


EMPIRICAL STUDIES

Caring for patients with end-stage renal disease during COVID-19 lockdown: What (additional) challenges to family caregivers?

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Funding information

This work was financially supported by the project POCI-01-0145-FEDER-030228, funded by FEDER, through COMPETE2020 - Programa Operacional Competitividade e Internacionalização (POCI), and by national funds (OE), through FCT/MCTES. It was also supported by National Funds through Fundação para a Ciência e a Tecnologia (FCT) within the CINTESIS R&D Unit (reference UIDB/4255/2020)

Abstract

Introduction: Caring for a patient with end-stage renal disease undergoing in-centre haemodialysis can be a stressful experience, likely to involve significant burden. Within the context of the new coronavirus pandemic, these patients are highly vulnerable to infection by COVID-19, which might increase the care demands and burden of family caregivers.

Aim: This study aimed to explore the subjective experiences of family caregivers of non-COVID-19 patients with end-stage renal disease undergoing in-centre haemodialysis during the COVID-19 lockdown.

Study design: A qualitative study was performed with a purposive sample.

Methods: Semi-structured telephone interviews were conducted with 19 family caregivers (50.7 ± 14 years old) of patients undergoing in-centre haemodialysis in April 2020.

Findings: Four major themes were identified: (1) emotional distress; (2) changes in caregiving responsibilities; (3) educational and supportive needs; and (4) coping strategies to deal with the outbreak and with the lockdown.

Discussion: The findings suggest that family caregivers of patients undergoing in-centre haemodialysis have to manage several additional care responsibilities due to COVID-19

lockdown. The dialysis team should consider the development of educational and supportive interventions to meet family caregivers' needs, mitigate emotional distress, fears and concerns, and prevent caregiver burden during the COVID-19 pandemic.

KEYWORDS

coronavirus, COVID-19, end-stage renal disease, family caregivers, haemodialysis, qualitative study

INTRODUCTION

In December 2019, the new coronavirus disease (COVID-19) was identified in China [1,2]. This virus (SARS-CoV-2) was first declared by the World Health Organization as a public health emergency of international concern and later as a pandemic [3]. Given its widespread nature, several prevention measures were adopted, including restrictions on the free movement and circulation of people [2]. Thus, numerous countries decreed a state of emergency with a set of exceptional and urgent measures to prevent virus transmission [4]. In Portugal, the state of emergency was declared by the Portuguese government on 18 March and a set of preventive public health measures were gradually implemented [5] such as physical distancing and social isolation.

Although these restrictive measures may help to protect peoples' physical health by preventing virus transmission [6], not all individuals can stay at home to protect themselves from getting infected by the new coronavirus. This is the case of patients with end-stage renal disease (ESRD), a serious health problem due to the permanent loss of kidney function [7]. Worldwide, the diagnosis of this condition is increasing especially in patients over 65 years old, mainly fuelled by other age-related chronic diseases such as diabetes and hypertension [8]. Individuals with ESRD need renal replacement therapy to survive, commonly in-centre haemodialysis, which requires them to travel to a dialysis centre usually 3 times a week, for 4–5 hours. Patients also have to adhere to restrictions in diet and fluid intake [9,10], attend frequent medical appointments and manage poly-pharmacy protocols [9,11]. These requirements increase patients' dependence on family caregivers, who are crucial for the provision of care and support [12]. As a consequence, family caregivers have to readapt their personal, family, social and labour activities to fit the demands of ESRD care [7,10,13,14].

In this sense, there is growing evidence that caring for a family member with ESRD receiving haemodialysis is one of the most burdensome experiences, as approximately 25% of caregivers self-reported having depression, poor quality of life and low sleep quality [11]. In fact, a recent systematic review has suggested that family caregivers of patients with ESRD experience moderate to severe burden and higher isolation, compared with caregivers of

patients with other chronic physical conditions such as cancer [15].

Considering the impacts of caring for a person with ESRD that studies have already reported before the COVID-19 pandemic, it is viable to hypothesise that caring during the lockdown may be more challenging. In addition to previous stressors, such as the strict regime of dialysis attendance or the management of several health behaviours, family caregivers of patients with ESRD now have to deal with the emotional distress caused by uncertainty and protect their family members from getting contaminated by the new coronavirus. Moreover, it is important to note that these patients are exceptionally vulnerable to infection by COVID-19 given that they combine several risk factors, such as advanced age and other comorbidities, along with a less efficient immune system [16].

However, the potential impacts of caring for patients undergoing in-centre haemodialysis during the COVID-19 lockdown are still unknown. Having this knowledge is particularly important, as it can guide the dialysis team in identifying family caregivers who need support for the continuity of care activities.

Aim

The present study aimed to explore the subjective experiences of family caregivers of non-COVID-19 patients with ESRD undergoing in-centre haemodialysis during the COVID-19 lockdown.

METHODS

Study design and participants

An exploratory qualitative study was performed with a purposive sample. In-depth, semi-structured individual interviews were conducted, transcribed verbatim and submitted to thematic analysis by two independent researchers.

The head nurses of two dialysis units were asked to identify possible eligible family caregivers who were then contacted by one of the researchers who informed them about the study and asked about their willingness to participate.

Participants were included if they were: ≥ 18 years old; the primary caregivers of the person with ESRD undergoing haemodialysis, defined as the person who provided the largest amount of physical and/or supportive care without receiving any payment [11]; able to understand the purpose of the study (according to the evaluation of the head nurse); and agreed to voluntarily participate. Participants were excluded if they presented an inability to understand the purpose of the study and to co-operate. Of the 23 family caregivers initially contacted, four declined to participate due to lack of time availability. Since it was not possible to perform a face-to-face interview, participants were contacted by telephone by the researchers, gave their oral informed consent and were interviewed by telephone.

In the end, 19 family caregivers of patients with ESRD participated in this study.

Participants' sociodemographic characteristics and health perceptions

Table 1 shows the sociodemographic and clinical characteristics of family caregivers and cared-for persons with ESRD.

The sample comprised 19 family caregivers with an average of 50.7 (± 14.0) years of age. Most of them were adult children (57.9%) caring for their parents with ESRD with an average of 70.5 (± 12.5) years of age. These patients were on haemodialysis for an average of 42.3 (± 35.9) months. All caregivers were living with the cared-for person before and during the COVID-19 lockdown. The majority (63.2%) reported having decreased mental health and sleep quality during this period.

Ethical considerations

The study received full approval from the Institutional Ethics Committee (Reference number 03/2019). Written consent forms were obtained prior to data collection, according to the Declaration of Helsinki and its later amendments. A numeric code was used to preserve participants' anonymity.

Data collection

Sociodemographic characteristics (e.g. gender, age, education, marital status and kinship with the patient with ESRD), caregiving and clinical information (e.g. time providing support, caregivers' mental health and sleep quality) were collected through a structured questionnaire. Information on sociodemographic and clinical characteristics of the cared-for person with ESRD was also collected.

TABLE 1 Sociodemographic, caregiving and clinical characteristics of the 19 family caregivers, and sociodemographic and clinical information of the cared-for persons with ESRD.

Sociodemographic, caregiving and clinical information	Family caregivers (n = 19)
Gender	
Female, n (%)	17 (89.5)
Male, n (%)	2 (10.5)
Age (years old), <i>M</i> \pm <i>SD</i> [MIN-MAX]	50.7 \pm 14.0 [22–81]
Education, n (%)	
Basic education	3 (15.8)
Middle school	8 (42.1)
Secondary education	5 (26.3)
Higher education	3 (15.8)
Marital status, n (%)	
Married	15 (78.9)
Single	4 (21.1)
Family relationship, n (%)	
Spouse – partner	7 (36.8)
Child (caregiver)	11 (57.9)
Sister	1 (5.3)
How long have you been providing support to your family member with ESRD?	
Less than 1 year	1 (5.3)
Between 1 and 2 years	6 (31.6)
Between 2 and 4 years	8 (42.1)
Over 4 years	4 (21.1)
Risk perception of the person with ESRD to be infected by COVID–19, n (%)	
Low risk	1 (5.3)
Moderate risk	1 (5.3)
High risk	15 (78.9)
Rather not answer	2 (10.5)
Decreased mental health status due to COVID–19, n (%)	
Yes	12 (63.2)
No	7 (36.8)
Decreased sleep quality due to COVID–19, n (%)	
Yes	12 (63.2)
No	7 (36.8)
Sociodemographic and clinical information	Cared-for person with ESRD (n = 19)
Age (years old), <i>M</i> \pm <i>SD</i> [MIN-MAX]	70.5 \pm 12.5 (49–87)
Gender, n (%)	
Male	12 (63%)
Female	7 (37%)
Time on haemodialysis (in months), <i>M</i> \pm <i>SD</i>	42.3 \pm 35.9 (11–135)

In-depth, semi-structured individual interviews were conducted by two trained clinical psychologists (HS and RF) with long expertise in qualitative research in ESRD. Only the participants and the researcher were present in the telephone interview. Participants could contribute to the response in ways they felt comfortable with, being encouraged to present their understandings and meanings. The researcher was free to explore a particular meaning and sentence, or clarify any question raised [17]. Appendix 1 presents the interview script, which comprised open-ended questions.

Interviews were digitally audio-recorded lasting, on average, 41.2 (± 26.3) minutes.

Data analysis

Data analysis was independently performed by two authors (RF and DF) and occurred in three phases: data reduction; data display; and conclusion drawing/verification [18]. For *data reduction*, significant segments of the interview were coded into themes. All interviews were carefully read to get a comprehensive picture, and interpretative notes were made. Emerging subthemes were subsequently grouped into major themes. The *data display* permitted drawing conclusions. Maps of themes and quotations were organised to facilitate data analysis. *Conclusion drawing/verification* implied that the researchers reviewed the meaning of the analysed data, confirming emergent conclusions as a means of testing the validity of the findings [18]. Themes and subthemes were reviewed and iterated to guarantee that they reflected the data collected. No substantial differences were found between the two researchers. The research team

conducted frequent online group meetings to discuss topics and ensure reflexivity.

The COREQ (consolidated criteria for reporting qualitative research) checklist was followed to report qualitative data [17] (Appendix 2).

FINDINGS

Four major themes were identified: (1) emotional distress; (2) changes in caregiving tasks; (3) educational and supportive needs; and (4) coping strategies. Below, each theme and corresponding subthemes are described. Table 2 presents the major themes, subthemes and the number of appearances of each subtheme across the caregivers' narratives.

Emotional distress

This theme covered the family caregivers' increased emotional distress due to fears and concerns about the patients' health.

Fear of being contaminated with COVID-19 and contaminating the relative with ESRD (n = 15)

Caregivers expressed fear of being contaminated by the new coronavirus, as they need to leave the house to perform activities of daily living such as going to work or shopping for groceries. Additionally, caregivers also feared that they could be a potential source for the infection of their family members with ESRD: 'I can be a carrier. I leave home and

Major themes	Subthemes	Number of appearances
Emotional distress	Fear of being contaminated with COVID-19 and contaminating the relative with ESRD	15
	Fear that the cared-for person with ESRD gets contaminated when going to haemodialysis	15
	Fear that the family member with ESRD dies due to COVID-19	10
	Concerns about the future	7
Changes in caregiving tasks	Increased number of caregiving responsibilities	13
	Decreased family interactions and help in the performance of care activities	12
Educational and supportive needs	Need for more information, better communication and support from the dialysis team	9
Coping strategies	Adherence to the prevention and protection measures	17

TABLE 2 Themes, subthemes and number of appearances of each subtheme across the family caregivers' narratives (n = 19).

go to the bakery or the supermarket, and there I have the chance of being contaminated and, consequently, if I have no symptoms, I can be the person who can lead my mother to get infected by this disease' [daughter, 69 years old]. This fear was based on the caregivers' beliefs that the patient is in a more vulnerable situation due to immunological fragility, advanced age, and the presence of comorbidities such as diabetes.

Fear that the cared-for person with ESRD gets contaminated when going to haemodialysis (n = 15)

Participants feared that the patient with ESRD could be contaminated when going to dialysis, as they had to travel in groups in ambulances. In addition, caregivers were concerned about patients' exposure during treatment as they were aware that dialysis centres are usually overcrowded. In their perspective, this increases the risk of exposure to the virus since physical distance can be compromised in these care settings: 'The fact that my mother has to leave the house three times a week to go to dialysis and travel in an ambulance with other people...The fact that she needs to be at the dialysis centre with several patients to perform treatment... People that might be infected...That is...Every day I think about this. This is a big concern' [daughter, 45 years old].

Fear that the family member with ESRD dies due to COVID-19 (n = 10)

Caregivers faced the fear that the patient could die, mainly because they recognise that this person is at greater risk of developing serious complications in case of being infected by COVID-19. Moreover, the pandemic led hospitals to impose a no-visitors policy to prevent the spread of the virus; therefore, caregivers were afraid of not being able to be with the patient in case of hospitalisation: 'The biggest concern is if she gets it [COVID-19]...Because I think that if she gets it, she will not survive. I say this, but I know she has a lot of chronic diseases and I think this type of virus... I don't know... She might even be able to survive, but I don't think so. And so, I'm really scared about it, because it is not the best time for me to lose her. It never is, but this time is much worse because (...) I wouldn't be able to be at the hospital close to her (...)'. [daughter, 64 years old].

Concerns about the future (n = 7)

Caregivers reported fears of uncertainty in a multitude of areas, including their work status and concerns of the

negative economic consequences caused by the lockdown that would be hazardous for patient care. In addition, participants were concerned about the repercussions of the lockdown on the patients' mental health and the health consequences of the virus if the patient gets infected: 'I know that the virus attacks the lungs essentially. I know that it leaves many sequelae like on the patients' heart, lungs, brain...And this is what I'm most afraid of, in case she survives it...' [sister, 81 years old].

Changes in caregiving tasks

This theme encompassed the perceived alterations during the COVID-19 lockdown on the caregiving activities of family members caring for a patient with ESRD.

Increased number of caregiving responsibilities (n = 13)

Caregivers reported now spending more time doing the groceries and shopping for themselves and for patients to prevent them from leaving their homes and being exposed to the virus. They acknowledged having more caregiving tasks and less time for other meaningful activities. Going to the pharmacy, managing medication, increasing house disinfection, and the care of the arteriovenous fistula were some of the additional responsibilities mentioned. To prevent contamination, some caregivers started to take their family members to the haemodialysis centres so that they would not have to travel by ambulance along with other patients: 'I shop for groceries. Before [the pandemic and the lockdown], he did it [the patient]. (...) I come home and disinfect everything I brought. I bring more than usual, so I don't have to go to the supermarket so often. (...) I also transport him to and from dialysis. Before, I would just take him home, because he would take the bus to go to treatment. (...). We both feel safer that way' [husband, 43 years old].

Some participants also mentioned the need to constantly remind the patient about the importance of some protective measures such as wearing a mask, washing and disinfecting hands, and increasing personal hygiene after dialysis: 'We have more careful when she gets home [from the dialysis unit]. We immediately remove the mask and throw it away. Then we wash her hands... She doesn't like it; she doesn't want to wash her hands so often. She starts to ask why, and I have to explain it to her (...). And taking off her clothes. It is the same. I have to say "Mom, don't be sad or mad, this is to protect you and us too". Sometimes she understands, but it is difficult. (...) I feel exhausted with all of this. I had to increase the care I had with my mother and I'm getting very tired' [daughter, 61 years old].

Decreased family interactions and help in the performance of care activities (n = 12)

Some caregivers mentioned a significant decrease in family interactions, especially with those with whom interactions used to be regular. For some caregivers, this meant a reduction in the number of visits of family members who used to help with care activities: 'When this all started, my siblings stopped coming here. I don't let them. My sister, who used to help me with our mom, works at a supermarket and there are many cases there. Her husband is quarantined. So, I stated, "nobody gets in here because of mom". So, this affects her [the patient], and it affects me as well'. [daughter, 41 years old]. This not only increased the caregiver's feelings of isolation but also decreased the level of instrumental support to perform the care tasks.

Educational and supportive needs

This theme encompasses the caregivers' perceived needs for educational and emotional support during the COVID-19 pandemic.

Need for more information, better communication and support from the dialysis team (n = 9)

Caregivers reported the desire to communicate with a nephrologist, nurse and/or psychologist about the virus, namely what could happen to their family members with ESRD if they presented symptoms or if they tested positive for COVID-19. The need to improve knowledge about COVID-19 and ESRD, how to care for a patient with ESRD during the lockdown, changes in the dialysis centres and how to use personal protective equipment were also mentioned. In addition, caregivers reported the desire to have more emotional support during the pandemic, due to the distress it is causing on the patient and the entire family: 'Even regarding the COVID-19 test, the dialysis centre tested him, but we never spoke with the doctor. A preparation. "Look if it is negative, you have to continue doing this type of care and if it is positive, we have to proceed this way or that way". Do you understand? I think there is a lack of closer care, a greater explanation of what is going on and what could happen' [husband, 43 years old].

Coping strategies

This theme included the coping strategies related to caring that helped family members deal with the impacts of the COVID-19 pandemic and lockdown.

Adherence to the prevention and protection measures (n = 17)

Caregivers reported that they adhered to a list of protective measures to prevent being infected or contaminating others as they considered that the cared-for person was in a high-risk group. They started to use face masks and gloves, avoiding going outside, washing their hands frequently and taking more baths than usual, using hand sanitiser, practising social distancing and disinfecting shopping bags, groceries, clothes and the shoes used outside. Although these measures were disseminated to the general population, caregivers expressed a reinforcement of this care to protect the patients they cared for: 'We are even more careful with hygiene. When we leave the house, we are very careful; but even with our hygiene at home. We are more careful and clean the house more often. I try to be protected and I try not to put myself in crowds and places where I can catch the virus' [wife, 67 years old].

DISCUSSION

This study explored the subjective experiences of family caregivers of non-COVID-19 patients with ESRD undergoing in-centre haemodialysis during the COVID-19 lockdown. The overall findings suggested that family caregivers expressed several fears and concerns associated with the new coronavirus, increased care responsibilities, educational and support needs, and coping strategies that help to mitigate the fear of contamination and increase patients' protection from the virus.

Caregivers expressed fearing that the family member with ESRD would die in case he or she gets infected by COVID-19. Fear of death of the cared-for person has been reported in other studies in this population [19]. However, it seems exacerbated by the current pandemic. One possible interpretation for this finding is the caregivers' recognition that these patients combine several risk factors for serious COVID-19 complications, such as older age, comorbidities and a less efficient immune system [16]. Having this knowledge leads to increased fears about the risk of contamination during haemodialysis, which has already been reported by patients undergoing this treatment [20].

When having a closer look at the impacts of the lockdown on the care provision within ESRD care, several additional impacts and challenges were identified. This study's findings suggested that the lockdown increased the number of caregiving tasks to minimise patient's exposure to the virus. Assuming the responsibility of shopping for groceries, going to the pharmacy and ensuring patients' transport to and from the dialysis unit were some of the additional responsibilities mentioned by family caregivers.

Participants also reported adhering to numerous preventive measures such as cleaning and disinfecting their houses,

disinfecting the groceries and having more careful with personal hygiene (e.g. doing the laundry more often, especially after being outside). These strategies helped them cope with the pandemic, as they increased a sense of control and minimised fear of contamination [20]. However, these tasks also meant additional responsibilities since they were now performed more often and more exhaustively. In addition, caregivers expressed the need to constantly remind and reinforce patient's adherence to the usage of masks and frequent hand washing. The participants' goal was to protect the patient, as 15 caregivers believed that their relative with ESRD was at a higher risk of being contaminated by the virus.

In line with these findings, previous research has shown that caregivers of people with dementia [21] and cancer [22] experienced similar challenges during the COVID-19 pandemic. However, such an intensification in the number of caregiving tasks can lead to increased burden [23], which has already been reported in caregivers of patients undergoing dialysis [11]. This is particularly important considering that burden may have several negative consequences for the caregiver and the cared-for person [24]. In the current study, family caregivers reported having had a decrease in both mental health and sleep quality during the lockdown. In addition to the increased caregiving responsibilities, this result may be due to feelings of uncertainty about the future, fears related to contamination and decreased family support in the provision of care. These impacts have already been described as important psychosocial consequences of COVID-19 for the general population [25,26]. However, the findings of this study suggest that more attention needs to be paid to family caregivers of patients with ESRD to prevent burden, as they combine several risk factors during the COVID-19 lockdown.

Furthermore, caregivers also expressed the need for more information about COVID-19 and its implications for patients with ESRD. In contrast to health professionals, family caregivers do not have the skills to manage or understand the unknown circumstances that COVID-19 requires, namely the necessary changes in the dialysis units such as lack of snacks and blankets, and the forbidden entrance of people who do not belong to the staff. Most of these changes met the international guidelines that dialysis units must follow to prevent the spread of the virus [27]; however, most of this information was not accessible to caregivers.

Previous research has suggested the effectiveness of intervention programmes that aim to reduce burden and improve the mental health of caregivers of patients with ESRD [28,29]. Based on the findings from the current study, these interventions should include an educational and a supportive component. On the one hand, the provision of reliable information about the pandemic and its impacts on ESRD care may improve knowledge and help mitigate caregivers' fears and anxieties. On the other hand, supportive interventions may help improve caregivers' ability to cope with the

emotional consequences of the pandemic and help relieve the burden associated with increased care responsibilities.

In these times of confinement due to the COVID-19 pandemic, it may be necessary to increase caregivers' virtual support [23]. In a systematic review conducted in 2015, 32 articles assessed the benefits of video and Web-based interventions for caregivers of patients with several conditions, including paediatric renal disease [30]. The results suggested significant improvements in caregivers' psychosocial outcomes. Participants also expressed being satisfied and comfortable with online support and telehealth [30]. However, these modalities have never been used with caregivers of adults with ESRD. Future research should focus on the development of educational and supportive online interventions, as they might be crucial for ESRD care during the current pandemic.

Limitations

Despite its contribution to better comprehend the lived experiences of family caregivers of non-COVID-19 patients with ESRD, the present study has some limitations that should be recognised. Firstly, participants were recruited from two dialysis units from the same geographical area, which limits the transferability of the findings. Secondly, due to social confinement, it was not possible to conduct face-to-face interviews, which may have hindered the participants' responses. Thirdly, this study used a purposive sample selected by the head nurses of each dialysis unit which may have resulted in the selection of the most distressed family caregivers that could, somehow, benefit from an interview with a psychologist. This means that these study findings are limited for this sample and their developmental and contextual factors.

CONCLUSION

To the best of our knowledge, this is the first study to report that caregivers of patients with ESRD have to manage several additional care responsibilities due to COVID-19. Thus, more attention should be paid to family caregivers' perceived burden during the lockdown, as they are fundamental to ensure patients' care, treatment adherence and support. The current findings also provide fundamental data that can assist the dialysis team in developing educational and support interventions for family caregivers of patients undergoing in-centre haemodialysis during the COVID-19 outbreak. Future studies should assess family caregivers' acceptability of such interventions during the pandemic.

CONFLICT OF INTEREST

No conflict of interest has been declared by the author(s).

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How to cite this article: Sousa H, Frontini R, Ribeiro O, et al. Caring for patients with end-stage renal disease during COVID-19 lockdown: What (additional) challenges to family caregivers?. *Scand J Caring Sci*. 2022;36:215-224. <https://doi.org/10.1111/scs.12980>

APPENDIX 1

Interview script.

What has changed in your life after the declaration of the state of emergency and all the measures regarding the new coronavirus?
How has this pandemic affected you? And your family member with ESRD?
What have you done to deal with the current situation?
What has been the most difficult? How have you dealt with this? What do you do to overcome these difficulties?
What has been easier and why? What could facilitate your family member's disease management in the context of the COVID-19 pandemic and lockdown?
Do you currently need some support? What are your main needs in the context of the pandemic and lockdown? And what are the needs of your family member with ESRD?
What are your concerns or fears about the coronavirus and ESRD? What about the haemodialysis treatment? What about you, as a family caregiver? What do you fear the most?

APPENDIX 2

The Consolidated Criteria for Reporting Qualitative Health Research (COREQ).

Topic	Item No.	Guide Questions/Description	Page
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD Response: HS is a MSc Research Fellow and RF is a PhD researcher.	NR
Occupation	3	What was their occupation at the time of the study? Response: HS is a MSc Research Fellow and RF is a PhD researcher.	NR
Gender	4	Was the researcher male or female? Response: Females.	NR
Experience and training	5	What experience or training did the researcher have? Response: All researchers had experience working with patients with ESRD.	NR
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	No
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research Response: All researchers had experience working with patients with ESRD.	NR
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic Response: All the research team members had experience working with patients with chronic diseases, but none had personally experienced an ESRD diagnosis.	NR
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	4
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	4
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	4

(Continues)

APPENDIX 2 (Continued)

Topic	Item No.	Guide Questions/Description	Page
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	5
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	5
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	Table 1
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Appendix 1
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	No
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the interview or focus group?	5
Duration	21	What was the duration of the interviews or focus group?	5
Data saturation	22	Was data saturation discussed?	No
Transcripts returned	23	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	5
Description of the coding tree	25	Did authors provide a description of the coding tree?	No
Derivation of themes	26	Were themes identified in advance or derived from the data?	5–6
Software	27	What software, if applicable, was used to manage the data?	NA
Participant checking	28	Did participants provide feedback on the findings?	No
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? E.g. participant number	7–12
Data and findings consistent	30	Was there consistency between the data presented and the findings?	7–12
Clarity of major themes	31	Were major themes clearly presented in the findings?	7–12
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	13–15