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Experiences of family caregivers of individuals undergoing hemodialysis in Iran about caring during the COVID-19 pandemic: a qualitative study

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Abstract

Background The Coronavirus disease 2019 (COVID-19) pandemic has significantly affected various aspects of public health. The virus poses a particular threat to individuals with kidney failure undergoing hemodialysis and their caregivers. The present study investigated the experience of family caregivers of individuals undergoing hemodialysis about caring during the COVID-19 pandemic in Iran.

Methods This qualitative study was conducted with 17 family caregivers of individuals undergoing hemodialysis in Bojnurd, Iran using inductive qualitative content analysis. The participants were selected using convenience and purposive sampling method with maximum variation. Semi-structured interviews were used in data collection based on the interview guide. The data were analyzed with MAXQDA10.

Results The results culminated in the identification of a main category of the COVID-19 care burden on caregivers and two generic categories including the COVID-19 Overt (financial/constraining) care burden (subcategories: Non-adherence to Health Protocols, COVID-19 Financial Costs, COVID-19 Restrictions and Hemodialysis Appointments, and Decreased Caregiver Support during the COVID-19 Era), and the COVID-19 Covert (emotional/psychological) Care Burden (subcategories: Caregiver's Loneliness in the Care, Stress of Contracting COVID-19, Psychological Consequences of individuals undergoing hemodialysis Staying at Home, The burden of other Individuals' Expectations of the Caregiver, and Physical and emotional pressure on the Caregiver).

Conclusion Caregivers during the COVID-19 period have experienced both overt and covert care burden. The results of this study can contribute to understanding the experiences of caregivers of individuals with chronic diseases such as kidney failure, in critical conditions like the COVID-19 pandemic, by healthcare teams and devising strategies and programs to support them.

Keywords Chronic kidney diseases, Hemodialysis, COVID-19, Family caregivers, Caregiver burden

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Background

Living with kidney failure imposes significant challenges such as financial strain, work disruptions, and family discord on both individuals and their families or caregivers [1]. This disorder is associated with irreversible loss of kidney function. There are various treatment modalities for kidney failure, with hemodialysis (HD) being the most common [2]. As of the end of 2020, the number of individuals undergoing renal replacement therapies worldwide has exceeded 5.2 million individuals, and it is predicted to increase to 5.4 million people by 2030 [3, 4]. Additionally, as of 2015, over 27,000 individuals in 500 HD centers in Iran have received treatment [5]. The growth rate of kidney failure in Iran is approximately 12% per year [6].

Despite HD preventing the death of individuals with chronic kidney disease, it induces significant changes in their lifestyle. HD reduces the energy levels of individuals and, with the frequent need for dialysis, affects their ability to work and perform daily activities, disrupting the normal lives of individuals and their family caregivers [7]. Typically, a family member of the individual undergoing HD is considered their partner in the disease process and the primary caregiver [8]. In this situation, in addition to the individual undergoing HD, there is another person whose life is severely affected, and that is the family caregiver [9].

Family caregivers are individuals who contribute the most to the care of individuals undergoing HD throughout the process of the disease and treatment. They assist individuals in adapting to and managing their chronic illness [10]. Individuals undergoing HD require caregiver support in various aspects, including transportation, preparing suitable foods, preparing meals, adhering to prepare a specific diet and fluid restrictions, accompanying them to medical visits, organizing necessary equipment and facilities, and managing the symptoms and signs of the disease [1, 11]. Informal caregivers can be family members or individuals with close relationships to the patient or client, volunteering their time and energy to support the physical, emotional, and financial needs of their loved ones [1].

Studies indicate that caregivers consistently report higher levels of stress compared to non-caregivers [12]. This stress has been linked to increased mortality among caregivers [13, 14]. Consequently, being engaged in caregiving and being a caregiver is a public health issue, impacting the living conditions and quality of life for millions of individuals [12]. Additionally, the psychological conditions of family caregivers have serious effects on the health of individuals with chronic diseases. Therefore, identifying the caregiver's situation and the effects of caregiving on their life is crucial [5].

The Coronavirus disease 2019 (COVID-19) pandemic has significantly affected various aspects of public health. The virus poses a particular threat to individuals undergoing HD and their caregivers [15]. Compliance with infection control strategies, such as social distancing and avoiding crowded places, and adhering to personal hygiene measures, is not always feasible for these individuals. [16]. Effective quarantine is not possible for these individuals, and they must regularly visit hospitals for their treatments. Additionally, these individuals often use public transportation to reach HD centers [16, 17], exposing them to high risks of COVID-19 infection. Moreover, due to their compromised immune status and the presence of multiple comorbidities and complications associated with kidney disorders, individuals undergoing HD are at a higher risk of severe manifestations of COVID-19 [18]. This situation can raise significant concerns for caregivers of these individuals. Considering the negative effects of caring for the individual undergoing HD reported in studies [19] before the COVID-19 pandemic, caregiving during quarantine may become more challenging and encounter additional changes.

In addition to pre-existing stressors, family caregivers during the COVID-19 pandemic must cope with emotional strains arising from uncertainty and protect their family members from contracting the new disease [20]. However, the experiences of family caregivers about caring for individuals undergoing HD during the COVID-19 quarantine remain poorly explored. Acquiring this knowledge is of particular importance as it can guide the dialysis team in identifying family caregivers who need support to continue their caregiving activities. On the other hand, In Iran, family caregivers do not receive formal support from governmental or institutional sources, which is a significant factor considering Iran's status as a middle-income country. This lack of formal support creates a unique context for family caregivers, potentially leading to distinct challenges and coping mechanisms that may not be as prevalent in high-income countries where more structured support systems are available. Therefore, evaluating the experiences of family caregivers during the COVID-19 pandemic in Iran may uncover new aspects and insights. These insights can contribute to a deeper understanding of the socio-economic and cultural factors influencing caregiver experiences in a middle-income country, thus adding valuable perspectives to the existing body of research on the global impact of the pandemic on family caregivers. Given these considerations, the present study aims to investigate the experiences of family caregivers of individuals undergoing HD in Iran during the COVID-19 pandemic.

Methods

Design

The present research is a qualitative study using the inductive qualitative content analysis method. This study has been designed and reported based on the Consolidated criteria for Reporting Qualitative Research (COREQ) [21].

Participants and sampling method

The research community consisted of family caregivers (the spouse, child, parent, friend, or relative who has direct responsibility for the individual undergoing HD care and does not receive any payment for providing this care) of individuals undergoing HD who were present in the waiting rooms of HD departments in hospitals in the city of Bojnurd city, Iran. The inclusion criteria for family caregivers of individuals undergoing HD as participants in the study included willingness to participate in the study, absence of known mental illness or a history of admission to psychiatric wards, ability to establish verbal communication, comprehension and speaking in Farsi, and the responsibility for the direct care of the individual undergoing HD at home. The sampling method in this study was convenience and purposive with maximum variation. Accordingly, an attempt was made to maximize diversity among research participants in terms of gender, age, education level, the length of time on HD of the cared-for individual with kidney failure, and socio-economic class. Data saturation was achieved with 15 interviews, and interviews 16 and 17 were conducted for assurance.

Data collection

Data were collected through face-to-face in-depth semi-structured interviews. The interviews were recorded. The data collection was carried out from October 2022 to January 2023. The participants were selected based on the inclusion criteria, and interviews were conducted with participants when they were willing and available. The researcher explained the purpose of the study and the interview process to the participants, ensuring them that the interviews would be kept confidential. Informed written consent was obtained for their participation in the study and audio recording. Sociodemographic characteristics (age, gender, marital status, kinship with the cared-for person on HD) were recorded in the sociodemographic form by the researcher.

Interviews were conducted in a dialysis unit room provided by the department officials, based on the participants' preferences and agreements. During the interview, no one other than the interviewer and the participant was present. No participant refused to participate or dropped out.

The interview guide was finalized after drafting and conducting an initial interview. It is noteworthy that the second author (RM, female) who, at the time of the study, held a master's degree in psychiatric nursing and was a faculty member at the university and had experience conducting interviews due to their professional expertise, conducted all interviews. There was no prior relationship between any of the participants and the interviewer before the study.

At the beginning of each interview, the researcher, after introducing herself and her expertise and research interests, initiated with broad questions and then delved into the interview topic with questions like:

- What challenges did you face during the COVID-19 pandemic in caring for your loved one who was undergoing HD?
- During the COVID-19 pandemic, what issues did you face in caring for your loved one undergoing HD?

Finally, with a few open-ended questions concluded the interviews. The interview guide is shown in Supplementary file 1.

The interviews, lasting between 30 and 50 min (average of 40 min), were face-to-face according to the interview guide. The interview process and analysis helped guide the selection of subsequent participants. After transcribed verbatim, transcripts were returned to participants for comment and correction. Then, the interviews were read multiple times by the researcher for immersion in the data. Subsequently, open coding, subcategory formation, and simultaneous generic and main category formation were performed as more interviews were conducted. This way, the process of data collection and analysis occurred simultaneously. Data collection continued until data saturation, meaning that the researcher did not discover new findings with new interviews. Saturation was reached after interviewing 15 participant, and interviews 16 and 17 were conducted for assurance. No interview was repeated.

Data analysis

In the present research, inductive qualitative content analysis was conducted based on the method proposed by Elo and Kyngas [22]. This method consists of three phases:

- A. Preparation, which includes: selection of the sampling method, decision-making regarding both explicit and latent content analysis based on the study's objectives, formulation of the interview guide, guidance and implementation of the interviews, followed by textual documentation after each

interview, determination of the unit of analysis, and immersion in the data.

- B. Organization, which include: open coding, formation of subcategories, formation of generic categories, and formation of main categories.
- C. Reporting, which involves presenting an overall report of the qualitative content analysis stages and findings (Supplementary file 2).

In this study, data analysis utilized an inductive content analysis approach. The analysis encompassed both explicit and implicit contents. Subsequently, during the phase of organization, open coding procedures were executed, culminating in the creation of a codebook. Consensus coding was adopted for this study, with the interviews being coded by the first and third authors. The coding outcomes underwent multiple review sessions by the research team until a unified coding system was established. Following this, data abstraction was conducted by delineating subcategories, general categories, and main categories, based on the commonalities observed among the codes, subcategories, and categories. The data were analyzed using version 10 of the MAXQDA software.

Data accuracy and rigor

To ensure the rigor of the data, the credibility, dependability, transferability, and confirmability, were examined [23, 24]. In this research, a method of controlling data through member and peer check was utilized to assess the credibility of the data. After conducting the interviews and coding them, the codes and interview text were provided to two participants, and they were asked to

express their opinions on the accuracy of the codes and their alignment with the intended meaning and experiences. Additionally, one interview text and the extracted codes were shared with faculty member colleague outside the research project, and the accuracy of the coding was questioned. Sufficient explanation about the interview process was also provided to participants to enhance research credibility. Moreover, detailed documentation of the interview process and data collection procedures was prepared, and the data’s credibility was examined by an external audit. Uniform opening questions were asked to all participants. The research also aimed to enhance the transferability of findings by providing an accurate report of the methodology, research findings, and quotations. To improve the confirmability of the data in this research, field notes were used. Participants were asked to clarify their speech if it was ambiguous or if their expressed feelings were ambiguous, and their perceptions were reflected to them for confirmation by the researcher. Accurate recording of research stages for evaluation by an external audit was also employed to enhance the confirmability of the findings. All audio files, full transcripts of interviews, initial coding, revised coding along with team feedback, and the data analysis process are preserved and can be reviewed by external audits.

Results

The participants in this research consisted of 17 family caregivers of individuals undergoing HD (age range=35–65 years; mean [standard deviation]=48.235[8.151]). The participants’ demographic characteristics are presented in Table 1.

Explaining the Experiences of Family Caregivers of Individuals Undergoing HD Regarding Care during the Coronavirus Disease 2019 Pandemic in Iran.

After analyzing the interviews, 472 codes were extracted. When the similar codes were merged, 76 codes were obtained. After merging the codes, nine sub-categories were obtained, which were assigned to two generic categories, including the COVID-19 overt care burden and the COVID-19 covert care burden, and a main category, including the COVID-19 care burden for caregivers of individuals undergoing HD. Table 2 presents the main category, generic categories, sub-categories, and codes.

COVID-19 overt care burden

The COVID-19 overt care burden was among the generic categories obtained in this research, consisting of four sub-categories: Non-adherence to health protocols, COVID-19 financial costs, COVID-19 restrictions and HD appointments, and decreased caregiver support during the COVID-19 era. These burdens were mainly

Table 1 The participants’ characteristics

N	Age (years)	Sex	Marital status	Kinship	Living with the individual undergoing HD
1	45	Male	Married	Son	No
2	42	Male	Married	Son	No
3	35	Female	Single	Daughter	Yes
4	48	Female	Married	Mother	Yes
5	42	Female	Married	Daughter	No
6	45	Male	Married	Son	No
7	48	Female	Married	Spouse	Yes
8	62	Male	Single	Father	Yes
9	44	Male	Married	Son	Yes
10	46	Male	Married	Son	No
11	36	Male	Single	Son	Yes
12	48	Male	Married	Son	No
13	65	Male	Married	Father	Yes
14	54	Female	Married	Mother	Yes
15	58	Male	Married	Father	Yes
16	50	Male	Married	Son	Yes
17	52	Female	Married	Mother	Yes

Table 2 The processes of combining codes, subcategories, generic categories, and main categories

Codes	Subcategories	Generic categories	Main category			
The individual undergoing hemodialysis refusal to adhere health protocols	Non-adherence to Health Protocols	COVID-19 Overt Care Burden	COVID-19 Care Burden on Caregivers of Individuals Undergoing Hemodialysis			
Non-adherence to COVID-19 health protocols by individuals related to the person undergoing HD						
Non-adherence to COVID-19 health protocols by the medical staff						
Lack of protective equipment for preventing COVID-19	COVID-19 Financial Costs					
Occupational issues and income reduction						
Costs of treating COVID-19						
Cost of protective equipment for preventing COVID-19						
Costs of transportation for medical interventions with existing limitations						
Costs associated with staying at home						
COVID-19 restrictions and not having personal transportation						
Fear of drivers about transporting individuals undergoing HD to the hospital						
Lack of support from healthcare organizations for caregivers				COVID-19 Restrictions and Hemodialysis Appointments	Decreased Caregiver Support during the COVID-19 Era	
Lack of support for caregivers from the family						
Being alone due to COVID-19 restrictions	COVID-19 Caregiver's Loneliness in the Care	COVID-19 Covert Care Burden				
Caregiver's reluctance to seek help from others due to COVID-19						
Caregiver's concern about the individual undergoing HD getting infected by COVID-19						
Stress about individuals close to the person undergoing HD becoming infected with the COVID-19						
Psychological pressure due to the behavior and speech of those around the person on HD						
Caregiver's obsession with adhering to health protocols by the person undergoing HD						
The individual's boredom and making excuses						
Disputing over adhering to COVID-19 restrictions with the person undergoing HD						
The sense of loneliness of person undergoing HD						
Caregiver's guilt about restricting the person undergoing HD at home				Psychological Consequences of individuals undergoing Hemodialysis Staying at Home		
The Burden of the healthcare team's expectations on the caregiver						
The burden of expectations from caregivers by relatives						
The burden of expectations from caregivers by the person undergoing HD						
The caregiver's feeling of guilt due to the person undergoing HD becoming infected with COVID-19						
The psychological changes in the person undergoing HD after COVID-19 and the caregiver's increased worry						
Pressure resulting from the strain on the caregiver's personal relationships due to taking care of the individual undergoing HD						
Double physical and mental pressure on the caregiver during the time of COVID-19						
	The Burden of Other Individuals' Expectations of the Caregiver					
	Physical and emotional pressure on the Caregiver					

related to financial issues and constraints associated with non-adherence to health protocols and the need to maintain social distancing.

Non-adherence to health protocols

Non-adherence to health protocols included the individual undergoing hemodialysis refusal to adhere health protocols, Non-adherence to COVID-19 health protocols by individuals related to the person undergoing HD, Non-adherence to COVID-19 health protocols by the medical staff, and the unavailability of protective equipment to prevent COVID-19.

Caregiver No. 8 talks about the non-adherence of health protocols by her son receiving HD:

At nights when I was at work, he was relieved to go out with his friends.

Regarding the non-adherence to COVID-19 health protocols by individuals related to the person undergoing HD, Caregiver No. 1 says:

For some time, my siblings and their families escaped from their cities and came to the village to my mother. No one paid attention. They came and made troubles for this individual undergoing HD.

Regarding the non-adherence to health protocols by the medical staff, Participant No. 2 says:

The doctor himself not wearing a mask, no clothes, and nothing... When my father saw him, he also removed his mask in front of the doctor and said, I cannot breathe.

Regarding the unavailability of protective equipment to prevent COVID-19, all participants residing in urban and rural areas stated that medicine, food, and treatment equipment were available as before, and no change has occurred between the COVID-19 era and before it. However, regarding access to the recommended protective equipment to prevent COVID-19, the participants residing in rural areas stated that the distant route from the village to the city had reduced their access to such equipment. In this regard, Caregiver No. 16 says:

It was difficult at first because there were few masks in the village, or they were not appropriate for our individual undergoing HD; I had to come to the city to buy them, and coming to the city might take a few days, and during this time, my son had no mask, either.

COVID-19 financial costs

Another sub-category of the COVID-19 overt care burden was COVID-19 financial costs, consisting of occupational issues and income reduction, COVID-19 treatment costs, the cost of protective equipment to prevent COVID-19, costs of transportation for medical interventions with existing limitations, and costs associated with staying at home.

During the COVID-19 pandemic, the closure of many businesses and the subsequent reduction in income, Caregiver No. 7 says:

Since the shop was closed, my income was extremely reduced. We had financial problems. Some costs were more necessary, such as buying medicine, or the costs of tests, which we had to pay for; so, sometimes, I had to prioritize more important things because I could not afford the costs.

Regarding the COVID-19 treatment costs, Caregiver No. 12 says:

My mother's hospitalization cost due to COVID-19 was so high that I had to sell my car to pay for her medicine and treatment.

The cost of supplying protective equipment to prevent COVID-19, such as masks, gloves, and disinfectants such as alcohol, was another point mentioned by caregivers of

individuals undergoing HD as the costs due to COVID-19. In this regard, Caregiver No. 1 says:

I knew that he should always wear a mask, but I could not afford to buy many. Alcohol became very expensive, too, and I could not buy it.

Transportation costs for medical procedures have also incurred additional expenses during the COVID-19 period. Given the limitations, residents of rural areas and caregivers without personal vehicles faced challenges in commuting. Caregivers mentioned that due to these limitations, inter-city travel was reduced, and public transportation was not suitable for individuals due to the risk of COVID-19. Consequently, they had to use internet taxi, incurring higher costs compared to public transportation. In this regard, Caregiver No. 13 says:

Financial problems increased; for example, at the time of COVID-19, we could not commute by car, and if we wanted, other passengers did not accept to sit in the same car with us, who were accompanied by an individual undergoing HD, so we had to pay more money and get a taxi.

Another problem mentioned by the caregivers was the costs that they had allocated for their individuals to stay at home during the COVID-19 era. In this regard, Caregiver No. 10 says:

At the time of COVID-19, I tried to provide everything at home for my mother at any cost; for example, sometimes the phone bill became so much that it exceeded the costs of my own family, but I paid without any complain.

COVID-19 restrictions and hemodialysis appointments

According to the caregivers of individuals undergoing HD, taking persons to HD appointments on time was one of their serious problems. They mentioned that they faced restrictions to get their individuals to the HD wards on time during the COVID-19 era. Some of these restrictions were due to the commuting and transportation restrictions imposed by the pandemic, and some others were related to the fear of the taxi and internet-taxi drivers taking individuals undergoing HD or going to the hospital.

Regarding commuting and transportation restrictions at the time of COVID-19 and the caregivers' problems concerning taking the individual to the HD appointment, Caregiver No. 17, who is taking care of her mother, says:

Commuting was our permanent problem, but it got worse with COVID-19 because we were not able to take a car from the village directly. We had to walk to the main road and then get in a car. During the COVID-19 era, there were very few passing cars stopping for passengers to pick them up; therefore, we missed our dialysis appointments several times.

Some participants also mentioned the drivers' fear of taking individuals undergoing HD and going to hospitals as some of their problems at the time of COVID-19. Caregiver No. 5 says:

During the pandemic, if we were going to come by taxi for dialysis, as soon as we said go to the hospital, the driver was afraid that we got COVID-19; the driver either did not take us at all or took us reluctantly.

Decreased caregiver support during the COVID-19 era

During the COVID-19 pandemic era, despite the existence of its particular risks and considerations, the participants in the research expected to receive specialized support concerning their individuals undergoing HD from healthcare organizations. In this regard, Caregiver No. 7 says:

During the COVID-19 era, healthcare centers did not indeed provide any services to persons at home; it would have been very helpful if a doctor came to the individual's home or we did not go to the clinic for testing.

Another aspect of support mentioned by the caregivers that was reduced during the COVID-19 era was their being supported by family members as the main caregivers of their individuals undergoing HD. The participants believed that although there were restrictions concerning the COVID-19 pandemic, their family members could still support them more. In this regard, Caregiver No. 6 says:

With the arrival of COVID-19, all my siblings made some excuses, and they did not even come over.

COVID-19 covert care burden

Another generic category obtained in this research is the COVID-19 covert care burden, consisting of the sub-categories of the caregiver's loneliness in the care, the stress of contracting COVID-19, the psychological consequences of individual staying at home, and other individuals' expectations of the caregiver. These burdens

were mainly related to the emotional psychological and physical consequences of caregiving during the COVID-19 pandemic. Many participants stated that caregiving for an individual undergoing HD during the COVID-19 period was, in the eyes of others, similar to previous caregiving responsibilities. However, they experienced issues due to the limitations imposed by COVID-19, which are sometimes challenging to explain to others because only they have closely experienced such problems.

Caregiver's loneliness in the care

The sub-category of the caregiver's loneliness in the care included being alone due to the COVID-19 restrictions and due to the caregiver's unwillingness to ask for help from others in taking care of the individual undergoing HD. This loneliness becomes more pronounced when some caregivers, despite contracting COVID-19, still consider themselves obligated to care for the individual undergoing HD. In some cases, they even blame themselves for contracting COVID-19 and believe that they cannot allow themselves to become ill because someone else depends on them for continued life. Some caregivers have rejected assistance from other family members during their COVID-19 infection due to fear of virus transmission and continued caregiving alone. Additionally, some caregivers stated that when their individuals undergoing HD needed hospitalization and professional care for non-COVID-19 reasons, they preferred to keep them at home due to fear of the individual undergoing HD contracting COVID-19 and worsening the situation.

Regarding the caregiver's loneliness in the care because of the COVID-19 restrictions, Caregiver No. 11 says:

My father said, 'Son, I never had anyone except you.' I cried so much that night; I was demoralized; I had never felt so alone; I really had no choice. I know that I am not allowed even to get sick.

The caregiver's loneliness due to his/her reluctance to ask for help from others was another problem expressed by caregivers regarding the reasons for their loneliness in taking care of the individual undergoing HD. Caregiver No. 7 says in this regard:

COVID-19 and its restrictions have led to our decreased relationship with family and relatives; well, every person has the right to protect themselves and their family. Although I was alone, I could not ask anyone for help.

Stress of contracting COVID-19

According to the results, family caregivers' stress of contracting COVID-19 has had various aspects. This stress

involved the caregiver's concern about the individual undergoing HD getting infected by COVID-19 when attending medical centers, particularly the presence in the dialysis ward, the stress about individuals close to the person undergoing hemodialysis becoming infected with the COVID-19, the psychological pressure due to the behavior and speech of those around the person on HD, and the caregiver's obsession with adhering to health protocols by the person undergoing HD.

Regarding the caregiver's concern about the individual undergoing HD getting infected by COVID-19 by being present in healthcare centers and the dialysis ward, caregiver No. 14 talks about the problem of the individual's hospitalization for reasons except COVID-19 during the pandemic and the fear of his/her infection with COVID-19:

He was hospitalized because he was in an unconscious state. They told me, 'This is the infectious COVID-19 ward and full of patients. If you want to keep your child safe, escape from here. We agreed and came home.

Another reason for caregivers' stress during COVID-19 was the stress about individuals close to the person undergoing hemodialysis becoming infected with the COVID-19 or carrying COVID-19 from the person on HD to other individuals. Caregiver No. 7, who is taking care of her husband, says in this regard:

I could not tell my husband not to hug or kiss the children. This permanently increased my anxiety.

One of the most stressful cases for caregivers was the psychological pressure due to the behavior and speech of those around the person on HD. Caregiver No. 4 also says in this regard:

The nurses were permanently talking about the consequences of COVID-19 on my individual undergoing HD ... these words made me crashed.

Another stressful problem regarding COVID-19 for caregivers was the anxiety and obsessive behaviors due to the pandemic to prevent it and protect the individual undergoing HD. Caregiver No. 3 explains her anxiety and insistence on adhering COVID-19-related hygienic instructions:

Whenever we bought something, I would wash it and spray alcohol on it; I used to constantly be afraid that it was not well cleaned and disinfected; I was afraid that something somewhere would be out of my sight.

Psychological consequences of individual undergoing hemodialysis staying at home

Another sub-category in the generic category of COVID-19 covert care burden was the psychological consequences of individual undergoing HD staying at home. The individual's boredom and making excuses, disputing with the individual undergoing HD over observing COVID-19 restrictions, the sense of loneliness of person undergoing HD, and the caregiver's feeling of guilt due to restricting the individual at home were among the cases mentioned by the caregivers.

Regarding the individual's boredom and making excuses due to staying at home following COVID-19 restrictions, Caregiver No. 6 says:

My father had become fussy and cried with the slightest word; a man of such an age used to cry like a baby.

Caregiver No. 2 says:

I used to spray alcohol on his hands, and he said, 'my skin would dry out and crack.' When I made him wear gloves, he would tell me, 'I cannot hold a cane in my hand.' When I made him wear a mask, he would tell me, 'I cannot breathe.' Shortly, he annoyed me very much.

From the participants' perspective, staying at home to observe COVID-19 restrictions led them to continuous disputes with their individuals undergoing HD, imposing more psychological pressure on them. In this case, Caregiver No. 8, who is responsible for taking care of her adolescent son, says:

He get dressed to go out. I could not stop him; he frequently shouted, and said that I had imprisoned him in the house. He was getting on my nerves.

Regarding the sense of loneliness of person undergoing HD by staying at home during the COVID-19 era, Caregiver No. 2 also says:

My father was very lonely and tired of sitting in the room. He used to cringe and sigh.

Another point mentioned by the caregivers was sense of loneliness of person undergoing HD and getting fussy due to COVID-19 restrictions and staying at home on the one hand and the caregivers' strictness to maintain and continue this restriction, on the other hand, caused caregivers' feelings of guilt that some caregivers had an unpleasant sense regarding continuing restrictions. In this regard, Caregiver No. 6 says:

My father had nothing to do at home. I felt bad; I was annoyed when I saw him like that, but there was no choice for him. I did not let him go out; it was risky.

The burden of other individuals' expectations of the caregiver

Caregivers reported being frequently encouraged to provide more and better care to their loved one undergoing HD during the pandemic through visits to the dialysis unit or telephone calls with other family members. Due to the exposure of the person on HD to COVID-19, caregivers have been criticized and threatened. According to caregivers, this issue not only increased pressure and stress for them but also diminished their self-confidence in controlling caregiving conditions, leaving them uncertain about continuing their caregiving responsibilities. They often questioned themselves about what more they should do for their individuals undergoing HD and how they could protect them from COVID-19. It appears that caregivers, by hearing others' expectations, have felt a sense of helplessness in navigating between increased caregiving pressure, the intensified effort to manage critical COVID-19 conditions, and the expectations and demands of others regarding the caregiver's role. This has led to significant stress, and caregivers have faced moments of doubt about how to balance their physical and mental well-being, their loved one's needs, and the expectations of others.

Regarding the healthcare team's expectations of the caregiver, Caregiver No. 1 says:

The nurses of the dialysis ward told me to take a female companion with my mother to help her put on and take off her clothes before entering the ward; I had no one.

Regarding the expectations of those around the caregiver, Caregiver No. 3 says:

When my mother got infected with COVID-19, everyone thought they had the right to advise me, blame me, and condemn me for carelessness. It was really difficult that they did not understand you and put so many responsibilities on you.

Family caregivers were offended by their loved ones expectations of them. They expressed that even though their individuals undergoing HD knew that all the restrictions were imposed to protect their own health, they still put pressure on the caregiver with unnecessary expectations. In this regard, Caregiver No. 9 says:

During COVID-19, everything got worse; my wife and I were working online, and most of the time, we were on the computer. My father constantly wanted to talk and spend time.

Physical and emotional pressure on the caregiver

Despite all the problems suggested regarding the caregivers of individuals undergoing HD during the COVID-19 era, the issue mentioned by the caregivers of the individuals undergoing HD over and over in the interviews was the increased caregiving pressure on them during the pandemic, an issue that, according to the participants, was not describable and even they have secretly cried because of it many times or have left caregiving for a while.

The sub-category of physical and emotional pressure on the caregiver consisted of the caregiver's feeling of guilt due to the person undergoing HD becoming infected with COVID-19 despite their caregiving efforts, The psychological changes in the person undergoing HD after COVID-19 and the caregiver's increased worry, disruption of the caregiver's personal relationships to take care of the individual undergoing HD, the double physical and mental pressure on the caregiver during the time of COVID-19.

Regarding the caregiver's feeling of guilt due to the person undergoing HD becoming infected with COVID-19 despite their caregiving efforts, Caregiver No. 10, who is taking care of his mother and has lost his father due to his mother's infection with COVID-19 and then other family members, says:

I used to constantly think to myself that if I were very hard on my mother, she would not get infected to make my father sick. If I had been more watchful, perhaps it would not have happened....

Regarding the psychological changes in the person undergoing HD after COVID-19 and the caregiver's increased worry about taking care of him/her, Caregiver No. 9 says:

After COVID-19, my father has become very taciturn; I am really worried.

Regarding the disruption of the caregiver's personal relationships to take care of the individual undergoing HD, Caregiver No. 5 says:

We were constantly disputing with my husband on going to my mother's home; he said, 'You have no right to go; your mother is sick; if you carry the illness into the home, we will be miserable.

Regarding the double physical and mental pressure on the caregiver during the time of COVID-19, Caregiver No. 3 says:

I am still tired of that time....

Caregiver No. 2 says in this regard:

When someone takes care of a patient, they have no right to get sick, to go somewhere, or even to want something because of the person undergoing HD. If necessary, you should smile for no reason, and should not complain.

Discussion

The present qualitative study utilized a qualitative content analysis approach to explore the experiences of family caregivers of individuals undergoing HD during the COVID-19 pandemic in Iran. The results of the content analysis led to the emergence of two categories: the COVID-19 overt care burden and the COVID-19 covert care burden. The findings of this study indicated that family caregivers of individuals undergoing HD experienced diverse caregiving burdens during the COVID-19 pandemic. Based on these results, all participants in the research understood that individuals undergoing HD, in particular, are vulnerable to infection from the coronavirus, and they experienced the caregiving burden resulting from this awareness.

The examination of the Coronavirus Disease 2019 Overt care burden revealed that the most prominent caregiving burden mentioned by participants was the financial costs associated with COVID-19. In this context, Xia et al. [25] reported that individuals undergoing HD infected with the coronavirus must be isolated in a single-room environment and be continuously prepared for HD. This treatment approach undoubtedly increases the costs of health care [25] and leads to relative dialysis insufficiency, further burdening their caregivers [26].

Particularly in the context of low- and middle-income countries like Iran, the absence of a dedicated transportation system for people undergoing HD presents a unique challenge. This lack of special patient transportation facility imposes a significant burden on both individuals and their caregivers, who must navigate logistical and financial difficulties to ensure access to HD centers. The COVID-19 pandemic has exacerbated these challenges, increasing the risk of exposure and adding to the stress and responsibilities of caregivers. This situation highlights the critical need for targeted support and infrastructure improvements to alleviate the specific burdens faced by these individuals and their families in such contexts.

The caregivers expressed the need for more information about caring for their individuals undergoing HD against the coronavirus. In line with the findings of this study, the examination shows that family caregivers need skills to manage or understand the uncertainties of the coronavirus. For example, they lack information about changes in HD units during the COVID-19 pandemic, such as the prohibition of patient companions or the restriction of certain foods in the dialysis ward. However, most of this information was not readily accessible to caregivers [27]. It is worth mentioning that in Iran for individuals undergoing HD and other chronic diseases such as diabetes [28] and their caregivers, there are no or limited special services or follow-up provided at home. Despite the COVID-19 pandemic, the study highlights the challenge faced by caregivers who must bear the increased caregiving burden alone while constantly being confronted with COVID-19 warnings from dialysis ward nurses and the media. Many participants admitted that managing these situations was difficult for them, and they needed psychological support for themselves and their individuals undergoing HD, along with the provision of caregiving and medical services at home. The study indicates that in some countries, the COVID-19 pandemic has been accompanied by a reduction in social services, either to protect recipients of care or due to general regulations to shut down some services during the pandemic [29].

In the context of reduced support from family members, participants in the current study expressed that, before COVID-19, the involvement of other family members with the individual undergoing HD was more significant, allowing caregivers to seek assistance in caring for them. However, with the advent of COVID-19, they have lost this support, leading to an increased caregiving burden on them. In line with this finding, Irani et al. [30] also reported that caregivers, despite the additional responsibilities in managing the care of their individuals undergoing HD during the COVID-19 period, experienced concerns and challenges due to limited assistance from other caregiving resources. They also demonstrated that more home and social services for their loved ones were less accessible or indefinitely suspended. Additionally, some caregivers reported not receiving support from other family members [30–32].

Another issue that caregivers pointed out was the non-adherence to COVID-19 health protocols by the person undergoing HD, individuals associated with them, and the healthcare staff. Caregivers reported that although adherence to COVID-19 health protocols was important to them, it was often not taken seriously by other individuals associated with the person undergoing HD, including the individuals themselves. The continuous efforts of caregivers to ensure compliance with health protocols

by the person undergoing HD and those associated with them seemed to be one of the concerning challenges for them. Sousa et al. [33] also reported that caregivers expressed the need for continuous reminders and reinforcement of individuals' adherence to mask-wearing and frequent handwashing for the purpose of protecting the patients with end-stage renal disease.

According to caregivers, their greatest concern during the COVID-19 pandemic has been the stress of their individuals undergoing HD contracting COVID-19 and losing them. The fear of the death of the person under care has been reported in other studies [34]. However, it seems to have intensified with the COVID-19 pandemic. This concern may be related to caregivers' awareness of the vulnerability of their individuals undergoing HD to the COVID-19 virus due to their older age, comorbidities, and weakened immune system [35]. This awareness leads to increased fear of the risk of COVID-19 infection during HD, as reported by caregivers participating in the present study.

In the present study, it seems that implementing COVID-19 protective measures was considered an additional responsibility for caregivers. This finding aligns with the results of Sousa and colleagues' study [33]. They also reported that the COVID-19 quarantine, aimed at minimizing the patient's risk of exposure to the virus, increases the number of caregiving tasks. On the other hand, according to the research findings, the added responsibilities for caregivers during COVID-19, in addition to the physical and psychological pressure, have led to disruptions in the personal relationships of some caregivers. This finding is consistent with the results of Irani et al.; study [30]. They reported that planning trips to the pharmacy and grocery shopping, attending to the needs of other family members, and even finding time for self-care have been stress-inducing factors for caregivers due to the additional responsibilities arising from COVID-19.

Limitations

One limitation of this research was the difficulty in accessing family caregivers. Due to repeated visits on different shifts and days to HD units, obtaining participants was challenging. Because some caregivers did not stay at the dialysis center throughout the entire session and only attended to bring the person to and from the center, the possibility of interviewing them was limited. Although efforts were made to coordinate meetings with these caregivers as well. Additionally, some participants had lost a family member due to COVID-19, which could potentially influence their caregiving experience during the pandemic. Given the nature of the current study, it was not possible to identify and distinguish these experiences. The passage of time from the peak of the pandemic to the study may have led to changes in participants'

perceptions and experiences of the issues and challenges during the coronavirus period. Therefore, the researcher attempted to clarify the type of caregiving experience and its timing and conditions during the interviews using phrases such as "Did you feel this at the same time?" and "What was your experience during the coronavirus?"

It is suggested that similar qualitative studies be conducted in different cultures and regions to achieve a more comprehensive understanding of the caregiving burden of family caregivers during the COVID-19 pandemic as a global crisis that may repeat in a different form. Additionally, conducting quantitative studies to examine the relationship between caregiving burden, access to health-care facilities, and the effectiveness of educational and support interventions in reducing caregiving burden in this population is recommended.

Conclusion

The present study demonstrated that family caregivers of individuals undergoing HD experienced both covert and overt care burden during the COVID-19 pandemic. The results also indicated that the pandemic imposed a greater caregiving burden on caregivers compared to the past. Even without new revelations, this study enhances the overall understanding of family caregivers' experiences during the pandemic, providing further validation of previously reported themes and issues. Given that family caregivers play a crucial role in managing chronic individuals and ensuring their adherence to treatment plans, policymakers, health planners, and relevant healthcare organizations should design and implement specialized programs for comprehensive support. This support should encompass structural support (in organizational and human resources domains) as well as functional support (in material, emotional, informational, and social domains) for these caregivers.

Abbreviations

COVID-19	Coronavirus disease 2019
HD	Hemodialysis

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

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Author contributions

SH, ASH and SG contributed to the conceptualization and design of the study. RM collected the data, and SH and ASH analyzed the data. SH, ASH, RM and SG revised the study. ASH, SH and MRN wrote the first draft of the manuscript. SH, ASH, RM, SG and MRN critically reviewed the first draft and commented

on it. SH, ASH, RM, SG and MRN read and approved the final manuscript. SH, ASH, RM, SG and MRN agreed to be personally accountable for their own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even the ones in which the author is not personally involved, are appropriately investigated and resolved, and the resolution is documented in the literature. All authors have read and approved the manuscript.

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Data availability

The datasets used and analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Written informed consent was obtained from the participants, and assurance of confidentiality of their information was provided. The Ethics Committee of North Khorasan University of Medical Sciences with the ethics code IR.NKUMS.REC.1401.052 approved its proposal.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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