

Facilitating Advance Care Planning for Patients with End-Stage Renal Disease: The Patient Perspective

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Comprehensive care of patients with ESRD requires expertise in advance care planning (ACP), including attention to ethical, psychosocial, and spiritual issues related to starting, continuing, withholding, and stopping dialysis. However, there are no standards of care regarding when to initiate or how to facilitate ACP. The purpose of this study was to determine the perspectives of patients with ESRD of the salient elements of ACP discussions. An ethnographic, qualitative, in-depth interview study was conducted of outpatients of a university-affiliated nephrology program. Twenty-four patients with ESRD were purposively selected from the renal insufficiency, hemodialysis, and peritoneal dialysis clinics. Establishing patient "buy-in" by identifying perceived benefits of ACP along with acknowledging patients' sense of personal empowerment were critical both for the effective framing of facilitated ACP and for determining patients' ability to participate in facilitated ACP. Patients required more information and earlier initiation of ACP discussions. Information needed to focus more on the individual and how his or her illness and interventions would affect his or her life and relationships and what he or she values most. Empathetic listening also was viewed as an integral component of facilitated ACP. Physicians clearly were seen as having the responsibility for initiating and guiding ACP. The role of patients and family within ACP is complex and varies significantly between patients. For most, family was an integral component of ACP, and many relied extensively on family to make end-of-life decisions. These findings identify a precarious tension between patients' preferences in terms of facilitated ACP and current clinical practice.

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Despite continuing technological improvements, >79,812 chronic dialysis patients die each year in the United States, with an annual unadjusted mortality rate of 20 to 25% (1). Approximately 15 to 25% of these deaths result from a decision to discontinue dialysis, representing the second leading cause of death after cardiovascular disease (1). Comprehensive care of patients with ESRD requires expertise not only in the medical and technical aspects of maintaining patients on dialysis but also in advance care planning (ACP) (2). Facilitated ACP is a process that involves understanding, reflection, communication, and discussion among a patient, the family (or other caregiver), and staff for the purpose of clarifying preferences for end-of-life care. It lays out a set of relationships, values, and processes for approaching end-of-life decisions for individuals, including attention to ethical, psychosocial, and spiritual issues relating to starting, continuing, withholding, and stopping dialysis (3).

Facilitated ACP is not occurring routinely in dialysis units: Only 6 to 35% of dialysis patients have advance directives (4). These are legal documents with powers and requirements that vary widely from jurisdiction to jurisdiction, and they tend to outline limited treatment options. Most patients do not complete advance directives even when educational initiatives, aimed at increasing pa-

tient awareness of the documents and their purpose and benefits, are present (5). Relatively few dialysis patients choose to implement a "do not resuscitate" order (6) despite the extremely poor chance of survival in this patient group after cardiopulmonary resuscitation (7). Patients often do not know that they have the option to withdraw from dialysis, and others believe that their physician would not support such an option (8–10). The few patients who do implement an advance directive usually do not address withdrawal of dialysis. Advance directives have failed to improve surrogate decision makers' knowledge of patient preferences and therefore have failed to promote patient autonomy (11). Most important, advance directives have failed to improve end-of-life care (12). For these and other reasons, there is a strong argument for shifting the focus away from the traditional information giving and document completion model of advance directives and replacing it with a relational, patient-centered process that focuses on broader goals of care. Advance directives are only one optional component within this broader activity of ACP. However, unlike many interventions in medicine, there are no standards of care regarding when to initiate or how to conduct ACP discussions. The purpose of this study was to determine perspectives of patients with ESRD of the salient elements of ACP discussions and to discover their preferences regarding how ACP could be facilitated by the health care team.

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Materials and Methods

An ethnographic study using personal interviews was undertaken to understand patients' perspectives of the salient features of effective facilitated ACP in the context of ESRD. The basic principle of ethnog-

raphy is to interpret phenomena and the meanings attributed to them within the terms of those who experience them, not through those of the professionals who provide care for these patients. Ethnography recognizes that human health and illness experiences are composed of complex interactions between psychosocial and biologic phenomena and that these experiences need to be understood in the specific behavioral and cultural context of any given group. Ethnographic research provides a conceptual description of how people experience their health and illness and provides a theoretical structure for our clinical knowledge. It generates new ideas for policy and can inform clinical reasoning and innovative practices of care. Within this ethnographic approach, a biographical constructionist paradigm was adopted to elicit personal histories of perceptions patients with ESRD of facilitated ACP and the importance and meaning attached to ACP within the context of their own lived experience. The study was approved by the University of Alberta Research Ethics Board, and written informed consent was obtained from all participants. All study procedures were in adherence to the Declaration of Helsinki.

Patient Recruitment and Sampling

The study consisted of personal interviews with 24 patients from the Northern Alberta Renal Program at the University of Alberta between August 2004 and June 2005. Participants were purposively selected on the basis of their willingness to discuss the issues and were stratified by age, gender, and dialysis modality. Fourteen patients were recruited from the Renal Insufficiency Clinic and were clinically expected to require dialysis within the next 12 mo. The palliative care paradigm suggests that this is the optimal time to initiate ACP discussions. Emerging themes were explored and challenged further in 10 subsequent dialysis (five hemodialysis and five peritoneal dialysis) patients using the same interview guide. The nursing directors of each of the units identified sequentially potential participants as they presented for clinics and informed these patients about the study. Names of patients who were interested in participating were given to an experienced qualitative interviewer who had no previous relationship with the patients; she subsequently contacted potential participants to obtain informed consent and set up an interview time. Of the 25 patients who were approached, only one refused participation. Interviews were conducted at a time and location of the patients' choice.

Data Collection and Analysis

Through the use of two exploratory focus groups with eight (predialysis and dialysis) patients, we developed an interview guide that highlighted their experience with and thoughts on ACP. The issues raised during these focus groups in conjunction with a critical review of the literature formed the basis for the study interviews. Personal audiorecorded interviews, typically lasting 60 to 90 min, subsequently were conducted in 24 study participants. All interviews were transcribed and validated against the recorded material by the interviewer. Data collection and analysis were continual and dialectic; constant comparative and iterative analyses were used. This analysis consisted of identifying and coding sections of transcribed text into thematic categories. Associations between the derived themes were sought by synthesizing, theorizing, and recontextualizing to create a framework to understand patients' perceptions of the salient elements of facilitated ACP.

Results

Patients ranged in age from 44 to 88 yr (mean 64 yr), and 12 were women. One patient was First Nations Aboriginal, and the rest were white. The cause of kidney failure was diabetic

nephropathy in eight (33%), hypertension or renal vascular disease in seven (29%), chronic glomerulonephritis in four (17%), polycystic kidney disease in one (4%), and unknown or other in four (17%). The themes that emerged from the data are summarized in Table 1. No participant had views that conflicted with the presented data, with the exception of a single patient, who did not want to discuss survival statistics.

Determining Patient Interest in ACP

Patient's Perceived Benefit of ACP. The perceived potential benefit of ACP for any given patient or family member varied significantly and reflected their beliefs, fears, and wishes for their end-of-life care. Patients clearly identified ACP as an important part of medical care when they had a clear idea of how the process would benefit them. They were much less likely to engage actively in a process from which no benefit was perceived.

"[ACP] is important to me because . . . I'm very concerned about the end. I don't want it to be in my home because of my kids. Will I get a warning to go to the hospital? I don't know any of this. They (doctors) don't really give me straight answers, and that's what bothers me. I want answers. I don't want (my children) to get up one morning to find me there."

"Talking about [ACP] lets you know what's going to happen. I need to know what the symptoms are and he wouldn't tell me . . . because I'm really worried about nausea, vomiting, and not being able to breath. Someone should be talking to you about what's coming."

Sense of Personal Empowerment. A closely related theme was the sense of empowerment—the perception that their opin-

Table 1. Patient preferences for ACP in ESRD^a

Determine patients' interest in participation
determine patients' perceived benefit of ACP
determine patients' sense of personal empowerment
Information giving
provide more information about prognosis and the disease process
provide earlier information, especially around the time of initiation of dialysis
provide information about the impact of treatment on daily life
use simple (lay) language, and confirm understanding
Role of physicians
physicians are needed to initiate and help guide ACP
empathetic listening
affirm self-worth of patients
Role of patients and family
identify locus of control and individual preferences for decision making
most of the ACP discussions will occur within the context of patient–family relationships

^aACP, advance care planning.

ions or wishes were important and would have an impact on the care received. Most patients believed that health care providers wanted to know their preferences and that this would influence not only how they were treated but also the outcomes of that treatment. This was a powerful stimulus to engage in ACP. Patients who seemed more fatalistic about their health felt less confident that they could influence the outcome of their end-of-life care and were less enthusiastic about the process of ACP:

“If it’s going to be, it’s going to be. I don’t think it [ACP] changes much.”

“It’s just the way things are and there’s not much you can do about it, so don’t think about it [death]. There is nothing you can do about it. It’s just going to progress the way it’s going to progress. But is there a good way to die?”

Information Giving

More Information about Prognosis and the Disease Process Earlier in the Illness. There was a considerable burden of worry: Patients experienced fear and uncertainty about their future. Information giving was seen by these participants as a critical element of the ACP process in that it promoted self-reliance; alleviated fear and uncertainties; helped prepare them for the future, including death; and gave them the knowledge to make decisions that were compatible with their values and beliefs. This process of information giving also was seen as key to building trusting relationships with the health care team. Participants universally spoke of the need for more information. They believed that ACP involved clear, honest discussions about their prognosis and future and that these discussions should occur early in the illness, particularly at the initiation of dialysis.

“I’m afraid of dialysis, I’m afraid of dying. I’m afraid. . . , so strategies like information knock this fear down to a reasonable size. The only one I’ve managed to come up with so far with is information.”

“I actually changed dialysis days because of a doctor who did rounds refused to talk with me about end-of-life issues. When I tried to ask him questions, he would not take me seriously and he was sort of like, oh there you silly girl, you don’t have to think about that yet. And I found that quite distressing. It was as if he could not bring himself to talk about those issues.”

A single participant stressed the difficulty that is inherent in receiving poor prognostic information with respect to survival and believed that she would not want such information. Despite this, she agreed with all other participants that postponing discussions about end-of-life issues increased her burden and that she required significantly more information about the impact of her illness on her life as described next.

Information about the Impact of Interventions on Daily Life. Patients tended to make decisions about end-of-life care on the basis of a broad set of values and beliefs that had relatively little to do with the objective effectiveness of a particular treatment but rather had more to do with the perceived impact of the care plan on their personal lives. The information that they required through facilitated ACP was about how

medical interventions could assist them in their daily lives and help them achieve their personal goals.

“You need more in education so you can deal with your [own] situation. You’ve got to start thinking about yourself and thinking about your family and, uh, there’s a lot of general practitioners and specialists that tell you what to do but they don’t give you guidance in how to do it.”

Lay Language. The language that health care professionals use when providing information and discussing end-of-life issues was highly influential in determining the comfort of the patient. Medical jargon created distance between patients and staff and had the potential to cause confusion and misunderstanding.

“Technology, it’s going by too fast . . . because I don’t know what everyone is talking about.”

Role of Physicians in Facilitated ACP

Physician Responsibility for Initiating ACP. Participants clearly believed that physicians were responsible for initiating and guiding facilitated ACP, mainly because physicians were seen as the primary source of information that is central to this process. It is interesting that, although many patients believed that staff were reluctant to discuss end-of-life issues, most of them trusted health care professionals, including nurses and social workers, to initiate these discussions when they became relevant to their care.

“They will tell me, they will let me know when it is time.”

“I would hope that health care providers are sufficiently trained to inform the patients at the right time what to expect and not wait until the very last minute.”

Empathetic Listening and Affirming Self-Worth of Patients. Participants did not view facilitated ACP as merely an information-giving session or as a way of providing solutions to all of their end-of-life concerns. They stressed the importance and acknowledged the therapeutic benefit of empathetic listening and viewed facilitated ACP as an opportunity to build trusting relationships with the health care team. Self-worth was affirmed when health care professionals reassured patients about the appropriateness of their end-of-life preferences and commended them for their efforts in the ongoing care of themselves.

“One thing I am missing in my life is someone I can really talk to. I have a good social worker, but she doesn’t think she can help. She doesn’t understand that just listening is a real help. To clarify my issues, to clarify my anger, to talk about the decisions I have to make.”

“Basically they [health care team] didn’t listen. They spent more time in kind of a social chit-chat, and they didn’t seem to understand the power of listening proactively. They seem to want to find solutions for me, and I didn’t want solutions, I just wanted to be able to find my own solutions.”

“[You want to hear] that you’re doing a good job, that you’re looking after yourself. . . ”

Role of Patients and Family in Facilitated ACP

Identifying Locus of Control for Decision-Making during ACP. The role that patients expect themselves and/or family to have in medical decision making varied considerably and

affected the process of ACP significantly. Defining these roles was identified as a key element in effective ACP. Some patients tended to make their own personal decisions without relying heavily on family members. Although family participation remained important, the thrust of questions and education needed to be aimed at the patient.

"I think patients should make their own decisions in what they want at the end depending on how much they have tolerated with this illness, how it makes them feel. It's my life, my body, my decision, nobody else's. . . . OK, I have a husband and kids, but do they really know what you are going through? So why should they make that decision?"

Most of these participants, however, preferred to have shared decision making with the health care team, with significant involvement of family. For these participants, the goals of ACP included relieving financial and end-of-life decision-making burdens on loved ones and strengthening relationships with those who are important to them (including the health care team with which they interacted so closely). This was believed to be achievable by including these individuals in the ACP process. Without family support, patients were less likely to be open to ACP, and end-of-life discussions were believed to be less likely to have a positive impact on care. However, despite wishing to make their own decisions, these patients still expected health professionals to guide them through the ACP process. Perceiving the full burden of decision making to be entirely theirs led to feelings of isolation and uncertainty.

"I hope that they [health professionals] talk to me and don't just assume things, because I have a right to make my own decisions. Health care providers are there to inform me and to carry out my wishes, uh, as they can, but the decision should be up to me."

A few participants viewed family as a potential barrier to ACP; they feared that family would be upset by the process of ACP or uncomfortable with the topic. These participants expressed feelings of isolation and hopelessness when they were not able to discuss honestly and opening with loved ones their hopes and fears for the future.

"I have some friends and I have discussed these things in a small part, but I don't like to burden them. I worry about my husband and I worry about my mother and I just worry about the impact."

"When I'm alone with myself, I'm afraid to die."

"I do not want dialysis. My kids are fine with it, but one—he's taking it very badly and he thinks that I'm a coward because I won't go on dialysis, but I don't see it that way. He won't talk about it. I want to talk about it . . . inside I'm hurting like mad, but I can't get that out."

A few participants preferred to have family members make end-of-life decisions for them should they become incapacitated, believing that their loved ones would apply their previously stated preferences to current circumstances. Unfortunately, this reliance on family was without explicit communication about expectations or personal preferences. For patients without family, health professionals replaced this role of family.

"I just put my trust in the doctors. I trust that they know what they are doing."

Discussion

These findings identify a precarious tension between patient preferences for facilitated ACP and current clinical practice. As described previously in the literature (13), these participants found value in ACP in that it addressed fears, helped prepare them for death, strengthened interpersonal relationships, and allowed them to achieve control over their life. However, individual participants prioritized these issues differently when it came to end-of-life care. Health professionals need to determine these priorities to establish patient "buy-in" and then frame ACP to address those concerns. This has not been stressed previously in the literature. ACP facilitators should acknowledge that actively promoting patient empowerment and providing assurance that patients' preferences will shape future care also likely would enhance ACP efforts.

Recent guidelines recommend shared decision making between patients and the nephrology care team (14). A key component of this decision making is informed consent, and it has been stated that nephrologists have an obligation to inform patients of their prognosis and that this needs to occur in a timely manner, even before patients make the decision to start dialysis (15). The patients in this study supported this statement and were starving for more information and earlier initiation of end-of-life discussions: Most had a difficult time conceptualizing what their future might hold for them, and this uncertainty was a source of fear. This is consistent with a survey of general nephrology patients: The vast majority (97%) wanted to be given life-expectancy information and expected the physician to do so without having to be prompted (16). Furthermore, this survey indicated that the majority of patients wanted as much information as possible, both good and bad.

The results of this study suggest that patients are more interested in process, communication, relationships, and how care plans affect them and their loved ones in their daily lives rather than the statistical effectiveness of treatments. Information, therefore, needs to focus more on the individual and how his or her illness and interventions will affect what he or she values most.

Language is a powerful tool in facilitated ACP, and patients clearly appreciate staff who are comfortable in discussing end-of-life issues, including breaking bad news and disclosing prognosis. Medicine, like most professions, has concepts, phrases, and keywords that are important to help categorize phenomena, save time, and provide a framework for working together (17). However, the use of such language can be misleading for patients. Health care providers should reflect on the language that people use and respond to them in kind. The literature and this study also stress the importance of empathetic listening (18). Interviewing skills that focus on empathy and strong reflective listening can be taught (19,20). It also is important to recognize that ACP is an evolving process and is not bound at one point in time. Patients often need time to reflect on information and how it has an impact on their life.

Physicians clearly were seen by patients as having the re-

sponsibility for initiating and guiding ACP. In fact, the lack of physician initiative was perceived by patients to be the largest barrier to ACP. The disturbing nature of the topic was not a major concern. It is identified clearly in the literature that clinicians have highly specific emotional, cognitive, and skill barriers to engaging in ACP (19). Emotional barriers often stem from their belief that such discussions would take away patients' hope, and physicians often explain their reticence to give a prognosis by virtue of the tendency of most patients not to ask for one (21,22). This study should help clinicians overcome some of the emotional barriers to ACP because these patients seemed more accepting of death as an inevitable outcome than their health care providers, and, contrary to popular belief, patients wanted to discuss end-of-life issues. This is consistent with other findings in the literature (23,24). This creates tension as patients are waiting to receive cues from their physicians that these end-of-life discussions are relevant to their care, trusting that ACP will be initiated when the time is right. The other obvious problem is the difference in perception as to the appropriate timing of ACP. For patients, this occurs much earlier than perceived by physicians. This is the case even in primary care patients without chronic illness (25).

Not all patients wanted to talk extensively with their physicians about ACP. Some patients saw conversations with their loved ones as the most valuable piece of ACP. That ACP frequently occurs within the patient–family relationship rather than within the patient–physician relationship is being recognized increasingly in the literature and was supported by these participants (9,26). Health professionals must be prepared to initiate end-of-life conversations and then step back while these conversations proceed outside the patient–health professional relationship. However, these findings clearly support a role for physicians that is much greater than merely introducing the topic and encouraging patients to discuss the salient issues with their families.

The role of loved ones and the patient him- or herself in facilitated ACP is complicated, and these various roles need to be identified clearly. For many, family members are an integral component of ACP because patients rely extensively on them to help make end-of-life decisions. Unfortunately, families often lack knowledge of the patient's values and preferences (5,10). Patients may overestimate the degree of autonomy that their surrogates want to exercise and underestimate the importance of ensuring that their surrogates have the information needed to make informed choices. When family members were perceived by patients as not being supportive of their end-of-life care preferences, patients experienced isolation and hopelessness, and this was perceived as a barrier to effective ACP. Encouraging enhanced patient–family communication allows for a richer understanding of prognosis and the likely outcomes of alternative plans of care, helps resolve misconceptions and uncertainties, and increases the likelihood of consensus and reconciliation (18). ACP facilitators also need to be vigilant because the role of patients and family in decision making may shift as events unfold. Substantial stress can arise for caregivers if they need to take on unexpected or changed roles.

With a qualitative method such as ethnography, no claim is

made for generalizability of results, and it is naïve to assume that all biases have been eliminated. However, the truth value (or theoretical validity) was supported by checking the data for disconfirming cases and by repeated interviewing using theoretical sampling in which emerging themes were subjected to critical analyses, thereby ensuring that researcher bias did not systematically skew the findings. This permits confidence that this interpretation of patient preferences for facilitated ACP is grounded in the data and is representative of shared realities rather than an artifact of design or researcher bias.

These results contribute significantly to our understanding of the salient features of facilitated ACP from the perspective of patients with ESRD and provide some evidence that our current clinical practices are inadequate in that they do not meet the needs of our patients. Determining how ACP will benefit any given patient from his or her perspective and fostering patient empowerment are critical to effective facilitated ACP and will guide the initial ACP process. Information giving is a fundamental component of facilitated ACP and is required early in the illness. Information needs to focus on the individual and how his or her illness and treatment will affect daily life and what he or she values most. Contrary to popular belief, there is no evidence to support the notion that engaging in end-of-life discussions will destroy hope. Rather, patients view this as an integral component of quality care. There will always be variability in patients' desire for information and involvement in medical decision making. Physicians need to tailor ACP according to the individual patient preferences and not impose a predetermined standard on all patients. Finally, health care providers need to assume the responsibility for initiating ACP and help guide patients and their families through the process, even if for some the majority of the discussions occur outside the patient–physician relationship. ACP is an essential element of quality palliative care that is likely to improve the lives and deaths of patients with ESRD.

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