

End-of-Life Care Discussions: A Survey of Dialysis Patients and Professionals

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Bearing in mind the high mortality rate among individuals with kidney failure—in 2005, of the 485,013 individuals with End Stage Renal Disease in the United States, there were 85,790 deaths (17.6%; U.S. Renal Data System, 2007)—coupled with the confluence of complex psychological, medical, emotional, spiritual, ethical, cultural, legal and familial factors involved with the dying process, the National Kidney Foundation conducted patient and professional surveys to advance understanding of end-of-life discussions. One-hundred and eighty-two in-center hemodialysis patients and 1,202 professionals responded to surveys distributed on e-mail lists and in a clinical meeting session. Most professionals (86%) reported having end-of-life discussions with patients; however, discrepancies associated with the topics they discussed as well as with the professionals responsible for discussions were found. Of patients, 75% were receptive to having end-of-life care discussions, with more interest in talking about advance directives and pain management than other topics. Current practices are insufficient in providing patients with the necessary information to empower them to make difficult decisions about the dying process.

INTRODUCTION

The confluence of psychological, medical, emotional, spiritual, ethical, cultural, ethnic, legal and familial factors surrounding caring for our loved ones toward the end of their lives challenges health care professionals to examine existing approaches and methodologies to end-of-life care discussions. The provision of end-of-life care for people on dialysis has multiple elements (e.g., advance directives, dialysis withdrawal, do not resuscitate order [DNR], palliative care and hospice) that are best attended to at various stages of the assessment and treatment processes, with both patients and their caregivers. Many of these are frequently neglected or ignored by health care providers, creating problematic and often disturbing circumstances for patients and their loved ones that could perhaps be avoided.

Among dialysis patients 20 to 64 years old, overall mortality rates are more than 8 times greater than those found in the general Medicare population; this difference falls slightly, to 7 times higher, in patients age 65 and older. In 2005, there were 341,319 people on dialysis in the United States, with 189,709 between the ages of 20 and 64, and more than half (55%) over the age of 60. One-quarter of the total number of people receiving dialysis treatment, or 85,759 dialysis patients, died in 2005, up from 21% in 2004 (U.S. Renal Data System, 2006, 2007).

LITERATURE REVIEW

There is ample evidence in the literature of multidisciplinary efforts and the medical community's commitment aimed at innovative initiatives, the development of model programs and research to improve the provision of advance care planning and quality palliative and end-of-life care (Blais, 2003; Clark, 2003; Davison & Torgunrud, 2007; Pitorak & Armour, 2002; Ternstedt, Andershed,

Eriksson, & Johansson, 2002). In the nephrology community, clinical practice guidelines address end-of-life issues such as withholding and withdrawing dialysis, palliative care and hospice (Holley, Davison, & Moss, 2007; Moss, 2001; National Kidney Foundation [NKF], 2006). The 2005 proposed Conditions for Coverage for End Stage Renal Disease (ESRD; Centers for Medicare and Medicaid, 2007) includes a regulation pertaining to the right of individuals to be informed about advance directives and to refuse treatment, whereas such issues were not addressed in the previous Conditions.

Nevertheless, much more is needed to enhance the care of people who are dying and minimize their suffering (Brody, 2003; Davison, 2002; Davison & Simpson, 2006; Henderson, 1995). All too often, life is prolonged in pain or discomfort, with medical interventions and procedures precluding an opportunity for loved ones to communicate and convey their wishes both with one another and their health care professionals. Holly (2007) points to the appropriateness of palliative care for ESRD patients and their families due to their high symptom burden, shortened survival and significant co-morbidity, and acknowledges that palliative care has much to offer toward improving the quality of dialysis patients' lives. Poor pain management, inattention to advance directives (Davison, 2006; King, 2007), underutilization of hospice care (Murray, et al., 2006), cultural differences (Mjelde-Mossey & Chan, 2007; Perry, 2005) and overall poor communication (Weiner, et. al., 2005) with patients and families about these issues are just some of the problems with established end-of-life care practices from the perspectives of patients, families, nephrology fellows and physicians that have been underscored in the literature (Davison, 2006; Hines et al., 2001; Holley et al., 2003; Moss et al., 2005; Warren et al., 2000).

Many individuals are more likely to discuss end-of-life issues with their family members than with their health care provider, and may even rely on them for making decisions (Lautrette et al., 2007). Failure to discuss end-of-life issues with families results in difficult situations in which decision makers are unprepared to make important end-of-life decisions for loved ones (Davison, 2006; ESRD Workgroup, 2001; Hines et al., 2001; Holley, 2007). Sanders et al. (2007) suggests that often all caregivers need is the opportunity to acknowledge their feelings of grief.

The Robert Wood Johnson Foundation Promoting Excellence in End-of-Life Care sponsored an ESRD Workgroup from 2000 to 2002 to improve supportive care and quality of life for ESRD patients and their families. Findings of 6 focus groups, 3 comprising dialysis patients and 3 made up of family members of deceased dialysis patients, showed that only 12% discussed end-of-life issues with the physician, and 58% did not discuss end-of-life issues at all. Even among the family members of deceased patients, many said health care providers never approached them about end-of-life issues or did so only at the very end of their loved one's life (ESRD Workgroup, 2001).

In a 2003 NKF survey about communication in dialysis facilities in which 474 in-center hemodialysis patients responded, survey respondents selected end-of-life care ($n = 324$; 68%) more often than 15 other topics as the topic they had not discussed with the health care team (Figure 1). Only 12% reported having discussions with the physician about end-of-life care, and slightly more than 12% reported such discussions with the social worker. Also significant was the low rate of end-of-life

care discussions in the southeast region compared with the rest of the country, suggesting geographic differences in communication (Weiner et al., 2005).

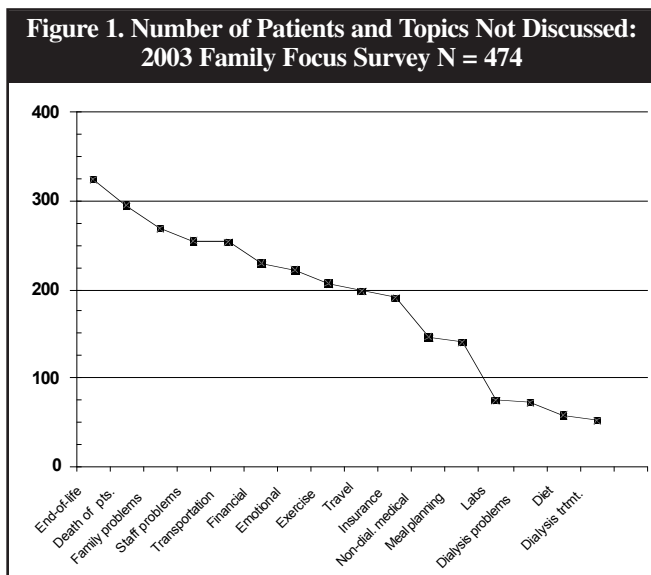
Advance care planning and communication about end-of-life issues with health care providers have been found to be beneficial on multiple levels for both patients and their loved ones. In a study that examined the role of peer mentoring on end-of-life decision-making in 203 dialysis patients in dialysis units, Perry (2005) reported improvements in comfort discussing advance directives, subjective well-being and anxiety levels, particularly in African-American individuals. In another study, Laurette et al. (2007) points to the effectiveness of a proactive communication strategy that allows family members of intensive care unit patients to express their emotions in a family conference during which the patient's prognosis and care options were discussed. The study intervention group had more realistic expectations of the patient's outcome and reduced prevalence of anxiety and depression.

Methods

In 2007, the NKF created two surveys about end-of-life discussions in dialysis units, with the intent of furthering the kidney disease community's understanding of the perceptions of people with kidney disease on dialysis treatment, and those of their health care providers. Two versions of the survey were created; one for people with kidney disease on in-center hemodialysis (Appendix A) and one for health care professionals. The 10-item survey for people on dialysis treatment and the 7-item professionals' survey both contained multiple-choice questions, as well as open-ended questions that provided qualitative data.

NKF Patient and Family Council Executive Committee members, a group of 12 esteemed individuals affected by CKD from around the nation, who are considered outstanding spokespersons on issues impacting those with kidney disease and were consequently selected to serve as representatives on this Council, were asked to review the survey and provide input prior to dissemination to help inform the researchers as to the appropriateness of the survey questions from the patient perspective. A few noteworthy comments were provided by these reviewers:

- "The term 'end-of-life' is so blunt, I'd cry when I saw that term."
- "If this is for all folks on dialysis, I think it is a little bit unsettling to ask us about end-of-life discussions. Is there another term that can be used?"
- "More (for) the family ... perhaps a lot of the questions could be pertinent to family."



This feedback afforded the NKF a deeper understanding of the gravity of the topic for people with kidney failure. To respond to the extreme sensitivity of the issue, the patient survey name and the announcement message (below) were altered to reflect these sentiments.

When you are feeling well, you may not be thinking about changes in your health condition. Though, planning for your care toward the end-of-life is best thought about early on, when you are well and able to carefully consider important decisions. With this in mind, the National Kidney Foundation is interested in hearing your thoughts about end-of-life care for people on dialysis so that we can help improve communication and care in dialysis units. If you are either on dialysis or a professional working in a dialysis unit, you can help by completing this survey.

Due to economic considerations, it was determined that both survey groups—individuals with kidney disease and renal professionals—would be solicited initially via e-mail to facilitate a cost-effective system for survey distribution. The NKF has several constituent memberships, all of which have e-mail lists, that were believed suitable for the purpose of this survey. Prior efforts to obtain constituent feedback on relevant kidney disease topics using similar survey formats have resulted in reasonable participation.

Participants

A total of 182 individuals on in-center hemodialysis treatment responded to the survey, an estimated 6% response rate. Most respondents were fairly new to dialysis with slightly more than half on dialysis less than 2 years (53%), 18% between 3 and 5 years and 29% more than 5 years. In total, 1,202 professionals responded to this survey, an estimated 17% response rate. Respondents included both online ($n = 1,141$) and NKF 2007 Spring Clinical Meetings (CM07) session attendees ($n = 61$). Social workers comprised the largest professional respondent group (28%), followed by dietitians (27%), nurses (25%), physicians (14%), nurse practitioners and technicians (2%), eight administrators and three physician assistants. Pastors were included as potential survey respondents, however, none participated.

Measures

Survey results, tabulated using Zoomerang survey software and exported as an Excel file, were analyzed for all of the professional groups combined to evaluate the groups' perceptions as a whole, as well as for the various disciplines separately. In addition, results were cross-tabulated to provide comparisons between

patients and professionals as well as among the professional groups.

Procedure

Fielding of the surveys occurred in several phases. In February 2007, an e-mail message, that explained the purpose of the survey and included a link to the survey on a Web site using Zoomerang survey technology was sent to 2,860 members (those individuals who provided an e-mail address in their membership material—10% of the total membership) of the NKF Patient and Family Council, and 288 members of the NKF "People Like Us" empowerment initiative. Some individuals may have been members of both of these listserv groups ($n = 3,148$). The listserv message with the survey link was redistributed approximately 3 months later to the same e-mail lists in an effort to recruit additional respondents.

In March, a message about the initiative with a link to the survey was posted to 3,364 NKF professional members, which included e-mail lists of the Council of Nephrology Social Workers (609), Council of Nephrology Nurses and Technicians (417), Council on Renal Nutrition (1,409) and 929 physician members. Additionally, survey announcements were sent to the 66 ESRD Kidney End-of-Life Coalition members, as this professional group was attainable electronically as well, and to more than 120 ESRD Network staff. In April, the survey was distributed to professional attendees at a CM07 session, "End-Of-Life Issues for People with Kidney Failure," for nurses and technicians, in an effort to obtain additional responses, as this group had a particularly low response rate subsequent to the initial e-mail announcements, in comparison to the other professional groups.

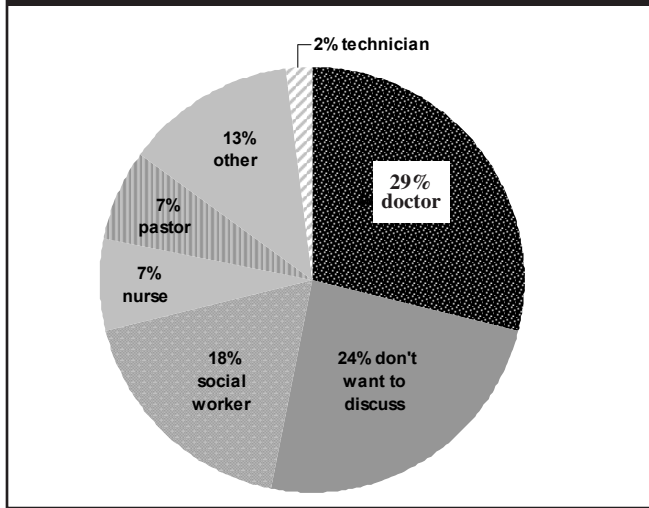
In addition, the survey was distributed to a NKF database list of 3,496 nurses and technicians in May. Some of these individuals may have received the initial survey announcement as well. Both the patient and professional surveys remained active for 5 months.

Results

Slightly more than half (54%) of all patient respondents said they have not talked about end-of-life care with a dialysis health care team member, despite the fact that more than three-fourths said they want to talk to their health care team member about end-of-life issues (76%; Figure 2). Of those who want to discuss end-of-life care, 38% wanted to talk with the doctor, followed by the social worker (24%).

Of those who had end-of-life care discussions with members of the health care team, when asked with

Figure 2. "I want to talk to the following person on my health care team about end-of-life issues." N = 180

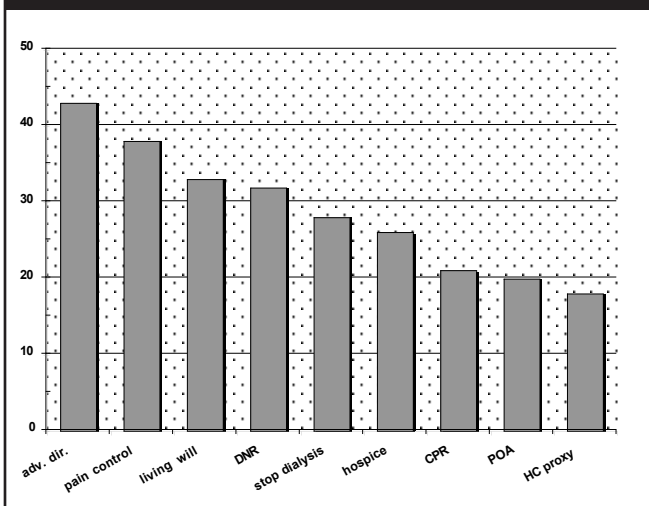


whom they talked, more respondents selected the social worker ($n = 48$), compared with 34 who said the doctor and 32 who checked the nurse. Eight individuals said they had talked with a pastor; however, there were no professionals who said that a pastor was responsible for end-of-life care discussions in their dialysis unit. It is speculated that patients who chose this option were referring to a pastor who was not a member of the dialysis health care team. Fifty-nine percent have talked with their family about their end-of-life care wishes.

Findings associated with dialysis patient tenure showed that significantly more individuals on dialysis for less than 2 years had not had end-of-life care discussions with health care team members (63%), compared with those on dialysis longer than 3 years (37%).

Respondents wanted to discuss a variety of topics associated with end-of-life care with their health care team;

Figure 3. "I want to talk with my health care team about the following topics."



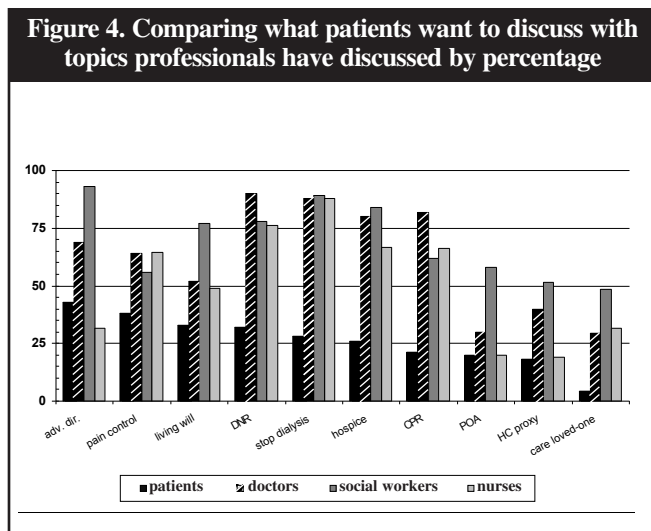
more respondents selected "completing an advance directive" (43%) and "pain control" (38%) compared with other topics (Figure 3).

When asked why they had not talked about end-of-life care with a team member, more than half (57%) reported that the reason was because "my health care team never talked to me about end-of-life care." Fourteen percent said they "do not feel comfortable talking about end-of-life care," and only 5% said "did not want to talk about it when I was asked." Twenty-one percent said they have had either one or two discussions, while 13% have had more than two. Five percent reported having such discussions on a regular basis.

The majority of the professionals (86%) said they have discussed end-of-life care with patients in the dialysis unit. Only 5 social workers and 9 physicians reported they had not had such discussions. Out of 11 topics associated with end-of-life care, both physicians and nurses, respectively, selected the same three topics as the ones they most often discussed: DNR (90/76%), stopping dialysis (87/87%) and CPR (82/65%). Social workers most often reported they were likely to talk about completing an advance directive (93%). Similar to the nurses and physicians, stopping dialysis (89%) was the second most frequently discussed topic according to social worker respondents. Hospice care (84%) was frequently discussed as well by social workers. Dietitians reported that they have informal discussions with patients (46%), and when they have had talked with patients it was most often about stopping dialysis (46%) and hospice care (30%). When all professional groups are combined, the topics most often discussed were stopping dialysis (77%), hospice care (65%), DNR (62%) and completing an advance directive (61%).

The topics patients wished to discuss differed markedly from those that doctors said they have discussed with patients (Figure 4). For example, while most patients chose advance directives as the topic they wish to discuss, and social workers also selected this as the topic they have talked about most often with patients, doctors said they are most likely to talk about DNR with patients. One might speculate that discussions about advance directives are perceived by doctors to be more within the scope of the social worker's role. Moreover, because most doctors talk with patients "when they have a major health crisis" (60%), it is logical that the majority of discussions would be about DNR.

While stopping dialysis is top among subjects both doctors and social workers talk about, only 15 patients reported they would like to discuss this topic. Patients



most often selected advance directives (43%) and pain control (38%) as the two topics they wished to talk about. Less than half of the total professionals (48%) said they have discussed pain control with patients. Sixty-four percent of physicians have discussed pain control with patients.

When asked to identify the one person most often assigned to the task of end-of-life care discussions in the dialysis unit, slightly more than half of professional respondents said it was the social worker. However, only a third of physicians identified the social worker as the responsible individual. Half of the physician group said the doctor is the professional identified to have these discussions. Conversely, only 12% of the social workers said it was the doctor, while 68% believed the social worker is the person responsible for end-of-life care discussions.

Many professionals were not certain who was primarily responsible for this task (e.g., “I don’t know,” “Unsure, assume the physician, social worker and private clergy if appropriate,” “No formally identified person,” “Unknown,” and in some instances there was variation as to who was assigned to this task, “Usually the social worker but sometimes the nurse.”) Several professional respondents explained that discussions were a multidisciplinary or team effort of many health care members, or occurred with two professionals in partnership. Many said that nutrition issues such as tube feeding, fluid management, use of supplements and withdrawal of nutritional support were often topics of discussion. Funeral information, spiritual and religious issues, quality of life, fears about dying and suicide were additional topics professionals discussed with patients.

The timing of discussions was sometimes arbitrarily determined (e.g., “Discuss as the topic comes up,”

“Varies depending on the situation,” “When patients are not doing so well,” “Patient says something that helps start talking,” “When they start talking in a hopeless fashion,” or “As deemed appropriate.”)

More than one-third of professional respondents said they do not have discussions because patients “do not usually want to talk to me about end-of-life care,” however, only 5% of patients concurred with this perception. Instead, more than half of patient respondents explained “my health care team never talked to me about end-of-life care.”

DISCUSSION

A valuable lesson learned from this survey of end-of-life care discussions in dialysis units is that health care providers need to be mindful of the tremendous sensitivity of the issues. Although the majority of patient respondents did not support the opinions of those individuals who were disturbed by end-of-life discussions, extreme care must be taken when approaching patients about such matters. More focused communication within the context of an organized program with skilled staff will likely help enhance facilitation of end-of-life discussions and ensure proper attention to the topics patients wish to discuss. Professionals identified to assume the task should receive appropriate training to increase their comfort level with the issues, enabling them to adequately manage the myriad of emotions and psychological responses that may unpredictably arise.

LIMITATIONS

Patient surveys were available for online completion only, thereby producing a select respondent group: individuals who were either proficient in accessing and comprehending the survey format or had someone available to assist them. Had the survey design allowed for respondents to complete it in a written format, this would have produced a more generalizable respondent group. The survey design neglected to comprise respondent demographics, such as geography, gender, age, education level, etc. The availability of such data would have provided a richer and more instructive view of the survey topic, allowing for more comprehensive examination. Because of the insufficient response from dialysis technicians, perhaps due to the unavailability of contact information and/or database list capabilities, we were unable to derive valuable perspectives from this professional group that is central to the care of individuals receiving dialysis treatment. As the survey was intended to evaluate the perspectives of dialysis patients and professionals exclusively, the researchers decided to exclude family members from this effort.

Nevertheless, understanding the role of the family/care-giver is integral and their input should be sought.

CONCLUSION

Misconceptions exist about patients' willingness to talk, as well as the subjects they wish to discuss. Consensus is lacking among health care team members regarding which individual in the dialysis unit is primarily responsible for end-of-life care discussions and when discussions should occur. The establishment of a structure and process in which health care professionals are trained, and discussions are initiated earlier on, targeting the subjects patients wish to discuss, e.g., advance directives and pain management, may help to cultivate an environment in which having end-of-life care discussions is an expectation.

In a culture such as this, random decision making regarding end-of-life discussions will be alleviated, and the pathway will be paved for the most difficult of discussions about topics, such as stopping dialysis and DNR. Patients will be encouraged to explore issues with their health care professionals, empowering them with the knowledge they need to make important choices with their loved ones about the dying process.

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APPENDIX A**Discussions About Care for the End-of-Life Survey: People on Dialysis**

Thinking about changes in health status is often very difficult. With this in mind, the National Kidney Foundation is interested in hearing your thoughts about end-of-life care for people on dialysis so that we can help improve communication and care in dialysis units. If you are on dialysis, you can help by completing this survey (***only people on dialysis should complete this survey***). It will take about 5 minutes to answer all of the questions. Your time can help you and others. Thank you very much!

1. Are you on dialysis?

- Yes
 No (**If no, please STOP and do not complete the rest of the survey.**)

2. How long have you been on dialysis? (Check only one answer.)

- Less than 6 months
 Between 6 months and 1 year
 1 to 2 years
 3 to 4 years
 5 to 10 years
 More than 10 years

3. I have had discussions about end-of-life care with the following members of my dialysis unit health care team. (Check all that apply.)

- Dietitian
 Doctor
 Nurse
 Pastor
 Social Worker
 Technician
 I have not had discussions about end-of-life care
 Other: _____

4. In these discussions about end-of-life care, we talked about the following topics. (Check all that apply.)

- Caring for loved ones/children if I am unable to do so
 Completing an advance directive (this includes stating my wishes about my health care and treatment at the end-of-life)
 Completing a Living Will
 CPR (Cardiac Pulmonary Resuscitation)
 DNR (Do Not Resuscitate)
 Hospice care
 Pain control
 Selecting a Power of Attorney
 Selecting a Health Care Proxy
 Stopping dialysis
 Had informal discussions (no specific topic)
 I did not have discussions about end-of-life care
 Not sure
 Other: _____

5. How many discussions have you had about end-of-life care with your health care team? (Check only one answer.)

- 1
 More than 2
 None
 2
 Not sure

APPENDIX A (Cont'd)

6. When did you talk about end-of-life care with your health care team? (Check all that apply.)

- When I started dialysis
- Sometime during the first year after I started dialysis
- More than a year after I started dialysis
- We talk about end-of-life care on a regular basis
- When I had a major health crisis
- I never had a discussion about end-of-life care with my health care team
- Other: _____

7. I did not have a discussion about end-of-life care because: (Check all that apply.)

- My health care team never talked to me about end-of-life care
- I did not want to talk about end-of-life care when I was asked
- I do not feel comfortable talking about end-of-life care
- I have talked about end-of-life care with my health care team
- Other: _____

8. I want to talk to the following person on my health care team about end-of-life care. (Check the one person you would most like to have this discussion with.)

- Dietitian
- Doctor
- Nurse
- Pastor
- Social Worker
- Technician
- I do not want to talk about end-of-life care
- Other: _____

9. I want to talk to my health care team about the following end-of-life care topics: (Check all that apply.)

- Caring for loved ones/children if I am unable to do so
- Completing an advance directive (this includes stating my wishes about my health care and treatment at the end-of-life)
- Completing a Living Will
- CPR (Cardiac Pulmonary Resuscitation)
- DNR (Do Not Resuscitate)
- Hospice care
- Pain control
- Selecting a Power of Attorney
- Selecting a Health Care Proxy
- Stopping dialysis
- Had informal discussions — no specific topic
- I did not have discussions about end-of-life care
- Not sure
- Other: _____

10. I have talked about my end-of-life care wishes with my family. (Check only one answer.)

- Yes
- No
- Not sure