ANNA
American Nephrology
Nurses Association

Position Statement

Nephrology Nurse's Role in Kidney Supportive Care, including Palliative and End-of Life Care

The American Nephrology Nurses Association (ANNA) recognizes that kidney supportive care includes palliative and end-of-life (EOL) care for persons with chronic kidney disease (CKD). This position statement provides nephrology nurses (and other nurses caring for persons with CKD) information, and guidelines related to primary palliative care skills including: shared decision-making, treatment preferences, symptom management, advance care planning and EOL care, with a focus on patient quality of life.

It is the position of ANNA that nephrology nurses (APRN and RN) should:

- *contribute to the body of knowledge and direct care interventions* related to kidney supportive care in populations with CKD or unresolved acute kidney injury (AKI).
- *engage in conversations regarding kidney supportive care* in an environment that supports informed decision making and the patients' wishes and values.
- be *involved in policy and advocacy* for all patients because of the physical and financial burdens of kidney replacement therapies (Diamond, et al., 2021; Gelfand, Mandel et al., 2020).
- implement an *evidence-based approach to symptom assessment and management* in all renal care settings. The use of evidence-based validated tools such as the Edmonton Symptom Assessment Scale-Renal (ESAS-R) or the Integrated Palliative Outcome Scale-Renal (IPOS-R) is important to optimize symptom assessment and management and patients' quality of life (Davison et al., 2024).
- *encourage and participate in the provision of comprehensive kidney supportive care* which is holistic and person/family-centered to address social, cultural, psychological, spiritual, religious, and physical concerns.
- *employ shared decision-making as a key component of patient-centered care*, in making decisions with individuals about their preferred treatments.
- *become competent in providing person-centered kidney supportive care* through effective communication and listening skills, collaboration with interprofessional teams and community services, and referrals to supportive care as a component of their professional and ethical responsibilities in patient care.
- *recognize their personal comfort, biases and beliefs* regarding supportive, palliative, and EOL care and not allow these to influence a person's decision-making process.
- be *committed to participating in professional discussions, educational programming, evidence-based clinical projects, research, policy and advocacy, and future development* of clinical practice guidelines that will assist in the inclusion of supportive care for those with advanced CKD.

Background and Evidence

- More recently, the term “supportive care” has been used instead of “palliative care” as it is generally preferred by patients and health care professionals. Supportive care generally refers to the care that the nephrology team provides, while palliative care refers to the care provided by specialists in palliative care” (Davison et al., 2024).
- Approximately 14% of persons needing palliative care actually receive it (WHO, 2020).
- Older adults experience higher symptom burden and higher mortality on dialysis, and represent the growing number of dialysis patients, with median age 74 (Chou et al., 2023).
- Barriers to palliative care include cultural and social beliefs, and lack of awareness and misconceptions of what palliative care is (WHO, 2020).
- Facilitators to palliative care include specific resources, training, and support to enhance primary palliative care skills (de Barbieri et al., 2024).
- Significant policy changes are needed “to improve patient-centered care and the quality of life for seriously ill patients with kidney disease” (Diamond et al., 2021, p. 529).
- The review of the literature points to the need for healthcare providers to be competent in all aspects of comprehensive kidney supportive care, including access to quality palliative/EOL care and for all persons living with CKD to have an advance medical directive. Nephrology nurses have the opportunity to improve a holistic, patient-centered approach to care by engaging in activities that support initiation of discussions around patient goals and prognosis and encouraging patient-family communication to reinforce the broader understanding of the palliative approach to ameliorate symptoms and to minimize suffering.
- ANNA supports the National Consensus Project’s *Clinical Practice Guidelines for Quality Palliative Care* (4th edition), as it relates to nephrology nursing care.

Glossary

Advance Care Planning (ACP) – an ongoing process of communication among patient, family, and friends, and the health care team in which the individual’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 (NIA, 2022; RPA, 2010).

Advance Directive (AD)/Advance Medical Directive (AMD) – an oral or written statement by an individual with decision-making capacity expressing their preferences for a surrogate and/or future medical care in the event they become 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 an instruction directive, indicates the patient’s wishes that are to be followed if they lose decision-making capacity. Wishes may refer to care in the event of medical conditions such as terminal illness or a persistent vegetative state. In some states, both functions are combined in the living will (NIA, 2022; RPA, 2010).

End-of-life (EOL) care – support and medical care provided to those who are terminally ill at the time surrounding death (NIA, 2022; RPA, 2010).

Hospice – a team approach to treating the terminally ill individual, usually in the home, that uses the principles of palliative care to help meet the physical, psychological, social, and spiritual needs of the individual 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 individual’s death (RPA, 2010).

Kidney supportive care – involves the components of shared decision-making, symptom management, crisis planning, advance care planning, spiritual care, integration with community services, and end-of-life care considerations and bereavement (Davison et al., 2024). Which includes palliative care and end of life care.

Palliative care – patient- and family-centered approach to improve quality of life in persons with life-threatening illnesses that "prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual" (WHO, 2020, para 1).

Shared decision-making - "Shared decision-making is the recognized preferred model for medical decision-making because it addresses the ethical need to fully inform individuals about the risks and benefits of treatments, as well as the need to ensure their values and preferences play a prominent role" (RPA, 2010, p. 1).

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Suggested Readings

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Suggested Tools

Edmonton Symptom Assessment-Renal:
https://www.albertahealthservices.ca/frm-20351.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

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Adopted by the ANNA Board of Directors in August 2024

ANNA Position Statements are reviewed and reaffirmed biennially.