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Lived Experiences of Patients Receiving Hemodialysis During the COVID-19 Pandemic: A Qualitative Study

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Abstract

Background: Hemodialysis patients encountered significant challenges during the COVID-19 pandemic. Frequent visits to dialysis centers increased their risk of exposure to the virus, and travel restrictions and lockdowns hindered access to these facilities. This heightened anxiety and fear of infection, leading some patients to miss essential treatments. Accordingly, this study aimed to examine the lived experiences of hemodialysis patients during the COVID-19 pandemic.

Methods: This qualitative study was conducted using Graneheim and Lundman's content analysis on 12 patients receiving hemodialysis at the Hajar hemodialysis center in 2021 and 2022. Participants were selected through purposive sampling, and data were collected via 15 semi-structured in-depth interviews. The trustworthiness of the data was ensured using Lincoln and Guba's method.

Results: The study included seven men and five women diagnosed with chronic renal diseases. Data analysis revealed two main categories including intrapersonal experiences and interpersonal experiences. The first category was further divided into several subcategories including adaptation to quarantine, near-death experiences, reassessment of life, enhanced spirituality, fear of the unknown, escalating daily life challenges, and reservations about vaccines and treatment. The second category encompassed several subcategories including fragility in social relationships, creating virtual connections to reality, external support, and changes in care and treatment routines.

Conclusion: Hemodialysis patients showed more adaptability to the COVID-19 pandemic than other patients due to their chronic condition. However, optimal adaptation in similar emergencies requires extensive support from healthcare staff and the wider community.

Keywords: Hemodialysis, Qualitative study, COVID-19, Iran

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Introduction

End-stage renal disease (ESRD) is characterized by the kidneys' inability to remove metabolic wastes and maintain fluid and electrolyte balance (1). Individuals with chronic renal diseases often undergo hemodialysis, which presents unique challenges due to its demanding, frequent, lifelong, and unchanging nature. Patients experience continuous reliance on healthcare facilities and various psychological issues stemming from necessary lifestyle adjustments (2-4).

In recent years, the World Health Organization (WHO) has identified dialysis patients as one of the most neglected groups among those with chronic diseases (5). When faced with new and stressful situations, these patients exhibit diverse experiences that offer valuable insights for tailoring care services to better meet their specific needs (6).

The COVID-19 pandemic, which spanned from 2020 to 2023, caused widespread global stress, (7), affecting over 209 countries and leading to numerous infections and fatalities (8-10). Hemodialysis patients, who must regularly visit medical teams, encounter significant challenges in effectively isolating during treatment, making them highly susceptible to contracting COVID-19 and resulting in varied experiences within this group (2,11,12).

Patients on hemodialysis who contracted COVID-19 faced difficult treatment regimens, increased anxiety, and exacerbated symptoms, leading to longer and more costly medical care (13). Malo et al highlighted the continuity of individual treatment processes and the emergence of

a new form of loneliness among hemodialysis patients during this period (12).

The patient experience is widely recognized as a key aspect of healthcare quality (14). Understanding patients' personal experiences is essential for improving the quality of care they receive (15,16). Each patient's journey is unique, and understanding it requires a broader comprehension of the human experience (14).

Individuals' experiences are influenced by their cultural, social, and societal backgrounds, and manifest differently in various healthcare interactions and scenarios (17,18). Therefore, it is evident that a more profound understanding of patients' experiences during biological crises can enhance service provision and contribute to a more fulfilling life for patients. Accordingly, this study aimed to explore the experiences of hemodialysis patients during the COVID-19 pandemic, acknowledging that the pandemic has concluded.

Methods

Diverse human experiences can be explored by qualitative research, particularly through content analysis. This study used a conventional content analysis approach to examine the experiences of patients with chronic renal diseases undergoing hemodialysis during the COVID-19 pandemic (19-21).

Participants

The study was conducted on 12 eligible patients with chronic renal diseases receiving hemodialysis at Hajar hospital (Shahrekord, Iran) during the COVID-19 pandemic. Inclusion criteria were having undergone hemodialysis for at least six months prior to the COVID-19 outbreak, willingness to participate, and having received hemodialysis treatment during the outbreak. Participants were selected using purposive sampling to ensure maximum diversity.

Data were collected through 15 semi-structured in-depth interviews, each lasting 45-60 minutes, depending on the participants' preferences. The time and place of the interviews were scheduled at the participants' convenience. Prior to the interviews, participants were informed about the research, and written informed consent was obtained. The interview process began with an interview guide prepared by the research team and continued with questions tailored to the study's objectives, such as, "What was your experience during the COVID-19 pandemic?". These questions were adjusted based on the participants' responses. Each interview concluded with the interviewer asking, "Do you have anything else to add? ".

Data analysis

Content analysis was conducted following the five stages outlined by Graneheim and Lundman. Interview transcripts were thoroughly read for content comprehension, and meaning units were identified, conceptually labeled, and abstracted. Coding considered the main context of the interviews; codes were compared, classified into categories, discussed, and revised by the research team. The resulting themes captured the meaning and latent content of the data (20,21). A comprehensive conceptualization of the categories was achieved after completing the interviews until saturation was reached.

To ensure data trustworthiness, Lincoln and Guba's four criteria including credibility, dependability, transferability, and confirmability were adhered to. For over 12 months, the researcher immersed themselves in the environment and conducted extensive interviews to gather valid data. Besides, member checks were performed with participants from diverse backgrounds to confirm the initial coding. Concerning peer review, three faculty members with expertise in qualitative research examined the codes and subcategories, agreeing on the interpretations (19,20,22).

Results

A total of 12 patients with chronic renal diseases participated in the study, comprising seven males and five females with education levels ranging from secondary school to bachelor's degrees. The patients had been living with chronic renal diseases for one to eight years. Throughout the study, all participants reported that their relatives had contracted COVID-19, with nine participants themselves having been infected (Table 1).

Data analysis led to the emergence of two primary categories including intrapersonal experiences and interpersonal experiences. The first category was divided into several subcategories including adaptation to quarantine, near-death experiences, reassessment of life, enhanced spirituality, fear of the unknown, escalating daily life challenges, and reservations about vaccines and treatment. The second category was further subcategorized into fragility in social relationships, creating virtual connections to reality, external support, and changes in care and treatment routines (Table 2).

Intrapersonal experiences

The intrapersonal experiences of patients undergoing hemodialysis encompassed adaptation to quarantine, near-death experiences, reassessment of life, enhanced spirituality, fear of the unknown, escalating daily life challenges, and reservations about vaccines and treatment.

Adaptation to quarantine

Hemodialysis patients often face lifelong restrictions similar to those imposed during the COVID-19 pandemic due to their susceptibility to infectious diseases and the chronic nature of renal failure. This facilitated their acceptance and adaptation to quarantine. In this regard, Participant 3 stated, "*I do not feel quarantined. Dialysis*

Table 1. Participants' demographic characteristics

Variables	Value
Mean age (year)	65.23
Gender	
Male	7
Female	5
Education level	
Secondary school	2
High school	7
Bachelor's degree	3
Occupation	
Working	4
Not working	8
Marital status	
Married	10
Not married	2
The mean duration of hemodialysis (year)	8.17
Vascular access	
Permanent	12
Temporary	0
Infected with COVID-19	
Yes	9
No	3
Having family members and relatives infected with COVID-19	
Yes	12
No	0

Table 2. Identified categories and subcategories

Categories	Subcategories
Intrapersonal experiences	Adaptation to quarantine
	Near-death experiences
	Reassessment of life
	Enhanced spirituality
	Fear of the unknown
	Escalating daily life challenges
	Reservations about vaccines and treatment
Interpersonal experiences	Fragility in social relationships
	Creating virtual connections to reality
	External support
	Changes in care and treatment routines

patients are always quarantined and alone". Participant 7 added, "*I used to go out less before COVID-19; after COVID-19, staying at home was not too challenging*".

Near-death experiences

The pandemic instilled a profound sense of proximity to death among patients due to the necessity to undergo dialysis and their compromised immune systems. Participant 8 expressed concerns, stating, "*I have always been worried about what to do in case of illness in this overcrowded hospital*".

Reassessment of life

Patients viewed quarantine as an opportunity for introspection, allowing them time to reflect on their personal lives and relationships. Living differently during the pandemic led to personal and relational growth. Participant 3 noted, "*The solitude and quarantine from COVID-19 allowed me to reflect more on the people around me, something I had overlooked in the routine of dialysis and normal life*".

Enhanced spirituality

Spirituality and religion play a crucial role in Islamic societies, including those in the Middle East. Iranians, deeply rooted in their faith, found solace in spirituality during hemodialysis. The fear of death intensified religious and spiritual practices. Participant 9 shared, "*The God who brought me into this world... He is aware and helps me not to get this disease*". Participant 4 expressed reliance on faith, saying, "*I seek refuge in God; He heals the pain Himself*". Moreover, Participant 12 stressed, "*Destiny lies in God's hands; I pray and pray more to alleviate my fear*".

Fear of the unknown

The recent COVID-19 pandemic, increased mental strain on dialysis patients, introducing uncertainty about the future, a lack of information, and new pandemic-induced experiences that caused internal tensions. Participant 9, expressed her overwhelming sense of unpredictability, saying, "*What's up with the Coronavirus? We were caught, and it got worse. I can't plan anything now*". The absence of reliable information about the disease, its complications, effective treatments, or ways of transmission created a general fear of the unknown. Participant 11, "*Nothing is known about this disease. It seems like a new one appears every day. I heard that it causes strokes*".

Escalating daily life challenges

During the pandemic, hemodialysis patients, already struggling with illness-related financial hardship, faced even greater economic pressures, particularly those with special needs. Inactivity and quarantine made it harder to adhere to fluid restrictions, diet, and weight management. Participant 8 mentioned, "*I spent a lot on masks and gloves, I can't afford them now; they are too expensive*". Participant 10 shared "*We used to walk to the park for half an hour every day, but we couldn't go anymore. I gained weight*".

In the early phase of the pandemic, some patients could not access essential medications and equipment due to economic challenges and closed import/export borders. Participant 10 highlighted the impact on diabetes

management, saying, "*We were miserable. I am a diabetic now. I used to inject pen insulin, but it doesn't stick anymore*". Participant 4 added, "*Getting equipment was very difficult, and we had to pay a lot for it*".

Reservations about vaccines and treatment

Hemodialysis patients were prioritized for vaccines and treatment during the COVID-19 pandemic. However, many were fearful of these measures, often complying reluctantly due to pressures from the treatment system. Participant 8 expressed uncertainty, saying, "*I don't know what this vaccine is? Where do you get it? They say it might cause cancer later*". Participant 4, compelled by the need for dialysis, said, "*I didn't want to get vaccinated, but they said I couldn't come for dialysis without it. I do not trust them*".

Interpersonal experiences

This category included *fragility in social relationships*, *creating virtual connections to reality*, *external support*, and *changes in care and treatment routines.*

Fragility in social relationships

This concept highlights the social detachment experienced by patients and their companions in daily interactions and caregiving. Participant 4 stated, "*I can't hug my child. He's afraid to hug me because he thinks I'm infected from dialysis. I really depend on him".* Participant 7 added, "*My neighborhood taxi used to take me for dialysis, but when COVID-19 started, he called me and said he wouldn't come anymore, he had a small child".*

Creating virtual connections to reality

The pandemic ushered in a significant lifestyle shift for patients, including online work, virtual shopping, and remote visits. Participant 12 embraced this change, saying, "*I've adapted to a different lifestyle now, which is why I'm into online marketing*".

This shift was particularly pronounced in developing countries such as Iran, where the pandemic accelerated technology adoption, making online shopping increasingly commonplace. Participant 1 noted, "*My children have learned to order everything online and have it delivered to avoid going out*". Quarantine and stricter restrictions also boosted electronic and remote medical services. Participant 10 explained, "*I wanted to see my physician that day. The internet doctor called us, and I sent the results to my daughter*".

External support

During the pandemic, patients received various forms of family and social support. Participant 3 mentioned, "*The nurses have been excellent, paying more attention to us since COVID-19 started and teaching us proper handwashing techniques*". Participant 4 highlighted the importance of a supportive environment, "*My child can study with a second-hand phone because the nurse voluntarily gave me money to purchase it*".

Changes in care and treatment routines

Patients had to navigate continuous changes in their hemodialysis treatment plans, hospital transportation, and daily interactions during the pandemic. Participant 6 said, "*Because of this illness, they changed my shift three times to reduce the number of patients in the ward*". Participant 2 expressed fear and caution regarding the shift from group to solo dialysis visits, noting, "*We couldn't come in a group for dialysis anymore. We had to travel alone by car; we were afraid, and I shouldn't have been accompanied*".

Discussion

This study explored the experiences of hemodialysis patients during the COVID-19 pandemic, revealing two main categories: intrapersonal experiences and interpersonal experiences. Historically, hemodialysis patients have faced constraints due to chronic diseases and other health issues. These preexisting limitations facilitated their adjustment to the pandemic-induced quarantine. Research indicates that kidney care recipients are generally more adept at handling restrictions as they are already familiar with the communication challenges in their healthcare experience (23).

Participants were highly concerned about contracting COVID-19, feeling imminent death during the pandemic. Chronic renal disease is a predisposing factor for COVID-19 infection in adults (24), with an infection rate of 38% reported in Paris, highlighting the need for specialized treatment (25) and a higher risk of hospitalization and infection (26,27). COVID-19 often presents differently in dialysis patients, typically without common symptoms such as fever, with fatigue being the most prevalent symptom (26,27).

Several countries have considered home dialysis as a preventative measure against COVID-19, recognizing the global significance of the disease and the vulnerability of this population (28). However, implementing such treatments requires substantial infrastructure investments and long-term financial commitments, posing challenges in many regions. Consequently, Iranian patients must rely on selected medical centers for hemodialysis.

During quarantine, dialysis patients had the chance to reflect on their lives, improve personal management, find inner peace, and spend quality time with families and friends. Musapur et al supported this sentiment, highlighting how quarantine can offer opportunities for self-improvement, reflection, and meaningful connections (29). Temporary separation allows individuals to cultivate independence and satisfaction amidst the demands of modern society, emphasizing the importance of living in

the present and reducing stress about the future or the past.

During the pandemic, spirituality became more prominent among patients, manifesting as faith in God and acceptance of unalterable destiny. Musapur et al identified spirituality as a central theme in navigating these challenges (29). Eisazadeh and Saffari Nia found that spiritual therapy reduced depression and improved mental health among COVID-19 survivors (30). Similarly, Mousavi-Almaleki et al found enhanced spirituality and motivation among Iranian COVID-19 patients (31). This aligns with qualitative studies on hemodialysis patients outside the COVID-19 context, which emphasize the enduring significance of spirituality (32). In Iran, where religious beliefs are deeply held, those with a religious background may cope with crises with greater resilience and hope.

Patients undergoing hemodialysis often face significant stress due to the fear of the unknown, uncertainty about their treatment, and a lack of information about how the disease spreads. Shechory Bitton and Laufer found that individuals fear the COVID-19 pandemic more than terrorism, and they find it more challenging to cope with the uncertainties of COVID-19 than to the familiar stress of war (33).

The quarantine period has made daily life even more challenging for these patients. Wang et al highlighted various difficulties faced by people in China during quarantine, including financial problems and a lack of information about the disease (34). The global economic instability caused by COVID-19 has led to millions of job losses, increasing the stress of unemployment and job searching (35). Dang et al reported that women lost jobs at a rate 24% higher than men, with an income drop of 50% (36). Von Wachter estimated that the economic strain from COVID-19-related unemployment in America could exceed two trillion dollars, potentially causing permanent job losses and severe consequences for individuals (37). In underdeveloped countries, insufficient economic support systems have made enforcing social distancing and restrictions more challenging than in wealthier nations (38). While many studies have focused on the general population, it is crucial to recognize that economic pressures from unemployment can disproportionately affect patients with chronic conditions, especially those undergoing dialysis. Therefore, policymakers should prioritize measures such as unemployment or disability insurance to address the unique challenges faced by these patients.

The pandemic has resulted in reduced physical activity and compromised self-management for many individuals. Patients receiving different levels of renal care reported weight gain, decreased adherence to dietary restrictions, and increased fluid intake during the pandemic (23). Mattioli et al found that global quarantine measures led to decreased physical activity and the adoption of unhealthy eating habits. Moreover, stress and anxiety weakened immune systems, increasing the risk of contracting COVID-19 (39). McDowell et al concluded that lifestyle and employment changes during the pandemic resulted in decreased activity levels, causing many individuals to become inactive (40). In an online survey of over 1400 Iranians aged 18 and older during the COVID-19 pandemic, more than half reported reduced physical activity (41). Hemodialysis patients, who often experience bone complications, found their condition worsened by the pandemic, thereby posing a threat to their physical health and making them more susceptible to other health issues.

Health organizations prioritized COVID-19 vaccines and specific treatments for hemodialysis patients; however, there is considerable skepticism regarding these new interventions. According to Wiysonge et al, vaccine skepticism is complex and influenced by various individual beliefs and societal values (42). In addition, Khankeh et al found that vaccine hesitancy in Iran is mainly due to multiple vaccination peaks in communities, inadequate disease control, and opposing media campaigns (43).

The stigma associated with living with a hemodialysis patient during the pandemic created a sense of shame among family members, undermining their ability to provide emotional support both individually and within the community. Masoudi et al highlighted societal stigma and fear of ridicule, leading caregivers to conceal their family member's illness due to societal pressures (44). Saffari et al used spiritual therapy methods to help families cope with the stigma and psychological pressure of dementia caregiving (45). In line with cultural norms, Iranian hemodialysis patients often hide their chronic renal diseases, resulting in the denial of certain rights (46). Davidson et al demonstrated a direct correlation between self-efficacy and the emergence of psychosocial problems among children (47). The stigma surrounding companionship and increased caregiving responsibilities during the COVID-19 pandemic caused significant psychological strain for patients and their families, sometimes leading to social isolation.

A further aspect of the COVID-19 pandemic experienced by hemodialysis patients was the change in care routines. Alexander and Qato advocated for transparent drug distribution systems to prevent hoarding and ensure access for those in need (48). Despite health and medical services being officially exempt from economic sanctions, these sanctions still significantly impact drug access and specific treatments (49). The escalating economic challenges caused by the pandemic have adversely affected individuals with chronic diseases, including hemodialysis patients. To ensure cost-effective treatment continuation, developed countries have implemented specialized drug registration systems (50). The ongoing trial of such a system in Iran, particularly for patients using insulin

pens, has the potential to streamline disease management if successful.

During the pandemic, patients adopted new lifestyles and formed virtual connections with the outside world. To minimize clinic visits and the risk of disease transmission, telehealth methods, such as phone and internet consultations, became increasingly popular. Studies indicate an increase in the use of telephone services for wound management (51) and enhanced remote health services (52), highlighting a broader adoption of non-face-to-face services during the pandemic compared to the pre-pandemic period. This trend shows patients with chronic conditions, such as those undergoing hemodialysis, are more likely to seek these services during the pandemic.

Patients reported increased support from medical staff as a positive outcome of COVID-19. Nurses provided essential training and emotional support to help hemodialysis patients cope with the challenges posed by the pandemic. Alleaume and colleagues' study on 2003 individuals in France during quarantine revealed that only one-third received emotional or psychological support, highlighting the importance of support for hemodialysis patients (53). Evidence from various countries indicates a decrease in family support and an increase in family violence (54). Families with a strong support system were more resilient to the stress and anxiety associated with the pandemic (55). The study by Pashaii Sabet et al on pre-pandemic experiences of living with hemodialysis identified family support as a consistent theme, emphasizing its fundamental role in patients' lives (32). Cultural factors such as philanthropy and Islamic teachings that promote love and empathy may contribute to differences in support structures between Iranian and Western societies.

The final extracted theme was changes in care and treatment routines. Patients reported that the pandemic affected work shifts, care delivery methods, and their presence in hemodialysis units. Noce et al found that patients were impacted by changes in transportation modes and hemodialysis sessions (56). Despite these adjustments, patients worldwide continued to receive all necessary medical services related to renal function replacement throughout the COVID-19 pandemic, with program modifications aligned with announced protocols.

Limitations

The study was conducted during the COVID-19 pandemic, which posed significant challenges in interviewing patients due to quarantine restrictions.

Conclusion

The COVID-19 pandemic has provided a valuable learning opportunity, enabling the healthcare system to better prepare for future crises. This study revealed hemodialysis patients experienced a unique lifestyle during the pandemic while continuing to receive routine medical care. Both the healthcare system and their families played crucial roles in helping these patients adapt during this challenging time.

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Authors' Contribution

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Competing Interests

There is no conflict of interest to declare.

Ethical Approval

This study was approved by the Ethics Committee of Shahrekord University of Medical Sciences (ethics code: IR.SKUMS.REC.1399.053). The researchers upheld ethical considerations by maintaining the confidentiality of participants, obtaining written informed consent, and allowing participants to withdraw from the study at any time.

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