End-of-Life Care: We Can Do Better

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The Kidney End-of-Life Coalition provides resources for staff, patients and families to facilitate education about death and dying issues and enhance their awareness and understanding of their emotions around these areas. The Coalition has four areas of focus: hospice, advance care planning, cardiopulmonary resuscitation and physician education. More education and resources in each of these areas will assist dialysis facilities and their staff in improving their delivery of care when faced with end-of-life issues. The Coalition's Web site, **www.kidneyeol.org**, *provides detailed information and a wealth of resources for each area.*

INTRODUCTION

One of the most rewarding, yet challenging, aspects of nephrology social work practice is helping patients and family members cope with end-of-life care. Although many dialysis patients live for many years, mortality and life expectancy statistics can be sobering. In 2004, there were 84,252 chronic kidney disease (CKD) patient deaths. Of those, 70,562 were dialysis patients. As of 2005, a person with CKD could expect to live an average of 5.6 more years after starting dialysis or an average of 15.7 more years after a kidney transplant. Although all individuals are in the process of dying, both of these life expectancy averages are considerably less than the average of 25 years expected remaining lifetime of the overall U.S. general population. Age further impacts survival. A child aged 0 to 14 on dialysis could expect to survive 18.7 more years compared to 1.8 more years for a person on dialysis who is 85 years or older. When further examining the impact of age, it was found that individuals on dialysis who were less than 30 years old could, on average, expect to live only one-fourth as long as people of the same age who were not on dialysis. Dialysis patients who were ages 40 to 59 could expect to live only one-fifth as long on average as a person of comparable age who was not on dialysis. Gender had a slight bearing on longevity. Overall, men on dialysis could expect a remaining lifetime of 5.6 years and females a remaining lifetime of 5.5 years. However, females with a kidney transplant could expect a longer remaining lifetime than men, 16.5 versus 15.2 years, respectively (U.S. Renal Data System, 2006).

It is imperative that dialysis staff receive training and resources to help patients with end-of-life issues. However, those on dialysis and their families have not universally reported positive experiences when interacting with dialysis staff around end-of-life issues. The Robert Wood Johnson End-of-Life Peer Workgroup conducted six focus groups, three each with dialysis patients and family members of deceased dialysis patients, in geographically and racially diverse areas of the United States. Family members whose loved ones had terminated dialysis and those from both patient and family groups who had experience with hospice were likely to report positive experiences in addressing end-of-life issues with providers. Some, however, were not as fortunate. Several patients reported that when they approached staff about potentially terminating dialysis, the only staff response had been to suggest taking antidepressant medication. Most importantly, however, was that many participants had no experiences to report. Numerous patients, as well as family members of deceased patients, reported that health care providers had not approached them about any end-of-life issues. Furthermore, family members shared that even when staff did initiate discussion of these issues, they did so only at the very end of their loved one's life (The Robert Wood Johnson Foundation, 2002).

Avoidance of death and dying issues by dialysis staff does not appear to be an uncommon occurrence. *Family Focus,* the patient newspaper previously published by the National Kidney Foundation, conducted a survey of its home subscribers in 2003. Only 12% of the 474 respondents, all of whom were on in-center hemodialysis, reported discussing end-of-life issues with either their physician or social worker. Fifty-eight percent of the participants indicated that they had never had an end-of-life discussion with any staff member. Participants were also asked to rank 16 different topics in order of frequency of discussion with dialysis staff, and end-of-life was the least likely of all topics to have been discussed (Weiner et al., 2005).

KIDNEY END-OF-LIFE COALITION

This discrepancy between the shortened life expectancy for individuals on dialysis and the infrequency of end-of-life discussions between dialysis health care providers and dialysis patients and their family members resulted in a CKD industry national end-of-life issues meeting in December 2004. This meeting resulted in the recognition that more needed to be done to address this issue in the kidney community, and as a result, the national Kidney End-of-Life Coalition was created under the direction of the Mid-Atlantic Renal Coalition. The Coalition included representation from dialysis and hospice providers, professional kidney and hospice organizations, patients and the Centers for Medicare and Medicaid Services (CMS). At the first meeting of the Coalition in June 2005, its members identified four general end-of-life goals:

- Palliative care should be discussed earlier with patients.
- Public understanding of death and dying needs to be improved.
- More attention is needed to help dialysis unit staff know how to respond to patients' deaths.
- State laws vary and create problems in determining consistent patterns and best practices in end-of-life care.

The mission statement, which is to promote effective interchange between patients, families, caregivers, payers and providers in support of integrated patient-centered end-of-life care for CKD patients, was developed to serve as a guiding principle for the Coalition's work. The Coalition members then divided into four workgroups—hospice, advance care planning, cardiopulmonary resuscitation (CPR) and physician education—to begin addressing the previously mentioned goals. The Coalition's Web site provides detailed information and a wealth of resources for each area.

Hospice

Recognizing that approximately 22% of all dying patients in the United States used hospice compared to only 13.5% of all dying dialysis patients, the hospice workgroup decided to focus on educating staff about hospice referral and the Medicare benefit for hospice care. Only 41.9% of patients who withdrew from dialysis used hospice care, and the group believed this percentage could be increased to provide a better end-of-life experience for both patients and their loved ones (U.S. Renal Data System, 2005). Additional areas of concern included lack of standardized terminology and each hospice organization's autonomy and ability to establish its own rules.

A common misunderstanding among health care professionals is that end-stage renal disease (ESRD) or CKD patients would have to discontinue dialysis in order to receive the Medicare hospice benefit. However, this may not be the case if patients have a non-ESRD terminal diagnosis (e.g., cancer, AIDS, chronic obstructive pulmonary disease). If a patient has a non-ESRD terminal diagnosis, the non-ESRD services would be covered under the Medicare hospice benefit. Dialysis services would continue to be covered under the Medicare dialysis benefit. The dialysis facility would continue to bill under the dialysis benefit, and the hospice agency would bill for the terminal illness under the hospice benefit. There are rare cases when hospice agencies would agree to allow a dialysis patient to continue dialysis even without a non-ESRD terminal diagnosis. This is up to the hospice agency to determine if they can provide all the patients' needs in addition to dialysis care. The bottom line is that two government benefits cannot pay for the same illness in one patient; however, two government benefits can pay for two different illnesses in the same patient (CMS, 2007).

The Coalition hopes that hospice benefit information provided on its Web site will provide social workers with more knowledge about Medicare coverage of hospice and ESRD benefits as they discuss hospice as a resource with patients and families. It can also serve as helpful information when social workers are working with hospice agencies who may want to deny services to dialysis patients.

Advance Care Planning

Of dialysis patients in one study, 77% indicated they wanted to discuss advance directives with dialysis staff (Perry et al., 1995). Another study found that 79% of in-center hemodialysis patients agreed that it was good for dialysis facilities to inquire if patients had completed advance directive documents. Although evidence of positive attitudes about advance care planning exists and the dialysis population experiences a reduced life expectancy, completion of advance care planning documents is uncommon among this population. Studies of dialysis patients have reported completion rates as low as 17–21%. (Holley et al., 1993; Perry et al., 1995). A survey of approximately 400 staff from 12 Michigan dialysis facilities documented that staff could recall no discussion about advance directives having taken place with nearly 70% of their patients and 39% of the staff reported they had when considering advance directives with any patient (Perry et al., 1996).

The advance care planning workgroup identified the following issues as important when considering advance care planning within the dialysis population:

- Dialysis facilities should clarify the staff members who have responsibility for advance care planning, although all staff should be educated about the subject.
- In addition to completing a living will document, patients should be encouraged to select an individual to serve as their legal decision maker.
- Dialysis facilities should assure that patients have access to the appropriate forms for advance care planning that are legally acceptable in their state.
- Recognizing that patients are more likely to engage in end-of-life discussions and complete advance directive documents when staff who approach them about these topics are comfortable in discussing end-of-life issues, it is important for dialysis facilities to enhance their staff's comfort level in this area.
- The lack of standardization of advance directive documents and the definitions used when discussing advance directive documents can be problematic.
- Laws about advance care planning vary among the states.
- Because dialysis patients' health care statuses may change rapidly, opportunities to clarify their wishes about their care may not exist if planning is not done in advance.

The workgroup suggested various resources to assist in addressing these issues. A model advance care planning policy for facilities to utilize was adapted, with permission, from a National Kidney Foundation document. Facilities are encouraged to use this policy as a template and modify it as appropriate for their use. Recognizing that it is insufficient to only complete advance directive documents, other tools were suggested to assist in clarifying the beliefs and values that underlie advance directive decisions. The workgroup researched various advance directive forms commonly used throughout the United States and found that none meet the legal requirements of all 50 states. As a result, the Web site **www.caringinfo.org** was recommended as an excellent resource for obtaining state-specific advance directive forms. Additional advance care planning resources for both patient and staff education are referenced.

All nephrology social workers should be familiar with their company's policy and procedure on advance care planning. It may be helpful for social workers to facilitate an interdisciplinary meeting to review existing policies with clinic staff and provide any education needed for staff to engage with patients in end-of-life discussions, completion of advance directive forms and other advance planning tasks. If their company does not have a policy, the model policy can be used as an example in developing one.

Cardiopulmonary Resuscitation (CPR)

Few patients with CKD benefit from cardiopulmonary resuscitation. Only 8% of dialysis patients who underwent CPR survived to hospital discharge in one study, and only 3% of those individuals were alive 6 months later (Moss et al., 1992). Also, similar to the findings of several advance care planning studies (Emanuel, 1993; Emanuel & Emanuel, 1992; Kelner et al., 1993), 35% of patients in dialysis facilities underwent CPR even if they had requested a do-not-resuscitate (DNR) order (Moss et al., 1990). It is not uncommon for dialysis providers to rationalize their decisions to ignore patients' resuscitation wishes by stating that fellow dialysis patients would be disturbed if CPR was not provided to a patient who experienced cardiac arrest in the dialysis facility. This assumption is not supported by research findings. A study of 830 in-center hemodialysis patients found that 100% of those who desired a DNR order and 92% of those who desired CPR believed that other patients' wishes regarding DNR should be respected (Moss et al., 2001).

The CPR workgroup identified the following issues surrounding CPR and the death of a patient in the dialysis unit:

- Patients need to understand the ineffectiveness of CPR.
- Health care team members need to know how to talk about CPR to patients.
- A DNR order requires a physician's order and appropriate communication with emergency medical services personnel about codes and no codes in the dialysis unit.
- Dealing with a deceased body in the dialysis unit is stressful for staff.
- The individual who is authorized to pronounce death varies by state, which causes difficulty in determining a recommended procedure for dealing with codes in the dialysis unit.

Dialysis clinic staff may view discontinuing treatment as giving up or suicide, or they may disagree with a decision made by a patient to terminate treatment. Staff may experience anxiety, loss of control, guilt and sadness when a patient expires. Or, they may close themselves off from patients and focus on self-preservation. The group identified continuing education modules and staff in-service programs and exercises to improve staff comfort and skills in managing CPR and DNR issues, as well as their own responses to death and dying issues. A patient education document on CPR was also developed by the workgroup. In addition, suggestions for recognizing patient deaths, such as posting obituaries of patients once the information is public, holding annual memorial services or spending time in staff meetings sharing patient memories, were provided. All of these materials are available on the Coalition Web site. The nephrology social worker is an appropriate member of the treatment team to lead staff in-services on these topics. Although discussing CPR and DNR issues with patients may be difficult, the patient education document can help lead social workers through the discussion with patients and family members.

Clarifying no code orders was also a focus of the CPR workgroup. No code orders are different than advance directive forms and need to be completed independently of living wills and/or durable powers of attorney for health care. No code orders need to be written by a physician, and some states require that they be recertified every 6 months. Some states also have laws regarding no code order transfers between hospitals, nursing homes and other outpatient settings. It is important that dialysis facilities be familiar with the laws governing no code orders in their states.

Physician Education

The Coalition recognized that physician support for dealing with any end-of-life issues (e.g., hospice, CPR, DNR and/or advance care planning) was crucial, and that without such support efforts to enhance end-of-life care would struggle to succeed. As a result, although physicians were members of the three other workgroups, a separate workgroup was formed to address physician education. It was decided that in addition to possible future projects such as developing clinical practice measures on end-of-life care for dialysis patients, this workgroup would review material developed or suggested by the other workgroups to enhance physician acceptance and usage. The specific issues identified by this workgroup were the following:

- Physicians need enhanced understanding of patient-centered care and palliative care.
- Physicians should be able to discuss the option of no dialysis treatment with patients, especially those who are elderly.

- Other physician specialty groups (e.g., primary care doctors who care for CKD patients) need to be informed about end-of-life issues with this population.
- Disagreements about end-of-life issues between the medical director and other physicians practicing in the dialysis facility are possible.
- Legal liability and malpractice issues may influence end-of-life decisions and policies.
- Ethics committees may be of benefit in dealing with end-of-life issues.
- Attention should be paid as to the best way to communicate the Coalition's messages and packaging materials to physicians.

CONCLUSION

Rosemary Hutchison, MD, stated:

> As physicians, we have emphasized scientific achievements at the expense of humanitarian concerns. We have deceived governments and patients alike into believing in the infallibility of high-tech medicine. Sadly, we have even deceived ourselves. In the euphoria of each new medical breakthrough, we have forgotten to consider the long-term costs to our patients…The glamorization of high-tech medicine encourages physicians-in-training to ignore areas of patient care that do not require advanced medical interventions. We should not emphasize scientific discoveries over spiritual and humanitarian concerns…High-tech interventions are not the answer to every patient's problems. When making major medical decisions, we should consider the wishes of the patient and his or her future quality of life. (1988)

It is this statement that sums up the type of end-of-life experience the Coalition hopes it can assist both dialysis patients and health care professionals achieve.

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