

Developing a renal supportive care team from the voices of patients, families, and palliative care staff

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ABSTRACT

Objective: Although half a million Americans suffer from end stage renal disease (ESRD), their quality of end-of-life care has been woefully inadequate. The Renal Supportive Care Team is a demonstration project that is designed to elicit and provide for the needs of dialysis patients and their families throughout the trajectory of their illnesses.

Method: Six focus groups, including medical health professionals, dialysis patients, family members, and bereaved family members, discussed how to promote improved palliative care and encourage hospice referral for patients with ESRD.

Results: Respondents agreed that there needed to be greater education of both patients and families regarding all aspects of the disease process, open communication, on-going support between patients, families, and the staff, continuity of care, pain control, and assistance with advance care planning.

Significance of results: Palliative and supportive care issues in ESRD need greater attention.

KEYWORDS: Palliative care, Dialysis, Advance care planning, Hospice

INTRODUCTION

There are more than 450,000 patients with end-stage renal disease (ESRD) in the United States, and more than 79,000 patients died of ESRD in 2004 (U.S. Renal Data System, 2004). Among these deaths, three quarters involved patients who were over the age of 65 (U.S. Renal Data System, 2005), and approximately 15%–25% of the deaths were the result of the decision to discontinue dialysis treatment (U.S. Renal Data System, 2004). Given that symptom management for this population is problematic and the quality of life often poor (Perry et al., 2003; Davison, 2006), there has been a surge of interest in looking at innovative ways to approach end-of-life issues and advance care planning (Perry et al., 2003).

The Renal Palliative Care Initiative is a demonstration project that has been conducting research

aimed at integrating nephrology and palliative medicine. This article focuses on the first part of a study to facilitate hospice referrals for severely ill patients with ESRD. The results of six focus groups are presented that included two groups with family members, two with patients, and two with staff, that is, nephrologists, nurses, internists, intensivists, social workers, and hospital chaplains. Between March 2000 and October 2001, the End Stage Renal Disease Workgroup on End-of-Life Care convened (End Stage Renal Disease Peer Workgroup, 2006). The workgroup recognized that dialysis units have not been successful in facilitating advance care planning (Holley et al., 1993, 1999). In part, this is because many dialysis patients do not consider themselves to be terminally ill and often falsely assume that they can be kept alive indefinitely on dialysis (Davison & Simpson, 2006). Patients are often unaware that they can discontinue dialysis and are usually uneducated about other options, such as vigorous palliative measures and hospice care. In addition, there is often collusion between patients and health

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care providers to avoid addressing death and dying issues until very late in the illness, when it is often too late to thoughtfully prepare for the end of life (Davison, 2006; Davison & Simpson, 2006).

One reason for the delay in these discussions is that many health care providers are concerned about having premature conversations with dialysis patients. Additionally, patients often wait for providers to initiate such conversations (Davison, 2006; Davison & Simpson, 2006). Another reason for the delay is the professionals' fear that patients will lose hope (Perry et al., 2003; Davison, 2006; Davison & Simpson, 2006). However, many authors have reported just the opposite, making the case that receiving end-of-life information earlier and having prognostic discussions is vital for maintaining hope (Perry et al., 2003; Davison, 2006; Davison & Simpson, 2006; Davison & Torgunrud, 2007). Davison and Simpson (2006), for example, conducted interviews with 19 patients (14 who had renal insufficiency and were expected to need dialysis within a year, and 5 currently undergoing dialysis) to explore their experiences regarding prognosis, end-of-life care, and hope. Their findings illustrated that receiving information about end-of-life decision making allowed patients to experience hope because patients were able to find greater meaning in relationships with friends and family and because distressing symptoms were minimized. Patients saw relationships as being central and they experienced a decrease in hope when they were *unable* to have honest, open conversations with loved ones and staff. Davison (2006) reported that 97% of her subjects wanted to be given direct life expectancy information early in the process. In addition, patients perceived the lack of physician initiative as the greatest barrier to advance care planning. Much of the writing on preparing dialysis patients for end-of-life decision making has emphasized the desire for shared decision making with family, nephrologists, and dialysis team members (Perry et al., 2003; Davison, 2006; Davison & Simpson, 2006; Davison & Torgunrud, 2007). A review of the literature surrounding prognosis, ethical/legal considerations, treatment, and end-of-life issues states a clear preference of patients for end-of-life discussions to be held with their families and with much less reliance on discussions with health care professionals (Cohen et al., 2006).

Most ESRD patients die and suffer with pain and terminal agitation in hospital settings and nursing homes (Cohen et al., 2005). The percentage of ESRD patients who receive hospice services prior to death is probably in the single digits, and even the most optimistic estimate (13.5%) finds the referral rate to be no greater than half that of the national average (A.H. Moss, A. Murray, personal communication,

October 31, 2004). One of the goals of the Robert Wood Johnson Foundation's ESRD Workgroup and the Renal Palliative Care Initiative was to help nephrologists understand the omnipresence of death and to promote new ways to address symptoms and minimize suffering. Because the average life expectancy after a patient stops dialysis is only 8 days (Cohen et al., 2006), ongoing discussions of end-of-life options are imperative.

But who should provide end-of-life care planning with dialysis patients and their families? In a joint collaboration with hospice and renal teams in the United Kingdom, Brick et al. (2005) describe the concept of a Conservative Management Team (CMT) as a means to provide support and information. The CMT is a multidisciplinary team whose primary goal is to smooth the transition from renal to palliative care for those who are either not going to receive dialysis or wish to withdraw from treatment. The role of hospice is a key factor in the support offered by the CMT. One of the components of the CMT is what is referred to as a "key worker." Each patient is assigned a key worker who serves as the main point of contact for the palliative care team, hospice, and other members of the CMT.

Having a "point of contact" to walk the patient and family through the trajectory of the illness and through the process of end-of-life decision making has been discussed by several authors (Perry et al., 2003, 2005; Davison & Simpson, 2006). Perry et al. (2003, 2005) address the usefulness of having a peer as a point of contact and means of identification and familiarity to reduce anxiety. Perry et al. (2005) also illustrate the cultural bias of written forms of communication (advance directive forms, written information describing hospice) and state that African Americans are much more likely to engage in end-of-life decision making when there is input from someone they trust and who understands their situation. Peer mentoring is another way to provide that support and input. This point is reiterated by Holley et al. (1993), who suggest that printed material does not appear to change attitudes regarding advance care planning unless there is input from a trusted health care professional.

METHODS

Six focus groups were initiated to obtain the insights, ideas, and experiences from four separate groups: (1) health care professionals (consisting of nephrologists, intensivists, dialysis nurses, social workers, and palliative care physicians and clinicians), (2) patients receiving maintenance dialysis, (3) family members, and (4) bereaved family members. Using a semistructured questionnaire, these four groups

were asked to discuss their experiences as well as their thoughts about the development of Renal Supportive Care Team (RSCT)—a multidisciplinary team designed to provide education and support to severely ill dialysis patients and their families.

Recruitment

Patients, families, and staff were recruited by the study's renal dialysis social worker from Western Massachusetts dialysis clinics and medical facilities. Focus groups were organized to take place at Bayside Medical Center. Cake and coffee were served, no financial compensation was provided to participants, and the groups lasted approximately 2 hours.

The Instrument and Form of Analysis

A semi-structured interview guide was developed and administered verbally to every group, and the co-leaders (the authors and principal investigator) led the groups, with one leader taking notes. All focus groups were audiotaped and transcribed. Using a qualitative analysis, the authors used axial coding to develop themes, subthemes, and categories, cross-checking their findings with each other for reliability while creating new categories of inquiry where appropriate. A grounded theory method was employed, as this approach offered the opportunity to enter into an in-depth discussion with participants and to ask exploratory questions in an area that has not been systematically explored. In grounded theory “unstructured data are used in order to capture the phenomena of interest in the words or activities of those who embody or live them and to capture them in context in terms that are as ‘experience-near’ as possible” (Anastas & McDonald, 1994, p. 109). The idea of capturing experience-near data from patients, families, and the professionals that serve them was imperative in understanding how to move ahead in the formation of the RSCT. In using this method, we were able to glean important insights into (1) better education, including the trajectory of the illness; (2) better pain control; (3) the need for more support from culturally competent caregivers; (4) greater continuity of care and comprehensive end-of-life care planning; and (5) increased communication and the need for advance care planning. Each of these will be discussed in greater detail in the Results section below.

RESULTS

Patients, families, and staff met in six groups: two staff groups, two patient groups, and two family groups (one bereaved and one nonbereaved). In all there were 36 participants.

Education

It was clear from the interviews with patients and families that both wanted more education from health care providers than they thought they had received. They wanted education on the procedure of dialysis, on the trajectory of the illness, on the side effects of the medications, on pain control, and on discontinuing dialysis.

For example, both patients and families wanted to understand what dialysis was prior to beginning treatment and felt that clear explanations had not been given. One patient said, “You’ll get better results at the end if we are knowledgeable about what’s happening at the beginning.” Another patient added, “I was scared to death the first time I went to dialysis. They told me where to go. I had no idea about the procedure. I had a shunt put in; I didn’t know how I was going to feel. I really believe you need someone to go into the hospital room and when they put that shunt in, someone needs to tell you what’s going to happen, what is the purpose of dialysis.”

Both patients and families added that they also wanted more education about the trajectory of the illness, including side effects, emphasizing that knowledge was empowering. Said one patient, “When you start dialysis, you need to know the course of the illness. You need to know about stopping or not stopping, how long will I do this, how long will it work for me.” A bereaved family member added this: “You see the body deteriorate, the side effects, the progression of the illness, but you don’t know what is happening. It is important for the team to give as much information as possible.”

Another family member acknowledged that knowledge is power. “It is important for the team to give as much information to the families as to the patients. Knowledge of the disease, the course of the illness, what will happen after 16 months, 5 years? It is helpful to know. What are the medications, the side effects, when is the disease reaching the end? It would have been empowering to have known.”

Although all of the bereaved families and families still coping with dialysis wanted more information, not all patients wanted to know their prognoses or the trajectories of their illnesses. Said one African American woman in her early 40s, “I will tell you right now that I’m trying my hardest and I pray every day, ‘Lord, don’t let me get sad,’ because once those negative thoughts start coming, you just feel: When is the end coming? No one wants to hear, so you have to think positively, move on with this thing, don’t worry about it.”

Almost all patients and families wanted to know about pain control. Said one patient, “If you are admitted into the hospital prior to going on dialysis,

no one tells you about lidocaine. The lidocaine hurts but it also helps. You need to know that.”

Patients also wanted to know about what they could and could not do nutritionally, physically, and psychologically. For example, one patient said, “Doctors tend to be less forthcoming about what’s going on.” Another family member averred that verbal communication was essential and said, “The education, the truth, . . . that’s what families need. That is a comfort for us. We need to know about the process and the problems. Not everyone stops to read pamphlets.”

Most of the patients, families, and staff agreed that families and patients need to be educated about stopping dialysis and to know that this is a treatment decision. One internist, for example, pointed out how difficult these conversations can be: “Patients may think that if you are asking these questions, it is because they are going to die. ‘Well, how long do I have? Am I not going to get well soon? Am I not going to be able to get my dialysis or is something going to happen in another way?’”

Indeed, patients, families, and staff thought that there needed to be a supportive environment to receive the information/education. Said one nurse, “There is so much activity going on. . . . There is too much distraction . . . when you are really trying to understand what is going on and take it in. . . . You need to have a more quiet area . . . to have that face-to-face conversation to get that basic information that you need.”

Support

Every patient and family wished that more support had been forthcoming. For some, support might come from the staff. For example, one patient reported, “My son is in denial and so he rarely comes to the dialysis unit. He used to come pick me up, but he wouldn’t come in, so when he does, in the few times he has, it’s like he is in a fog. He never talks to staff. I introduce him, but for them to sit down with me and explain to him what is going on, to ask if there are any questions, that’s never happened.” One staff member said, “So maybe it would be helpful if the team is matched up with a particular patient. The family is going to need a lot of support so you match them up with the social worker.”

For others, the idea of peer support arose as being even more useful. Said one family member, “There used to be a support group and it would meet once a month—for family, friends, anybody to talk about problems patients are having over the years. We could do that by phone.” Another family member agreed saying, “Family members are the best tea-

chers. They are the experts. We need to hear from them.”

In the bereaved family focus group, three out of four bereaved families offered to provide telephonic support to other families who were currently struggling with end-of-life issues for their family members. Said one family member, “I need someone who has walked in my shoes.” Another patient agreed, saying, “Nobody understands how you feel when you are on dialysis. You need someone to say, ‘I know, you feel shitty, I was there too.’”

A theme emerged about offering support groups that were peer led and even telephonic. One bereaved family member said, “Groups can help patients talk about DNRs. It would have been really helpful; I would have done things differently (with my mother) if I had had a support group.” Another patient agreed, saying, “Groups can make you feel less alone, less vulnerable.” One patient added, “Groups should be offered in a safe place, near the dialysis unit, or they can be offered telephonically and at home, which is more convenient to the patient and family.” And another bereaved family member added, “Bereavement follow-up groups would have been helpful.”

One idea for a support group was to hold it telephonically. A family member said, “It is hard to get groups together. . . . People are tired.” Another agreed saying, “I like the idea of a telephone support group, because people are often exhausted . . . and you don’t want to go out.” Another patient added, “When I have questions, concerns, or need support, it would be nice to just be able to call . . . and ask: How can I deal with this?”

A family member also suggested that the groups should be homogenous saying, “Everybody needs to have a similar situation, . . . so maybe an older group and a younger group, . . . maybe another group for patients that have other complicating health factors.”

Communication

Every respondent—staff, patients, or families—emphasized the importance of communication for end-of-life planning. Many stressed the value of a relationship. For example, one nephrologist said, “The challenge is to get to know these patients. These are individual cases. Just like pain is subjective, so are patients’ needs.” Another nephrologist emphasized that having an ongoing relationship between the nephrologist and patient was essential to communication and said, “When something comes up, you know their issues, you know their family at that point, and so the relationship is there.” Indeed all three nephrologists in the staff group thought that they should be the contact person for ongoing communication. Said one, “A lot of patients have an

ongoing relationship with the nephrologist way before they start dialysis.” That person should be the primary person. They really should be discussing end-of-life care before initiating the dialysis.

There was consensus that the relationship with the staff should be culturally competent. One internist said, “I think, culturally, the way you present it to a Hispanic family is not the same as you explain it to a Russian family. Culturally, their ideas of health care, or things related to their bodies, are different. When you go to talk with families, some families are tighter than others.” A social worker added, “There is an interesting cultural piece. We need to think about how you use an interpreter.” One of the psychiatrists, who was cognizant of cohort differences among different generations of patients and families, added, “And this was the generation that went through the Depression. . . . This generation that tell us that this is nothing compared to things they’ve pulled through. . . . It’s important to weigh in religion and different religious beliefs, . . . how that changes how people do things and make decisions.”

Continuity of Care

There was consensus that there needed to be continuity of care. Among the staff focus groups, a theme emerged that the team should act like a buddy system or concierge. In this model, one staff person would be available for the patient or family to call. One physician said, “The team is like a big brother or buddy; there should be one person to call who would bring in the rest of the team.” A nephrologist agreed saying, “If it were the nurses in the dialysis unit (who were called on to be the concierge), then you could have a disconnect. You (the nephrologist) are going to have to connect the dots.”

Uniformly, patients, families, and staff thought that the team should offer patient and family-centered help and outreach to the different places where patients live and die. A number of staff thought that there should be monthly meetings. One nurse said, “Maybe there could be a monthly meeting where everyone—families, doctors, patients—talk to each other, help with the lack of communication.”

Advance Care Planning

There was consensus about the need for education, for communication, and for support, but there was less agreement about advance care planning. For example, patients and families felt quite differently about when to introduce the topic of hospice. Families, in particular, wanted to know about advance directives and hospice early. One bereaved family member said, “It is important to talk about this before renal failure occurs.” Another family member

said, “Pull in the families early. It can make a huge difference.”

On the other hand, patients were much more resistant to discussing advance directives or hospice. One patient said, “I’ve had five bypasses. I just had colon surgery. I don’t want to talk about it.” Indeed, another patient said that talk about hospice has felt very threatening. “One day, you are having a bad day and someone says, ‘Sign this; this is your death package.’ But that’s how you feel. I’m happy. I’m feeling good, and then they throw the package on the table and the first thing you see is a living will. Am I sick? I want to get off. I want to get off. I want to go because the fear.” A different patient said, “Don’t come talk to us while we are having dialysis about end-of-life care. Don’t have these conversations. Start with something positive instead of end-of-life issues.” Perhaps one patient best summed up the feelings in both groups saying: “Don’t talk to me about hospice when I am on dialysis. You feel very vulnerable. You don’t feel good. It’s upsetting your vascular system. Come to my house and let’s talk about it, but don’t come to me when I’m in a crisis, when I feel vulnerable. Don’t dwell on what is wrong with us. You need somebody to lift you up and say kind things to you. You don’t want to hear you are in end stage renal failure.”

Staff members were also very aware that timing—when and how to talk about hospice care with patients and families—needed to be assessed with care. One nephrologist said, “There are times when we know this is not right for this family at this time, and we really just need to say, ‘Okay, we’ll leave the material and you let us know, or the dialysis staff can tell us if you are ready.’ But we need just to back down.” Another nurse said, “I am not sure most people want to know. They say they wish they knew, but we really don’t know how much they want to know.” Her colleague, the chaplain, agreed and commented, “A lot of times the family will say, ‘Don’t use the “h” word.’ Often it is the families who really do not want the loved one to know, but the patient, in fact, does know. We take the family’s cue and try to meet them where they are.”

Another physician in the focus group added: “One of the problems when patients are first admitted to a dialysis unit is that they are hoping they or their loved ones will get better. So it’s kind of a balancing act: helping them adjust to this new treatment they are going to have three times a week and hoping that they will be able to maintain kind of a normal lifestyle. Then, at the same time, we introduce them to DNRs and end-of-life issues, but it often does not feel like the right time to do it.”

A social worker added: “The issue is to assess the readiness of the patient and family to hear what

the prognosis is. Are you ready? Are you close to being ready? Should we use a stage or change model? We have to be very careful that we are not pushing patients and families to readiness. Patients and families say they wish they knew, but we really don't know how much they want to know."

An internist cautioned that there is an added fear associated with the palliative care team. He said, "After all, we don't want to be seen as the death squad."

Importantly, the staff focus groups agreed that the task of end-of-life planning should balance compassion and hope. Said one nephrologist, "You don't want to take away their hope, but also they need to know that I have to make the decision at the end."

DISCUSSION

One of the purposes of the six focus groups was to make recommendations to the RSCT about the kinds of interventions that were needed as they developed methods to offer end-of-life care planning to renal patients and their families at the pilot sites. These recommendations were made on the basis of the data presented above.

The first recommendation for developing a renal care support team has to do with education. It was clear from the data that the team should provide patients and families with education about pain, the course of the illness, and options for advance care planning during the illness—but not necessarily in a crisis or while the patient is being dialyzed.

It is also important that the team selectively identify useful information because, in the words of one patient, "So many people turn to the internet these days and it can be overwhelming." Information should be offered verbally and should be culturally appropriate. The team should be a central line of information regarding issues such as nutrition, pain, hospice care, and trajectory of the illness, offering periodic reviews while remaining compassionate about difficult news.

Communication is a crucial role for the team. For example, the team needs to provide ongoing information about options about the trajectory of the illness, pain, and side effects. In end-of-life discussions it is also crucial that the team be mindful of language and wary of using the word "hospice." In fact, the team would benefit from training in communication, to learn how to balance hope with compassion so patients and families remain positive and realistic. To communicate effectively, the team needs to be culturally competent and aware of generational or cohort differences. Further, the team needs to assess patient and family readiness to talk about advance directives and to give patients and

families the time that is needed to absorb news about hospice.

Support also played a crucial role in the discourses of families, bereaved families, patients, and staff. All emphasized that the team needs to offer forms of support—either in person or via telephonic support groups, which may be peer led. It is empowering for patients and for families to receive support from peers.

The team needs to address the whole person in his or her whole environment, so that when it comes time to discuss hospice, the team knows who the patient and his or her loved ones are. This often requires there be one point person, and the consensus was that the nephrologist should ideally serve as the chief point of communication. This may not always be realistic, however, given the time constraints of physicians, and it may have to be the social worker's or nurse's role. It is also important that the RSCT identify those individuals who need support, especially those who are anxious or depressed.

The team should individually assess patient and family's abilities to handle conversations about death and dying. Although families sought to know about the reality of the patients' conditions, the patients were less sanguine concerning hospice or end-of-life planning. This poses an interesting dilemma for health care professionals.

What was less contentious was that the RSCT needs to know the family history and draw upon it, establish trust, and help the patient make decisions. Being involved with the family also allows for more than one conversation about the illness and its progression. Continuity of care allows for an assessment of patient readiness to discuss end-of-life issues, including hospice. Therefore a part of the relationship with the nephrologist should be an ongoing process of assessment of patient and family readiness for end-of-life conversations.

The findings suggest that the team needs to offer better continuity of care and might act as a concierge, an advocate, or a buddy. Ideally, the same person should be available to the patient and family for both inpatient and outpatient purposes. In addition, the team needs to provide outreach to patients and families where they live and where they die. In this way, the team should act as a liaison of sorts—a go between—somebody to help put the information together, be sensitive enough to know how to deliver it, offer information in a timely and consistent manner, and be responsive to changing needs of patients and families. One of the roles of the RSCT is to help troubleshoot problems while being consistent with the changing needs of patients and families.

Important goals for the RSCT should be the provision of comfort care, reduced suffering and pain, and better symptom management. To be effective in

all of these roles, the team's composition should ideally include a nephrologist, a social worker, dialysis nurses, a hospice social worker, a hospice nurse, a chaplain, a palliative care specialist, and volunteer patient.

CONCLUSION

This qualitative study of bereaved families, patients, and staff identified the common needs to be addressed as patients progress toward the end-of-life. All of the subjects agreed that attention must be paid to the course of disease, education, communication, support, continuity of care, and maintenance of a relationship with one point person as caregiver. These findings are important to other renal providers—nurses, nephrologists, psychiatrists, chaplains, and social workers—and they offer suggestions for improving the quality of living with renal disease. Patients and families do not always want to know the same things at the same time, and both need to hear about end-of-life issues more than once during the disease trajectory. Written materials are insufficient, and relationships are crucial to making end-of-life decisions. The role of communication with the primary health care provider, the nephrologist, is crucial, but if the team is to act as a concierge or buddy, there is an important need for communication among all of the staff. Providing end-of-life care requires balancing hope and compassion with reality, and this is not always easy to do. Training for the team is one way to gain the skills to intervene effectively along the trajectory of illness, including information or advice about providing pain management and culturally, socially, and spiritually appropriate treatments.

The next step in this study is the establishment of separate renal support care teams at the study pilot sites. The teams will be acquainted with the findings of the focus groups and offered training in palliative care, hospice referrals, and communication. Future studies on this model will focus on the effectiveness of the interventions.

Finally, it is crucial that doctors, nurses, social workers, and chaplains begin to attend systematically to the care of patients and families with renal disease, as this is a population that has not received the attention that it deserves. Communication, support, education, and continuity of care are all issues that need to be better addressed.

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