

Kidney Clinicians' Perceptions of Challenges and Aspirations to Improve End-Of-Life Care Provision



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Introduction: End-of-life care is an essential part of integrated kidney care. However, renal clinicians' experiences of care provision and perceptions of end-of-life care needs are limited. This study explored renal clinicians' experiences of providing end-of-life care and developed recommendations to improve experiences.

Methods: An exploratory qualitative study using semistructured focus groups and 1 interview was undertaken at 5 kidney services in Victoria, Australia. The transcripts were analyzed thematically.

Results: Between February and December 2017, 54 renal clinicians (21 doctors and 33 nurses) participated in the study. Clinicians reported multiple challenges of end-of-life care experiences resulting in compromised treatment planning and decision making and highlighted priorities to guide better care experiences. Challenges of providing end-of-life care were underpinned by mismatches in illness and treatment expectations, limited engagement in advance care planning, medical complexity, and differences between clinicians and patients in what constituted quality of life. These challenges were associated with compromised end-of-life care planning, which resulted in care experiences that were rushed with a prolonged treatment focus, risking limited preparation for death and moral distress. Clinicians aspired for positive end-of-life care experiences, including patient control and consensus in decision making, and a coordinated and collaborative approach across healthcare providers.

Conclusions: Renal clinicians highlighted multiple factors and circumstances which resulted in experiences of compromised end-of-life care for patients with kidney disease. To improve care experiences, clinician-directed priorities included more training and support to facilitate systematic and earlier discussions about illness expectations and end-of-life care planning and greater communication and collaboration across healthcare providers is required.

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KEYWORDS: end-of-life care; experiences of care; kidney disease; palliative care; qualitative

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People with kidney disease have variable and complex care needs as they approach the end of their lives. Chronic kidney disease management includes treatments such as dialysis therapies, conservative kidney management, and kidney transplantation. All patients with chronic kidney disease experience variable illness trajectories with different health expectations, information requirements, and care needs in the final days, weeks, and months before death.^{1–4} The care needs for patients with advanced chronic kidney disease have

been highlighted in the literature, including the significant symptom and treatment burden,^{5,6} explicit support and communication requirements for end-of-life planning and decision making,^{7–9} and existential distress such as feeling like being on borrowed time.^{10,11} Kidney health providers must be able to consider a patients' illness trajectory, recognize an irreversible decline in health, and communicate this effectively with patients, loved ones, and caregivers.¹² Adequate provision of end-of-life care necessitates shared illness expectations, decision making of treatment goals and preferences, while maintaining an individuals' sense of choice and dignity, addressing symptoms and quality of life issues, and providing psychological support.^{13,14}

Integrating aspects of palliative care is essential for providing end-of-life care for people with end-stage

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kidney disease (ESKD).¹⁴⁻¹⁶ Palliative care focuses on symptoms, treatment decision making, and interdisciplinary team support to address physical and psychosocial needs and can be provided by the nephrology team or specialist palliative care consultation, depending on the care requirements and resources available.^{17,18} Kidney supportive care or kidney palliative care is a recommended clinical approach which incorporates palliative care to improve health related quality of life and can be provided alongside kidney therapies which intend to prolong life such as dialysis.^{19,20} However, there are no local or international standards articulating how to best provide end-of-life care for people with advanced kidney disease and gaps between clinical recommendations and practice exist. Transitioning treatment goals from curative to end-of-life care are particularly challenging for patients with ESKD on dialysis and, in turn, this has been reflected in more intensive patterns of treatment and hospitalizations at the end of their lives than those managed with conservative kidney management.^{21,22} Recent studies suggest that 17% to 21% of patients have dialysis regret,^{23,24} kidney physicians do not routinely initiate discussions about prognosis,²⁵ end-of-life discussions are late in the course of illness²⁶ and the timing of cessation from dialysis can be perceived as too late.²⁷ Barriers to adequate end-of-life care for patients with ESKD have been associated with limited and variable palliative care integration,²⁸ a lack of a systematic approach to advance care planning,^{16,25} and a clinical focus on disease states and dialysis at the expense of more patient-centered goals and outcomes.²⁹

Embedding a systematic approach to facilitate shared decision making, patient education, and future treatment planning may improve end-of-life care experiences for patients with ESKD.³⁰⁻³³ Early and timely discussions between clinicians and patients about goals and preferences can assist end-of-life experiences by reducing psychological distress, perceptions of suffering, and confer a greater likelihood of providing end-of-life care being aligned with patient preferences.^{26,34,35} However, it is likely that discussions about values and preferences for end-of-life care are not consistently articulated or documented. An Australian survey of 375 kidney clinicians found that 54% of respondents thought that advance care planning was performed “*ad hoc*” and 61% “*poorly*.”³⁶ Involving family members and next-of-kin in end-of-life planning discussions may not be widespread. An American qualitative study of 172 family members of patients on dialysis, found that 63% had discussed values and preferences at the end-of-life, 27% of patients had discussed dialysis cessation with their loved

one and only 45% had a concordant agreement about treatment goals.³⁷

Given that health professionals are central in decision making and are often expected to lead clinical discussions, and provide advocacy and psychosocial support,^{4,38} it is fundamental to understand the perspectives of clinicians who guide this care. This study aimed to explore kidney clinicians' understanding, experience, and perspectives of end-of-life care and to provide recommendations to improve care experiences.

METHODS

A prospective qualitative methodology with an interpretive phenomenological framework³⁹ was used to explore end-of-life care as reported by kidney clinicians. This study was part of a larger study which investigated the views of palliative care and kidney supportive care. The method used is presented according to the Consolidated Criteria for Reporting Qualitative Research (COREQ)⁴⁰ (Supplementary Material S1).

Participants were invited to participate via e-mail and were voluntary and purposefully sampled across 5 public hospital nephrology services in Victoria, Australia (3 metropolitan and 2 regional centers). Institutional ethics approval was obtained (LNR/16/SVHM/116). Participants were kidney nurses (hospital ward, dialysis, managers, educators, and nurse practitioners) and nephrologists (consultant physicians and advanced trainees) who spoke English. All clinicians participated in private meeting rooms in their hospitals, provided written informed consent, and none withdrew consent. There were no repeat interviews and no nonparticipants present.

Before commencement of the focus groups, the purpose and intent of the study was communicated by the researchers (JP, KD, and JW). The clinician researchers had a deep understanding of the topic's issues; and KD, a nephrologist, had a prior collegial relationship with many of the participants. An interview guide (Table 1) was followed, based on a literature review, including qualitative studies from oncology and palliative care, which aimed to understand clinicians' views of end-of-life and palliative care provision.⁴¹⁻⁴³ Additional demographic data were collected from the participants. Nine 1-hour semistructured focus groups and 1 in-person interview occurred between February 6 and May 30, 2017. The single interview was performed at a hospital with 1 nephrologist. Field notes were recorded by researchers (JP, KD, and JW) during and after each focus group. Recruitment was ceased when data saturation was reached. All discussions were digitally recorded and transcribed verbatim into a Microsoft Word document by the primary researcher (KD), and participants were nonidentifiable.

Table 1. Interview guide to elicit clinicians' experiences of end-of-life care, kidney supportive care and palliative care

Topics	Guiding questions
1. Patient Death	When thinking about a clinical experience, can you tell us about a time when a patient died? - What were the issues that arose? - What worked well / didn't work well? - Where did the patient die? - Was palliative care involved?
2. Patient Symptoms	Can you tell us about a renal patient who had significant symptoms? - What were the issues? - What were the challenges faced? - What worked well? - How did it affect the team you work in?
3. End-of-life care provision	Can you tell us about a time when you have looked after a patient facing end-of-life? - What was important for this patient and his/her family? - What were the issues that arose? - What were the characteristics of the care that worked well? - What do you think you do well? - What do you think we could improve?
4. Experiences of kidney supportive care	What is your experience of kidney supportive care? - How does it work in practice? - What does it involve? - What are the key concepts?
5. Components of Kidney Supportive Care	When thinking about kidney supportive care: - What are the important factors that need to be present? - What are the challenges faced in the current clinical context? - What would be some recommendations to improve the care we provide?
6. Experiences of palliative care	What is your experience with palliative care? - How does it work in practice? - What does it involve? - What are the key concepts?
7. Interactions between kidney supportive care and palliative care	How does kidney supportive care compare with specialist palliative care? - Differences - Similarities
8. Referral practices	When would you refer a patient to kidney supportive care or to palliative care?

The data were analyzed thematically using a phenomenological approach to ascribe meaning from lived experiences through the interpretation of social interactions.^{39,44} Ideas were coded by KD and developed with 2 independent researchers (KD and JP) reviewing the transcripts. Data were discussed and ideas grouped into categories, then into subthemes and themes using an iterative interpretative phenomenological analysis. A third reviewer, HG, assisted with clarity of themes and subthemes. The results were consistent and checked by participants when reported at the Kidney Scientific Conferences and departmental meetings.

RESULTS

Fifty-four clinicians participated in this study, including 33 nursing staff and 21 doctors (Table 2).

Overarching Theme

Challenges and Aspirations of Providing End-Of-Life Care

Clinicians emphasized the complexity and challenges when providing end-of-life care which centered around experiences of treatment decision making (Figure 1). Difficult experiences were understood as involving a series of contributing factors and circumstances which will be outlined in detail in the following themes and subthemes. The poor outcomes of these collective factors resulted in perceptions of compromised treatment decision making which contributed to experiences of late or rushed provision of end-of-life care, continuing dialysis for longer than appropriate, limited patient or caregiver preparation for dying, and moral distress where clinicians felt ethically compromised. The characteristics and circumstances of positive end-of-life care experiences included the following: patient leadership in decision making, consensus of treatment goals and plans, and a coordinated and collaborative approach across healthcare teams.

Theme 1. Challenges in End-Of-Life Care Planning and Decision Making

Clinicians reported recognizing an irreversible decline in patient health and multiple factors contributing to the challenges experienced when navigating discussions and decisions about end-of-life care with patients and caregivers.

Table 2. Demographic characteristics of participants

Characteristic	n (%)
Gender	
Female	36 (67%)
Male	18 (33%)
Occupation	
Consultant nephrologist	18 (33%)
Nephrology registrar	3 (5%)
Dialysis nurse	16 (30%)
Nurse practitioner	3 (5%)
Acute ward nurse	5 (9%)
Nurse unit manager	4 (7%)
Nurse coordinator/educator	5 (5%)
Location	
Metropolitan	44 (81%)
Regional	10 (19%)
Years of experience in Renal Care	
<5 yrs	8 (15%)
5–9 yrs	13 (24%)
10–19 yrs	17 (31%)
>20 yrs	16 (30%)

THEMES & SUBTHEMES	EXAMPLE QUOTATIONS
<p>Theme 1</p> <p>Challenges in end-of-life care planning and decision making</p>	<p>1.1 Mismatched expectations and engagement</p> <p><i>"(U)sually the ones (patients) who need it the most (conversations about end-of-life care) are the ones that will refuse to...."</i> Nurse S4</p>
	<p>1.2 Navigating competing wishes between patients, families and treating teams</p> <p><i>"She was a lady in an awful amount of pain ...and because of religious... considerations the family said no, we are not going to stop dialysis."</i> Nurse B1</p>
	<p>1.3 Balancing uncertainty and illness complexities</p> <p><i>"(Y)ou can dialyse if you want to live longer, then you need to know there isn't a great deal of evidence to suggest that. So you might, or you might not... there is no way of knowing."</i> Nephrologist G2</p>
	<p>1.4 Understanding differences in perceptions of quality of life</p> <p><i>"Quality of life, and acceptable quality of life is an individual and personal assessment and this may be different to a clinicians' assessment.. this can be confronting."</i> Nephrologist S2</p>
<p>Theme 2</p> <p>The impact of compromised end of life decision making on care experiences</p>	<p>2.1 Late or rushed decisions in the final phase of life</p> <p><i>"It (the patient's death) was very drawn out without a particular plan until the last 10 days..."</i> Nurse S5</p>
	<p>2.2 Limited patient and caregiver preparation for dying</p> <p><i>"We see them ... every 2 to 3 months in a clinic ... for only 5 to 10 minutes to explore those issues... which are clearly really important ... the spiritual and emotional issues...it's something we could improve."</i> Nephrologist R4</p>
	<p>2.3 Continuing dialysis as a default</p> <p><i>"We would see patients ... started on dialysis ...some of them will just deteriorate ... there is nothing in place (for them)"</i> Nurse R1</p>
	<p>2.4 Moral distress</p> <p><i>" (B)loody religion, bloody life, bloody culture, bloody everything ... There is no humanity in all these decisions and that is what upsets me all the time... She is a human being. She is suffering."</i> Nurse R3</p>
<p>Theme 3</p> <p>Aspirations for future end-of-life care</p>	<p>3.1 Patient control</p> <p><i>"She (the patient) wanted to do it (withdraw from dialysis)... rather than... hang on... It was sort of controlled almost, it was decided before she started dialysis"</i> Nurse G2</p>
	<p>3.2 Consensus in decision making</p> <p><i>He did that (continue dialysis) ... to keep his family happy, I actually remember the time that he said, 'can you please ring my wife because I can't do it any longer...'"</i> Nurse W1</p>
	<p>3.3 Care coordination and collaboration</p> <p><i>"Working as a collective group without having those pressures because you are sharing the load..."</i> Nurse B2</p>

Figure 1. Challenges and aspirations of end-of-life care.

Mismatched Expectations and Engagement

Clinicians described difficulties in decision making when patients were not willing to engage in end-of-life conversations. This limited engagement was closely associated with a perception of dialysis “as a sort of cure,” (Nurse S2) with “...unrealistic expectations that it will keep them on this plateau”

(Nurse B2). When patients were deteriorating, clinicians acknowledged the imperative of initiating conversations about dying; however, they described resistance when patients were not able to accept this. “(T)here is the whole denial (of death). You know it’s difficult to deal with... sometimes impossible really.” Nurse B9

Clinicians reported challenges when introducing patients to palliative care. These experiences were explained by a mismatch of dialysis treatments expectations between clinicians and patients. "(P)eople on dialysis seem to have this detachment that it is actually a life sustaining treatment and they don't see that they fit into the palliative care group" Nurse W2. Such resistance also stemmed from differing expectations of palliative care referral between clinicians and patients. "If you mention palliative care to our patients, they think they are going to be dying in the next week to a month... it would be really nice if ... it all wasn't so stigmatised" Nurse W2.

Some clinicians acknowledged their responsibility to provide realistic illness expectations and lead discussions about appropriately limiting treatment options, yet others described difficulty in doing this. "They (the hospital) had a wave of enthusiasm for it (advance care planning) ... after the first 2 patients I had the discussion... they said, 'yes, I want intensive care intubation, inotropes everything'... I gave up... I couldn't say to them, 'I am not going to provide those things for you.'" Nephrologist G1. Other clinicians described avoiding conversations about death when providing kidney disease education, which may have hindered the early establishment of realistic illness and treatment expectations. "We don't tell them that their life expectancy is as dreadful as it is, they have got no idea ... it's the elephant in the room, we don't speak to them about death..." Nurse S1.

Navigating Competing Wishes Between Patient, Families, and Treating Teams

Clinicians reported challenging provision of end-of-life care when preferences for treatments differed between patients, caregivers, and the kidney treating team. Even when a patient was dying, clinicians felt compromised in attempts to navigate treatment decisions when patients or family members insisted on continuing dialysis. Clinicians perceived that those motivations to continue dialysis were associated with a fear of death and being unable to shift unrealistic expectations that dialysis could provide extra time. "To delay (death) ... even for an extra 2 weeks... No matter how much ... I suppose we impress on them that it is quite tortuous, the fact is ... the fear of death trumps whatever intervention you have" Nephrologist R2. Cultural and religious factors added further complexity and difficulty for clinicians in progressing end-of-life treatment conversations and decision making. Clinicians reported experiences of family members viewing cessation from dialysis as the equivalent of suicide, which was not acceptable. "The family said 'no, we are

not going to stop dialysis. She is committing suicide and she will not go to heaven.'" Nurse B1

Balancing Uncertainties of Outcomes and Illness Complexities Before the Final Phase of Life

The inherent uncertainties of illness outcomes before a patient was imminently dying contributed to challenges perceived by clinicians. It was difficult to determine the "optimal time" to introduce discussions about cessation of treatments, particularly if the illness course was punctuated by numerous acute exacerbations. One nurse described initiating conversations about dying with a patient's family who questioned the doctor's prediction that a patient with ESKD might die; this admission compared with previous ones. "You can't just expect someone to come in and ... say 'oh he is going to die this time,' 'oh how come?' ... 'Because last month he was here and you didn't say this'" Nurse R3.

Clinicians noted that many kidney patients also had multiple illnesses, which added to complexities in treatment planning and decision making in attempts to balance both acute and chronic medical issues. In addition, there were frequently multiple specialists involved in the patients' care, thereby adding further variables to consider for treatment decisions. "Some of these patients have really, really complex other medical issues going on... the patients are left with 2 different specialities who ... are struggling to make a joint decision how to best treat them..." Nephrologist R7

Understanding Differences in Perceptions of Quality of Life

Clinicians described challenges in understanding the meaning of quality of life for their patients, including the individual influences of illness perceptions, cultural, social, and spiritual factors. Some nephrologists reported feeling compromised when patients' views of quality of life differed markedly from their own. The sense of discomfort increased when those differences were more pronounced, such as younger patients who wanted cease life sustaining treatments like dialysis. "It (cessation of dialysis) brings up their own mortality and I think you find that with a lot of nephrologists ... particularly (for) younger patients... Why are they saying a 30-year-old can't have that option?" Nurse R6.

Theme 2. The Impact of Compromised Decision Making on End-Of-Life Care Experiences

The widespread challenges reported when navigating the provision of end-of-life care for kidney patients were often associated with perceptions of insufficient processes of shared decision making. Clinicians reported negative implications for patients, caregivers, and themselves as a result of insufficient end-of-life treatment planning and decision making.

Late or Rushed Decisions in the Final Phase of Life

Many clinicians described decisions about end-of-life care being made "...too late" Nurse W1. When clinicians recognized that patient deterioration was inevitable, there was a delay in discussions about dying until the patient was seriously unwell. "We were ... waiting for him to become really septic which was going to affect his hemodialysis. ...We should have thought about how that would play out and at least broach the subject with the patient and the family...." Nurse S5. Clinicians worried that if decisions were made late in the illness course, they risked losing the opportunity to understand the patient's preferences. "(I)t needs a bit more in depth conversation before they (the patients) even start dialysis so they don't wait ... to the point where they can't make that decision (dialysis cessation)" Nurse W2.

When end-of-life care planning was not being undertaken preemptively or routinely, some clinicians described experiences of starting dialysis acutely for a medical crisis. That was followed by a period of stability, then clinicians waited for another sentinel event to prompt discussions about dialysis cessation. "There are the patients that ... crash landed in the intensive care unit and they are clearly not suitable for long term dialysis and it's hard to take them off ... then you wait for another event to come along" Nephrologist B6.

Limited Patient and Caregiver Preparation for Dying

The challenges and avoidance in engaging to plan end-of-life care risked inadequate preparation for patients who were rapidly deteriorating. Clinicians described experiences of late decisions to withdraw dialysis with limited opportunities for patients and families to experience a comfortable and peaceful death. "(H)e had been on dialysis for 14 years ... it was just inevitable that he was going down that trajectory quite quickly ... in the end ... he was so delirious, and he had an ischemic leg... it was an awful way to go" Nurse S4.

There were perceptions of families being ill-prepared for their loved one to die. An expectation that dialysis would result in a clinical improvement, even in settings where patients were at high risk of dying was considered difficult to correct. Ongoing attempts to continue dialysis occurred, at times, at the expense of preparations for dying. Therefore, no decisions were made about end-of-life care before death occurred if there was a sudden deterioration. One dialysis nurse described such an experience; "...she arrested (on dialysis)... it was the expectation of the family that dialysis was going to make her better." Nurse B1

Continuing Dialysis as a Default

Some clinicians described the challenge in changing treatment approaches even when it had become

apparent that the patient's deterioration would continue. "They (the patients with ESKD) have been so unwell for so long that they (the nephrologists) should introduce something in the mix rather than us (dialysis nurses) putting a patch on them... that is how it feels like they are full of band aids ... just to keep them ... going." Nurse R1. Clinicians described defaulting to continue dialysis even when patients became increasingly unwell and questioned the increasing risks of doing this. "(T)hey (the patients) don't say 'I'm too sick ... I want to withdraw treatment... One lady had cardiac failure and ... her blood pressure was like 60 ...(dialysis) was very inappropriate. And then ... we started treatment (dialysis) and then ran her blood straight back and took her off...and just went...'what are we doing?'" Nurse W2

Moral Distress

Clinicians reported moral distress when recalling experiences of providing end-of-life care that threatened or compromised their ethical values or duties. At times, clinicians expressed powerlessness and despair in situations where they were unable to facilitate better end-of-life care such as symptom management for a patient. "They got palliative care involved for him but I think it was done too late... the whole day he was absolutely screaming and that stuck with me" Nurse N9. Moral distress was reported when death was imminent and inevitable, however life supporting treatments were continued instead of preparation for dying. In these circumstances, clinicians described feeling distressed because of increasing concerns that continuing dialysis could increase the clinical risk of sudden death or prolongation of dying. "It is very stressful when you are trying to keep someone alive on dialysis when you know that they are not going to be around much longer. It's very stressful for all of us." Nurse R2

Theme 3. Priorities to Improve End-Of-Life Care Experiences

Patient Control

Clinicians aspired for more positive experiences of end-of-life care. Positive experiences occurred when patients were supported and had an active role in or led end-of-life care discussions. This was evident with regard to descriptions of patients withdrawing from dialysis who were sufficiently informed to take control of decisions regarding how this would eventuate. Clinicians explained that the decision was easier when patients had gained understanding and perspective from engagement in discussions with health care providers and other key stakeholders such as patients. "If they ... feel that they really need to stop (dialysis) then

usually, they have a pretty good grip of the issues... it's not that hard... they have made the decision." Nephrologist B1

Clinicians described confidence and satisfaction in their role in preserving patient control in decision making, even in situations in which patients had lost capacity through preexisting advance care directives. "(H)e had a really clear advance care plan, you know, 'in my dialysis journey if I reach this stage that is when I would like to stop.' So, we were able to have a family meeting, it was all very calm and controlled ... Helpful in a positive way" Nurse B8.

Consensus in Decision Making

Clinicians described positive end-of-life care experiences when there was agreement and support from family members and caregivers for patients to be cared for and to die, according to their (the patient's) wishes. Clinicians reported the importance of undertaking end-of-life care planning with both patients and families to preserve patient autonomy and harmony between with grieving family who may have varying degrees of acceptance. "(B)efore they (the patients) get to the stage that they cannot make their own mind or express themselves, then this conversation should have taken place in advance with the family. So that the family will not be contradicting to what the team is suggesting" Nurse R1.

Care Coordination and Collaboration

Clinicians prioritized coordination and collaboration between health care services as key components of ideal end-of-life care. For patients, it provided much needed continuity of care given the number healthcare providers involved. "(T)he whole team was involved, it was brilliant." Nurse B2. For some clinicians, positive experiences of kidney supportive care assisting integration between palliative care and kidney teams helped provide continuity. "We are quite well set up here for that (end-of-life care)... If they are going home, then she (Kidney Supportive Care nurse) organizes for them to come to their clinic" Nephrologist R1.

DISCUSSION

These findings illustrate the depth and breadth of kidney clinicians' experiences when navigating end-of-life care. It provides powerful insights into why end-of-life care experiences are challenging for clinicians and helps to explain the factors and circumstances that contribute to concordance and discordance between consumers and clinicians in terms of what constitutes quality end-of-life care.⁴⁵ This process of understanding patients' wishes, values, and preferences, and reconciling those with clinicians' views of their best interests was

emphasized in this study; and, not infrequently, there was a mismatch between those positions reported. Several factors widened this gap, such as other medical opinions, family members' influence, illness, treatment expectations, and existential or spiritual concerns such as the fear of death. All these factors prevented clinicians and patients from contemplating dying and impeded the transition of treatment goals toward end-of-life care. These findings also highlighted the ongoing impaired end-of-life care experiences associated with insufficient confidence, training, and resources for kidney clinicians.^{18,46-48} Future qualitative studies that investigate strategies and experiences of clinicians to help overcome these barriers are needed.

Such confounders limited clinicians in their attempts to engage and initiate early conversations about advance care planning and end-of-life care and could perpetuate a delay in end-of-life care activities until a crisis occurred. This scenario resulted in heightened challenges to provide optimal end-of-life care and promoted late provision of end-of-life care. Such findings elucidate recent results suggesting insufficient time for palliative care collaboration and coordination⁴⁹ and infrequent and late hospice referral among patients on maintenance hemodialysis.⁵⁰

The most difficult experiences of clinicians occurred when the provision of care appeared to lose sight of the patients themselves, their wishes, or best interests. In these instances, it was likely that some clinicians experienced moral distress, where their ethical values were perceived to be compromised and clinicians felt powerless to change the circumstances because of hierarchical barriers, resource limitations, or impaired processes of communication.⁵¹ In recent times, moral distress in health care providers is associated with symptoms of depression, anxiety, posttraumatic stress disorder and burnout,⁵² and a higher "intention to leave" the profession.⁵³ A recent American survey of 142 nephrology fellows showed that 81% of respondents experienced moral distress related to starting dialysis in futile circumstances and 75% experienced moral distress when continuing dialysis on hopelessly ill patients.⁵⁴ Therefore, more education, training, and support is urgently needed for clinicians to prevent moral distress resulting from compromised end-of-life care experiences.

From these results, several priorities are defined by clinicians to improve end-of-life care experiences and should contribute to work in developing end-of-life care standards for patients with kidney disease. First, conversations about dying need to be early, multiple, and across the illness course. They should not follow a

prescriptive, formal, inflexible approach because patient-clinician relationships differ, as does readiness to engage, talk, and listen. Recent publications have shown benefit of dedicated approaches of shared decision making to support renal clinicians and patients, and provide a practical and holistic approach to inform treatment choices.^{55,56} End-of-life conversations and planning must be embedded as an early, ongoing, and standard practice with continuity and adaptability according to patient circumstances, analogous to any other medical intervention.

To reframe and equate illness expectations and prognosis between kidney clinicians and patients requires dialogue and feedback between all parties. At present, clinicians in this study and elsewhere^{57,58} describe significant variability and uncertainty regarding who, how much, and when to provide information about dying to patients and their caregivers. Complexity, fragmentation of communication among health care providers, and ambiguity of responsibility for advance care planning has resulted in variable understanding and development in clinical practice.^{57,58} This study revealed mixed views, depending on the skill, experience, and clinician confidence. Dedicated training in communication skills such as estimating and conveying prognosis, elicitation of patient preferences regarding goals of treatment, and overcoming conflict or uncertainty may better prepare clinicians and patients for end-of-life decision making.⁵⁹ In addition, a pilot study assessing the feasibility of a shared decision making tool for planning end-of-life care is currently underway and aims to facilitate a more systematic approach to advance care planning and end-of-life care within kidney care services.⁶⁰ Specific supports are also required for family and caregivers who experience overwhelming grief or have conflicting goals at the time they are required to make end-of-life decisions on behalf of their loved one.⁸ System-wide changes in resources and education for clinicians are essential to support and give legitimacy to all health care professionals undertaking these discussions as part of a team approach, and clearer pathways of communication and governance are required.

These results could be considered as key aspects for future work to aid comprehensive and equitable end-of-life care for kidney patients. However, there are limitations. Data were collected between 2017 to 2018 and, therefore results may not apply to current times; however, these results display the similar issues faced by clinicians in recent publications such as the challenges in systematic advance care planning^{3,57,58} and barriers to palliative care integration

in terms of models of care, training, and clinical skills.^{61,62} The generalizability of these findings were confirmed across multiple health contexts in Australia and New Zealand in a follow-up online survey of 382 kidney clinicians⁶³; however, it is unknown whether these results reflect a global context. Clinicians participating in this study were volunteers and engaged in the topics discussed, therefore results may not have represented all views. This study did not include patients, caregivers, or allied-health clinicians which would be critical in future studies to improve end-of-life care experiences.

These results are significant because they describe the details of the multiple and complex issues faced by clinicians when navigating end-of-life care with their patients, explain why and how clinicians can experience compromised end-of-life care, and highlight the necessity of healthcare system-wide changes required in kidney care provision. However, the starting points are simple and fixed. First, the commitment of clinicians in caring for kidney patients at end-of-life is considered unwavering. Second, patients with kidney disease often die early. That leaves kidney clinicians with the necessity of incorporating the attributes of end-of-life care throughout the patient's experience of illness.

DISCLOSURE

The authors declared no competing interests.

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The authors declare that they have no other relevant financial interests

SUPPLEMENTARY MATERIAL

[Supplementary File \(PDF\)](#)

S1. Summary of Qualitative Research Reported (COREQ).

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