Original Article

Cancer Caregivers Advocate a Patient- and Family-Centered Approach to Advance Care Planning

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Abstract

Context. Cancer caregivers have important roles in delivering practical, emotional, and end-of-life support to patients; however, they express multiple unmet needs, particularly information on future care planning. Early regular communication and decision making may improve access to timely information, alleviate anxiety, reduce uncertainty, and improve coping strategies.

Objectives. This study examines how cancer caregivers view advance care planning (ACP) to inform an ACP program in an Australian cancer center.

Methods. This study used a qualitative descriptive design with grounded theory overtones. Eighteen caregivers of patients from lung and gastrointestinal tumor streams participated in focus groups or semistructured interviews, which incorporated the vignette technique.

Results. Caregivers believe that, although confronting, ACP discussions can be helpful. Conversations are sometimes patient initiated, although caregivers may intend to sensitively broach conversations over time. Findings highlight the impact of caregiver hierarchies, adaptive family decision-making styles, and complex cultural influences on decision making. Some caregivers may develop subsidiary care intentions, based on "knowing" or overriding patients' desires. Hindrances on caregivers supporting patients' ACPs include limited information access, patient or caregiver resistance to engage in conversations, and ACPs association in oncology with losing hope. Many caregivers wanted professional support and further opportunities to obtain information, develop subsidiary plans, and help patients engage in ACP discussions.

Conclusion. Findings highlight the influence of cancer caregivers and family dynamics over ACP decisions and actualization of future care plans. A patient- and

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family-centered care approach to ACP, promoting shared decision making and caregiver support, is recommended. Given that caregivers may override and, plausibly, misinterpret patients' desires, caregivers' subsidiary planning warrants further investigation. J Pain Symptom Manage 2014;47:1064–1077.

Key Words

Advance care planning, cancer, caregivers, shared decision making, qualitative research, decision making

Introduction

Family caregivers assume an important role in the delivery of practical, emotional, and end-of-life (EOL) support for patients with advanced cancer,[1] with recognized direct and indirect detrimental effects on their psychosocial, physical, emotional, and financial well-being.[2–4] A caregiver (The term "caregiver" is used interchangeably with the term "family caregiver" throughout this article.) may be a relative, friend, or partner who has a significant relationship and provides assistance (physical, social, and/or psychological) to a cancer patient.[5] Cancer caregivers continue to report multiple unmet needs,[6,7] in particular informational needs relating to prognosis, options for future treatment, and EOL symptom management.[8,9] As "they do not know what they do not know,"[10] encouraging regular communication and decision making at the earliest opportunity will possibly improve patient and caregiver access to timely and clear information, alleviate anxiety, reduce uncertainty, and improve coping strategies.[11,12]

A patient-centered approach to cancer treatment planning is widely recommended in Western cultures based on the principles of patient autonomy and shared decision making.[13,14] However, cancer patients may wish for their family caregivers to be involved in decisions about their medical care and may even choose to delegate medical decisions to their caregivers. The influence of family caregivers is particularly relevant with regard to decisions about EOL care when patients may no longer be competent to make decision for themselves.

Advance care planning (ACP) has been advocated to allow patients to plan for and inform their health care providers and family caregivers about their future care wishes and should they ever lose capacity to be involved in medical decision making.[15] ACP may involve a substitute medical decision maker,[16,17] a person either appointed or identified to make care decisions on behalf of a person whose decision-making capacity is impaired. Caregivers commonly assume this role[18] and may use ACP conversations to consider further contingencies of EOL care, such as funeral planning, deposition of the body, and ongoing care needs of immediate family members.[10,19]

Although ACP is a recognized indicator of quality cancer care, many cancer patients display reticence and ambivalence in engaging in ACP conversations with health professionals,[19–21] prefer discussions at various points or late in their illness,[19,22] or engage in informal spontaneous EOL conversations with caregivers.[23] Furthermore, recent exploratory studies of cancer patients have described ACP as a cyclical[24] or iterative[19] process that is individualized, dynamic, and shared, with patients choosing to actualize, relinquish, and/or reject its individual components.[19]

Research from cancer and noncancer settings suggests that interventions that facilitate open discussions about ACP between patients and caregivers promote shared decision making, improve congruence and decisional satisfaction, reduce decisional conflict,[25,26] and improve caregiver bereavement outcomes.[27] When making substitute decisions, caregivers rely on their beliefs and preferences, shared decision making with others, including family, clergy, and clinicians,[28,29] and "just knowing" based on values and life experiences shared with the patient.[28] Nonetheless, caregivers can experience discomfort in surrogate decision making[29,30] and have contrasting illness-related hopes and fears to patients.[31] Despite this, with concerted effort and support, caregivers are able to transition from ambivalence,