

Planning for a Good Death: A Neglected but Essential Part Of ESRD Care



Mary S. Haras

“There is a dignity in dying that doctors should not dare to deny.”-Anonymous

Dialysis as a treatment for end stage renal disease (ESRD) is relatively new when compared to other treatments for chronic conditions. When the concept of intermittent hemodialysis for chronic renal failure (CRF) was introduced in the early 1960s, patient selection was accomplished with the use of clinical evaluation committees and committees of community members to decide who would benefit most from this treatment (Moss, 2000). The medical profession did not generally discuss end-of-life (EOL) or palliative care for patients on dialysis because only the healthiest patients were selected to initiate dialysis. With the passage of the Social Security Act of 1972 (PL 92-603), which provided Medicare coverage for dialysis and transplantation for individuals who are eligible for Social Security and for their spouses and dependent children, more patients gained access to dialysis and transplantation to treat their renal failure. Nephrology as a nursing specialty emerged based on the need to provide these treatments in a hospital or outpatient setting. The American Association of Nephrology Nurses & Technicians (AANNT) was formed in 1969; the name was changed to the American Nephrology Nurses' Association (ANNA) in 1984. The organization developed professional standards of care for patients undergoing dialysis in the 1970s. Guidelines for EOL and palliative care for the patient with chronic kid-

Planning a “good death” is a neglected, but essential, part of the care of patients with end stage renal disease and their families. Many of these patients do not have advance directives and few utilize palliative care. Guidelines from medical and specialty nursing organizations regarding end-of-life (EOL) issues and palliative care have been developed, but they are not consistently used by the nephrology community. Nephrology nurses are frequently positioned to begin EOL discussions with patients and families, and advanced practice nurses are in a unique position to coordinate and facilitate a patient’s transition from chronic to terminal illness and to increase the likelihood that the patient and family experience a “good death.” This article reviews the need for practice improvement in EOL care and a review of the current literature.

Goal

To provide information about end-of-life issues and palliative care for patients with end stage renal disease.

Objectives

1. Define palliative/end-of-life care.
2. Identify the “lived” experiences of survivors with ESRD.
3. Explain the role of the advanced practice nurse in the end-of-life care of patients with ESRD.
4. List three standards, guidelines, recommendations, and/or resources of end-of-life care.

ney disease (CKD) who is undergoing dialysis are included in the most recent ANNA standards of practice and guidelines for care (Burrows-Hudson & Prowant, 2005).

In 2005, there were nearly 472,000 individuals with ESRD living in the United States (United States Renal Data System [USRDS], 2007). Two-thirds of these individuals were on dialysis, with 92% on hemodialysis (USRDS, 2007). During the same time period, nearly 70,000 patients on dialysis (22% of the population) died (USRDS, 2007). This number is pro-

jected to increase at a rate of 6% to 10% annually, as the incidence of diabetes and hypertension increases.

The dialysis population is becoming increasingly elderly. The median age of newly diagnosed patients with ESRD in 2005 was 64.6 years, and the prevalence rate has more than doubled in the past 10 years for persons aged 75 and older (USRDS, 2007). The over-65 population has been identified as the fastest growing segment of persons with ESRD on dialysis. Limited studies have been done with individuals older than 80

Mary S. Haras, MS, MBA, APN, NP-C, CNN, is an Assistant Professorial Lecturer, Saint Xavier University School of Nursing, Chicago, IL, and a Member of ANNA’s Windy City Chapter.

Disclosure Statement: *The author reported no actual or potential conflict of interest in relation to this continuing nursing education article.*

This offering for 1.5 contact hours is being provided by the American Nephrology Nurses' Association (ANNA).

ANNA is accredited as a provider of continuing nursing education (CNE) by the American Nurses Credentialing Center's Commission on Accreditation.

ANNA is a provider approved by the California Board of Registered Nursing, provider number CEP 00910.

This CNE article meets the Nephrology Nursing Certification Commission's (NNCC's) continuing nursing education requirements for certification and recertification.

years. Kurella, Covinsky, Collins, and Chertow (2007) found that there was a 57% increase in persons older than 80 years who started dialysis from 1996 to 2003, and that the one-year mortality was 46%. The number of co-morbid conditions, older age, mental status, and non-ambulatory status were characteristics associated with death.

Need for Practice Improvements

Palliative measures are aimed at providing quality EOL care in an attempt to improve the quality of dying, which will hopefully result in a good death. Palliative care, according to the World Health Organization (WHO) (n.d.), is the total care of patients with terminal illness; it includes pain management and symptom control, and addresses patients' social, spiritual, physical, and psychological problems. It is not limited to patients who are at the end of their life and should be offered throughout the continuum of their care (Jablonski, 2007). Hines, Babrow, Badzek, and Moss (1997) defined an EOL decision as one in which a patient decides whether to continue or withdraw from life-sustaining treatments when faced with an incurable condition. This definition can guide the multidisciplinary team's planning process to encompass all of the components necessary to plan for a good death. The patient with kidney disease must face the inevitable prospect of dying, and the nephrology nurse is often the first person who hears of the patient's request to withdraw dialysis (Price, 2003).

Since the 1991 Patient Self-Determination Act and the Social Security Act of 1972 (PL 92-603) were implemented, studies indicate that only 32% to 51% of patients on hemodialysis have yet to complete advance directives (Calvin, 2004; Holly et al., 1999; Moss, Hozayen, King, Holley, & Schmidt, 2001; Weisbord et al., 2003). Despite the growing numbers of clinical practice guidelines and resources available to the nephrology community, less than

10% of patients with ESRD are enrolled in hospice after they discontinue dialysis (Braveman & Cohen, 2002). Many factors have been cited as possible reasons for the status quo, including ambivalence among patients and the health providers, a lack of understanding of reimbursement regulations, and the inherent implications in making the decision to either forego or withdraw from dialysis. Valente (2007) also found that physicians might be an obstacle to affording a good death due to their own beliefs in preservation of hope and life, and an inadequate educational preparation to deal with EOL issues. Neely and Roxe (2000) support the need for palliative and hospice care in patients who withdraw from dialysis and found that patient ambivalence may contribute to the low numbers of patients referred to hospice. For all healthcare decisions, there is more than one choice and no "correct" choice; personal value and circumstances must be taken into consideration (Price, 2003).

The vast majority of studies undertaken by physician groups, reviews of relevant case studies, and family interviews conclude that further education and skills development in palliative care are needed, and that nephrology nurses and nurse practitioners are frequently in the best position to facilitate EOL decision-making with patients and their families. The Renal Physicians Association (RPA) and the American Society of Nephrology (ASN), along with ANNA, believe there is a substantial need to educate all members of the medical community, including patients, physicians, nurses, and other health care professionals, regarding what constitutes quality care at the end of life (Danko, 2002).

The clinical practice guidelines for EOL care in the patient with kidney disease have been in place for almost 10 years. Many tools have been developed to assist medical professionals and patients in preparing for the end of life. While current research supports the on-going need for these guidelines, data show that the

nephrology community is not where it should be in providing comprehensive EOL care to this population. In addition, limited studies exist in evaluating the guidelines in the octogenarian and older population (Cohen, Moss, Weisbord, & Germain, 2006; Kurella et al., 2007).

Review of Literature

Studies that focus on "a good death" and the use of palliative care are numerous. Objective means to quantify a good death have been designed, tested, modified, and adapted (Calvin & Eriksen, 2006; Cohen & Germain, 2004; Cohen, Poppel, Cohn, & Reiter, 2001; Jablonski, 2007).

The concept of dying a good death is universal, and medical professionals in many countries are equally interested in studying the factors that will promote a good death. The Debate of the Age Health and Care Study Group (1999) identified 12 principles of a good death (see Table 1). The study group identified three themes that continued to emerge during the debate – control, autonomy, and independence. Smith (2000) recommends that these principles be incorporated into plans of care, professional codes, and the goals and objectives of healthcare institutions.

Objective Measurements

A number of authors have attempted to identify objective measurements related to the quality of dying. Cohen et al. (2001) developed the Dialysis Discontinuation Quality of Dying (DDQOD) tool that incorporated the domains of pain and suffering, psychosocial factors, and duration to assess the circumstances in which patients chose to withdraw from dialysis. These domains corresponded to the descriptions by patients, families, and staff that a good death was when the dying was pain-free, peaceful, and brief. In this tool, the higher the score, the better the death. The tool was tested at eight research sites, and the analysis of the reliability data was

Table 1
Principles of a Good Death

• To know when death is coming and to understand what can be expected.
• To be able to retain control of what happens.
• To be afforded dignity and privacy.
• To have control over pain relief and other symptom control.
• To have choice and control over where death occurs (at home or elsewhere).
• To have access to information and expertise of whatever kind is necessary.
• To have access to any spiritual or emotional support required.
• To have access to hospice care in any location, not only in hospital.
• To have control over who is present and who shares the end.
• To be able to issue advance directives, which ensure wishes are respected.
• To have time to say goodbye and control over other aspects of timing.
• To be able to leave when it is time to go, and not to have life prolonged pointlessly.

Source: Debate of the Age Health and Case Study Group, 1999.

consistent across the sites. The sum of the DDQOD scores could range from 3 to 15, and the scores were used to distinguish between a good death and a bad death. While the DDQOD tool had been successfully used in a Japanese study, the authors determined it was not applicable to patients who died who did not withdraw from dialysis.

Cohen et al. (2001) then developed the Dialysis Quality of Dying Appgar (QODA). This new tool had five domains (pain, non-pain symptom, advance care planning, peace, time). The sum of the domain scores provides the total QODA score, with the maximum score being 10. The higher the score, the better the death. The user has the option of indicating any unusual events and can supplement the tool with a narrative. The authors believe that use of the tool enables practitioners to provide better physical care and a good or very good death. Moss (2001) suggested that the tool be modified to include the patient and family perspective, and commended the authors on their inclusion of a number of domains to compare the quality of dying among patients. Steinhauer et al. (2000) conducted a study using focus groups that included patients, bereaved family

members, and a wide variety of members of the healthcare team to identify attributes of a good death from their individual perspectives. "Six themes emerged: pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person" (p. 826). While all groups shared these six themes, there were differences in emphasis by the various groups. The psychosocial and spiritual issues of patients and families were identified as important as the physiologic issues, whereas physicians focused mostly on physiologic concerns.

Calvin and Eriksen (2006) used the theory of personal preservation to develop an Advance Care Planning Readiness Instrument (ACPRI) to attempt to evaluate a patient's readiness to undergo the discussion of advance care planning. The tool went through the process of initial development, assessment of content validity, and pilot testing. The overall content validity index was 0.90 and Cronbach's alpha was 0.73. Calvin and Eriksen (2006) purport that one of the reasons the completion rate of advance directives is low is that health care providers have not assessed the patients' readiness to discuss these issues.

Patient and Family Perspectives

Patient and family perspectives are integral in defining a good death. A prospective cohort study was conducted to define the experience of dying from the perspective of the patient's surrogate decision makers (Lynn et al., 1997). The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) and the Hospitalized Elderly Longitudinal Project (HELP) attempted to understand and improve decision making for seriously ill and elderly hospitalized patients. The SUPPORT project identified that dying is not only what the patient experiences but also what the family remembers. Identified limitations to that study indicated that the surrogate population over-represented the general population, and that surrogates may have over or under-reported patients' symptoms. Lynn and colleagues (1997) highlighted the areas that need improvement in caring for dying patients.

With the information obtained from these studies, Hammes and Rooney (1998) conducted a qualitative study to examine EOL decision making and planning in a community where an extensive advance directive education program existed. The La Crosse Advance Directive Study (LADS) utilized interviews by nurse researchers to hear unsolicited stories and events about the dying process of their loved one. The constant comparative method was used to analyze the data, and six propositions were identified that fostered the understanding of the "lived" experiences of the survivors:

- Being present or absent at the death of their loved one was a significant memory for survivors.
- Survivors need and expect honest and open communication from a consistent health care provider during the dying process.
- Families want information about the dying process and want to know what to expect during this time.
- Keeping promises and wishes made to the dying person helps families cope with the death.

- Giving a patient the permission to die is a powerful directive that families feel should be in their control.
- Families remember details of the events surrounding the death and will describe their loved one's death as either peaceful and comfortable, or as painful and struggling.

The study demonstrated that friends and family want to share their experiences about their final moments with their loved ones. By understanding the importance of what family members report about the events of the death of their loved one, health care providers can improve the quality of EOL care (Berns & Colvin, 1998).

Peer mentoring by patients experienced on dialysis who have adapted a positive coping mechanism and have been trained in the mentoring process has been an effective means to help newer patients on dialysis begin to adjust (Perry, Swartz, Kelly, Brown, & Swartz, 2003). They have also been effective in mentoring patients on advance directives. Patients respect the input of these mentors who have been in similar situations, and they were more likely to complete advance directives after participating in a peer-mentoring program.

Cultural Issues

Inclusion of cultural awareness and ethnicity is necessary in the review of EOL care. The cultural caring theories of Leininger, Swanson, and Watson have been incorporated into analyses on EOL care (Andershed & Ternestedt, 1999; Mitchell, Gale, Matzo, McDonald, & Gadmer, 2002). Dobbins (2005) noted the potential impact of individuals' religious, racial, and ethnic backgrounds on their EOL decisions. Nahm and Resnick (2001) studied treatment preferences among older adults. While they found ethnicity not to be a factor in the patient's choice of care, they did find differences between individuals from African-American and Asian cultures in their treatment preferences. African Americans were more likely to seek aggressive interventions compared to the Asian population. Searight and Gafford (2005), in

reviewing research in this area, found that the three dimensions in EOL treatment that vary by culture are how "bad news" is communicated, attitudes toward advance directives and EOL care, and locus of decision making.

The American Psychological Association (APA) has done an extensive literature review and found similar findings regarding cultural differences and their impact on EOL care. Valente and Haley (2007) identified that ethnic groups use advance directives differently from one another, and have varied values and beliefs about certain life-sustaining treatments; some had a greater distrust of the healthcare team than others.

Palliative Care

Virtually all studies reviewed support the need for palliative care in the patient with CKD. The inclusion of symptom management is important because pain and agitation are quite common. Advance directives are also an important component of EOL care and should be the starting point of the discussion (American Academy of Family Physicians, 2003; Cohen, Germain, Poppel, Woods & Kjellstrand, 2000; Cohen et al., 2006; Davison, 2001; Jablonski, 2007).

Hackett and Watnick (2007) reviewed the medical, social, and psychological issues in withdrawal from dialysis, as well as the practice guidelines established jointly by the RPA and ASN in 2000, which state that all patients should be offered palliative services, including hospice or bereavement, after the decision has been made. Hackett and Watnick (2007) discuss how the difficult decision to withdraw from dialysis by a competent octogenarian affected his significant other. While the patient was comfortable with the decision to enter hospice, interactions between the significant other and hospice team became more and more difficult. She was concerned about her financial status because they were not married. The nephrologists and hospice team had frequent discussions with the couple, and the patient's wishes prevailed.

Baystate Medical Center and eight

dialysis clinics initiated the Renal Palliative Care Initiative (RPCI) to address the unique needs of the patient with ESRD. Improved symptom assessment and management, advanced care planning, high quality palliative care, and family support during the EOL stage and after death are incorporated into the programs offered by the RPCI (Braveman & Cohen, 2002; Poppel, Cohen, & Germain, 2003). As a result of these interventions, the nephrology team became more comfortable addressing EOL care and withdrawal of dialysis with patients and more adept in symptom control. Interest in and awareness of palliative medicine changed the dialogue in various dialysis units and became a high priority agenda item at interdisciplinary meetings.

Role of Advanced Practice Nurses

Nurse practitioners are becoming a greater presence in the nephrology community and are often the primary care providers for patients with kidney disease. Nursing organizations have globally endorsed an agenda for EOL care and have published numerous resources for nurses to utilize in their practice. A non-experimental descriptive research design by Tyree, Long, and Greenberg (2005) used the End-of-Life Care Decision Questionnaire II (EOLCDQ II) to survey nurse practitioner attendees at an annual conference. The results of this convenience sample found that 82% of nurse practitioners had initiated EOL discussions during their career, the majority felt that their work experiences qualified them to have the discussion, the majority seemed comfortable using the words "death" and "die," and that these EOL discussions facilitate treatment choice agreement by the patient-provider team.

Nurses have highlighted the successful achievement of a good death in patients with ESRD through case study presentations. In one scenario, while the patient had not voluntarily withdrawn from dialysis, he achieved a good death on dialysis (Hayslip, 1998). The outpatient unit had implemented a

plan of care for patients who had opted for No Code status. During the plan development, they explored the areas of concern, patients' rights, and ethical and legal responsibilities, and they thoroughly involved the patient and family in the process. This information was incorporated into the patient teaching program so all patients in the unit were familiar with the plan. By respecting and honoring the patient's wishes, the staff felt that they had treated the dying patient with dignity and respect in his final moments when he died peacefully in the dialysis unit.

Another case study highlights the role of the advanced practice nurse (APN) in advocating for the patient and family. Dethloff (2004) described a situation in which an elderly dialysis patient had suffered an irreversible stroke and was left with significant speech and cognitive deficits. The patient had not clearly specified his wishes regarding dialysis, so his family was left to make the decision for him. The APN facilitated a multidisciplinary meeting with the family and their pastor. Questions were answered, support provided, and referrals made to the appropriate resources. Concerns about pain were addressed, and the family discontinued care. The patient went home with hospice and died several days later with his family at his side. Because of open communication, utilization of resources, and knowledge of the dying process, the family was able to make an informed decision so that the patient could experience a good death.

Standards, Guidelines, Recommendations, and Resources

A number of organizations have recognized the need for EOL care and have developed standards, guidelines, recommendations, and resources.

American Nurses Association. In 1997, the American Nurses Association (ANA) issued a position statement on EOL care:

- *The goal of providing quality end-of-life care challenges the very integrity of health care professionals. The American Nurses Association, in its*

deep concern about the quality of care rendered at the end of life, is determined to meet this challenge and remains firmly committed to improving that care while upholding the ethical mandates of the nursing profession and not participating in assisted suicide. We believe that the accrued experience and expertise of nurses is essential to advancing such an initiative.

American Association of Colleges of Nursing. In 1998, the American Association of Colleges of Nursing (AACN) issued recommendations for nursing education EOL competencies that should be included in undergraduate curricula. The document, *Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care*, provides details on needed competencies as well as recommendations on where such competencies can be integrated into the curriculum.

Robert Wood Johnson Foundation. The Robert Wood Johnson Foundation (RWJF) has been instrumental in improving the dying experience of patients with ESRD. The ESRD Peer Workgroup, an expansion of the 1997 Promoting Excellence in End-of-Life Care program, was initiated to study this population of individuals. Workgroup members included physicians, nurses, social workers, attorneys, nutritionists, and administrators. The workgroup was divided into the three sub-groups of Quality of Life (QOL), Quality of Dying, and Education, and met from March 2000 through October 2001. In their Final Report Summary on End-of-Life Care, the findings of the various subgroups were reported (RWJF, 2003). The Quality of Life subgroup found that current instruments were insufficient or non-existent to assess patient satisfaction, perception of QOL, or spiritual concerns related to quality. The Quality of Dying subgroup found that available literature was inadequate to describe patient and family perspectives, that there were no consistent policies to respect the wishes of patients, and that there was insufficient information about the process of dying. The third

subgroup, Education, identified gaps in knowledge, attitudes, and practice of palliative care.

Nephrology Organizations. The renal community has begun to embrace the need for clinical practice guidelines EOL care, including the initiation and withdrawal of dialysis that clearly identify the role of palliative care, as a result of the changing dialysis population and increasing frequency of patients voluntarily withdrawing from dialysis (Moss, 2000).

The RPA and ASN collaborated in 2000 to develop a guideline on shared decision making in the appropriate initiation of and withdrawal from dialysis (RPA & ASN, 2000). The impetus for this guideline came from the Institute of Medicine's (IOM) 1998 recommendation to develop a guideline regarding the evaluation of patients so that the burden of renal replacement (dialysis) does not outweigh the benefit (Moss, 2000). It is intended to benefit the patient and family by seeking their active participation in decisions about their treatment and honoring their rights. The nine recommendations in the guideline incorporate shared decision-making, advance directives, withholding or withdrawing dialysis, time-limited trials, conflict resolution, estimating progression, palliative care, informed consent, and special patient groups. The recommendations are based on extensive review of the relevant nephrology and medical literature, ethics, case and statutory law, and data sources descriptive surveys, case-control studies, cohort studies, and randomized trials. Expert consensus and peer review were utilized to formulate and validate the recommendations.

In 2000, RPA, ASN, and ANNA developed a joint position statement and recommendations for the nephrology community. ANNA has since developed guidelines related to palliative and EOL care based on their work with the RWJF ESRD Workgroup as part of the Promoting Excellence in End-of-Life Care program (Burrows-Hudson & Prowant, 2005). The strength of these standards

lie in the rigorous literature review and expert consensus. The ANNA (2004) standard states, "The patient and family will receive guidance with advance care planning. The patient will receive appropriate pain and symptom management, and psychosocial and spiritual support throughout the chronic kidney disease and dying experience" (p. 128). The guidelines recommend that the nurse review the patient's readiness for EOL and assess the patient's mental, physical, symptom, psychological, emotional, and treatment history. Patient teaching on palliative care, benefit of advance directives, and reinforcement of the patient/family as the prime decision maker in the decision to withdraw from dialysis are key educational components. The ANNA Ethics Committee (2007) has also developed a learning module to facilitate advanced care planning discussions between the patient and the nephrology nurse.

The Kidney End-of-Life Coalition (n.d.), initiated by ESRD Network 5 in 2004, was created to discuss furthering the education of the kidney community in EOL issues. Work groups were established to address specific EOL issues and discuss barriers to hospice for patients with ESRD. The Coalition's mission is to improve communication between patients, their families, and the entire health care community to support integrated patient-centered EOL care of patients with chronic kidney disease (CKD). Resources have been developed for patients and providers. The Coalition Web site (www.kidneyeol.org) is an invaluable resource for patients, families, and providers on relevant issues, and summarizes the extensive work of this group.

American Psychological Association. In 2001, the American Psychological Association (APA) adopted a Resolution on End-of-Life Issues and Care and endorsed the work of the Institute of Medicine regarding EOL care. Fact Sheets have been developed based on extensive literature review (APA, 2001).

American Academy of Family Physicians. The American Academy of Family Physicians (2003) policy statement on ethical principles for EOL care specifically addresses cultural diversity. They provide guidelines for translation with a medical interpreter, cross-cultural interview questions, and guidelines for serious medical illnesses. The clinical recommendations are consensus-based and referenced to medical experts.

National Consensus Project for Quality Palliative Care. The National Consensus Project for Quality Palliative Care (2004) clinical practice guidelines were developed based on patient need by five major United States palliative care organizations: the American Academy of Hospice and Palliative Medicine, the Center to Advance Palliative Care, Hospice and Palliative Nurses Association, Last Acts Partnership, and the National Hospice and Palliative Care Organization. Many individuals and organizations contributed to the development of the guidelines. Patients with a chronic progressive disease, including CKD, are one of the many populations these guidelines are designed to serve. The purpose of these guidelines is to structure an environment that meets the needs of the entire patient and is based on the WHO definition of palliative care (WHO, n.d.). These guidelines are designed to be a resource to the primary care provider dealing with these issues and on what constitutes a good palliative care program. They represent the goals that a good program should attain (rather than a minimum standard), are not mandatory, were developed through expert consensus based on past standards developed by various organizations, and assume continued professional education by the provider. There are eight identified domains to quality palliative care that encompass the physical, social, spiritual, psychological, cultural, ethical and legal aspects, and the care of the imminently dying patient.

Summary

The guidelines for EOL care are

comprehensive and have been developed by expert consensus. Most are recommendations and not a mandatory requirement. What all have shown is that there is much room for practice improvement. All strongly support the team approach and encourage continued professional education. Many have developed valuable resources that are available on the Internet.

Implications for Professional Practice

To be an effective primary or specialty care provider to patients with a chronic illness and their family requires the practitioner to incorporate spiritual, cultural, emotional, educational, and physical aspects into an appropriate plan of care. A heightened awareness of the reality of a chronic illness progressing to a terminal one and planning for inevitability of death will facilitate discussions about EOL issues and advance care planning. Having an in-depth knowledge about the likely progress of the dying process will minimize the patient's feelings of the fear of dying. Asking for their wishes, plans, and goals further fosters a trusting relationship between the patient and provider. Utilizing the rigorously tested tools available will provide an objective assessment of the patient's readiness to discuss these issues. Evaluating the effectiveness of one's interaction is necessary. Because patients absorb only a small percentage of the information presented in educational sessions, repeat interactions are often necessary. The timing and location of the interaction may have a negative or a positive impact on a patient's ability to process information, as does the influence of family members. Establishing an open dialogue with patients as to their specific wishes about who should be involved in the discussion enables practitioners to be culturally sensitive.

Utilizing specialty nursing organization continuing education programs and remaining current with published literature on the subject

will enable nurses to answer questions from patients and families. The ANNA Web site links members and non-members to modules addressing guidelines for patient education in CKD, EOL issues, and the role of the nephrology nurse.

Graduate schools of nursing would do well to incorporate a case-based course on EOL issues. Bringing the subject to a personal level will mean much more to nurses than generally talking about the need to provide for a good death. Studies have shown that the lack of involvement with palliative care comes from the health professional's own sense of discomfort with the topic, either because of educational or emotional reasons. A fault of many programs, either university-based or continuing education, is that nurses are told what to do, but often are not told how to do it or how to do it well.

Further nursing research is needed to develop more objective tools to either plan for or evaluate a good death. The tool to assess the readiness to discuss advance directives is an excellent starting point. Moss (2001) suggests that nurses should look deeper into what criteria define a good or exceptional death, whose perspective is most important, and how the dying experience should be measured. Andershed and Ternstedt (1999) have asked how the staff can support families to help the patient yet still set limits. Knowing what the patient and family want and can do is a necessary requirement to facilitating a good death.

The nephrology community as a whole, and nursing as a major component, should look at the impact of applying the guidelines to the older patient with kidney disease. How are nurses doing today, nearly a decade after the guidelines have been implemented? Few recent studies are available that have taken on this task. Time and resources will continue to be a barrier in this evaluation process. Retrospective cohort studies will be a starting point for nephrology nurses to measure their own effectiveness. Just as planning for EOL care is an

evolutionary process, so is the evaluation of the effectiveness. Developing a prospective study with input from older adults as compared to younger adults should be initiated. This area is ripe for further study and is limited only by the researcher's desire to delve further.

Conclusion

Recognizing that advance care planning is one component of EOL planning will remind the practitioner to look at all components in designing a plan of care for patients. Further, understanding that it is an evolutionary process and should be revisited frequently will enable practitioners to incorporate the understanding that palliative care/hospice should be offered with dialysis, instead of taking an either/or approach.

The unique issues facing the older adult must also be evaluated and discussed with patients and families. An understanding of co-morbid conditions, mental status, and ambulatory status will help determine the probable outcome and success of initiation of treatment. A constant reminder that patients can change their minds at any point needs to be made. As the dialysis population and number of patients with CKD continue to grow, nephrology nurses and the nephrology community are obligated to revisit and evaluate the success of their personal implementation of the guidelines that have been so rigorously formulated.

References

- American Academy of Family Physicians. (2003). *Recommended curriculum guidelines for family practice residents*. End-of-life care [Electronic Version]. AAFP Reprint No. 269.
- American Association of Colleges of Nursing (AACN). (1998). *Peaceful death: Recommended competencies and curricular guidelines for end-of-life nursing care*. Washington, DC: Author. Retrieved June 26, 2008, from <http://www.aacn.nche.edu/Education/deathfin.htm>
- American Nephrology Nurses' Association (ANNA) Advanced Practice Special Interest Group. (2004). Advanced practice in nursing: Ethical and role issues in end-of-life care. *Nephrology Nursing Journal*, 31(1), 87-88.
- American Nephrology Nurses' Association (ANNA) Ethics Committee. (2007). *End-of-life decision-making and the role of the nephrology nurse. Module 1. Techniques to facilitate discussion for advanced care planning*. Retrieved June 26, 2008, from http://www.annanurse.org/cgi-bin/WebObjects/ANNANurse.woa/wa/viewSection?s_id=1073744057&ss_id=536873360
- American Nurses Association (ANA). (1997, January 7). *Statement by ANA on measuring the quality of care at the end of life*. Press Release. Retrieved July 1, 2008, from <http://www.needlestick.org/pressrel/1997/endoflife.htm>
- American Psychological Association (APA). (2001). *APA activities on end-of-life care*. Retrieved June 26, 2008, from <http://www.apa.org/pi/eol/activities.html>
- Andershed, B., & Ternstedt, B.M. (1999). Involvement of relatives in care of the dying in different care cultures: Development of a theoretical understanding [Electronic Version]. *Nursing Science Quarterly* 12(1), 45-51.
- Berns, R., & Colvin, E.R. (1998). The final story: Events at the bedside of dying patients as told by survivors. *ANNA Journal*, 25(6), 583-587.
- Braveman, C., & Cohen, L.M. (2002). Discontinuation of dialysis: The role of hospice and palliative care [Electronic Version]. *Quarterly Newsletter of the American Academy of Hospice and Palliative Medicine*, 3(1), 15-17.
- Burrows-Hudson, S., & Prowant, B.F. (2005). *Nephrology nursing standards of practice and guidelines for care*. Pitman, NJ: American Nephrology Nurses' Association.
- Calvin, A.O. (2004). Haemodialysis patients and end-of-life decisions: A theory of personal preservation. *Journal of Advanced Nursing*, 46(5), 558-566.
- Calvin, A.O., & Eriksen, L.R. (2006). Assessing advance care planning readiness in individuals with kidney failure. *Nephrology Nursing Journal*, 33(2), 165-170.
- Cohen, L.M., & Germain, M.J. (2004). Measuring quality of dying in end-stage renal disease. [Electronic Version]. *Seminars in Dialysis*, 17(5), 376-379.
- Cohen, L.M., Germain, M.J., Poppel, D.M., Woods, A., & Kjellstrand, C.M. (2000). Dialysis discontinuation and palliative care [Electronic Version].

- American Journal of Kidney Diseases*, 36(1), 140-144.
- Cohen, L.M., Moss, A.H., Weisbord, S.D., & Germain, M.J. (2006). Renal palliative care [Electronic Version]. *Journal of Palliative Medicine*, 9(4), 977-992.
- Cohen, L.M., Poppel, D.M., Cohn, G.M., & Reiter, G.S. (2001). A very good death: Measuring quality of dying in end-stage renal disease [Electronic Version]. *Journal of Palliative Medicine*, 4(2), 167-172.
- Danko, H. (2002). Initiatives in quality care at the end of life. *Nephrology Nursing Journal*, 29(2), 210.
- Davison, S.N. (2001). Quality end-of-life care in dialysis units. *Seminars in Dialysis*, 15(1), 41-44.
- Debate of the Age Health and Case Study Group. (1999). *The future of health and care of older people: The best is yet to come*. London: Age Concern.
- Dethloff, S.B. (2004). A family decision to discontinue dialysis treatment for a parent: An advanced practice nurse (APN) guided process. *Nephrology Nursing Journal*, 31(4), 443-444.
- Dobbins, E.H. (2005). Helping your patient to a "good death" [Electronic Version]. *Nursing2005*, 35(2), 43-45.
- Hackett, A.S., & Watnick, S.G. (2007). Withdrawal from dialysis in end-stage renal disease: Medical, social, and psychological issues. *Seminars in Dialysis*, 20(1), 86-90.
- Hammes, B.J., & Rooney, B.L. (1998). Death and end-of-life planning in one Midwestern community. *Archives of Internal Medicine*, 158, 383-390.
- Hayslip, D. (1998). Death with dignity. *ANNA Journal*, 25(6), 588.
- Hines, S.C., Babrow, A.S., Badzek, L., & Moss, A.H. (1997). Communication and problematic integration in end-of-life decisions: Dialysis decisions among the elderly [Electronic Version]. *Health Communication*, 9(3), 199-217.
- Holley, J.L., Hines, S.C., Glover, J.J., Babrow, A.S., Badzek, L.A., & Moss, A.H. (1999). Failure of advance care planning to elicit patients' preferences for withdrawal from dialysis. *American Journal of Kidney Diseases*, 33, 688-693.
- Jablonski, A. (2007). Level of symptom relief and the need for palliative care in the hemodialysis population [Electronic Version]. *Journal of Hospice and Palliative Nursing*, 9(1), 50-58.
- Kidney End-of-Life Coalition. (n.d.). *Kidney End-of-Life Coalition*. Retrieved June 26, 2008, from <http://www.kidneyeol.org>
- Kurella, M., Covinsky, K.E., Collins, A.J., & Chertow, G.M. (2007). Octogenarians and nonagenarians starting dialysis in the United States [Electronic Version]. *Annals of Internal Medicine*, 146(3), 177-183.
- Lynn, J., Teno, J.M., Phillips, R.S., Wu, A.W., Desbiens, N., Harrold, J., et al. (1997). Perceptions by family members of the dying experience of older and seriously ill patients [Electronic Version]. *Annals of Internal Medicine*, 126(2), 97-106.
- Mitchell, A.M., Gale, D.D., Matzo, M.L., McDonald, M.C., & Gadmer, N. (2002). Critique of transcultural practices in end-of-life clinical nursing practice [Electronic Version]. *Nursing Forum* 37(4), 24, 30-31.
- Moss, A.H. (2000). A new clinical practice guideline on initiation and withdrawal of dialysis that makes explicit the role of palliative medicine [Electronic Version]. *Journal of Palliative Medicine*, 3(3), 253-260.
- Moss, A.H. (2001). Measuring the quality of dying [Electronic Version]. *Journal of Palliative Medicine*, 4(2), 149-151.
- Moss, A.H., Hozayen, O., King, K., Holley, J.L., & Schmidt, R.J. (2001). Attitudes of patients toward cardiopulmonary resuscitation in the dialysis unit. *American Journal of Kidney Diseases*, 38, 847-852.
- Nahm, E.S., & Resnick, B. (2001). End-of-life treatment preferences among older adults [Electronic Version]. *Nursing Ethics*, 8(6), 533-543.
- National Consensus Project for Quality Palliative Care. (2004). *Clinical practice guidelines for quality palliative care*. Retrieved June 26, 2008, from <http://www.nationalconsensusproject.org>
- Neely, K.J., & Roxe, D.M. (2000). Palliative care/hospice and the withdrawal of dialysis [Electronic Version]. *Journal of Palliative Medicine*, 3(1), 57-67.
- Perry, E., Swartz, J., Kelly, G., Brown, S.L., & Swartz, R.D. (2003). Palliative care in chronic kidney disease: Peer mentoring program personalizes advance directives discussions. *Nephrology News & Issues*, 17(8), 28-31.
- Poppel, D.M., Cohen, L.M., & Germain, M.J. (2003). The renal palliative care initiative [Electronic Version]. *Journal of Palliative Medicine*, 6(2), 321-326.
- Price, C.A. (2003). Resources for planning palliative and end-of-life care for patients with kidney disease. *Nephrology Nursing Journal*, 30(6), 649-656.
- Renal Physicians Association (RPA) & the American Society of Nephrology (ASN). (2000). *Clinical practice guideline: Shared decision-making in the appropriate initiation of and withdrawal from dialysis*. Washington, DC: Author.
- Robert Wood Johnson Foundation (RWJF). (2003). ESRD workgroup final report summary on end-of-life care: Recommendations to the field. *Nephrology Nursing Journal*, 30(1), 59-63.
- Searight, H.R., & Gafford, J. (2005). Cultural diversity at the end of life: Issues and guidelines for family physicians [Electronic Version]. *American Family Physician*, 71(3), 515-516.
- Smith, R. (2000). A good death [Electronic Version]. *British Medical Journal*, 320, 129-230.
- Steinhauser, K.E., Clipp, E.C., McNeilly, M., Christakis, N.A., McIntyre, L.M., & Tulsky, J.A. (2000). In search of a good death: Observations of patients, families, and providers [Electronic Version]. *Annals of Internal Medicine*, 132(10), 825-832.
- Tyree, T.L., Long, C.O., & Greenberg, E.A. (2005). NPs vs. other healthcare providers in end-of-life care [Electronic Version]. *The Nurse Practitioner*, 30(3), 58-59.
- U.S. Renal Data Systems (USRDS). (2007). *USRDS 2007 annual data report: Atlas of chronic kidney disease and end-stage renal disease in the United States*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. Retrieved July 30, 2008, from <http://www.usrds.org/adr.htm>

continued on page 483

Nephrology Nursing Journal Editorial Board Statements of Disclosure

In accordance with ANCC-COA governing rules *Nephrology Nursing Journal* Editorial Board statements of disclosure are published with each CNE offering. The statements of disclosure for this offering are published below.

Paula Dutka, MSN, RN, CNN, disclosed that she is a consultant for Hoffman-La Roche and Coordinator of Clinical Trials for Roche.

Patricia B. McCarley, MSN, RN, NP, disclosed that she is on the Consultant Presenter Bureau for Amgen, Genzyme, and OrthoBiotech. She is also on the Advisory Board for Amgen, Genzyme, and Roche and is the recipient of unrestricted educational grants from OrthoBiotech and Roche.

Holly Fadness McFarland, MSN, RN, CNN, disclosed that she is an employee of DaVita, Inc.

Karen C. Robbins, MS, RN, CNN, disclosed that she is on the Speakers' Bureau for Watson Pharma, Inc.

Planning for a Good Death

continued from page 458

- Valente, S. (2007). *Fact sheet on end-of-life care: What are older adults' mental health needs near the end of life?* Washington, DC: American Psychological Association. Retrieved July 30, 2008, from [http://www.apa.org/pi/eol/fact sheet1.pdf](http://www.apa.org/pi/eol/fact%20sheet1.pdf)
- Valente, S., & Haley, B. (2007). *Culturally diverse communities and end-of-life care*. Washington, DC: American Psychological Association. Retrieved July 30, 2008, from <http://www.apa.org/pi/eol/fsculturallydiverse.pdf>
- Weisbord, S.D., Carmody, S.S., Burns, F.J., Rotondi, A.J., Cohen, L.M., Zeidel, M.L., et al. (2003). Symptom burden, quality of life, advance care planning and the potential value of palliative care in severely ill hemodialysis patients. *Nephrology Dialysis Transplantation*, *18*, 1345-1352.
- World Health Organization (WHO). (n.d.). *WHO definition of palliative care*. Retrieved July 30, 2008, from [http://www.who.int/cancer/palliative/definition/en/Additional Reading](http://www.who.int/cancer/palliative/definition/en/Additional%20Reading)
- Price, C. (1998). Nephrology community initiatives to develop guidelines for end-of-life care. *ANNA Journal*, *25*(6), 573.