Position Statement

The Nephrology Nurse’s Role in Palliative and End-of-Life Care

The American Nephrology Nurses Association recognizes the importance of palliative 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 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 end-of-life 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 end-of-life (EOL) care in populations with advanced chronic kidney disease (CKD).

- 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 that affect quality of life, such as pruritus, insomnia, nausea, muscle cramps, fatigue, anorexia, chronic pain, anxiety, and depression (Flythe et al., 2018). An organized approach to palliative care for symptom management should be implemented in all renal care settings.

- Comprehensive palliative and EOL care should include individualized considerations for social, cultural, psychological, spiritual, religious, and physical concerns.

- Nephrology nurses, individually and as part of the interdisciplinary team, should support efforts to provide person-centered care that includes discussions and care coordination for palliative and end-of-life 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 advanced medical plans 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 should have knowledge and be aware of when and whom to contact in assisting persons with CKD to provide palliative/EOL care conversations, discuss advance care planning, and initiate nursing interventions to manage symptoms.
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- Nephrology nurses should be 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.


Background and Rationale

The American Nephrology Nurses Association (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 decisions regarding the best treatment options. This includes kidney replacement therapies (hemodialysis, peritoneal dialysis, continuous renal replacement therapy, and transplantation) and no kidney replacement therapy. Palliative care may be appropriate for some individuals receiving kidney replacement therapies. There is a need for research to explore the best way to deliver palliative care for persons with CKD. Nephrology nurses must assume responsibility for initiating discussion of goals of care and prognosis by encouraging communication with the person and family. In addition, nephrology nurse 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 should recognize and respect the advanced care planning decisions a person may choose or refuse. It is also important the nephrology nurse honor the person’s decision to revise advanced directive 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


In 2008, the former ANNA Ethics Committee members 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 identified 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 in and participate in future research. In 2017, 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 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, and these individuals have higher mortality rates than those without CKD, including those with cancer, diabetes, or cardiovascular disease. Mortality rates almost triple in persons 85 years old and older with CKD 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 and lack of hospice use has significant emotional and psychological cost for persons with CKD and their families, as well as significant economic cost. The estimated cost of an ESRD patient who uses hospice care for more than 2 weeks at the EOL have health care costs of $1,553.00 versus $11,036.00 if that patient is not referred to hospice until the final 2 days of life (USRDS, 2016).

USRDS 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.

The review of the literature points to the need for access to quality palliative/EOL care and for all people living with CKD to have an advance medical directive. Nephrology nursing has 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 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(ies) - 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. (U.S. Dept. of Health and Human Services, CMS, National Quality Forum, 2006).

References


**Suggested Readings**


2017 ANA Code of Ethics With Interpretive Statements

*Adopted by the ANNA Board of Directors in TBD*

*ANNA Position Statements are reviewed and reaffirmed biennially.*