Comparative Analysis of Caregivers' Perspective from Patients under Hemodialysis versus Conservative Kidney Management

Filipa Trigo[1*], *Ana R Ramos*[1], *Cátia Figueiredo*[1], *Patrícia Barreto*[1], *Flora Sofia*[1], *Karina Lopes*[1], *Paulo Santos*[1]

1. Nephrology Department, Unidade Local de Saúde Médio Tejo, Torres Novas, Portugal

https://doi.org/10.71749/pkj.126

Abstract

Introduction: Elderly patients with advanced chronic kidney disease (CKD) experience a significant physical and emotional burden, regardless of treatment choice. However, little is known about the challenges faced by their families throughout the disease. This study aimed to evaluate how caregivers of patients over 75 years-old with advanced CKD perceive and cope with the disease.

Methods: A qualitative study was conducted through semi-structured telephone interviews with 22 caregivers [11 of hemodialysis (HD) patients and 11 of conservative kidney management (CKM) patients]. Thematic analysis was performed to identify key themes related to communication, quality of life, caregiver burden, and advance care planning.

Results: Caregivers of CKM patients reported greater involvement in decision-making and better awareness of prognosis, while HD caregivers felt less included in patient management. Symptom control concerns were common in both groups, but HD caregivers experienced more uncertainty in communication with the medical team. Loss of personal freedom was noted in both groups - HD caregivers linked it to treatment constraints, while CKM caregivers attributed it to mobility loss. Although caregivers reported emotional and physical burden, many were reluctant to acknowledge it explicitly. HD caregivers were more open to discussing advanced care planning, whereas CKM caregivers preferred ongoing informal discussions.

Conclusion: Caregivers play a critical role in CKD management but often lack adequate support. The palliative approach in CKM facilitates structured communication and shared decision-making, while its inconsistent integration in HD may contribute to caregiver distress. These findings highlight the need for enhanced caregiver support through multidisciplinary strategies.

Keywords: Aged; Caregivers; Global Burden of Disease; Global Health; Renal Dialysis; Renal Insufficiency, Chronic/epidemiology; Renal Insufficiency, Chronic/therapy

INTRODUCTION

Chronic kidney disease (CKD) is a significant global health challenge, with its incidence and prevalence steadily increasing worldwide. Population growth and aging demographics are the primary reason for this rise, particularly in high-income countries.[1] CKD imposes a substantial disease burden, as its mortality rates have increased by 137% compared to 1990s, contributing to a growing number of disability-adjusted life years (DALYs).[2]

For patients with advanced chronic kidney disease (CKD), several treatment options are available, including renal replacement therapies (RRT) – hemodialysis (HD), peritoneal dialysis or kidney transplantation – as well as conservative kidney management (CKM). Given the increasing incidence and prevalence of CKD, a growing number of individuals will progress to an end-stage, requiring either RRT or CKM.[3]

The increasing prevalence of CKD and its treatments places a significant strain on health care systems and society, both in economic and social terms.[4] However, beyond these systemic challenges, both patients and caregivers experience profound socio-economic, physical, and psychological burdens.[5,6]

Received: 15/12/2025 **Accepted:** 30/01/2026 **Published Online:** 31/01/2026 **Published:** 16/03/2026

* **Corresponding Author:** Filipa Trigo | anatrigo_347@hotmail.com | Avenida Xanana Gusmão, 2350-399 Torres Novas

Caregivers play a crucial role in supporting CKD patients, particularly older adults, throughout the course of the disease. As healthcare system constraints increase due to aging populations and resource limitations, the role of caregivers becomes even more essential.[7] Despite this, their contributions often remain unpaid and largely unrecognized to society.[6,8]

Studies have shown that caregivers experience high levels of anxiety and depression, regardless of whether the patient is undergoing CKM or RRT.[6,9,10] However, research exploring caregivers' perceptions, experiences, and coping strategies in the context of CKD remains limited, and even fewer studies have examined how caregivers' experiences differ based on the patient's treatment choice. To our knowledge, this is one of the first qualitative studies comparing caregivers' experiences between HD and CKM in very elderly patients. Therefore, this study aims to assess how caregivers of patients with advanced CKD aged 75 and older perceive and cope with the disease.

METHODS

Between November 2023 and January 2024, a semi-structured telephone interview was conducted following a qualitative research method.[11]

The study involved 22 caregivers of patients aged 75 or older, diagnosed with advanced CKD and undergoing either maintenance HD (11 patients) or CKM (11 patients), all of whom were followed at the same center. Caregivers were identified through the contact information in the patients' medical records. They were contacted by phone, and the interview was conducted after obtaining verbal informed consent.

The inclusion criteria required participants to be the primary caregiver; aged 18 or older; a relative of the patient; providing care for only one patient; and caring for a patient who had been on maintenance HD or CKM for at least three months. The exclusion criteria included refusal to participate in the study and providing care for more than one patient.

All interviews were audio-recorded and analyzed by two independent investigators, and discrepancies were resolved through discussion. To maintain confidentiality, personal identifiers were replaced with coded filenames. Participants were free to withdraw from the study at any time.

Data were analyzed using thematic analysis, following Braun and Clarke's six-phase framework, which facilitated the identification of emerging themes through an inductive approach.[12] Our research question was: *"how do caregivers of patients with advanced CKD perceive care?"*. A top-down exploration was conducted.

RESULTS

A total of 27 previously identified caregivers were contacted, of whom 22 agreed to participate in the interview. Among them, 11 were caregivers of patients undergoing HD. These patients were predominantly male (n=7, 63.6%) with a mean age of 82.1 years. The remaining 11 caregivers were providing care for patients receiving CKM, who were primarily female (n=6, 54.5%), with a mean age of 88.9 years.

Regarding caregivers, a majority were sons or daughters (n=20, 90.9%), while the remaining were spouses.

The thematic analysis of the interview data identified three main themes: caregivers' perception of relatives' quality of life (QoL), communication with the medical team and caregiver burden. These themes, along with some subthemes, are identified in Table 1, along with some related quotes.

Caregivers' Perception of Relatives' QoL

Caregivers primarily focused on and were concerned about their relatives' QoL. As their main role is to provide care, their main concern was whether they were doing it correctly and meeting all relatives' needs. Consequently, they reported several symptoms and sought confirmation during the interview regarding their ability to manage them effectively. They also expressed some concerns about how the disease impacted the patient's sense of freedom.

Uncertainty and Responsibility in Symptom Management

Caregivers of both HD and CKM patients identified a range of symptoms, including physical, psychological, spiritual, and social aspects – such as feelings of loneliness or isolation, and family conflicts.

However, while caregivers from both groups recognized these symptoms, those caring for CKM patients more often reported being aware that their relatives' medical team was actively monitoring and effectively managing them with their support. In contrast, caregivers of HD patients expressed greater uncertainty regarding symptom management and reported difficulties in communicating these concerns to the medical team.

Treatment as a Constraint on Autonomy

A major concern for caregivers of HD patients was the perceived loss of personal freedom experienced by their relatives due to the treatment regimen. They expressed distress over the fact that dedicating three days per week to HD sessions often meant missing important family events and gatherings.

Recognizing the importance of this issue, CKM caregivers were also asked about their perception of their relatives' personal freedom. Some shared similar concerns, particularly on the patients' declining mobility and increasing dependence on assistance for daily activities.

Navigating Communication with the Medical Team

Communication regarding their relatives' illness, treatment and prognosis was also a key theme. Before the start of HD or CKM follow-up, all caregivers stated that information was provided in a safe, private, and unhurried manner. Their only complaint was occasionally feeling to overwhelmed by the amount of information given.

Access to Prognostic Information

After treatment choice, some caregivers of HD patients felt excluded from ongoing discussions, as medical management was handled solely between the medical team and the patient. They felt they did not have adequate space or time to discuss their relative's condition and that conversations were limited to treatment-related topics.

In contrast, caregivers of CKM patients found information about prognosis the most difficult to understand. However, they generally felt that other aspects of communication were provided in a timely and appropriate manner.

Inclusion in the Decision-Making

Regarding decision-making, caregivers from both groups agreed on the importance of involving both the patient and their family in the process.

They emphasized that, whenever possible, decisions should be made by the patient. However, they recognized that their involvement is valuable, as it enables prior discussions about the patient's wishes in case they become unable to make decisions in the future.

Some caregivers of HD patients expressed discomfort about being excluded from these discussions, as they were only informed about the decisions afterward by their relatives, rather than being actively involved in the process.

Advance Care Planning as Emotional and Moral Preparation

Caregivers of HD patients demonstrated a greater willingness to discuss future care decisions, expressing a sense of preparedness and acceptance. Some emphasized the importance of being mentally and emotionally ready when the time comes.

In contrast, caregivers of CKM patients were more reluctant to engage in these conversations, often avoiding discussions about the future and instead relying on healthcare providers to support them when necessary. Their responses suggested a preference for focusing on the present, as they believed these discussions were already occurring informally with the medical team and did not require formalized planning.

Caregiver Burden

Initially, all the caregivers stated that they felt a sense of obligation to care for their relatives. They also expressed joy in fulfilling this role and avoided directly acknowledging their burden. However, as the conversations progressed, it became evident that all caregivers experienced some level of distress, whether in a physical, social, emotional, or financial aspect.

Physical Strain of Caregiving

Many caregivers reported that the continuous physical strain negatively impacted their own health, often resulting in fatigue. Both spouses and some patients' offspring admitted that they struggled to manage all their relatives' daily activities on their own, leading them to seek additional support.

Emotional Distress and Social Withdrawal

Caregiving imposed a significant emotional and social burden on family members, affecting both their well-being and daily lives. Emotionally, caregivers experienced anxiety and fear about their relatives' health. One caregiver, for instance, recalled crying upon hearing concerns about a life-threatening infection, illustrating the strong emotional dependency that often develops between caregivers and patients. This strong attachment reinforces the fear of loss and the uncertainty surrounding their loved one's condition.

Socially, caregivers had to adjust their daily lives, often sacrificing personal and community activities. Although some did not explicitly express feelings of loneliness, their caregiving responsibilities limited their ability to engage in social interactions as freely as before. This gradual reduction in social engagement suggests that caregiving may contribute to a progressive sense of isolation over time.

Financial Considerations in Caregiving

Financial strain was not a predominant concern for most caregivers, as only a few reported experiencing financial difficulties related to caregiving responsibilities. While many acknowledged the need for careful budgeting and financial adjustments to accommodate the demands of care, they did not identify it as a major burden.

DISCUSSION

CKD is a condition characterized by profound physical and behavioral changes, complex medical decision-making, and significant lifestyle adjustments.[13,14] These challenges are not only faced by patients, but also by their caregivers, who play a critical role in providing support. They frequently assume responsibilities beyond emotional support, often taking on the coordination of care – including scheduling medical appointments, arranging transportation, managing medication administration, and ensuring dietary adherence.[15,16]

Given these complexities, it is unsurprising that caregivers of CKD patients feel unprepared for the role they assume in managing their relatives' condition. Investigating their experiences and challenges is essential to gaining a deeper understanding of their needs, ultimately enabling the development of more effective support strategies.[8,15,17]

This comparison study provided important insights into the impact of a more palliative-oriented approach, such as the one implemented in CKM, on caregivers.

The primary concern among caregivers of both patient groups was their relatives' QoL. While both groups identified a wide range of symptoms, caregivers of HD patients expressed greater uncertainty regarding symptom management and reported difficulties in effectively communicating these concerns to the medical team. This finding aligns with previous reports from HD patients themselves, who highlight that the most burdensome symptoms are often those that remain inadequately controlled.[18] Additionally, beyond symptom burden, both groups perceived a loss of freedom in their relatives- HD patients due to the rigid schedule of frequent treatment sessions, and CKM patients due to their limited mobility.

Caregivers experienced a high burden across multiple aspects, with fatigue and emotional stress being the most frequently reported. Notably, no significant differences were observed between the two groups, as all caregivers acknowledged some degree of burden, even though many were initially reluctant to admit it.

Several noteworthy findings emerged regarding communication. Its importance in patient management is undeniable and should be maintained throughout all stages of CKD. However, caregivers of HD patients reported feeling less involved in care after treatment initiation, which limited their ability to aid or to participate in decision-making. In contrast**,** the continued provision of information to caregivers of CKM patients may explain their greater reluctance to engage in advance care planning: since these discussions occur continuously during routine appointments, they may not perceive the need for a distinct moment to formalize decisions.

These findings underscore broader issues in the management of advanced CKD, particularly the differing approaches to patient care. The approach to patients in CKM is essentially palliative, prioritizing QoL and symptom control. These patients are regularly evaluated by multidisciplinary teams trained in palliative care, who promote shared decision-making and more efficient communication about disease progression and prognosis for both patients and their families. Despite evidence and expert consensus advocating for the integration of palliative care for all patients with advanced CKD, its implementation remains inconsistent among those undergoing HD, which may explain the previously discussed findings in caregiver experiences.[19,20] The impact on caregivers' perceptions further underscores the need to enhance support for caregivers of all advanced CKD patients, ideally through a multidisciplinary approach.

This study has some limitations that should be acknowledged. The single-center design and the use of convenience sampling may limit the transferability of the findings to other settings. In addition, the small sample size may limit the variety of perspectives captured, while the predominance of filial caregivers may restrict the applicability of the results to spousal or non-family caregivers. Data collection through telephone interviews, while necessary to facilitate participation, may have limited the ability to capture non-verbal cues and could have influenced the depth of some accounts. As with all self-reported data, the possibility of social desirability bias cannot be excluded. Nevertheless, to enhance methodological rigor and credibility, investigator triangulation and peer debriefing were employed throughout the analytic process.

CONCLUSION

This study stands out as one of the pioneers in this field, emphasizing the critical role of caregivers in supporting elderly patients with advanced CKD, as well as the multifaceted challenges they face. While caregivers of both HD and CKM patients experience significant burdens, key differences emerged, particularly in communication and symptom management. The findings suggest that the palliative approach used in CKM facilitates more structured communication, while its limited integration in HD may contribute to increased caregiver uncertainty. Given the essential role caregivers play in patient management, there is an urgent need to implement multidisciplinary support strategies to ensure that all caregivers receive adequate guidance, recognition, and resources. These findings support the integration of structured caregiver support pathways in both HD and CKM programs.

Table 1. Answers of CKM and HD family members and summary of supporting quotes

Theme	Subtheme	Quotes	
		Hemodialysis	Conservative Kidney Management
Caregivers' Perception of Relatives' QoL	Symptoms of ACKD	"To be honest, I was hoping that dialysis was going to improve all his symptoms. It is true that some were gone, but others remain or have come, and I don't know if he has exposed them or if I'm supposed to talk about them to anyone (…)"	"Well, he still says he tired, but they've explained to me that some of it won't go away. However, I know he feels better as now he was able to play with his grandson again!" "(…) I was worried because she told the doctors that she was so alone she would rather die. We weren't aware of that, and we started to always take her with us to family gatherings, and if you could see her. She smiled again!"
	Impact of Treatment on Patients' Freedom	"You know, sometimes it feels like hemodialysis is similar to serving jail time (…)"	"Well, sure, I think that with the progressive loss of her mobility, her freedom is also going away!"
Communication with the Medical Team	About the Disease	"I would prefer if some more information was given (…) because before he started the treatment I would go with him to the medical appointments, now he goes alone to the center, and I end up knowing nothing."	"(…) each appointment the medical team explains to me and my mother what's going on!"
	About the Prognosis	"No one can really tell me how long he has to live (…)" "I don't know how long I can expect she will be around to see her grandkids grow."	
	Decision-making process	"He is the one who makes the decision! I'm only informed by him afterward."	"There isn't a decision where we're not included. But if she can, we only help her in the process."
	Advance Care Planning	"Yes, when the time comes (…)" "Besides a part of me will go away when the time comes, I would like to be prepared."	"I don't even want to talk with him about that… the time will come, and we know you are also going to be there for us." "Well, you have been doing that with us already right? I don't think we need to formally address it."
Caregiver Burden	Physical, Social and Emotional	"Of course not! We do what we can." "Yes, when you talk about that I do have to tell you that I needed to get help because I was no longer able to move him!" "I cried when you told me you thought she wouldn't make it when she had that infection. Who would I have if that had happened?" "No, no, I don't feel lonely. But I must miss some church events, for example."	
	Financial	"We have to manage with what we have."	

Prizes and Previous Publications

Sub analysis of this study were presented as oral communications in "ERA EDTA 2024", in "Curso de TMC" and "Curso de Comunicação em Nefrologia".

Acknowledgements

The authors sincerely thank all the caregivers who participated in this study for their time and valuable insights.

Contributorship Statement

FT: Conceptualization, methodology, data collection and curation, formal analysis and results interpretation, writing – original draft.
ARR: Collection and curation, writing – original draft.
CF: Conceptualization, methodology, data collection and curation, formal analysis, results interpretation, writing – review and editing, supervision, project administration.
PB, FS and KL: Data collection and curation.
PS: Formal analysis and results interpretation, writing – review, editing and supervision.
All author approved the final version to be published.

Ethical Disclosures

Conflicts of Interest: The authors have no conflicts of interest to declare.

Financing Support: This work has not received any contribution, grant or scholarship

Confidentiality of Data: The authors declare that they have followed the protocols of their work center on the publication of patient data.

Protection of Human and Animal Subjects: The authors declare that the procedures followed were in accordance with the regulations of the relevant clinical research ethics committee and those of the Code of Ethics of the World Medical Association (Declaration of Helsinki as revised in 2024).

Provenance and Peer Review: Not commissioned; externally peer-reviewed.

REFERENCES

1. Francis A, Harhay MN, Ong AC, Tummalapalli SL, Ortiz A, Fogo AB, et al. Chronic kidney disease and the global public health agenda: an international consensus. Nat Rev Nephrol. 2024;20:473-85. doi:10.1038/s41581-024-00820-6
2. Qin K, Qing J, Wang Q, Li Y. Epidemiological shifts in chronic kidney disease: a 30-year global and regional assessment. BMC Public Health. 2024;24:3519. doi:10.1186/s12889-024-21065-9
3. Liyanage T, Ninomiya T, Jha V, Neal B, Patrice HM, Okpechi I, et al. Worldwide access to treatment for end-stage kidney disease: A systematic review. Lancet. 2015;385:1975-1982. doi:10.1016/S0140-6736(14)61601-9
4. Wang V, Vilme H, Maciejewski ML, Boulware LE. The economic burden of chronic kidney disease and end-stage renal disease. Semin Nephrol. 2016;36:319-30. doi:10.1016/j.semnephrol.2016.05.008
5. McClellan WM, Abramson J, Newsome B, Temple E, Wadley VG, Audhya P, et al. Physical and psychological burden of chronic kidney disease among older adults. Am J Nephrol. 2010;31:309-17. doi:10.1159/000285113
6. Adejumo OA, Iyawe IO, Akinbodewa AA, Abolarin OS, Alli EO. Burden, psychological well-being and quality of life of caregivers of end stage renal disease patients. Ghana Med J. 2019;53:190-6. doi:10.4314/gmj.v53i3.2
7. Stephenson AL, Raj M, Thomas SC, Sullivan EE, DePuccio M, Fleuren B, et al. Reconceptualizing family caregivers as part of the health care team. J Hosp Manag Health Policy. 2022;6. doi:10.21037/JHMHP-21-56
8. Maddalena V, O'Shea F, Barrett B. An exploration of palliative care needs of people with end-stage renal disease on dialysis: Family caregiver's perspectives. J Palliat Care. 2018;33:19-25. doi:10.1177/0825859717747340
9. Walavalkar A, Craswell A, Gray NA. Experiences of caregivers of patients with conservatively managed kidney failure: a mixed methods systematic review. Can J Kidney Health Dis. 2022;9. doi:10.1177/20543581221089080
10. Farzi S, Farzi S, Moladoost A, Ehsani M, Shahriari M, Moieni M. Caring Burden and Quality of Life of Family Caregivers in Patients Undergoing Hemodialysis: A Descriptive-Analytic Study. Int J Community Based Nurs Midwifery. 2019;7:88-96. doi: 10.30476/IJCBNM.2019.44888.
11. Erlandson D, Harris E, Skipper B, Allen S. Doing Naturalistic Inquiry: A Guide to Methods. London:SAGE Publications, Inc; 1993.
12. Braun V, Clarke V. Using thematic analysis in psychology. Qual Res Psychol. 2006;3:77-101. doi:10.1191/1478088706qp063oa
13. Webster AC, Nagler EV, Morton RL, Masson P. Chronic Kidney Disease. Lancet. 2017;389:1238-52. doi:10.1016/S0140-6736(16)32064-5
14. Hussien H, Apetrii M, Covic A. Health-related quality of life in patients with chronic kidney disease. Expert Rev Pharmacoecon Outcomes Res. 2021;21:43-54. doi:10.1080/14737167.2021.1854091
15. Brown SK. Challenge of Managing Chronic Kidney Disease: Patient and Caregiver Perspectives. Popul Health Manag. 2023;26:S23-S24. doi:10.1089/pop.2023.0126
16. Kalantar-Zadeh K, Li PKT, Tantisattamo E, Kumaraswami L, Liakopoulos V, Lui SF, et al. Living Well with Kidney Disease by Patient and Care-Partner Empowerment: Kidney Health for Everyone Everywhere. Am J Nephrol. 2021;52:1-7. doi:10.1159/000513952
17. Gayomali C, Sutherland S, Finkelstein FO. The challenge for the caregiver of the patient with chronic kidney disease. Nephrol Dial Transplant. 2008;23:3749-51. doi:10.1093/ndt/gfn577
18. Flythe JE, Hilliard T, Castillo G, Ikeler K, Orazi J, Abdel-Rahman E, et al. Symptom Prioritization among Adults Receiving In-Center Hemodialysis. Clin J Am Soc Nephrol. 2018;13:735-745. doi:10.2215/CJN.10850917
19. Kane PM, Vinen K, Murtagh FE. Palliative care for advanced renal disease: A summary of the evidence and future direction. Palliat Med. 2013;27:817-21. doi:10.1177/0269216313491796
20. Kurella Tamura M, Cohen LM. Should there be an expanded role for palliative care in end-stage renal disease? Curr Opin Nephrol Hypertens. 2010;19:556-60. doi:10.1097/MNH.0b013e32833d67bc