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An Exploratory Qualitative Study of Patient and Caregiver Perspectives of Ambulatory Kidney Palliative Care

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Abstract

Objectives: The ideal clinical model to deliver palliative care to patients with advanced kidney disease is currently unknown. Internationally, ambulatory kidney palliative care clinics have emerged with positive outcomes, yet there is limited data from the United States (US). In this exploratory study we report perceptions of a US-based ambulatory kidney palliative care clinic from the perspective of patient and caregiver attendees. The objective of this study was to inform further improvement of our clinical program.

Methods: Semi-structured interviews were conducted to elicit the patient and caregiver experience. Eleven interviews (8 patients with chronic kidney disease stage IV or V and 3 caregivers) were analyzed using qualitative description design.

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Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Results: We identified 2 themes: “Communication addressing the emotional and physical aspects of disease” and “Filling gaps in care”; Subthemes include perceived value in symptom management, assistance with coping with disease, engagement in advance care planning, program satisfaction and patient activation.

Significance of Results: Qualitative analysis showed that attendees of an ambulatory kidney palliative care clinic found the clinic enhanced the management of their kidney disease and provided services that filled current gaps in their care. Shared experiences highlight the significant challenges of life with kidney disease and the possible benefits of palliative care for this population. Further study to determine the optimal model of care for kidney palliative care is needed. Inclusion of the patient and caregiver perspective will be essential in this development.

Keywords

ambulatory; kidney disease; palliative care; qualitative

Introduction

Individuals with end stage renal disease (ESRD) and advanced chronic kidney disease (CKD) often experience a significant symptom burden, decreased quality of life and have high healthcare utilization, particularly at the end-of-life.¹⁻⁵ Palliative care addresses these challenges through assistance with complex medical decision making, provision of expert symptom control, and facilitation of advance care planning for patients with serious illness.⁶ Despite well-documented needs, there is limited integration of palliative care in nephrology practice in the United States (US).^{1,7} Nephrology professional societies have responded with guidelines calling for the incorporation of palliative care into standard nephrology care, yet the ideal clinical model of delivery is unknown.⁸⁻¹⁰ Internationally, ambulatory kidney palliative care clinics report positive outcomes, however this approach is lacking in the US.¹¹ Understanding the patient and caregiver experience with palliative care in the US can aid in the design and implementation of patient-centered care practices, which may result in improved patient health and quality of life outcomes.¹²⁻¹⁴

Prior qualitative research has identified the profound physical and emotional struggles of life with advanced CKD and the numerous barriers to engagement in advance care planning, reinforcing the presence of unmet palliative care needs in this population.¹⁵⁻¹⁸ However, to the best of our knowledge, there has been no prior work exploring patient and caregiver experiences receiving ambulatory palliative care specific to kidney disease. We previously described patient demographics and clinical activities of an integrated ambulatory nephrology and palliative care clinical program at our institution called The Kidney CARES (Comprehensive Advanced Renal disease and ESRD Support) Program.¹⁹ We now present findings from an exploratory qualitative study of patient and caregiver perceptions of the clinic. The objectives of this work are to identify the perceived value and impact of the clinic, the palliative care needs of a patient population that would attend the clinic and facilitators or barriers to care delivery.

Methods

Study Design

We used a qualitative description design²⁰ to explore patient and caregiver experiences to characterize acceptability, value, and access to the clinic. Results are reported using published standards for reporting qualitative research.²¹

Study Setting: Kidney CARES is an ambulatory palliative care clinic embedded in New York University (NYU) Langone Health's Nephrology Faculty Group Practice. The clinic targets patients with advanced CKD with a high symptom burden, those approaching dialysis decision making, or those who have decided or who are contemplating not starting dialysis or dialysis withdrawal. One-hundred and twenty patients have been seen since it's opening in May of 2016. The clinic is staffed by a physician boarded in both palliative care and nephrology (J.S.S) and through 2017 included a clinical psychologist with training in palliative care.

Participant Selection: A consecutive sampling of patients and caregivers was done with the following eligibility criteria: 1) seen in the clinic at least once; 2) English speakers; 3) adults age 18, and 4) able to provide written consent. Exclusion criteria included any mental, physical, or behavioral conditions that precluded participation in interviews. Eligible individuals were invited to participate after a clinic visit between December, 2016 and February, 2019. Sampling occurred with patients and caregivers until thematic saturation was reached regarding experiences with the clinic. Although small in number, caregivers were included in our sampling population as their experience is seen as essential to program development.

Data Collection: Consented participants completed an audio-recorded semi-structured interview lasting 45-60 minutes. Consent was obtained by non-clinical study staff. Three trained interviewers conducted interviews either in-person or over the phone, at the preference of the participant. The interview guide was developed by RW, a qualitative researcher with a background in palliative care nursing, and JSS. The guide (Table 1) used open-ended questions to explore the participant's 1) description of the value of the care delivered; 2) experience accessing the clinic and its services; and 3) the overall impact of clinical visits. Participants received a \$25 gift card upon interview completion. Data collection continued until data saturation was reached.

This study was approved by the NYU Institutional Review Board.

Data Analysis

We applied a thematic approach to data analysis.^{22,23} Interviews were transcribed using an on-line transcription service. Three authors with training in qualitative research (JSS, SC, AAB) performed data analysis using the supportive qualitative data analysis software Atlas.ti., version 8. Three interviews were first coded independently. The authors then met to verify the alignment of codes and their meanings. For any discrepancies, a consensus was achieved through group discussion and review of the relevant transcribed texts. The analysis

team then used open coding to identify key words and phrases across the transcripts, providing insight into the broad range of patient or caregiver experiences.²⁴ In addition to separate interview coding, we used team member checking to ensure consistency across the coding process. Finally, codes were collaboratively reviewed and developed into themes. (Table 2)

Results

Participant Demographics

Twenty-one eligible participants consented. Twelve (57%) completed interviews: 9 patients and 3 caregivers (Table 3). One interview was discarded as it was clear in retrospect the participant did not understand the questions asked. Reasons for non-participation were hospitalizations, scheduling difficulties, or an inability to contact the participant after multiple attempts. Interviewed patients were seen in the clinic a range of 1 to 4 or more visits prior to their interview. The sample population was representative of the general clinic population¹⁹ as most were of advanced age (median age: 67; range: 46-97) and male gender, with approximately 90% having CKD stage V. All individuals on renal replacement therapy (n = 5) were receiving hemodialysis (HD). All the patients interviewed (n = 8) were male, while the all caregivers interviewed were female (n = 3, 2 daughters and 1 spouse).

We identified 2 themes: 1) communication addressing the emotional and physical aspects of disease and 2) filling gaps in care (Table 2).

Theme 1: Communication Addressing the Emotional and Physical Aspects of Disease

Participants reported that empathic communication from clinic providers was effective in leading to a better understanding of the life changes associated with advanced kidney disease. Participants described that during clinic visits, disease education was communicated in a manner that concurrently addressed the psychological impact of kidney disease. For example, one participant shared:

“They are concerned about your quality of life, your home living. They even asked about your relationship with your relatives. Something my clinic never asked me about and I’ve been on dialysis since 2002.” [Participant 3]

Participants reported that increased knowledge of their disease allowed them to set achievable goals, such as vacationing while on dialysis. Such goal-setting led to improved emotional health with one participant stating: “It was nice to set up goals, setting up things that make you feel worth living.” [Participant 10]

Disease education also included delivery of what is known as “bad news” regarding the serious nature of advanced kidney disease, sometimes including discussion of mortality.

“It [the clinic] made me aware of how serious this disease is. It’s a life-threatening situation ... Whereas before, I didn’t think it was that serious.” [Participant 11]

This statement contrasts with the described helplessness and feeling unprepared for their diagnosis prior to clinic visits. One participant shared “I wish that I knew some of these things beforehand so I could prepare.” [Participant 6]

This effective communication occurred despite reports of confusion about the role of palliative care in kidney disease prior to one's first clinic visit, often a result of lack of a clear explanation of the referral. For example, one participant said the appointment was described as a visit with only a nephrologist and not a palliative care provider; another revealed that a referring provider ended their therapeutic relationship upon referral to Kidney CARES. Participants also expressed sentiments such as, "people thought I was giving up and they thought that I was giving up on life." [Participant 10] In one interview, the answer "no" was given when asked about palliative care familiarity. Another expressed good understanding of the specialty, describing the clinic as a place where:

"You can sit down and discuss your feelings and talk about things about life and stuff, which is good." [Participant 2]

Subtheme1: Increased ability to cope with disease.—Visits to the clinic strengthened participants' ability to cope with their illness. Participants shared that they learned to view their situation "in balance" and that they were now "optimistic."

One participant described the clinic as:

"A department where patients can express their emotions, feelings, what they're going through, pros and cons of what ails them." [Participant 8]

Participants welcomed this psychosocial support, as they described their emotional distress as a barrier to managing practical elements of life. A participant shared:

"As a patient, you're so overwhelmed with processing what's actually happening to you, putting everything else into perspective and getting things accomplished at the same time ... It's kind of hard." [Participant 6]

During visits, patients and caregivers were not only able to discuss their needs, but also were able to identify coping mechanisms including feelings of community and establishing a sense of control. Restoring control was a process that was highlighted as even more critical for older adults. One participant shared about her elderly mother,

"... [The clinic] did a really good job of giving her [the patient] the power and the control and that's so important." [Participant 7]

Subtheme 2: Patient and caregiver satisfaction and activation.—Participants expressed gratitude for the clinic, describing it as "awesome" and "beyond wonderful." One caregiver said, "I just hope this clinic stays on and keeps going and going." [Participant 7]. These feelings of gratitude spurred clinic attendees to share information about the clinic with others at their dialysis sessions. One participant described "see[ing] others who might benefit from the same program" [Participant 9].

In particular, gratefulness was expressed for the responsive nature of the clinic, especially in the context of multiple subspecialists and providers. One participant reflected on how this translated into a more pro-active approach to their medical care, stating, "I felt comfortable to vent ... on any concerns that I might've had" [Participant 2]. Another stated, "I felt

reassured because I thought the 2 doctors participating ... were human and informal, and that I could ask questions” [Participant 4].

Overall, participants reported an increase in confidence to reach out to healthcare providers with questions or concerns.

Theme 2: Filling Gaps in Care

Participants identified gaps in their care that were addressed at the clinic. Two gaps identified were: 1) symptom management and 2) engagement in advance care planning.

Subtheme1: Symptom management.—The search for symptom relief was a large factor influencing the decision to initially attend the clinic. One participant described, “I needed relief from that [pain] in order to exhale a little bit.” [Participant 9] The clinic was often successful at pain management, described by one participant:

“I don’t suffer every day like I normally suffer ... the ritual and the format that Kidney CARES got me on ... turned my life around.” [Participant 3]

Although the clinic tried to incorporate non-pharmacological strategies through referrals to interdisciplinary providers such as integrative health, participants expressed mixed reaction to these therapies. One participant stated, “its kind of overwhelming sometimes so I choose not to even try.” [Participant 6]. Another said, “I didn’t feel it did anything for me and it was not necessary.” [Participant 4]. In contrast, another participant stated, “the DVD that they sent me, I watch it every other day and it tells you how to ... block mental pain out of your mind.” [Participant 9]. Overall, the services offered were appreciated by participants, even if not accessed.

Subtheme 2: Engagement in advance care planning.—Many participants engaged in advance care planning during their visits, noting that this was process was novel for them.

“They [dialysis center] don’t even ask you questions if something was to happen to you while you’re on the machine, who should they contact, who is your proxy?” [Participant 3]

Engagement in this process was appreciated, described as “easing the burden” [Participant 1]. Participants report learning more information about their disease, including concerning the process of dialysis withdrawal.

“[You] can’t survive without it but if [you] stop, doesn’t mean suicide.” [Participant 9]

One participant revealed that having thoughts about prognosis and mortality were not new saying.

“I had a general thought about how long I might live or whether there’s something predictable about it.” [Participant 8]

Overall, participants shared positive experiences regarding the clinic’s inclusion of advance care planning discussions.

Discussion

The severe emotional and physical impact of kidney disease is well described, however, little research has explored the perspective of individuals receiving targeted management of this distress.²⁵⁻²⁷ We found that patients, or their caregivers, who attended a dedicated ambulatory kidney palliative care clinic viewed their visits favorably and perceived the clinic's services as compassionate and care enhancing. Clinic visit activities including disease education, emotional support, assistance with coping, symptom management, and engagement in advance care planning, were positively received and described as filling gaps in care. Additionally, patients of the clinic felt empowered to be more engaged in their care.

Our study participants describe a clinical experience of ambulatory kidney palliative care relatively unknown in the U.S. These data are of value to our program's expansion and to other nephrologists seeking to develop more patient-centered models of care. Currently, efforts to integrate palliative care into routine nephrology care in the US are promising, but reported outcomes are preliminary and observational.^{7,19} The incorporation of the patient or caregiver voice into the development of these models can be valuable in identifying the needs of this population when designing interventions, increasing the likelihood of model success and clinical impact. Our program design was informed by prior research in which CKD patients identified symptom management, quality of life, coping with disease, and dialysis preparation as outcomes of high priority.^{28,29} Participants in our study described receiving care that addressed these needs at Kidney CARES. These findings suggest that an ambulatory kidney palliative care clinic can enhance patient care through provision of services found to be important and needed by patients.

Our work supports program development as participants described facilitators and barriers to care delivery. Participants enjoyed coming to the clinic and found it to be essential, enough to serve as ambassadors for the clinic in their dialysis centers. Participants particularly found comfort in the communication styles of the providers and welcomed the support given to cope with their disease. In CKD, a disease with multiple stressors, coping mechanism are associated with quality of life,³⁰ therefore improving one's ability to cope with disease can have significant impact. In Urquart-Secord et al's study which aimed to identify outcomes of importance to hemodialysis patients and their caregivers, capacity to cope was identified as a key subtheme in their qualitative analysis.²⁵ In this study, patients who described "mental strength" to cope with the physical or emotional burdens of their kidney disease ranked these intrusive aspects of disease as less important outcomes, suggesting the positive impact increased ability to cope can have on a patient's experience of symptoms of their disease. Further development of our program's ability to facilitate coping with disease has the potential to provide similar significant benefit for patients. Not unexpectedly, we found that participants also described a misperception of palliative care as solely end-of-life care before attending the program. This reflects limited palliative care awareness and understanding of its relevance to nephrology practice.³¹⁻³⁴ In future work, we plan to focus on educational efforts concerning palliative care for both patients and providers to overcome this barrier.

Interestingly, patients described that attending the clinic led to an intention to become more activated and engaged in their care. Patient activation is defined as an individual's

willingness to take independent actions to manage their health.³⁵ It is associated with improved health care outcomes, increased treatment adherence, and patient experiences.³⁵ In kidney disease, there is limited work on the impact of patient activation, but its importance in clinical care has been recognized.³⁶ It has recently been included as a quality metric in two payment options of the Center for Medicare and Medicaid Services' Kidney Care Choices Model. The identification of this theme in our study is hypothesis-generating, suggesting that exposure to palliative care may impact this metric. In future studies, we plan to incorporate formal testing of the impact of the clinic on patient activation and feelings of empowerment.

Engagement in advance care planning was a clinical activity that particularly was appreciated. Advance care planning is the process of eliciting patients' values and goals in the context of medical decision-making and care for serious illness and at end-of-life.³⁷ Despite its significance, kidney disease patients describe a lack of engagement in advance care planning with their providers, while simultaneously citing that they would welcome this process.³³ In our study, patients described this process as informative, specifically concerning dialysis withdrawal, and positive, described as "easing a burden." Davison and Simpson in a qualitative study of 19 ESRD patients identified this process as one that enhances hope and empowerment through provision of information and creation of realistic goals that are consistent with patient values.³⁸ In that same study, participants identified reliance on health care providers to initiate this conversation as a barrier to engagement in advance care planning. Our findings suggest that our clinic design was able to remove some of these barriers. We have previously described that advance care planning occurred in 87% of clinic visits,¹⁹ demonstrating the opportunity this model gives to increase engagement in advance care planning.

This study's limitations include low caregiver participation, exclusion of non-English speakers, gender imbalance of participants, and low rate of study completion. However, the sample size enabled a comprehensive exploration of participant experience, although our findings may not be more generalizable, particularly due to the lack of female patient voices. Given the novelty of the clinical program, despite the low participation by caregivers, their perspective is essential as they provide vital care to those with kidney disease, and therefore were included analysis. In future work, we hope to study the experience of ambulatory kidney palliative care in a larger sample.

In this work, we describe for the first time, patient and caregiver perceptions of an ambulatory integrated kidney palliative care clinical model in the US. As a result of our findings, we will continue to focus on psychological support for patients, to expand engagement in advance care planning and to improve integration of non-pharmacological services into the clinic. We will use these data to refine our clinic and to inform future research.

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Table 1.**Semi-Structured Interview Guide.**

Question 1: What does palliative care mean to you?

- Probe: Had you heard of palliative care before you went to the clinic?
- What did you think about the explanation of palliative care during your visit?
 - i. Did this differ from what you expected?
- Probe: Did your opinion of palliative care change after the visit?
- Do you think it makes sense to see palliative care providers if you have kidney disease?

Question 2: What did you know about the clinic when you first came?

- Probe: How did it feel to be referred to the palliative care clinic?
- Probe: Tell me about the services you thought you would be offered by the Kidney CARES clinic.
- Probe: Tell me about any concerns you had about your referral to the clinic.

Question 3: Before you came to the clinic, tell me about your experience with kidney disease?

Question 4: Tell me about your experience(s) with the Kidney CARES Program:

- Probe: Did you feel comfortable during your visit to the Kidney CARES clinic?
- Probe: Was there anything that surprised you during your visit to the Kidney CARES clinic?
- Probe: Did you learn anything new at your visit?
- Probe: What did you need help with when you first came to the clinic?
- Prompt: How well do you think that the clinic is meeting these needs?
- Probe: Was there anything you felt was missing from your encounter in the Kidney CARES clinic?
- Probe: Are there any difficulties to accessing the Kidney CARES clinic services?

Question 5: How did your visit impact your understanding of your disease?

- Probe: How did the visit change your understanding of your disease? If yes, in what ways?
- Probe: Did your visit impact your thoughts about the future?
- Probe: Did your experience with this team change how you interact with other doctors?
- Did you engage in advance care planning during your visit? If so, how did that feel for you?
- If you are a caregiver, how did the clinic help you specifically?
- Any change with your interactions with community resources?

Question 6: Is there anything else you would like to tell us about your experience with the Kidney CARES clinic?

Table 2.

Themes and Subthemes

Theme	Subthemes	Participant examples
Communication Addressing the Emotional and Physical Aspects of Disease	• Increased ability to cope With disease	• "I have a different outlook now, more positive" (Participant 2)
	• Patient and Caregiver Satisfaction and Activation	• "I don't have to go home depressed anymore" (Participant 9)
		• "I think its [the clinic] excellent because it makes you aware of the kind of problems that you have, and possibly what you're going to run into" (Participant 1)
Filling Gaps in Care	• Symptom Management	• "I felt reassured ... I could ask questions" (Participant 4)
		• "I appreciate [the clinic] very much because I still enjoy living" (Participant 5)
Engagement in Advance Care Planning	• Symptom Management	• "I feel trust, I feel comfortable ... I feel like I literally can call the doctor and say this is happening ... and they call me back" (Participant 7)
	• Engagement in Advance Care Planning	• "Programs like this keeps you going, keeps you up" (Participant 10)
		• "His symptoms are managed" (Participant 3)
		• "So far I am out of the discomfort that I was going through" (Participant 6)
		• "I'm in pain every day without this program" (Participant 9)
	• "More guidance, more guidance ... trying to figure out a plan" (Participant 3)	
	• "Questions about death and dying are not ... they're not easy ones for me" (Participant 4)	
	• "It's like [the doctor] eased that burden up off me ... You don't have to let your family make the decision for you" (Participant 10)	
	• "The issues [are] familiar with me ... because my wife was sick with cancer and I knew that I had to take care of things like that" (Participant 11)	

Table 3.

Patient and Caregiver Demographics (n = 11).*

Patient demographics	Value
Age: n (%)	
< 65	5 (45.4%)
65-75	3 (27.3%)
75-80	0
>80	3 (27.3%)
Sex: n (%)	
Male	8 (72.7%)
Female	3 (27.3%)
Race/Ethnicity: n (%)	
African American	3 (27.3%)
Hispanic	4 (36.4%)
White	4 (36.4%)
Marital Status: n (%)	
Married	3 (27.3%)
Divorced	2 (18.2%)
Single	3 (27.3%)
Widowed	3 (27.3%)
Reason for Referral: n (%)	
Dialysis Decision Making	1 (9.1%)
Symptom Management	10 (90.9%)
Advance Care Planning	11 (100.0%)
CKD Stage: n (%)	
Stage IV	1 (9.1%)
Stage V	10 (90.9%)
Dialysis Status: n (%)	
On Dialysis	5 (45.5%)
Not on Dialysis	6 (54.5%)
Etiology of Kidney Disease: n (%)	
Diabetes	5 (45.5%)
Hypertension	7 (63.6%)
Polycystic Kidney Disease	1 (9.1%)
Autoimmune	1 (9.1%)
Infectious	1 (9.1%)
Other	3 (27.3%)
Karnofsky Performance Score (range 0-100):	
Mean \pm SD	60.0 \pm 10.0
Charlson Comorbidity Index:	
Mean \pm SD	7.5 \pm 3.1
Total Symptom Scores	

Patient demographics	Value
Median (range)	14.5 (1-46)
Mean (SD)	16.2 (\pm 14)
Total Number of Symptoms per Patient	
Mean (SD)	7.2 (\pm 4.5)
Code Status: n (%)	
Full Code	9 (81.8%)
DNR	2 (18.2%)
Caregiver demographics	
Value	
Age: Range	53-60
Gender	
Female	3 (100%)
Level of Education	
High School	1 (33%)
College Degree	1 (33%)
Graduate Degree	1 (33%)
Relation to the Patient	
Spouse	1 (33%)
Child	2 (67%)

Legend: CKD: Chronic Kidney Disease; ESRD: End Stage Renal Disease; SD: Standard Deviation; DNR: Do Not Resuscitate.

* Patient Characteristics includes patients of caregivers interviewed.

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