4
	Hemorrhagic	1	5.6
<b>Comorbidities</b>	Yes	15	83.3
	No	3	16.7
<b>Number of drugs used</b>	0-4	10	55.6
	5 and above	8	44.4
<b>Post-stroke disability</b>	Yes	10	55.6
	No	8	44.4

<b>State of having a stroke during the pandemic process</b>	Yes	10	55.6
	No	8	44.4
<b>State of being infected with Covid-19</b>	Yes	0	0
	No	18	100
<b>Need for caregivers</b>	Yes	7	38.9
	No	11	61.1
<b>Caregiver presence</b>	Yes	5	27.8
	No	13	72.2

Table 2. Main Themes and Sub-themes

Main themes	Sub-themes
<b>Difficulty in Access to Healthcare</b>	Not Getting an Appointment Inability to Reach the Hospital
<b>Fear</b>	Fear of Being Infected with the Covid-19 Fear of Transmitting Covid-19
<b>Change in the Flow of Daily Life</b>	Inactivity A Decrease in Social Relationships
<b>Inability to Access Sufficient Information</b>	Lack of Knowledge of the Effects of Covid-19 Distrust of Public Information in the Pandemic
<b>Adaptation</b>	Adapting to Disease Management in a Pandemic Adapting to Pandemic Protection Measures Adapting to a Restricted Social Life

**Difficulty in Access to Healthcare****Not Getting an Appointment**

The participants of our study stated that they could not go to hospitals for their ongoing follow-up and treatment, their existing appointments were canceled, outpatient clinics were closed, and they were not given enough attention due to patients with Covid-19. Patients who could not get their appointments expressed that they had a hard time in this process because they delayed their health controls and hospital visits, as well as could not get any support from health professionals.

*“The most challenging thing for us during the pandemic process was that*

*we could not get an appointment from the hospitals. So we couldn't visit the doctor.”(P6)*

**Inability to Reach the Hospital**

Our participants revealed that they could not use public transport due to the strict prohibitions within the scope of social containment measures and had difficulty in transportation because they had to stay home due to lockdown.

*“Because we were over the age of sixty-five, we could not go out freely. We had to use public transport to go to more distant places such as hospitals, but we were forbidden to use public transport.”(P8)*

## Fear

### **Fear of Being Infected with the Covid-19**

Our participants have stated that they were afraid of being infected with Covid-19, the likelihood of having a stroke might increase with the adverse effects of Covid-19 or after its treatment. They stated that they were worried about not depending on someone else. PwS suggested that the public transportation was crowded and social distance rules were not followed, and they avoided even going to the hospital for a while.

*"I'm already old; I think I cannot go through these troubles as I see people who are intubated on TV. And I'm a lonely person, who will come and help me if I get sick?"(P9)*

### **Fear of Transmitting Covid-19**

Our participants stated that they were afraid of transmitting the Covid-19 infection to their vulnerable family members at home while accessing healthcare services. PwS who used their relatives' cars to avoid getting infected expressed that they were worried about their relatives becoming infected due to usage of public transport at that time.

*"When I go to the hospital, what will controls if I am infected with Covid-19 or if Covid-19 is transmitted from me to my loved ones? Because of me, I am terrified that my loved ones are at risk will get infected with Covid. I do would not want to cause such distress to anyone."(P1)*

### **Change in the Flow of Daily Life Inactivity**

In line with the recommendations of health professionals, our participants who exercise after an episode of stroke stated that they cannot do physical activity as much as they used to, due to several reasons such as strict lockdowns, avoiding crowded environments, and closed gyms. Although there were patients who tried increasing movements at home, still the activity levels of these patients were much lower compared with the pre-pandemic period.

*"We are always at home, I could not go out for walks due to restrictions. I went up and down the stairs, in my*

*building, but it was too tiring, and I got sick."(P3)*

### **A Decrease in Social Relationships**

Our participants suggested that their family and social relations were decreased due to pandemic measures, and they were bored by staying at home as well as due to widespread restriction of social opportunities. They also suggested that they couldnot get support from their social environment in stressful situations and could not support them enough when their loved ones were in a difficult situation; they required other adequate solutions rather than technological advances.

*"Staying at home during the pandemic was very difficult. Our group of friends was very cooperative. When we had a problem, we shared it, met with each other, and felt good. We're talking on the phone now, but it's unlike getting together."(P3)*

### **Inability to Access Sufficient Information**

#### **Lack of Knowledge of the Effects of Covid-19**

Our participants stated that they have insufficient information about how Covid-19 and its treatments affect the body, whether it will increase the severity and frequency of stroke.

*"I heard that the symptoms of the disease are severe in stroke patients suffering from Covid-19, that the drugs used in the treatment of Covid cause stroke as well as clotting. But I do not know the accuracy of this fact."(P1)*

#### **Distrust of Public Information in the Pandemic**

Our participants disclosed that they did not trust the public information about Covid-19 from the mass media and the statements made by public institutions.

*"I could not trust the information given on the television or issued by the government institutions. I still cannot trust him."(P11)*

## Adaptation

### ***Adapting to Disease Management in a Pandemic***

Our participants revealed that they get appointments from the polyclinics opened over time by using technology, also walk and exercising by providing appropriate conditions. They stated that they were satisfied with the facilitation of the purchase of regularly used medications from pharmacies with the decision of the ministry in Turkey, and they also received support from the pharmacist and other family members for other drugs that they needed to buy from the pharmacy.

*“It has been a great convenience for us to obtain our regular medicines without a prescription. There were some setbacks, but we overcame them.”(P12)*

### ***Adapting to Pandemic Protection Measures***

Our participants divulged that they adapted to the containment measures and the precautions during the pandemic process by following necessary warnings and vaccinations as well as protecting themselves and the people around them better.

*“I think I’m vulnerable to infection because I have had a stroke and take medications. I told my relatives who wanted to visit me that I do not accept visitors even though I knew they would be offended.”(P7)*

### ***Adapting to a Restricted Social Life***

Our participants stated that regarding managing their diseases during the pandemic period, they tried new methods for staying away from stress and that they came together with their family members and social circles by taking appropriate precautions. They also tried to reduce crowded social interactions by moving to distant areas and maintaining outdoor interactions in rural areas.

*“We did not meet anyone in the homes as much as possible, but we met our relatives outside under this tree.”(P17)*

## Discussion

As far as we know, our study is important because it is the first study to include the experiences of PwS during the pandemic period. The most difficult experience of PwS in our study during the pandemic period was the difficulty in accessing healthcare services. The transformation of general hospitals with the pandemic conditions has been a very difficult experience in Turkey as well as worldwide (Altunisik & Arik, 2021; Bersano et al., 2020; Rinkel et al., 2021; Zhao et al., 2020). With the opening of outpatient clinics caring for fewer patients after the acute pandemic phase, transportation problems emerged as another challenge. Restricting access to health care resources due to widespread prohibitions caused patients to not be able to benefit from health checks again. Recent studies indicate that transportation problems are among the prime reasons for the decrease in hospital admissions of susceptible patients (Rinkel et al., 2021; Zhao et al., 2020). It is a prominent finding that the transportation problem of the patients in our study was due to social containment restrictions other than individual reasons. The Covid-19 pandemic is an unexpected crisis that has strained healthcare resources worldwide. In our country’s current conditions, where remote patient follow-up methods are not used to manage this crisis in the acute process, our participants felt that they were left alone by the health system. Similar to the experience of our study participants, in a study determining the experiences of patients with chronic diseases, it was seen that the fear of being infected with Covid-19 and experiencing negative health consequences came into prominence (Michaud et al., 2020). It is known that Covid-19 infection causes stroke by activating the coagulation mechanism with many physiopathological processes (Varga et al., 2020). In this context, it is an expected result that PwS fear being infected with Covid-19. The fact that the patients in our study, as in the general population (Stockwell et al., 2021), could not move as much and live their social lives as before the pandemic started harmed the management of their diseases.

In secondary prevention, stress management and exercise play important roles for PwS (Gladstone et al., 2020; MacKay-Lyons et al., 2020; Pastor et al., 2021). The pandemic and the restrictions experienced may have created dissatisfaction in the participants by blocking getting support from their loved ones while managing the stress factors and displaying healthy lifestyle behaviors. The patients in our study found solutions to the problems they experienced at the beginning of the pandemic period with the support they received from both their families and the ministry and they adapted. Furthermore, as most of the study patients live in rural areas, they may experience positive effects of less severe restrictions and greater adaptation to pandemic conditions. Similarly, in a study, the individuals living in rural areas continued social interaction in the open air during the pandemic, and restrictions did not create serious changes in their lives (Herron et al., 2021). It is a striking finding of our study that our participants displayed conflicts with their family members who wanted to continue the cultural rituals while taking precautions, and they maintained the visitor restrictions despite these conflicts. The difficult conditions in the hospital due to a stroke during the pandemic period, and the increase in awareness with the loss of health may have supported the continuation of compliance with preventive measures.

**Limitations:** The data were collected from only those PwS who were registered with one neurology outpatient clinic in western Turkey. Hence, the findings obtained from this qualitative study cannot be generalized to all PwS.

**Conclusion:** Our study patients stated that they had difficulties in many areas during the pandemic process due to fear and a lack of enough support from the health system, but over time, they overcame the difficulties and adapted to the pandemic conditions. It is recommended to create accessible health systems, increase online health services, and implement initiatives that support individuals with strokes in bio-psycho-social aspects, not only during the pandemic but also for all extraordinary conditions that may be experienced later. It is recommended that nurses use remote access opportunities such

as virtual care, telehealth to maintain the care of patients at home for secondary prevention.

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