
COPING ISSUES AMONG PEOPLE LIVING WITH ADVANCED CANCER

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OBJECTIVES: *To provide an overview of the complex issues and communication needs of patients and families coping with advanced cancer and discuss issues related to their physical, psychosocial, spiritual, and emotional needs.*

DATA SOURCES: *Published articles and personal experience.*

CONCLUSION: *The response to illness throughout the disease continuum is a dynamic process for both patient and caregiver. The nurse has a responsibility to be a patient advocate, and serve as a trusted caregiver and resource.*

IMPLICATIONS FOR NURSING PRACTICE: *Oncology nurses are in a pivotal position to assure that communication throughout the continuum demonstrates and incorporates awareness of patient and family beliefs and quality-of-life needs.*

KEY WORDS: *Dying, decision-making, communication, end of life, advocacy, quality of life.*

THE DIAGNOSIS of cancer is an unsettling intrusion into the lives of patients and their families. A cancer diagnosis is often accompanied by an uncomfortable and increased awareness of one's mortality,

resulting in patients taking a closer look at their lives. Whether newly diagnosed or living with advanced cancer, this self-assessment may cause the individual to be more conscious of life and make choices that are more congruent with the person's desires.¹ Ironically, the cancer diagnosis is often described as a turning point – and sometimes even a blessing – by those who transform their lives in a positive manner. Whether or not individuals are declared “cured of cancer,” lingering uncertainties affect how they experience their lives over the long term.² Living with advanced cancer entails an ongoing awareness of the fragility of life as people seek to organize their lives to incorporate treatment and personal goals.

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Because the diagnosis of cancer affects the physical, psychosocial, spiritual, and emotional well-being of both patient and family, it is important for the nurse to assess and respond to the needs, goals, and beliefs of the patient and family throughout the continuum of care. The patient and family response to illness and decision-making is a dynamic changing process and it will require assistance to help them develop their coping skills and obtain the resources that may be required as they live with advanced disease and face end-of-life issues.

COPING WITH THE DIAGNOSIS

Effective communication is one of the most important aspects of care at the time of the patient's diagnosis. Addressing issues such as fear or dying, the need for truthful information, what information is necessary, and what information the patient and family desire will help them cope at the time of diagnosis and provide continued support during the course of care.

Fear of Dying

The majority of patients think about dying at the time of diagnosis and must have the opportunity to share their concerns without the health care professional dismissing the conversation as 'unnecessary,' 'thinking negatively,' or 'untimely.'³ Education about disease progression and the dying process may help with emotion-laden questions, such as whether to continue treatment versus whether to discontinue treatment.

Twenty-one year old Brianna said, "My mother didn't want me to talk about it, I think it scared her more than it scared me. None of my doctors wanted to talk about it either, thinking I was being negative rather than just wanting to know. I searched book-stores for any information I could find and that helped, but I couldn't share it with anyone I knew...it was taboo. I felt pretty alone."

Contrary to the belief that talking about dying will cause psychological harm, Quill and colleagues⁴ report that it is often the inability to articulate fears and concerns that can increase depression and anxiety in patients. Findings from Alexi et al⁵ indicate that conversations about

end-of-life issues result in the positive outcomes of less depression, improved satisfaction with informed decision-making, less use of aggressive and futile care such as dialysis and ventilators, fewer ICU deaths, improved use of available resources, and better quality of life and death. Aggressive care near the end of life is associated with worse patient quality of life and worse bereavement adjustment by the family.⁵ These findings reinforce the importance and need for end-of-life discussions to help patients and family members cope and adjust to their diagnosis and future transitions.

THE NEED FOR TRUTH-TELLING

Findings from several studies on truth-telling indicate that 91% to 98% of all cancer patients want to be told the truth about their disease and prognosis.^{6,7} It is worth questioning the underlying cause of resistance to truth-telling by health care providers. Is it fear of taking away hope? Health care providers must examine their own fears of death, their sense of helplessness when a patient is given a poor prognosis, their difficulty in remaining present in the midst of pain, grief, regret or anger of patients and families to provide information and support for the patient and family.³

As a caring health care professional, it is difficult to witness the pain of others without wanting to soften the blow or perhaps avoid the conversation altogether. However, without truthful information about natural disease progression and prognosis, patients cannot make informed or autonomous decisions. It is the responsibility of the entire health care team to ensure that necessary information is adequately communicated, otherwise patients and families facing advanced disease may refrain from making necessary preparations, including preparation of wills and advanced directives, mortuary arrangements, financial planning, and personal closure for life's final months and days.⁶

OVERCOMING BARRIERS TO RECEIVING INFORMATION

Providing truthful information is only the beginning. The next step is to assure the information has been received and understood by the patient and family. The family may happily declare that

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