Seminars in Oncology Nursing, Vol 00, No 00 (), 2018: pp 1–11

Advance Care Planning and End-of-Life Decision Making for Patients with Cancer

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Objective: *To highlight the importance, challenges, and evolution of advance care planning for patients with cancer.*

Data Sources: *Peer-reviewed journal articles and clinical guidelines.*

Conclusion: *Advance care planning is fundamental to support the personhood of patients with advanced cancer. Patients must be encouraged by physicians and nurses to articulate what matters and provides meaning to them as they live, cope, and receive treatment for their cancer.*

Implications for Nursing Practice: *Nurses can facilitate advance care planning and primary palliative care, to support patients and families to make informed and value-concordant decisions regarding cancer and end-of-life treatments.*

Key Words: *advance care planning, advance directives, cancer, value-concordant care .*

Advance care planning (ACP) is an essential process by which patients with serious illnesses are empowered to articulate their personal values, preferences, and goals to make decisions for their future care. Because ACP is an important domain in providing high-quality palliative care, all physicians and nurses have an obligation to openly discuss prognosis, the uncertainty of treatment outcomes, and provide recommendations for end-of-life care options, at times that are appropriate for each individual relative to his or her disease course. This responsibility is critical for patients to achieve closure, spend meaningful time with their loved ones, and die with dignity. Though widely recognized as an integral component of oncologic care, ACP has not been systematically implemented into everyday practice. Further research is needed to facilitate informed and personalized medical decision-making across the treatment trajectory and at the end of life.

The primary aim of this review article is to emphasize the undeniable value, current challenges, and recent improvements in supporting

This research was funded in part through the NIH/NCI Cancer Center Support Grant P30 CA008748.

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0749-2081
https://doi.org/10.1016/j.soncn.2018.06.012

optimal ACP. Based on a PubMed database search for the most relevant and updated literature pertaining to ACP in patients with cancer, we provide a brief description of the origin and impact of ACP for patients with cancer, summarize the common instruments used for documenting advance directives and patient preferences, and highlight the myriad challenges of incorporating high-quality ACP into standard oncologic practice. We then summarize current research that seeks to improve communication techniques, establish models for patient-centered and values-focused care, and define a standardized set of ACP guidelines. The article concludes by specifically addressing the importance of ACP for oncology nursing practice and how nurse-led interventions that utilize primary palliative care skills can enhance end-of-life decision-making for patients with cancer.

ACP: History, Impact, and Documentation

ACP was developed as a result of legal recognition of self-determination and the right of patients or their caregivers to decline life-sustaining treatment or interventions. In the 1970s and 1980s, two landmark cases in the United States involved young women in their twenties who were in persistent vegetative states and whose family members sought removal of life-sustaining interventions, such as ventilatory support and tube feeding. The case of Karen Ann Quinlan in 1976 was the first right-to-die case in the US, and ultimately led to California state legislation of the Natural Death Act of 1976, which allowed individuals to express in advance their wishes for their medical care if terminally ill or if lacking the capacity to make decisions. The case of Nancy Cruzan in 1983 led to the US Supreme Court stipulating that though individuals have the right to die and forgo life-sustaining measures, every state can also govern and set standards to guide these individual rights. As a result, the US Congress passed the Patient Self-Determination Act in 1990. The Patient Self-Determination Act requires that health care institutions provide information to patients upon admission about their rights in decision-making and the state policies for making advance directives.[1] These two cases established a new standard for patient autonomy with advance directives, and provided insight into the importance of ACP and the complex relationship between patients, caregivers, and health care providers in end-of-life decision-making.

ACP discussions for patients with cancer are dynamic, complex, and unique to each individual's medical condition and values. Patients must be prompted and supported as they receive disease-directed therapies to express their care goals and make decisions for their future care that are congruent with their wishes. These conversations may evolve over time, and represent a balance between patient autonomy and the input and guidance from caregivers and health care teams.[2,3] Decision-making and ACP discussions must also attend to the culture and relationship between patients and their family members. For some patients of minority ethnic groups, cultural values and family dynamics have greater influence on end-of-life decision-making. Oncology providers should ask for preferences on how patients wish to receive information about end-of-life options and prognosis, recognizing that a family-centered approach for making medical decisions may be more effective for certain cancer patients.[4–6] Successful and culturally appropriate ACP therefore concentrates on eliciting patient and family values, reviewing possible clinical scenarios, and discussing appropriate end-of-life care options, in relation to a patient's prognosis.

Though ACP discussions are complex and challenging, the impact for patients with cancer is substantial. Without ACP, there is an increased risk for patients to receive undesired life-sustaining measures and value-discordant care. In a landmark analysis of data from the Health and Retirement Study, Silveira et al[7] showed that many patients needed to make decisions at a time when they lacked the capacity to do so. Moreover, those patients who had advance directives or who designated a durable power of attorney received care that was consistent with their preferences. This study also demonstrated a positive correlation between those patients who had the opportunity to articulate their wishes and less aggressive care, with 92.7% of patients with advance directives wanting limited care compared with 1.9% desiring all care possible.[7] ACP may help patients with cancer participate more fully in treatment decision-making, resulting in less chemotherapy and cancer-directed treatment in the last few weeks of life, fewer hospitalizations, and increased hospice utilization.[8,9]

While the focus of ACP is on having conversations between patients, providers, and families, it

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