

Perceived challenges faced by family caregivers of chronic kidney disease patients and suggested solutions: A qualitative study

Pravin Surendran¹, Vinayagamoorthy Venugopal¹, Amol R Dongre¹, Ravikumar Paninjukkunnath²

¹Department of Community Medicine, Sri Manakula Vinayagar Medical College and Hospital, Puducherry, India, ²Department of Nephrology, Sri Manakula Vinayagar Medical College and Hospital, Puducherry, India

Correspondence to: Vinayagamoorthy Venugopal, E-mail: drvinayagamoorthy@gmail.com

Received: March 04, 2018; **Accepted:** March 19, 2018

ABSTRACT

Background: The role of family caregivers in the provision of palliative care services to patients with chronic kidney disease (CKD) is substantial. They encounter many hurdles in the process of caregiving. If not taken care properly, it results in poor quality of service offered to patients and also affects the health of the caregivers. **Objectives:** To explore the perceived challenges of caregivers of CKD patients on regular dialysis and to identify the suggested solutions for the same. **Materials and Methods:** It was a phenomenological type of qualitative study carried out using in-depth interviews by researchers trained in qualitative methods among the 18 caregivers of the patients with CKD. Responses given in Tamil were noted down verbatim and were translated into English. The manual content analysis was carried out. Ethical principles have adhered. **Results:** Descriptive coding of the text information was done, and later, similar codes were merged together to form the categories. Eight broad categories emerged each under the theme of perceived challenges of caregivers and suggested solutions to them. They were (1) family or day-to-day life related; (2) psychological; (3) financial; (4) social; (5) spiritual; (6) physical; (7) treatment-related; and (8) travel-related issues. **Conclusion:** Providing support for family caregivers is considered as a key component of palliative care. Multicomponent interventions involving various stakeholders are required to address the challenges faced by the caregivers. Effective coordination among family members, community volunteers, health system, and government for the betterment of caregivers is the main need.


KEY WORDS: Caregivers; Chronic Kidney Disease; Qualitative Research; Palliative Care

INTRODUCTION

The caregiver is an individual who during the course of the treatment of a patient is most closely involved in caring for him or her and helping the patient cope with and manage illness.^[1,2] Caregiving is defined broadly to include the informal (i.e., unpaid) care provided that goes beyond customary and normative social support provided in social relationships.^[3]

Family caregivers, in particular, play significant roles in the context of palliative and end-of-life care.

Chronic kidney disease (CKD) has become an emerging public health problem in developing countries including India that increases patient morbidity and mortality risks and the major economic strain on the health-care systems.^[4] The incidence of CKD in India has been increasing progressively. It is estimated that there are about 55,000 patients on dialysis in India, and the dialysis population is growing at the rate of 10–20% annually.^[4,5] Although the patients with CKD follow a disease trajectory similar to that of any chronic organ failure, their life expectancy and health-related quality of life (HRQOL) vary widely. It depends on various factors including age, comorbid conditions, and type of treatment chosen.^[6] Caregivers actually fill the service gaps that

Access this article online	
Website: http://www.ijmsph.com	Quick Response code
DOI: 10.5455/ijmsph.2018.0307819032018	

International Journal of Medical Science and Public Health Online 2018. © 2018 Vinayagamoorthy Venugopal, *et al.* This is an Open Access article distributed under the terms of the Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>), allowing third parties to copy and redistribute the material in any medium or format and to remix, transform, and build upon the material for any purpose, even commercially, provided the original work is properly cited and states its license.

exist in the health system and governance, and hence, the involvement of the family caregivers significantly impacts the HRQOL of CKD patients.

Long-term caregiving any chronic and incurable illness, especially CKD, on a day-to-day basis ultimately results in step-by-step progression of frustration and exhaustion which gives rise to physical and psychological illness.^[7] Failure to recognize, identify, and address the issues of caregivers will ultimately decrease the HRQOL of the patients and also the health of the caregivers. Hence, it is of utmost importance to provide support and service to caregivers.^[8,9]

Community-based and hospital-based palliative care services have been initiated by the Department of Community Medicine in collaboration with the Department of Anesthesia in a private medical college in rural Puducherry. As a part of hospital-based palliative care services, it was decided to provide services to patients of CKD who were registered and undergoing hemodialysis in the department of nephrology. To develop and deliver comprehensive, patient-centered, cost-effective palliative care services, the context-specific challenges of the CKD patients and their caregivers need to be explored. Hence, on the occasion of World Kidney Day 2017 celebration, all registered patients and their caregivers were invited to share their lived-in real-life experience. The present study was designed with the objectives to explore the challenges and suggested solutions of caregivers of CKD patients.

MATERIALS AND METHODS

Study Design

It was a phenomenological type of qualitative research design.^[10] In-depth interview (IDI) technique was used to understand the lived-in experiences of several caregivers in the process of providing care to the CKD patients. In this phenomenological inquiry, the participants were trying to make sense of their personal and social challenges of caregiving, and the researcher was trying to make sense and interpret the essence of caregivers' experiences.

Study Setting

This study was conducted in collaboration with the Department of Nephrology and Department of Community Medicine at a tertiary care teaching hospital in rural Puducherry. The nephrology outpatient department is visited approximately by 30–35 patients on daily basis. Around 150 CKD patients have been registered and receiving dialysis service. Per day 30–45 patients undergo dialysis. Dialysis service is provided 24 h on all days throughout the year. The department accepts Government Health Insurance Scheme for providing free dialysis service.

Study Participants and Sampling

Caregivers of CKD patients were the participants. All the 150 registered CKD patients undergoing dialysis and their caregivers were invited to participate in World Kidney Day celebration on March 2, 2017. Around 50 patients and their caregivers turned up to the program. Of these 18 caregivers who were willing to share their experience were interviewed. They were selected based on the homogenous type of purposive sampling.^[11] The participants were homogenous by the role they play that was caregiving. The criterion used was caregivers of CKD patients who were undergoing regular hemodialysis for a period of minimum 6 months and willing to narrate their lived in experience. The participants were invited for IDI with the purpose of exploring the perceived challenges and suggested solutions after taking informed verbal consent.

Data Collection

Participants were invited to World Kidney Day celebration organized at the seminar hall in hospital block. Before the commencement of function as and when participants gathered in the hall individually they were approached, briefed about the interview, and the consent was obtained from the caregivers who were interested to share their lived-in experience. Privacy and comfort were ensured for responding freely to their issues. The interview guide was prepared consulting the last author, an expert in qualitative research methods (QRM). IDI's were conducted by the first and second authors who were trained in QRM. Probing questions were asked as and when required by the interviewer to get the in-depth information. The debriefing was done before closing interview with each caregiver to ensure participant validation. Each interview lasted for a period of 20–30 min. Interviews were carried out in the local language "Tamil." The personal details of the participants were not reported to ensure the anonymity. The psychological emotions of the participants were acknowledged and the silence was observed for a short while to space their emotions. It was decided to contact the available psychologist in case if they were overwhelmingly emotional. Caregivers were interviewed one by one till the point of saturation of provided information was attained. Refreshments were served at the end of the function. First, second, and third authors were trained in the conduct of qualitative research. The data were collected as a part of World Kidney Day celebration with the aim to improve the needs of the patients seeking care in our hospital and their caregivers. Ethical principles have adhered to data collection and analysis. The permission from Institutional Review Board has been obtained for this secondary data analysis and anonymity of respondents has been maintained.

Data Analysis and Interpretation

Responses were given by the caregivers in their native language (Tamil) were noted down verbatim by the

interviewers and then they were translated into English on the same day of the interview. The first author did the manual content analysis of the transcripts developed from interviews in consultation with the second author. The statements that were distinct and meaningful in the nature of responses were noted. Such sentences were decided to be the unit of coding. Similar such texts were clubbed to form inductive codes. Codes were clubbed based on content and broad categories of perceived challenges and solutions were formed.^[12] The codes, categories, and themes were reviewed by the third author. The final results of the analysis were shared with third and fourth authors for better interpretation and validity of the interpretations. The analysis was carried out using standard guidelines.^[13,14] Statements in *italics* indicate direct quotations or verbatim from the respondents and the quotations stated, are either in support or in addition to the description of results and help to explain what respondents shared. Similar codes were clustered to form themes. The findings were reported using “consolidated criteria for reporting qualitative research” guidelines.^[15]

RESULTS

A total of 18 caregivers participated in the IDI. Out of these, 13 (72.2%) were female and 5 (27.8%) were male. Mean (standard deviation) age of the female caregivers was 40.69 (13.3) and mean (standard deviation) age of male caregivers was 35.4 (14.7). Of the 18 caregivers, 14 (77.8%) were from rural setup and 4 from urban (22.2%). 44.4% of the caregivers had secondary school level education and 27.8% had no formal education. Majority of them were of Hindu religion (88.9%). Median per capita income of the family of caregivers was 1710 INR per month (interquartile range: 1000–2400) and median duration of caregiving was 6 months (interquartile range: 2–13).

The manual content analysis of responses generated 43 codes and 27 codes under themes of perceived challenges of caregivers and suggested solutions to handle those challenges, respectively. Eight broad categories each under the above-mentioned themes were formed. The categories were (1) family or day-to-day life related; (2) psychological issues; (3) financial issues; (4) social issues; (5) spiritual; (6) physical; (7) treatment; and (8) travel-related issues. The perceived challenges of caregivers and the solutions suggested by them were presented together.

Category-1: Family or Day-to-day Life-related Issues

Majority of the caregivers were of the view that the burden of caregiving was hindering their family responsibilities and day-to-day activities. A 35-year-old woman caregiver responded, “*I am not having enough time to take care of my family responsibilities as I am always busy in providing care to my husband.*”

The caregivers suggested that some form of assistance such as looking after children and taking care of family issues either by family relatives, friends, and neighbors can solve their family-related issues to a great level.

Category-2: Psychological Issues

Many caregivers stated that they get stressed over patient’s health status and also got stressed over the lack of leisure in their personal life. Most of them could not find time for personal needs. A 56-year-old man responded, “*I am always worried over the fact that my wife is suffering from a disease which has no cure and that she may die eventually*” and a 23-year-old male said, “*I haven’t sat with my friends or watched a movie for such a long time as I am always busy with care of my father.*”

Caregivers suggested that interventions to reduce emotional instability in form of counseling by service providers, motivating conversations with friends or neighbors, and practicing other measures to reduce stress such as yoga, meditation, and other relaxation techniques will help to alleviate these issues.

Category-3: Financial Issues

Frequent expenses of treatment and lack of resources for the needs of other family members have become a perennial problem for caregivers. A 38-year-old woman said, “*Every week I have to run for arranging money for the travel and other expenses during treatment, as my husband is now not able to work and there is no one else to give us money, and government scheme doesn’t cover all treatment expenses.*” A 37-year-old woman responded, “*We can’t find any money for our daughter’s college fees and other needs as all our money goes into the treatment of my husband and I am also not able to go for work as I need to accompany him.*”

The suggested solutions to relieve their financial burden by the caregivers were (a) Government Insurance Scheme can cover the direct and indirect expenses of dialysis and drugs, (b) service from private hospitals can be offered at subsidized cost, and (c) availability of interest-free loans or loans with less interest.

Category-4: Social Issues

Young caregivers at times even face difficulty while seeking marriage alliances and many caregivers experienced alienation from relatives, friends, and community who kept themselves at a distance from them or were insensitive to their conditions. A 28-year-old man responded that, “*I am finding difficulty in getting an alliance for marriage as I am burdened with father’s care and people shy away from my marriage proposals*” and a 35-year-old woman complained that, “*My neighbours and relatives don’t come to us anymore*

as they are afraid of the disease and of being asked for financial help.”

Many caregivers felt the need of better cooperation of the relatives, friends, and community members or at least moral support which would have given them the much needed social and mental support.

Category-5: Spiritual Issues

Majority of the caregivers were having spiritual issues regarding why the patient and the family are met with such an ordeal and were puzzled by the reason of such fate. However, many were still hopeful in the justice of God. A 27-year-old man was complaining, “I can't believe in God anymore after what has happened to my father, as he was a virtuous and hardworking person with no harmful habits” and at the same time a 45-year-old lady was saying, “I am confident that almighty will surely give my husband a cure for this disease.”

Many were of the view that prayers to God will still help them out of these woes, while few of them thought that their own effort will only help them because they did not believe in God after their ordeal.

Category-6: Physical Issues

Majority of caregivers responded that disturbed sleep pattern due to patient care was making them physically tired and that they were getting ill themselves due to such physical stress. A 25-year-old lady claimed that “I get so tired of the care of my brother that I feel like I am ill myself.”

The caregivers were of the view that, availability of an extra person to provide physical assistance to the patients in times of ill-health of the caregiver or during lack of sleep of caregivers will be beneficial.

Category-7: Treatment Issues

Treatment schedule and intensity were much struggling for many caregivers as frequent weekly dialysis were much tiresome and troubling for both patients and caregivers. Hospital-related issues such as, the rude and insensitive attitude of hospital staff and delay in procedures and laboratory tests were other issues related to treatment. Other complaints regarding treatment were that they were not given enough information on treatment and effective caregiving. A 38-year-old man told, “We feel much disturbed by the need of traveling every week for dialysis and the long dialysis procedure is seriously troubling my father.”

Better information on the nature of disease and treatment offered; training on effective caregiving and home-based interventions; better attitude of hospital staff; exploring options for home-based treatment and care; and the possibility

of kidney transplantation was suggested for the betterment of treatment issues.

Category-8: Travelling Issues

Many of the caregivers who live in distant and remote villages shared their difficulties related to frequent travel from such places. Traveling with patients, that too especially in public transport was an issue for some caregivers as patients often get nauseated and feel much pain during jerky travels. A 45-year-old man shared that, “Travelling every week from our village to this hospital is costly and we have to change 3 buses, which causes many difficulties to patient and frequent expenses.”

Solutions suggested for solving traveling issues were free ambulance service by government, transport assistance by the hospital from nearby cities; free transport to the hospital from nearby bus stop should be provided by the hospital at regular intervals, travel concessions from the government or other agencies.

DISCUSSION

The in-depth discussion with the caregivers of CKD patients on regular hemodialysis showed that they were subjected to workload and stress. The perceived areas of challenges were related to travel for dialysis, treatment of disease, physical ailments, psychological issues, spiritual matters, social worries, financial burden, and family or day-to-day life chores. Caregivers were consistent and similar in their views on many issues such as the inconsiderate and uncompassionate attitude of relatives, friends, treating team, community and government. The suggested solutions for their problems to reduce burden were proper time management in treatment schedule; compassionate relatives, friends, and community members; adequate rest and sleep; physical help or respite in caregiving by means of temporary replacements; complete and clear information on nature and course of illness; training inpatient health care to aid in home-based management; reduction in financial strain; and responsible behaviour and attitude of treating team.

Existing evidence on challenges faced by caregivers of CKD patients and their possible solutions were few globally, and at the regional level, they are almost absent. However, the previous studies carried out among the caregivers of elderly; caregivers of chronic illnesses such as Parkinson's disease, psychiatric illnesses, cancer; and other progressive degenerative conditions showed the similar type of challenges that were captured by the current study.^[16-19] The interventions designed to assist and help caregivers must consider carefully the practical application and context specific solutions to increase the likelihood of effectiveness. Without this disclosure, there is a danger that the solutions may not be relevant within the specific setting and may fail to meet intended purpose.

As the palliative care services are still underdeveloped in many countries including India, the brunt of care of those chronically ill patients is borne by the family caregivers. The cultural norms, family, and societal value system in our country often transpose the family member who is physically available and emotionally bonded with the patient to assume and accept the role of caregiver.^[20] To assume this role is a Himalayan task and is likely to develop stress and burden. To provide substantial care that has the immense scope, high intensity, and long duration the entire family members need to be involved. The prepared family caregiver model teaches family caregivers how to deliver both medical and psychological services in an orderly manner and is coordinated with care plans of health professionals.^[21] Thus, it helps the psychosocial morbidity of caregivers both during palliative care and across the later phase of bereavement. Most of the challenges identified in the present study such as taking care of day-to-day activities, psychological issues, socioeconomic issues, spiritual, medical, and travel-related issues can be handled with support from other family members. In their absence, the other options can be considered.

Patients with CKD and their caregivers require continuous care, especially at their doorstep. The majority of the care required by them was non-medical in nature such as financial, psychological, social, spiritual, and travel-related concerns. These could be taken care of by the local community members effectively. If they undergo some training, they can even take care of minor nursing and medical issues of the CKD patients. Only when people take ownership meaningful palliative care can be provided that addresses all concerns of patients and caregivers. It is required to create a network of such trained volunteers to initiate seamless comprehensive patient and family-centered palliative care services. Neighborhood network palliative care model^[22] established at Calicut is a proof that community members can identify, support, and care for others, especially who are terminally ill and diagnosed with chronic incurable illness without any external support.^[23]

Deeply rooted in the core of palliative care philosophy is support for the patient as well as the family caregivers.^[24] Certainly, caregivers get very little help from health-care professionals in managing their tasks and the emotional demands of caregiving. The challenges mentioned by the caregivers related to treatment were mainly due to lack of proper communication skills by the treating team members. Family caregivers often feel unprepared to provide care, have inadequate knowledge to deliver proper medical and nursing care. This is mainly because little guidance is provided by the health-care providers. Capacity building of health-care providers and other health professionals such as dieticians, dialysis technician, and the staff nurse who are involved in delivering the comprehensive medical care to CKD patients is essential. All these will reduce the burden and stress of caregivers. Clinicians should screen caregivers periodically

for preventing and timely identification of negative physical and psychological symptoms and suggest appropriate solutions.

In the absence of political commitment for resource allocation, guiding policies and programs to render service the concept of provision of holistic palliative care services to the family caregiver's remain unrealistic. The demand for dialysis and transplantation is increasing constantly and so the demands of caregivers.^[4] The Indian Government has already included the care for kidney disease in its 12th 5-year plan cycle and is currently in the process of developing a framework for dialysis and transplantation that reduces the financial burden of patients and caregivers.^[25] For CKD patients managed at the private sector, the government will reimburse these costs at a predetermined rate. The government should plan and provide subsidized dialysis for the needy poor patients. A nationwide organ procurement network has been created by the government as per the directions of the National Transplant Program.^[26] Innovative government schemes are required to fund the treatment and travel-related cost. Insurance schemes that collect small regular contributions per person by the government can help poor citizen to reduce their economic burden.

CONCLUSION

Caregivers play a crucial role in providing palliative care to CKD patients. They are involved in providing multiple services to the patients that make them burdened and distressed which needs to be acknowledged, screened, and addressed by all the team members involved in providing service to the patients. The main perceived issues of the caregivers were (a) providing physical care to the patients daily at home; (b) economic burden related to treatment and travel; and (c) distress and discomfort due to lack of personal and social support. Other family members and the community ought to extend their support in managing their daily activities at home. Availability of support system in the community in the form of non-governmental organization, volunteers and government schemes together can take care of the economic, transport and other social issues. Treating team has the responsibility to improve caregiver's level of preparedness to offer care at home. The team has to provide counseling to them at regular intervals. The findings of this phenomenological study can help the treating team to prepare counseling guides that can be used while addressing the emotional issues of the caregivers.

REFERENCES

1. Cantor MH. Strain among caregivers: A study of experience in the United States. *Gerontologist* 1983;23:597-604.
2. Fujinami R, Otis-Green S, Klein L, Sidhu R, Ferrell B. Quality of life of family caregivers and challenges faced in caring for

- patients with lung cancer. *Clin J Oncol Nurs* 2012;16:E210-20.
3. Hauser JM, Kramer BJ. Family caregivers in palliative care. *Clin Geriatr Med* 2004;20:671-88, vi.
 4. Modi G, Jha V. Incidence of ESRD in India. *Kidney Int* 2011;79:573.
 5. Modi GK, Jha V. The incidence of end-stage renal disease in India: A population-based study. *Kidney Int* 2006;70:2131-3.
 6. Schell JO, Da Silva-Gane M, Germain MJ. Recent insights into life expectancy with and without dialysis. *Curr Opin Nephrol Hypertens* 2013;22:185-92.
 7. Tong A, Sainsbury P, Craig JC. Support interventions for caregivers of people with chronic kidney disease: A systematic review. *Nephrol Dial Transplant* 2008;23:3960-5.
 8. Reinhard SC, Given B, Petlick NH, Bemis A. Supporting Family Caregivers in Providing Care. US: Agency for Healthcare Research and Quality; 2008. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK2665>. [Last cited on 2017 Jul 11].
 9. Mitnick S, Leffler C, Hood VL, American College of Physicians Ethics, Professionalism and Human Rights Committee. Family caregivers, patients and physicians: Ethical guidance to optimize relationships. *J Gen Intern Med* 2010;25:255-60.
 10. Smith DW. Phenomenology. Available from: <https://www.plato.stanford.edu/archives/fall2011/entries/phenomenology>. [Last cited on 2017 Jul 8].
 11. Palinkas LA, Horwitz SM, Green CA, Wisdom JP, Duan N, Hoagwood K, *et al.* Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Adm Policy Ment Health* 2015;42:533-44.
 12. Dhikale P, Muruganandham R, Dongre A. Perceptions of the community about epilepsy in rural Tamil Nadu, India. *Int J Med Sci Public Health* 2017;6:628-33.
 13. Kvale S. *Doing Interviews*. Oliver's Yard. London, England: EC1Y 1SP, United Kingdom: SAGE Publications, Ltd; 2007. Available from: <http://www.methods.sagepub.com/book/doing-interviews>. [Last cited on 2017 Jul 11].
 14. *Designing and Conducting Mixed Methods Research*. India: SAGE. Available from: <https://www.in.sagepub.com/en-in/sas/designing-and-conducting-mixed-methods-research/book233508>. [Last cited on 2017 Jul 27].
 15. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349-57.
 16. Selamat Din SH, Nik Jaafar NR, Zakaria H, Mohamed Saini S, Ahmad SN, Midin M, *et al.* Anxiety disorders in family caregivers of breast cancer patients receiving oncologic treatment in Malaysia Asian Pac J Cancer Prev 2017;18:465-71.
 17. McCann TV, Lubman DI, Clark E. First-time primary caregivers' experience of caring for young adults with first-episode psychosis. *Schizophr Bull* 2011;37:381-8.
 18. Sabzwari S, Badini AM, Fatmi Z, Jamali T, Shah S. Burden and associated factors for caregivers of the elderly in a developing country. *East Mediterr Health J* 2016;22:394-403.
 19. Zhong M, Peppard R, Velakoulis D, Evans AH. The relationship between specific cognitive defects and burden of care in Parkinson's disease. *Int Psychogeriatr* 2016;28:275-81.
 20. Veloso VI, Tripodoro VA. Caregivers burden in palliative care patients: A problem to tackle. *Curr Opin Support Palliat Care* 2016;10:330-5.
 21. Houts PS, Nezu AM, Nezu CM, Bucher JA. The prepared family caregiver: A problem-solving approach to family caregiver education. *Patient Educ Couns* 1996;27:63-73.
 22. Kumar SK. Kerala, India: A regional community-based palliative care model. *J Pain Symptom Manage* 2007;33:623-7.
 23. Stjernsward J. Community participation in palliative care. *Indian J Palliat Care* 2005;11:22.
 24. Hudson PL, Trauer T, Graham S, Grande G, Ewing G, Payne S, *et al.* A systematic review of instruments related to family caregivers of palliative care patients. *Palliat Med* 2010;24:656-68.
 25. Jha V. Current status of end-stage renal disease care in India and Pakistan. *Kidney Int Suppl* 2013;3:157-60.
 26. Agarwal SK, Srivastava RK. Chronic kidney disease in India: Challenges and solutions. *Nephron Clin Pract* 2009;111:c197-203.

How to cite this article: Surendran P, Venugopal V, Dongre AR, Paninjukkunnath R. Perceived challenges faced by family caregivers of chronic kidney disease patients and suggested solutions: A qualitative study. *Int J Med Sci Public Health* 2018;7(6):487-492.

Source of Support: Nil, **Conflict of Interest:** None declared.