

## **Nephrology Nurse's Role in Palliative and End-of-Life Care**

The American Nephrology Nurses Association recognizes the importance of palliative and end-of-life (EOL) care within nephrology nursing practice. A position statement on this topic provides nephrology nurses (and other nurses caring for persons with chronic kidney disease) information and guidelines related to palliative and EOL care. In addition, it will help to identify, communicate, and encourage recognition of the role of the nephrology nurse in assisting persons and their families with decision making about palliative and EOL care.

### **It is the position of ANNA that:**

- Nephrology nurses are in a unique position to contribute to the body of knowledge and direct care interventions related to palliative and EOL care in populations with advanced chronic kidney disease (CKD) or unresolved acute kidney injury (AKI).
- People living with CKD often have multiple comorbidities, high rates of cardiovascular disease, and shortened lifespans. These health challenges highlight the need for people living with kidney disease to receive education regarding palliative and EOL care in an environment that supports their right to make informed decisions about their care needs.
- CKD is associated with many unpleasant symptoms, such as pruritus, insomnia, nausea, muscle cramps, fatigue, anorexia, chronic pain, anxiety, and depression that affect quality of life (Flythe et al., 2018). An organized, evidence-based approach to palliative care for symptom management should be implemented in all renal care settings. The use of valid and reliable tools is important to consider supporting measurement of effective shared decision making and symptom management.
- Comprehensive palliative and EOL care should be person/family-centered to address social, cultural, psychological, spiritual, religious, and physical concerns.
- Nephrology nurses individually, and as part of the interdisciplinary team, support efforts to provide person-centered care that includes interactive dialogue and care coordination (i.e., transition from one area of care to another and as the person transitions across the disease trajectory) for palliative and EOL care.
- Nephrology nurses have the professional and ethical responsibility for obtaining the competencies to help provide person-centered care through referrals to palliative care and EOL programs, attending professional education programs, collaborating with the interdisciplinary team and with external care providers, and using effective communication and listening skills to develop person-centered goals of care and decisions about palliative and EOL care.
- Nephrology nurses have the responsibility to be cognizant of their personal feelings and values regarding palliative and EOL care and not allow personal assumptions and feelings to influence the person's decision-making process.

- Nephrology nurses have knowledge and must be aware of when and whom to contact in assisting persons with CKD to provide palliative and EOL care conversations, discuss advance care planning, and initiate nursing interventions to manage symptoms.
- Nephrology nurses are committed to contributing and supporting evidence-based practice and the development of clinical practice guidelines for palliative and EOL care for individuals with advanced CKD.
- ANNA supports the National Consensus Project's *Clinical Practice Guidelines for Quality Palliative Care* (4th edition), as it relates to nephrology nursing care.

## Background and Rationale

ANNA recognizes the importance of person/family-centered care that considers what matters most regarding wishes and preferences for care. Persons must be provided information to assist in making informed, personalized decisions regarding their treatment options. This includes kidney replacement therapies (hemodialysis, peritoneal dialysis, continuous renal replacement therapy, and transplantation) and medical management without dialysis. Palliative care may be appropriate for some individuals receiving kidney replacement therapies. The surprise question — “Would I be surprised if this patient died in the next 6 months?” — has demonstrated validity in adults with CKD and end-stage renal disease (ESRD). Despite emerging evidence regarding palliative and EOL care in individuals with CKD, there remains a need for future research exploring the best way to deliver palliative and EOL care in this population. Nephrology nurses must assume responsibility for initiating discussion of goals of care by encouraging communication with the person and family. In addition, nephrology nurses should have a broad understanding about a palliative approach to CKD care and strategies to ameliorate symptoms and minimize suffering for persons with advanced CKD. Nephrology nurses must recognize and respect the advance care planning decisions a person may choose or refuse. It is also important that nephrology nurses honor the person's decision to revise advanced directives anytime during the disease trajectory. It is the goal of this position statement to encourage professional discussions, educational programming, evidence-based clinical projects, research, and future development of clinical practice guidelines that will assist in the inclusion of palliative care for those with advanced CKD.

## Review of Relevant Literature

The ESRD Workgroup, funded by the Robert Wood Johnson Foundation from 2000-2002, developed recommendations for nephrology care providers on ways to advance palliative care and quality of life for individuals receiving dialysis (2003). In 2000, the Renal Physicians Association (RPA) developed clinical practice guidelines for “Shared Decision-Making in the Appropriate Initiation of and Withdrawal from Dialysis” with a revision in 2010.

In 2008, the former ANNA Ethics Committee presented an educational module on advance care planning, which included an informal survey. That survey identified several barriers that nephrology nurses perceived to impact advance care planning discussions with their patients. These barriers include lack of confidence in starting the conversation, fear of patient/family reactions, uncertainty that colleagues and supervisors would be supportive, and uncertainty regarding divergent cultural beliefs and practices (Ceccarelli, Castner, & Haras, 2008). Moss (2016) describes the similarity of symptom burden and shortened life span of persons with CKD to those with cancer, suggesting the benefit from early palliative care and advance

care planning in both populations. Haras (2014) reported limited studies related to palliative or hospice care for patients in the U.S. with ESRD, which should be seen as an opportunity for nephrology nurses to lead and participate in future research. In 2014, the United States Renal Data System (USRDS) published "Special Study Center on Palliative and End-of-Life Care," which reinforces that palliative and hospice care is underutilized, often comes close to the time of death instead of proactively, and many persons have no advance medical directive completed prior to entering either type of program.

### **Evidence to Support the Position Statement**

The USRDS Special Study Center (SSC) on Palliative and End-of-Life Care (2014) provided "nationally representative information about a domain of ESRD care for which little information is currently available to guide policy and practice" (p. 212). This study revealed that despite more attention on the subject of palliative and EOL care, advance medical directives are only completed by 35%-38% of persons with ESRD. The largest group starting hemodialysis are those persons 75 years and older, and the second largest group starting dialysis are those persons aged 65 -74 years old. In the first year on dialysis, the mortality rate is highest in those 65 years old and older.

Morbidity and mortality rates increase with CKD staging. Individuals with CKD have higher mortality rates than those without CKD, including those with cancer, diabetes, or cardiovascular disease. Mortality rates almost triple in persons with CKD who are 85 years old and older. The USRDS data for 2016 continues to report that 20%-25% of people on renal replacement therapy (RRT) withdraw from treatment annually (period from 2000-2013). Eighty-two percent of people on RRT withdraw from dialysis before transitioning to hospice care. The number of persons with ESRD admitted to an intensive or coronary care unit during the last 90 days of life has increased from 50% to 63% (USRDS, 2016).

Accessing acute hospital services in place of hospice use has significant emotional and psychological costs for persons with CKD and their families, as well as significant economic cost. The estimated health care cost of an ESRD patient who uses hospice care for more than 2 weeks at the end of life is \$1,553 versus \$11,036 if that patient is not referred to hospice until the final 2 days of life (USRDS, 2016).

The literature further reports persons with ESRD more often die in the hospital and have a lower use of hospice services compared to patients with heart failure, for example. Sixty-nine percent of the 138 deaths occurred during an inpatient admission; yet, only 28% of these patients had discussed EOL issues with their medical team in the year prior to death. (Arulkumaran, Szawarski, & Philips, 2012).

The review of the literature points to the need for access to quality palliative/EOL care and for all persons living with CKD to have an advance medical directive. Nephrology nurses have the potential to benefit professionally by engaging in activities that support initiation of discussions around goals and prognosis and that encourage patient-family communication to reinforce the broader understanding of the palliative approach in nephrology care to ameliorate symptoms and to minimize suffering.

### **Glossary**

Advance care planning (ACP) – a process of communication among patient, family, and friends, and the health care team in which the patient's preferences for a surrogate and for future medical care are determined prospectively (sometimes including the completion of a written medical directive), updated periodically, and respected when the patient no longer has the capacity to participate in medical decision-making (RPA, 2010).

Advance medical directive (AMD) – an oral or written statement by a patient with decision-making capacity expressing his/her preferences for a surrogate and/or future medical care in the event he/she becomes unable to participate in medical decision-making. All 50 states have one or more laws recognizing written advance directives. There are two types of advance directives: a health care proxy and a living will. The health care proxy designates a person to make decisions if the patient loses decision-making capacity. The health care proxy is known in some states as a medical power of attorney or a durable power of attorney for health care. The living will, also known as instruction directive, indicates the patient's wishes that are to be followed if he/she loses decision-making capacity. Wishes may refer to care in the event of particular medical conditions such as terminal illness or a persistent vegetative state. In some states, both of these functions are combined in the living will (RPA, 2010).

End-of-life (EOL) care – a subset of palliative care that is provided to patients who are terminally ill (RPA, 2010).

End-stage renal disease (ESRD) – permanent kidney failure that requires a regular course of dialysis or a kidney transplant (Centers for Medicare & Medicaid Services, 2018).

External care provider – a health care provider (for example, nurse, physician, medical assistant, social worker) or facility such as an acute or skilled nursing facility or rehabilitation center, caring for a person living with CKD outside of the nephrology care environment.

Family - Families are important and are considered included where ever “person” is mentioned. A family is not just a blood relation. A person can define family as any supportive, personal relationship with another.

Hospice – a team approach to treating the terminally ill patient, usually in the home, that uses the principles of palliative care to help meet the physical, psychological, social, and spiritual needs of the patient and family. Hospice treats the person not the disease; considers the entire family the unit of care; and provides bereavement counseling for the family after the patient's death (RPA, 2010).

Palliative care – patient- and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and facilitating patient autonomy, access to information, and choice (National Quality Forum, 2006).

## References

- Arulkumaran, N., Szawarski, P., & Philips, B. (2012) End-of-life care in patients with end-stage renal disease. *Nephrology Dialysis Transplantation*, 27(3), 879-881. doi:10.1093/ndt/gfs028
- Ceccarelli, C., Castner, D., & Haras, M. (2008). Advance care planning for patients with chronic kidney disease - Why aren't nurses more involved? *Nephrology Nursing Journal*, 35(6), 553-557.
- Centers for Medicare and Medicaid Services. (2018). Stage 2: Critical elements for hospice, end of life and/or palliative care. Retrieved from <https://www.cms.gov/MEDicare/Provider-Enrollment-and-Certification/SurveyCertificationGeninfo/Downloads/CMS-20073-Critical-Elements-Hospice.pdf>

- Flythe, J.E., Hilliard, T., Castillo, G., Ikeler, K., Orazi, J., Abdel-Rahman, E., Pai, A.B., ... Mehrotra, R. (2018). Symptom prioritization among adults receiving in-center hemodialysis: A mixed methods study. *Clinical Journal of the American Society of Nephrology*, 13(5), 735-745. doi:10.2215/CJN.10850917
- Haras, M. (2014). Exploring the evidence for end-of-life care in patients with chronic kidney disease. *Nephrology Nursing Journal*, 41(4), 416-423.
- Moss, A.H. (2016). Palliative care in patients with kidney disease and cancer. In *Onco-nephrology curriculum*. Washington, DC: American Society for Nephrology. Retrieved from <https://www.asn-online.org/education/distancelearning/curricula/onco/Chapter19.pdf>
- National Consensus Project for Quality Palliative Care. (2018) *Clinical practice guidelines for quality palliative care* (4th edition). Richmond, VA: National Coalition for Hospice and Palliative Care. Retrieved from <https://www.nationalcoalitionhpc.org/ncp-guidelines-2018/>
- National Quality Forum. (2006). Palliative care and end-of-life care project view. Retrieved from [http://www.qualityforum.org/projects/palliative\\_care\\_and\\_end-of-life\\_care.aspx](http://www.qualityforum.org/projects/palliative_care_and_end-of-life_care.aspx)
- Renal Physicians Association. (2010). *Shared decision-making in the appropriate initiation of and withdrawal from dialysis*. Rockville, MD: Author.
- Robert Wood Johnson Foundation End-Stage Renal Disease Workgroup (2003). *Completing the continuum of nephrology care: Recommendations to the field (promoting excellence in end-of life care)*. Retrieved from <http://promotingexcellence.org/esrd/>
- United States Renal Data System. (2016). *USRDS annual data report: Incidence, prevalence, patient characteristics, and treatment modalities*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. Retrieved from [https://www.usrds.org/2016/view/v2\\_01.aspx](https://www.usrds.org/2016/view/v2_01.aspx)
- United States Renal Data System. (2014). *USRDS annual data report: USRDS special study center on palliative and end-of-life care*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. Retrieved from [https://www.usrds.org/2014/view/v2\\_11.aspx](https://www.usrds.org/2014/view/v2_11.aspx)

## Suggested Readings

- American Nurses Association. (2015). *Code of ethics for nurses with interpretive statements*. Silver Spring, MD: Author.
- American Nurses Association. (2012). *Nursing care and do not resuscitate (DNR) and allow a natural death (AND) decisions* (Position Statement). Silver Spring, MD: Author. Retrieved from <https://www.nursingworld.org/~4ad4a8/globalassets/docs/ana/nursing-care-and-do-not-resuscitate-dnr-and-allow-natural-death-decisions.pdf>
- Berger, J., Jaikaransingh, V., & Hedayati, S. (2016). End-stage kidney disease in the elderly: Approach to dialysis initiation, choosing modality, and predicting outcomes. *Advances in Chronic Kidney Disease*, 23(1), 36-43.

Castner, D. (2015). Advance care planning and palliative/end-of-life care. In C.S. Counts (Ed.), *Core curriculum for nephrology nursing. Module 2: Physiologic and psychosocial basis for nephrology nursing practice* (6th ed., pp. 242-247). Pitman, NJ: American Nephrology Nurses Association.

Davison, S.N., Levin, A., Moss, A.H., Jha, V., Brown, E.A., Brennan, F., ... Obrador, G.T. (2015). Executive summary of the KDIGO Controversies Conference on Supportive Care in Chronic Kidney Disease: Developing a roadmap to improving quality care. *Kidney International*, 88(3), 446-459. doi:10.1038/ki.2015.110.

Gomez, N. (2017). *Nephrology nursing scope and standards of practice*. Pitman, NJ: American Nephrology Nurses Association.

### **Suggested Tools**

Edmonton Symptom Assessment-Renal:

[http://www.palliative.org/NewPC/\\_pdfs/tools/ESASr%20Renal.pdf](http://www.palliative.org/NewPC/_pdfs/tools/ESASr%20Renal.pdf)

Integrated Palliative Care Outcome Scale-Renal (IPOS-Renal):

<https://pos-pal.org/maix/ipos-renal-in-english.php>

Predicting 6 and 12 month mortality in CKD patients:

[https://qxmd.com/calculate/calculator\\_446/predicting-6-and-12-month-mortality-in-ckd-patients](https://qxmd.com/calculate/calculator_446/predicting-6-and-12-month-mortality-in-ckd-patients)

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