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Preferences for Advance Care Planning in Patients with End-Stage Kidney Disease: A Cross-Sectional Survey among Nephrology Healthcare Providers in a Tertiary Care Center in India

Bharathi Naik[a] Arun Ghoshal[b] Anuja Damani[b] Pankaj Singhai[c] Ravindra Prabhu Attur[d] Naveen Salins[b] Ajith M. Nayak[a] Shankar Prasad Nagaraju[d]

[a]Department of Renal Replacement Therapy and Dialysis Technology, Manipal College of Health Professions, Manipal Academy of Higher Education, Manipal, India; [b]Department of Palliative Medicine and Supportive Care, Kasturba Medical College, Manipal Academy of Higher Education, Manipal, India; [c]Department of Palliative Medicine, Sri Aurobindo Medical College and PG Institute, Sri Aurobindo University, Indore, India; [d]Department of Nephrology, Kasturba Medical College, Manipal Academy of Higher Education, Manipal, India

Keywords
Advance care planning · End-stage kidney disease · ACP questionnaire

Abstract

Introduction: Advance care planning (ACP) is essential in managing patients with end-stage kidney disease (ESKD), yet its integration into clinical practice remains limited, particularly in low- and middle-income countries. This study explores the preferences, attitudes and perceived barriers of nephrology healthcare providers toward ACP for patients with ESKD in a tertiary care center in India. ***Methods:*** A cross-sectional survey was conducted among nephrology healthcare providers at a tertiary care center in India. The survey, developed from literature reviews and pretested, covered demographics, ACP knowledge and attitudes, current practices, and perceived barriers and facilitators. Data collection occurred from September 2022 to March 2023. Quantitative data were analyzed descriptively, and qualitative data through thematic analysis. ***Results:*** A total of 50 healthcare providers participated. While 36% acknowledged the importance of ACP, only 8% routinely engaged in ACP discussions. Major barriers included inadequate training (22%), lack of awareness about the importance of discussing ACP among stakeholders (20%), cultural barriers (18%), lack of time (14%), and the absence of institutional protocols for discussion on ACP (14%). Additional barriers included instances where families withhold health information from patients due to fear of losing hope (16%) and patient/family discomfort in discussing ACP (12%). Providers expressed a need for structured ACP protocols and educational programs. ***Conclusion:*** Despite recognizing its importance, ACP is underutilized in the care of patients with ESKD in India. Addressing the identified barriers through targeted interventions may enhance ACP practices and improve patient outcomes.

karger@karger.com
www.karger.com/nef

Correspondence to:
Anuja Damani, anuja.damani@manipal.edu

Introduction

End-stage kidney disease (ESKD) represents the final, permanent stage of chronic kidney disease (CKD), where kidney function deteriorates to a point where dialysis or transplantation is required to sustain life [1]. Globally, the incidence and prevalence of ESKD are rising, posing significant challenges to healthcare systems, particularly in low- and middle-income countries like India [2]. The complexity of ESKD management and associated comorbidities underscores the necessity for comprehensive care strategies beyond mere clinical management.

The Need for ACP in ESKD

ACP is a process that supports patients at any stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. ACP ensures patients receive medical care that aligns with their values and preferences during serious and chronic illnesses. For patients with ESKD, ACP is especially critical due to the progressive nature of the disease, the high burden of symptoms, frequent hospitalizations, and the complex decisions surrounding dialysis and end-of-life care.

The integration of ACP in the management of ESKD can lead to numerous benefits, including improved quality of life, reduced hospitalization rates, and increased satisfaction with care among patients and their families. Furthermore, ACP facilitates better alignment of medical treatments with patients' values, reduces unnecessary and often burdensome interventions, and aids healthcare providers in making informed decisions during critical moments [3].

Global and Local Context of ACP

In Australia, kidney clinicians have highlighted systemic challenges and care compromises in their experiences [4]. They advocate for developing kidney supportive care services, emphasizing a consistent and systematic approach that integrates palliative care and embeds kidney supportive care within kidney health service delivery. A study from Singapore suggested that enhancing ACP training and empowering nephrology nurses are crucial steps toward effective ACP for patients with ESKD [5]. While ACP is well-established in many high-income countries, its adoption in low- and middle-income countries remains limited. In India, the practice of ACP is relatively new and not widely implemented. Although there are legal provisions for ACP documentation in India, practical barriers exist [6]. Cultural, societal, and systemic factors contribute to the challenges of integrating ACP into routine care. Culturally, discussions about death and dying are often considered taboo, leading to reluctance among patients and families to engage in ACP. Additionally, there is a lack of structured protocols and formal training for healthcare providers, which hampers the implementation of ACP [7].

Despite these challenges, there is growing recognition of the importance of ACP among healthcare providers in India. Previous studies have highlighted a positive attitude toward ACP among clinicians, yet actual practice remains inconsistent. The gap between knowledge and practice necessitates a closer examination of the specific barriers faced by healthcare providers and the potential strategies to overcome them [8, 9].

Objectives of the Study

This study aims to explore the preferences, attitudes, and perceived barriers toward ACP among nephrology healthcare providers in a tertiary care center in India. By understanding these perspectives, we can identify key areas for intervention and develop tailored strategies to promote the integration of ACP into the care of patients with ESKD. Specifically, this study seeks to:

1. Assess the level of knowledge and attitudes toward ACP among nephrology healthcare providers.
2. Identify current practices related to ACP discussions in the care of patients with ESKD.
3. Determine the primary barriers that hinder the implementation of ACP.
4. Explore preferences for the timing and approach to ACP discussions.
5. Propose recommendations to enhance ACP practices in the context of ESKD in India.

Methods

Study Design and Setting

This study employed a cross-sectional survey design to collect data from nephrology healthcare providers at a tertiary care center in India. We used the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines for reporting this study [10]. The chosen study center is a leading institution in nephrology, providing comprehensive care to a large and diverse population of patients with ESKD. This setting was selected to ensure a representative sample of healthcare providers who are directly involved in the management of ESKD.

Participants

The study targeted nephrology healthcare providers, including nephrologists, nephrology fellows, dialysis nurses, and allied healthcare professionals such as dialysis technicians. The inclusion criteria were as follows:

- At least 1 year of experience in nephrology.
- Direct involvement in the care of patients with ESKD.
- Willingness to participate in the study.

Survey Instrument

A structured survey instrument was developed by some of the study authors based on a thorough review of existing literature and validated tools used in previous studies on ACP [11]. The survey was designed to capture a comprehensive range of information and was divided into four main sections:

- Demographic information: Questions on age, gender, professional role, years of experience in nephrology, and type of healthcare provider.
- Knowledge and attitudes toward ACP: Items assessing the participants' understanding of ACP, its perceived importance, confidence in discussing ACP, and previous training received.
- Current ACP practices: Questions on the frequency of ACP discussions, the typical initiator of these discussions, preferred timing for ACP, and methods used to facilitate ACP conversations.
- Perceived barriers and facilitators: Items identifying barriers to ACP implementation, such as lack of time, inadequate training, cultural factors, and institutional support. Additionally, preferences for potential facilitators, including structured protocols and educational programs, were explored.

The survey was pretested previously with a small group of nephrology healthcare providers to ensure clarity, relevance, and reliability [11]. Feedback from the pretest was used to refine the survey instrument.

Data Collection

Data collection occurred between September 2022 to March 2023. Surveys were distributed in paper formats to accommodate the preferences of the participants. Paper surveys were distributed and collected by investigators within the nephrology department.

Participation was voluntary, and informed consent was obtained from all participants before survey administration. Confidentiality was maintained by anonymizing responses and ensuring that data were stored securely.

Data Analysis

Quantitative data were analyzed using descriptive statistics to summarize the demographic characteristics, knowledge, attitudes, and practices of the participants. Frequencies and percentages were calculated for categorical variables, while means and standard deviations were used for continuous variables.

Qualitative data from open-ended questions were analyzed using thematic analysis [12]. Responses were coded, and themes were identified to capture the nuanced perspectives of healthcare providers regarding barriers and facilitators to ACP.

Statistical Analysis

The data analysis was performed using statistical software (e.g., SPSS, version 26.0). The primary analysis focused on the following:

- Descriptive statistics: to summarize the demographic characteristics and responses to survey items
- χ^2 tests: to examine associations between demographic variables (e.g., professional role, years of experience) and attitudes toward ACP.
- Thematic analysis: for qualitative data, open-ended responses were transcribed and coded, with themes emerging from the data through an iterative process of review and refinement.

Ethical Considerations

The study protocol was reviewed and approved by the Institutional Review Board of the Tertiary Care Center. Ethical considerations included ensuring informed consent, maintaining participant confidentiality, and minimizing any potential risks associated with participation. Participants were assured that their responses would be anonymized and that they could withdraw from the study at any time without any consequences.

Results

Participant Demographics

A total of 50 healthcare providers participated in the survey out of the 54 approached (Fig-1). The demographic characteristics of the respondents are summarized in Table 1. Most participants were from the Department of Renal Replacement Therapy and Dialysis Technology (RRT and DT) students (40%, n = 20), followed by nephrology nurses (20%, n = 10), RRT and DT staff (22%, n = 11), and nephrology staff and fellows (18%, n = 9). The median years of experience in nephrology among the participants were 4 years (range

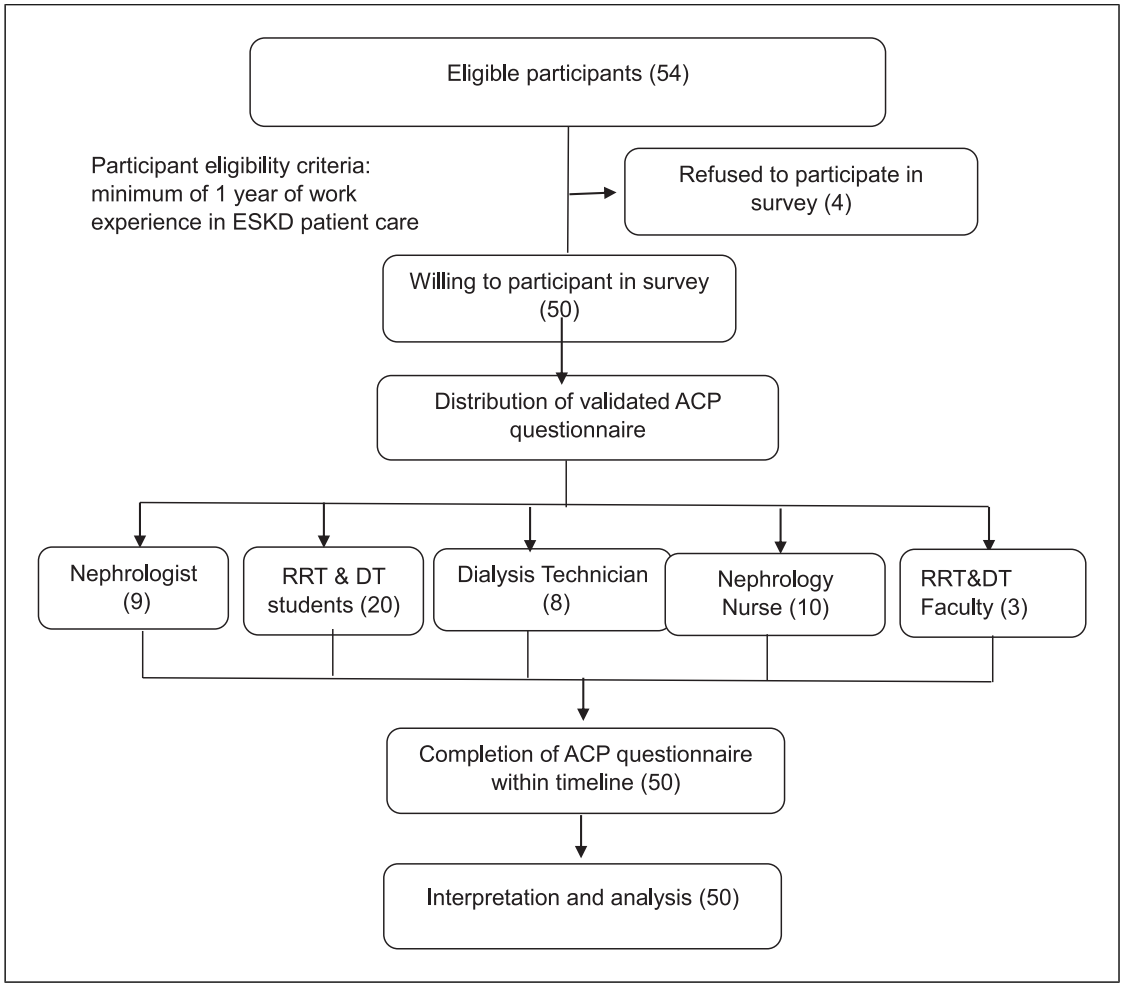

Fig. 1. Flow diagram illustrating recruitment of study participants and the study process. HCPs, healthcare providers; RRT&DT, Renal Replacement Therapy and Dialysis Technology; ACP, advance care planning; ESKD, end-stage kidney disease.

1–32 years), 32 (64%) were female and 18(36%) were male respondents. Age distribution showed that 27 (54%) participants were between 25 and 53 years old (median age = 26.5 years, range 21–53 years) (Table 1).

Knowledge and Attitudes toward ACP

The survey revealed that 36% of respondents (n = 18) agreed that ACP is important for patients with ESKD (online suppl. Annexures 1, 2; for all online suppl. material, see https://doi.org/10.1159/000541347). However, only 8% (n = 4) reported routinely engaging in ACP discussions with their patients. Confidence levels in discussing ACP were average to moderately high, with 30% (n = 15) of providers expressing confidence in their knowledge about ACP. Despite this, only 18% (n = 9) had received formal training in ACP, highlighting a significant education gap.

Current Practices

Among the providers who engaged in ACP, RRT and DT professionals were the most common initiators of ACP discussions (12%, n = 6), followed by nephrologists (8%, n = 4). The preferred timing for initiating ACP discussions varied: 36% (n = 18) preferred during pre-dialysis education sessions, 28% (n = 14) during routine outpatient visits hospital, 18% (n = 9) during admissions for complications, and 12% (n = 6) at the diagnosis of ESKD (online suppl. Annexure 1).

Perceived Barriers

The primary barriers to ACP implementation identified by respondents included inadequate training (22%, n = 11), lack of awareness about the importance of discussing ACP among stakeholders (20%, n = 10),

Table 1. Demographic and baseline data of Nephrology HCPs

Characteristics	All HCPs (50)	Nephrologist/ nephrology trainee (9)	RRT&DT students (20)	Dialysis technician (8)	Nephrology nurse (10)	RRT&DT faculty (3)
Age, mean = 28.1, median = 26.5, range = 21–53 years						
<25 years	23 (46%)	0	18	4	1	0
>25 years	27 (54%)	9	2	4	9	3
Gender						
Male	18 (36%)	5	6	2	4	1
Female	32 (64%)	4	14	6	6	2
Education qualification						
Diploma	11 (22%)	0	0	5	6	0
Bachelors	20 (40%)	0	12	2	4	2
Masters	10 (20%)	0	8	1	0	1
MBBS/MD/DNB in Nephrology	9 (18%)	9	0	0	0	0
Experience, average = 4 years, range = 1–32 years						
1–3 years	21 (42%)	4	12	2	3	0
3–5 years	17 (34%)	4	8	2	1	2
>5 years	12 (24%)	1	0	4	6	1

HCPs, healthcare providers; RRT&DT, Renal Replacement Therapy and Dialysis Technology; MBBS, Bachelor of Medicine and Bachelor of Surgery; MD, Doctor of Medicine; DNB, Diplomate of National Board.

cultural barriers (18%, $n = 9$), lack of time (14%, $n = 7$), and the absence of institutional protocols for discussion on ACP (14%, $n = 7$). Additional barriers included instances where families withhold health information from patients due to fear of losing hope (16%, $n = 8$) and patient/family discomfort to discuss ACP (12%, $n = 6$). Qualitative responses highlighted specific cultural challenges, such as the taboo nature of discussing death and dying, which impeded open communication between healthcare providers and patients (online suppl. Annexure 1).

Preferences for ACP Implementation

Healthcare providers expressed clear preferences for strategies to facilitate ACP. A significant majority (32%, $n = 16$) emphasized the need for structured ACP protocols within the institution. Educational programs to enhance ACP knowledge and skills were desired by 40% ($n = 20$) of participants. Additionally, 34% ($n = 17$) highlighted the necessity for dedicated time within clinical schedules for ACP discussions. There was also support for ACP awareness programs for all stakeholders and the need for a multidisciplinary team approach to ACP, advocating for the involvement of social workers, psychologists, and palliative care specialists in ACP discussions (online suppl. Annexure 1).

Thematic Analysis of Open-Ended Responses

The qualitative analysis of open-ended responses revealed several key themes. Many respondents emphasized the cultural sensitivity required for ACP discussions, noting that patients and families often gatekeep information from each other and avoid talking about end-of-life issues. Some providers suggested incorporating ACP into regular patient education programs to gradually introduce the concept. Others highlighted the need for institutional support, including policy changes and administrative backing, to make ACP a routine part of patient care (online suppl. Annexure 2).

Summary of Key Findings

- The importance of ACP is widely recognized among nephrology healthcare providers, but the barriers include lack of awareness, inadequate training, cultural challenges about how healthcare providers communicate with caregivers rather than patients about serious illnesses, and subsequent gatekeeping of health-related information by caregivers.
- The nephrology healthcare providers expressed a strong preference for structured protocols, educational initiatives, and dedicated time for ACP.
- A multidisciplinary approach and institutional support are critical for effective ACP implementation.

Discussion

Importance of ACP in ESKD Management

The study underscores the critical importance of ACP in the management of end-stage kidney disease (ESKD). Despite the well-recognized benefits of ACP, such as enhancing patient autonomy, improving quality of life, and reducing unnecessary hospitalizations [13–15], its routine implementation remains limited among nephrology healthcare providers in India [6, 16, 17]. The findings align with global literature, which similarly highlights the gap between the acknowledged importance of ACP and its practical application in clinical settings [3, 18].

Barriers to ACP Implementation

The primary barriers to ACP identified in this study – lack of awareness, inadequate training, cultural factors about communication related to serious illnesses and uncertainty about prognosis – mirror those reported in other healthcare contexts [19, 20]. The lack of time is another ubiquitous issue in busy clinical environments, where the demands of patient care often leave little room for in-depth ACP discussions [21, 22]. Inadequate training further compounds this problem, as many healthcare providers lack the necessary skills and confidence to initiate and conduct ACP conversations effectively. This finding is consistent with prior research indicating that formal training in ACP is often lacking in medical and nursing education curricula [22–24].

Cultural factors present a unique challenge in the Indian context [25–27]. Discussions about death and dying are often considered taboo, making patients and families reluctant to engage in ACP due to fear of upsetting the patient or losing hope [6, 28]. This cultural sensitivity necessitates a tailored approach to ACP that respects these values while gently encouraging open communication [29]. The uncertainty about prognosis in ESKD also complicates ACP discussions, as providers may find it difficult to predict the course of the disease and thus hesitate to initiate conversations about future care preferences [30–33].

Current ACP Practices

The study reveals that ACP discussions are mostly initiated by RRT and DT staff, indicating their pivotal role in this process. However, the low routine engagement rate by the nephrologists suggests that many potential opportunities for ACP discussions are missed [32]. The preferred timing for ACP discussions – during diagnosis and hospital admissions – reflects critical junctures in the patient's disease trajectory when they and their families might be more receptive to discussing future care preferences [34, 35]. Yet, the variation in preferred timing also indicates a need for a more standardized approach to ensure that ACP is consistently addressed at appropriate points in care [35].

Recommendations for Enhancing ACP

To address the barriers and enhance ACP practices, several recommendations emerge from this study, which are also supported by the available literature [23, 36]:

- Education and training: implementing comprehensive ACP training programs for healthcare providers is essential. These programs should cover communication skills, cultural competency, and the ethical aspects of ACP. Simulation-based training and role-playing can be particularly effective in building confidence and competence [37].
- Structured protocols: developing and standardizing ACP protocols can provide clear guidelines for when and how to initiate ACP discussions. Protocols should be integrated into the workflow of nephrology departments to ensure consistency and coverage [38].
- Cultural sensitivity: tailoring ACP discussions to be culturally sensitive is crucial in the Indian context. This can involve using culturally appropriate language, engaging family members in discussions, and being respectful of patients' beliefs and values [16].
- Institutional support: institutional backing is vital for the successful implementation of ACP. This includes administrative support, policy changes, and allocating dedicated time within clinical schedules for ACP discussions. Institutions should also consider incorporating ACP metrics into quality improvement initiatives to monitor progress and impact [39].
- Multidisciplinary approach: involving a multidisciplinary team in ACP can enhance the process by bringing in diverse perspectives and expertise [40]. Social workers, technicians, psychologists, and palliative care specialists can provide valuable support and address various aspects of ACP, including informational, emotional, social, and spiritual needs [41].
- Patient and family education: enhancing patient and family understanding of ACP through educational initiatives is important. Information sessions, brochures, and digital resources can help demystify ACP and encourage proactive participation in care planning [42].

Strengths and Limitations of the Study

This study has several strengths, including a diverse sample of nephrology healthcare providers and a comprehensive survey instrument that captures multiple

dimensions of ACP knowledge, attitudes, and practices. The use of both quantitative and qualitative data provides a robust analysis of the issues at hand.

However, there are also limitations to consider. The cross-sectional design captures a single point in time and does not account for changes in attitudes or practices over time. The study is conducted within a single tertiary care center with a small sample size, which may limit the generalizability of the findings to other settings. Additionally, self-reported data may be subject to social desirability bias, where participants respond, to what they perceive to be more favorable.

Future Directions

Future research should aim to address these limitations by employing longitudinal designs to track changes in ACP practices over time and expanding the study to include multiple centers to enhance generalizability. Additionally, intervention studies testing the effectiveness of specific training programs, protocols, and cultural adaptations in improving ACP practices would be valuable. Exploring patient and family perspectives on ACP in the Indian context would also provide a more comprehensive understanding of the challenges and opportunities for improving care.

Conclusion

This research emphasizes the significant disparity between the acknowledged importance of ACP and its actual implementation in the care of patients with ESKD in India. By overcoming the identified barriers through targeted interventions such as education and training, structured protocols, cultural sensitivity, institutional support, and a multidisciplinary approach, healthcare providers can better align treatment with patients' preferences. This might ultimately lead to an improvement in the quality of care for patients with ESKD. These findings lay the groundwork for creating strategies to incorporate ACP into standard nephrology practice, ensuring that patients' values and preferences are honored and upheld throughout their care journey.

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Statement of Ethics

This study protocol was reviewed and approved by the Institutional Ethics Committee of Kasturba Medical College, Manipal, India, Approval No. IEC-214/2021. Written informed consent was obtained from participants to participate in the study.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

Bharathi Naik contributed to the study's conception and design and statistical analysis of the data, prepared the materials, collected the data, wrote the manuscript's original draft, and read and approved the final manuscript. Arun Ghoshal contributed to the statistical analysis of the data, substantially modified the manuscript's original draft, and read and approved the final manuscript. Anuja Damani contributed to the study's conception and design, prepared the materials, collected the data, supervised data collection, critically revised the manuscript's original draft, and read and approved the final manuscript. Pankaj Singhai, Ravindra Prabhu Attur, Naveen Salins, and Ajith M Nayak contributed to the study's conception and design, supervised data collection, and read and approved the final manuscript. Shankar Prasad Nagaraju contributed to the study's conception and design, prepared the materials, collected the data, and read and approved the final manuscript.

Data Availability Statement

Data are available with the corresponding author on request but might need permission from the Ethics Committee before release.

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