


BMJ Open Caring burden and coping with haemodialysis: a qualitative study with family caregivers in Sri Lanka

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ABSTRACT

Objective The number of patients with end-stage kidney disease (ESKD) requiring renal replacement therapy in Sri Lanka is significantly rising. Most of these patients depend on haemodialysis, carrying a significant burden on their family caregivers. To develop care and support for both the patient and their family caregiver, it is crucial to understand how caregivers experience their caregiving situation. Therefore, this study aimed to explore family caregivers' experiences of burden and coping when caring for a family member receiving haemodialysis in the Sri Lankan context.

Design Qualitative study with an exploratory design.

Setting Family caregivers were recruited at a haemodialysis unit of a main government sector hospital in Sri Lanka between October and November 2021.

Participants A purposive sampling of 11 family caregivers who cared for a family member receiving haemodialysis in a main government teaching hospital in Sri Lanka for at least 3 consecutive months. Data were collected through individual semistructured telephone interviews and analysed using qualitative content analysis.

Results The results showed an overarching theme, 'striving to hold on and not let go', with four categories: (1) feeling exhausted by the care burden, (2) feeling burdened as failing the care responsibility, (3) striving to cope and find meaning in caregiving, and (4) coping with caregiving through others' support.

Conclusion The results show that the family caregivers have a multifaceted burden. They continued caring for their family member receiving haemodialysis while making adjustments to the burdensome caregiving situation despite many constraints and suffering. Psychosocial support and financial assistance, including family counselling, are needed by family caregivers, through a community support system, to ensure endurance during their family members' illness trajectory. Advance care planning is vital to alleviate care uncertainty and to meet the care needs of patients with ESKD, particularly in resource-constrained settings.

INTRODUCTION

A life-threatening disease such as chronic kidney disease affects the whole life of a patient and their family, which leads to suffering.¹ The number of patients with end-stage kidney disease (ESKD) requiring renal

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The qualitative exploratory design with purposive sampling captured the experience of participants who are well informed about the topic in depth.
- ⇒ The telephone interviews avoided long-duration face-to-face contact during the COVID-19 pandemic and allowed adequate time for the interview without any disturbances.
- ⇒ Data triangulation was limited since the data collection was carried out via telephone interviews only.
- ⇒ Transferability of the findings can be considered limited because data collection was done in one haemodialysis centre in Sri Lanka.

replacement therapy in Sri Lanka is significantly rising, whereas haemodialysis therapy has become the main treatment modality.² The patients undergoing haemodialysis need caregiver support; most often, this is given by the informal support system comprised of family members who become family caregivers for several years.³ Family caregivers fulfil most of the patient's physical, emotional, financial and social care needs throughout the continuum of care, from being hospitalised to providing care at home, without incentives.⁴⁻⁶ The patients' dependency on their family caregivers, complications of the disease and the many drastic changes they must go through in their life impose a significant burden on family caregivers.⁷ Even though family caregivers are vulnerable since they are exposed to many adverse health risks related to caregiving, their needs have been less considered.⁸

Countries have different challenges and possibilities in family caregiving. For instance, family caregivers of patients receiving haemodialysis in Iran face difficulties such as repeated and more frequent hospital admissions of patients compared with the caregivers of patients having other chronic diseases.⁹ In addition, a study from Jordan shows that family caregivers become

socially isolated, are overwhelmed by responsibilities and have their own deteriorating health.¹⁰ A systematic review of qualitative studies shows that family caregivers of patients receiving haemodialysis suffered from responsibilities caused by social and financial restrictions.¹¹ Since long-term caregiving is often burdensome, it is essential to understand how family caregivers cope with the stressful caregiving situation. A qualitative study conducted in Iran revealed that family caregivers were committed to caregiving and their religion recommended them taking care of their family member. In addition, a sense of responsibility, an ability to self-restraint and experiencing satisfaction in caregiving were identified by them as coping strategies.¹²

Sri Lanka is a developing country with only a few haemodialysis centres attached to state hospitals, offering haemodialysis free of charge where the number of patients exceeds the capacity of the unit. The patients who can afford the treatment cost attend private sector hospitals, which are also limited in the country.² Thus, fewer and inadequate haemodialysis treatments give rise to patient suffering from a high symptom burden. Consequently, it might instigate a huge physical, financial and psychosocial burden on the patient and their family. Worldwide, family caregivers have a significant role during haemodialysis treatment and are paramount for the effective and continued delivery of patient care with desired outcomes.^{9 13} However, according to the literature, this role may lead to adverse health effects and vulnerable situations,⁷ while little is known about these aspects in developing countries such as in Sri Lanka. Thus, similar to the attention paid to the patients, the family caregivers' overall health also needs to be taken into account, and more attention should be paid to their quality of life, social welfare and level of satisfaction.⁷ Therefore, this study aimed to explore family caregivers' experiences of burden and coping when caring for a family member receiving haemodialysis in the Sri Lankan context.

METHODS

Study design and participants

A qualitative study was conducted with an exploratory design and an inductive approach.¹⁴ A purposive maximum variation sampling¹⁵ was chosen to capture a wide range of experiences related to family caregiver burden and way of coping. There was variation in age, gender, ethnicity, religion, educational level, type and extent of caregiving and financial status of family caregivers of patients receiving haemodialysis in a main government sector teaching hospital in Sri Lanka. The inclusion criteria were family caregivers older than 18 years old who cared for a family member receiving haemodialysis for at least 3 consecutive months and could communicate in their native language (Sinhalese). For description of the participants, see [table 1](#).

Table 1 Participant characteristics (n=11)

Gender	Female	8
	Male	3
Age (median: 51 years)	Below 45	1
	46–59 years	7
	Over 60 years	3
Caregiving duration (min: 6 months; max: 7 years; median: 18 months)	Less than a year	5
	More than a year	6
Relationship to the patient receiving haemodialysis	Parent	4
	Spouse	7
Participants' employment status	Not employed	7
	Self-employed	2
	Employed	2
Nature of caregiver role	Shared	3
	Solo	8
Level of education	Up to grade 5 (primary)	1
	Up to grade 11 (ordinary level)	9
	Up to grade 13 (advanced level)	1
Religion	Buddhist	7
	Christian	2
	Islam	2
Self-reported diagnosis: diabetes/hypertension/hyperlipidaemia/heart disease/chronic kidney disease/others	Yes	7
	No	4

Data collection and procedure

Individual semistructured interviews were conducted over the telephone as the data collection was carried out during the COVID-19 pandemic period.

Before starting data collection, the family caregivers were approached by the first author (CL) while they were waiting outside the haemodialysis unit until their family members' haemodialysis session was going on. A total of 13 family caregivers were administered a letter with information about the study, the aim and a question to participate in an individual interview. Two family caregivers declined to participate in the interview, while eleven agreed to participate. Both verbal and written informed consent and telephone numbers were obtained from the family caregivers who agreed to participate in the study and consented to record the interview. The time for conducting the interviews was prescheduled according to the family caregivers' preferences and at the same time when obtaining the informed consent.

An interview guide (for the questions, see [Box 1](#)) was prepared by the first author (CL) based on literature and discussions with dialysis nurses and coauthors.

Box 1 Interview guide
Introductory questions

- ⇒ For how long have you been a caregiver to your family member?
- ⇒ Tell me about your life before becoming a caregiver to your family member.

Caregiver burden experience

Please tell me about your experience of being a caregiver to your family member receiving haemodialysis.

- ⇒ How do you feel about this change?
- ⇒ How do you experience the tasks you fulfil when caring for your family member?
- ⇒ How do you feel about fulfilling those tasks for your family member?
- ⇒ What challenges do you experience in relation to caregiving?
- ⇒ How does caring for your family member affect your own health?
- ⇒ How do you experience limitations or barriers when caring for your family member?

How do you cope with or handle those challenges, barriers or limitations you encountered as a family caregiver?

- ⇒ How do you feel about that?
- ⇒ Could you please tell me more about that experience?
- ⇒ Why do you believe that it is like that?

Interview closing questions

- ⇒ Tell me if you have any final thoughts related to your life experiences with regard to providing care for your loved one that you like to share with me at this time.

Before the interviews, two pilot interviews were conducted and minor modifications were made to the interview guide. The interviews were conducted from October until November 2021, each lasting 30–45 min (median 30 min). Interviews were conducted until no new information was obtained.¹⁶ The interviews were recorded and transcribed verbatim by the first author (CL).

Pre-understanding

All four authors have a background as registered nurses, where one has expertise in patients receiving haemodialysis. Two authors have vast knowledge of geriatric care and palliative care. One author has specific knowledge as a mental health/psychiatric nurse. All authors have experiences as researchers in the qualitative field.

Data analysis

Qualitative content analysis, described by Graneheim and Lundman, was used to analyse the data. The analysis was done using the manifest content (what is visible in the text) of the transcribed text, and latent content (what is hidden deep within the text) for a thorough understanding of the meaning of the text.¹⁷ According to Graneheim and Lundman, qualitative content analysis involves reading the transcribed text multiple times to understand the content. Therefore, the interviews were read throughout their entirety several times. After reading, meaning units were extracted, that is, text that was judged to answer the aim of the study. Thereafter, the meaning units were condensed, that is, shortened to

describe the essence of the meaning unit. Every condensed meaning unit was then given a code to identify the overall content interpreted in the data. Then, the codes were sorted into content areas in relation to similarities and differences and organised into subcategories. The next phase involved forming the subcategories into categories, that is, similar subcategories were gathered into one place to create a group to describe its characteristics as a group. The categories were interpreted to an overarching theme which illuminates the latent meaning and deeper understanding of the experiences of family caregivers of patients receiving haemodialysis in Sri Lanka.

Trustworthiness

The study's trustworthiness was maintained in terms of credibility, dependability, confirmability and transferability.¹⁸ In terms of credibility, the interview guide was tested through two pilot interviews before data collection and open-ended questions were used to explore the informants' experiences. During the analysis process, continuous discussions were conducted between the first author and the last author, and the second and third authors read and confirmed the analysis. In terms of dependability,¹⁸ quotations from raw data are used to present the results. To safeguard confirmability,¹⁸ the authors discussed their pre-knowledge along the process of analysis. To illustrate for readers who are unfamiliar with the Sri Lankan care context, and thus make it possible for readers to understand the results,¹⁸ the context of the study is described in the Methods section. To capture a broad range of experiences, the participants had a variation in age, gender, educational level, religion and caregiving duration which might strengthen the transferability of the findings to several care settings.

Standards for Reporting Qualitative Research was used when reporting the study¹⁹ (online supplemental file 1).

Patient and public involvement

None.

RESULTS

Four main categories were identified: (1) feeling exhausted by the care burden, (2) feeling burdened as failing the care responsibility, (3) striving to cope and find meaning in caregiving, and (4) coping with caregiving through others' support. From these categories, an overarching theme emerged: striving to hold on and not let go. Throughout the informants' narrations in all four categories, the family caregivers' efforts to hold their family member tightly even in the highly burdensome situations were interpreted while coexisting coping strategies seemed as a support for them to revive their life by overcoming suffering and struggles.

The theme, categories and subcategories are presented in [table 2](#).

Feeling exhausted by the care burden

This category covers the exhaustion and lack of freedom of caregivers when constantly, day and night, they are

**Table 2** Theme, categories and subcategories related to caregivers' burden and way of coping

Theme	Categories	Subcategories
Striving to hold on and not let go	Feeling exhausted by the care burden	Having a heavy care load
		Being in a suffering situation
		Feeling trapped by the caregiver role
	Feeling burdened as failing the care responsibility	Fear of failing own health
		Care-related financial strain
		Challenges in healthcare to meet caregiving demands
	Striving to cope and find meaning in caregiving	Giving care by compassion
		Seeking faith in religion
	Coping with caregiving through others' support	Sharing experiences with others in the same situation gives relief
		Being grateful for and using all forms of external support

on standby to help their family member, never knowing when it is possible to rest and recover. The category 'feeling exhausted by the care burden' conceptualises the following: strain of family caregivers when having a heavy care load, being in a suffering situation and feeling trapped by the caregiver role.

Having a heavy care load

Family caregivers described their everyday life at home as something filled with a heavy care load due to numerous caregiving tasks to be done on a daily basis.

I have too much household work, too much work now. So now I need to stay only for him (patient)... I also need to look after other people at home, she (patient's wife) is going to have a baby, I need to fulfill those things too... (Caregiver A)

The family caregivers needed to be responsive to their family members' well-being during day and night. They expressed the care situation as a burden and that it was difficult to have sleep at night when their family member could not sleep, because of breathing difficulties.

It's heavier than caring for a baby; I need to stop him from drinking water and prepare hot water for him to bathe. I need to wash his clothes; I need to feed him three times a day. If I cannot watch him for a while, he drinks water. Caring for him is a big task; it's more difficult than looking after a little child... He wakes up frequently at night. When he drinks more water, he cannot sleep due to a lot of water in the body. (Caregiver C)

Being in a suffering situation

Though the family caregivers provided the best possible care, they could not see their family member's improvement. The family caregivers felt useless to the patient as their situation seemed to have no end. It gradually made them lose their normal life, leading to suffering.

I feel fed up... finally, nothing will remain of us. All are losing; we fall into zero. I feel like mentally down, and all my efforts are useless. (Caregiver F)

The family caregivers experienced suffering when struggling to hold on and disguise their feelings from their family members to facilitate a good atmosphere.

I feel so sad about my husband's illness. I'm crying without showing it to him. But when I'm with him, I always smile. (Caregiver B)

Feeling trapped by the caregiver role

The family caregivers described their situation as feeling trapped since they could not spend their daily lives as they used to. Some felt restrained when looking after their family member.

He's like a war to me. I'm suffering like a prisoner when taking care of him. (Caregiver C)

The family caregivers described how they had to give up their social life due to full-time caregiving. They were entirely confined to their home for years and were isolated from their own relatives and society, unable to participate in social gatherings.

I must stay with him all day. I have not been able to leave the home for 3 years now. One of my brothers passed away, and I couldn't attend the funeral. (Caregiver C)

Feeling burdened as failing the care responsibility

This category covers the fear of not being enough for the other person in caring and meeting financial and health-care needs. 'Feeling burdened as failing the care responsibility' conceptualises the factors such as fear of failing own health, care-related financial strain and challenges in healthcare to meet caregiving demands.

Fear of failing own health

The family caregivers expressed fear and uncertainty about caregiving in the future because of the gradual deterioration of their health.

I'm gradually becoming weak. I won't be able to look after my daughter for longer; I have dedicated all my time to her. I feel fear when I'm thinking about the future. (Caregiver I)

Care-related financial strain

The family caregivers expressed how they felt burdened with financial hardships as they could not have a permanent job because of full-time caregiving.

I do some odd jobs to earn money, but I can't go to any work on the dialysis date. We had good economic status before. But now, we are helpless. (Caregiver D)

Finding a suitable kidney donor for transplantation was expressed as one of the biggest challenges because of the lack of access and increased financial problems.

There's no one to give a kidney to transplant free of charge. We looked for, but they expect money for that in return. (Caregiver K)

Challenges in healthcare to meet caregiving demands

The family caregivers felt like failing in their responsibility as accessing adequate healthcare resources was difficult, including dialysis beds, transport facilities and healthcare workers. They also experienced unexpected changes in healthcare during the COVID-19 lockdown.

There are COVID patients also admitted to the dialysis unit, and four beds are allocated for them. So, the routine patients do not have enough beds. Then we have to return home, and our patients suffer a lot. (Caregiver C)

Striving to cope and find meaning in caregiving

This category covers the love and passionate care for the person who was undergoing haemodialysis even though the family caregivers did not receive any remuneration aside from merits. 'Striving to cope and find meaning in caregiving' conceptualises the following aspects: giving care by compassion and seeking faith in religion.

Giving care by compassion

The family caregivers tried to show their love and care to their family members by valuing how they had been before. They wished their love and care positively encouraged and strengthened their family member.

This is the lady that I got married to. It's not good to leave them when they cannot do anything. We have to take care of them. I do this as much as I can. I will not leave her anyway. (Caregiver F)

Seeking faith in religion

The family caregivers gained spiritual healing through support from their religion and by engaging in religious activities.

We listen and chant *pirith* (Lord Buddha's chanting) and make up our minds by listening to them; we wish not to have this kind of tragedy again in the next life. We pray for that when we worship Lord Buddha.... (Caregiver D)

According to their religious beliefs, the caregivers described the illness experienced by their family members as a result of 'karma' (bad luck resulting from one's previous actions either in present or previous life) and believed that caring for them gives them merits to their next life.

Many villagers say that spending my life with her is a huge support for her. They give me merits all the time. They say that this is enough for me for my next life. This may be 'karma' what we did in our previous life. (Caregiver F)

Coping with caregiving through others' support

This category reveals the support received from others as a strategy to cope with the burden of caregiving. Predominantly, the various forms of support strengthened them both mentally and financially. 'Coping with caregiving through others' support' conceptualises the following factors: sharing experience with others in the same situation gives relief and being grateful for and using all forms of external support.

Sharing experiences with others in the same situation gives relief

The family caregivers described how they shared experiences with peers with the same caring experience of family members with the same illness and how this helped them to cope with the burden they experienced.

We attend dialysis twice a week. We chat with other patients and their family members for 4 hours of dialysis session. We share our feelings and experiences all the time. We try to enjoy that time. (Caregiver G)

Being grateful for and using all forms of external support

The family caregivers described the importance of having a good social network for their family members through the healthcare team to help them with compassionate care. Consequently, this helped them feel secure when facilitating the family member's care needs.

All my neighbours are our relatives. No one is an outsider there. They say I'm looking after my husband well, so they help me. I don't want to lie; everyone helps us. (Caregiver B)

Family caregivers expressed how they felt about the healthcare team's support and how much they were grateful for their help and care.

The support that's given by healthcare staff is maximum and best. Doctors and nurses compassionately help us. They worry about these patients a thousand times, so we need to appreciate them all... (Caregiver I)

DISCUSSION

This study aimed to explore family caregivers' experiences of burden and coping when caring for a family member receiving haemodialysis in Sri Lanka. The findings reveal that family caregivers experienced exhaustion because of full-time and long-term caregiving and failure when they could not meet the expected caregiving demands. Family caregivers strove to cope with the burden they experienced by finding meaning in caregiving and using other forms of external support. The overarching theme, 'striving to hold on and not let go', was interpreted as the latent meaning that deepens the efforts of family caregivers to tightly hold on to save their family member's life during the illness trajectory. The family caregivers strove to hold on by finding their own coping methods to adjust and adapt to the challenging caregiving situations. The findings of the present study can be understood in relation to the Resiliency Model of Family Stress, Adjustment and Adaptation (RMFSAA) which describes the way of managing a disruptive experience in family caregiving.²⁰ The model includes different elements such as stressors that give rise to family caregiver burden and coping strategies such as family's resources to resistance.

The first category revealed the caregivers' exhaustion due to the struggles of providing endless care. The family caregivers may feel physically and emotionally drained particularly when taking care of a family member with end-stage illness for a long period of time. The emotional exhaustion was brought about by sadness, fear of the future, and uncertainty for themselves and their family member. The burdensome situation of exhaustion is not unique for caregivers in Sri Lanka but relatively common in other countries. A challenge is that this way of performing care is not solely due to a lack of healthcare resources but also attributed to cultural, ethnic and social norms as they believe it is appropriate for a family member to provide patient care,²¹ as one of their personal responsibilities.²² The suffering became apparent when they witnessed the suffering of their family member with burdening symptoms while making an effort to hide their own emotions. Similarly, a qualitative meta-synthesis by Kim and Lee revealed physical and emotional exhaustion among family caregivers when ignoring their own emotions.²³ This finding is also consistent with the finding of the study among Iranian family caregivers who experienced caregiving as progressive exhaustion.⁷ Thus, an interdisciplinary team approach in healthcare, which includes nurses and social workers, must be expedited for early identification of potential psychosocial concerns to initiate advance care planning for patients

and their family caregivers. A family therapy intervention might support in identifying existing resources and new opportunities²⁴ to cope with family caregiving burdens. The patients with ESKD receiving haemodialysis have complex illness trajectories with high symptom burden and numerous comorbidities, though the palliative care for these patients is still suboptimal. Family caregivers have reported the end-of-life care for these patients as significantly more challenging in comparison with that of patients with cancer and dementia.²⁵ Therefore, collaboration between caregivers, family and the healthcare team is essential to plan necessary interventions to meet these patients' early and timely end-of-life palliative care needs.²⁵ Family caregivers' role as care facilitators in the healthcare team should be reinforced²⁶; therefore, working in a team might alleviate the care-related exhaustion among family caregivers.

Feeling burdened as failing the care responsibility was another concern among family caregivers. Accordingly, finding a living person willing to donate a kidney for transplantation was extremely hard, while depending on a deceased donor in the cadaver list gives only a rare chance to get a matched kidney. As donor crisis is a major problem in developing countries,²⁷ this was an endless struggle among family caregivers. Hence, a systematic and legal approach must be initiated, or existing law has to be revised and reinforced to reach a donor without risks of going through kidney scams and reduce related financial burdens. Similarly, facing an economic crisis due to lower income and high care costs contributed to suffering among family caregivers in Thailand.²⁸

The constraints on existing healthcare resources pose a significant challenge in providing care for patients with kidney disease in developing countries. In Nigeria, a study found that there is also poor interest and limited funding to support patients with kidney disease.²⁹ However, this is a common situation in most developing countries where collaboration between government and non-governmental organisations is needed to find funding sources for developing healthcare infrastructure to provide optimal kidney care to patients. A larger dialysis workforce with formal training is required to expand the dialysis service capacity in Sri Lanka,² and improving palliative care is vital to accommodate the patient's and family caregivers' care needs.

Having coping strategies to overcome the family caregiver burden was a significant aspect of family caregiving in Sri Lanka. When the family caregivers provided compassionate care to their family members, they had a meaningful life. They expressed the importance of having a sense of belongingness, being respected and appreciated by others, and feeling of gratitude as the motivational pointers in providing care. In accordance with the findings of a study, Rwandan family caregivers expressed personal satisfaction and a sense of responsibility as their motives in care provision.⁶ In previous studies, religion and spirituality as a coping strategy mainly emanated in the Islamic context.³⁰ In contrast, the present study

provides a new ground for coping through religion such as Buddhism. Coping through religion was an active coping strategy among Iranian family caregivers, whereas believing in destiny or faith was their passive coping strategy.³¹ Unbearable suffering with endless haemodialysis treatment and the related care burden was believed by family caregivers in Ethiopia as a punishment for their sin.¹³ However, Sri Lankan family caregivers experience progressive health decline and the endless suffering of their family members because of the 'bad karma' from their previous life. They accepted the nature of life and the importance of engaging in good work, such as caregiving, to gain merits as a passive coping strategy.

When there is a family member who is diagnosed with end-stage disease, it is an overwhelming experience. In this study, stressors such as a heavy care load, suffering, financial stress, social isolation, and lack of resources and support piled up and challenged families' vulnerability to disruptive experiences. However, according to the RMFSAA model,²⁰ any adversities in life may foster methods to recover from such situations through the adjustment and adaptation process. The family caregivers in the present study adjusted their life to maintain similar roles and functions as previously established, particularly with the present study's external support encompassing family and social support. Family caregivers developed confidence, tolerance and endurance in caregiving through the experience gained in the caregiving journey and learnt to navigate everyday life by alleviating caregiver burden. This model can be used to understand the influence of family caregiver experience on the entire family's health and to improve family health by holistic means and alleviating the burden of family caregiving.

Strengths and limitations

This is probably the first qualitative exploratory study of family caregivers of patients receiving haemodialysis in the Sri Lankan setting which provides in-depth understanding of family caregivers' situation. The study contributes to filling a part of the knowledge gap regarding clinical care for patients and their families. Though the researchers tried to increase maximum variability of participant selection, the transferability of the findings can be considered limited because data collection was done based on one haemodialysis centre in Sri Lanka and the study could only capture the perspectives of either a parent or a spouse (husband or wife).¹⁸ However, all informants have the caregiver role in common. Nevertheless, in Sri Lankan patriarchal culture, women are the main caregivers in a family. Rarely, if the woman is sick, the male partner, father or spouse takes the responsibility. Thus, the sample diversity of the present study is almost similar to the other haemodialysis units in Sri Lanka.

CONCLUSION

Family caregivers strove to balance their life between the burden of caregiving and coping with it, hoping for a

better life. The family caregivers tend to adopt their own coping strategies; however, it seems inadequate to maintain their entire physical and mental well-being. Since physical exhaustion and emotional suffering are evident, regular assessment of both patients' and family caregivers' healthcare needs should be carried out. Therefore, collaboration between the family, the healthcare team of the hospital and the community (primary healthcare) including community health nurses and social workers is essential to conduct frequent health follow-ups and counselling sessions to secure family caregivers' health which is the key for the continuity of patient care. Interventions should be designed to strengthen the family caregivers financially and psychosocially with the support of local and international community support services. A more patient and family-centred advance care planning with a multidisciplinary approach could be initiated to alleviate uncertainty of care among family caregivers and to reduce their suffering throughout their family members' illness trajectory. Since finding a donor for kidney transplantation is problematic and a huge burden on family caregivers, a systematic and legal approach has to be initiated and existing law has to be revised in order to reach a donor without having to go through kidney scams.

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Patient and public involvement Patients and/or the public were not involved in the design, or conduct, or reporting, or dissemination plans of this research.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was conducted in accordance with the Declaration of Helsinki. The study was approved by the Ethics Review Committee, Kurunegala Teaching Hospital, Sri Lanka (PGH/HIRU/ERC/2021/04). Telephone-based data collection has ethical challenges in obtaining informed consent and maintaining confidentiality. Therefore, informed consent was obtained during a visit to the study setting. The use of telephone interviews during the COVID-19 pandemic prevented the family caregivers from the risk of getting infected. Sharing sensitive information over the phone might keep the participant emotionally at risk. Thus, the researchers strove to be sensitive during the interview if the questions invoked any burdensome feelings. It was made clear to the participants that their participation was voluntary and that they, at any time and without explanation, had the right to withdraw their consent to participate in the study. They were also assured that their participation or non-participation would not affect the care their family member received. Pseudonyms were used when transcribing the interviews to not reveal the identity of the participants. All non-electronic items (transcripts with real names and data) of the study were kept locked in a key and all electronic data were password protected. Only the first author (CL) has access to the original data.

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