Chapter 5

Considering Informal Caregivers' Needs in Palliative Care and Bereavement:

Making the Case for Family-Centered Care

Amanda M. Baranski
https://orcid.org/0009-0005-9701-8366
Metropolitan State University of Denver, USA

Elena Sandoval-Lucero
https://orcid.org/0000-0002-6010-2055
University of Colorado, Denver, USA

Michelle R. Simmons
https://orcid.org/0000-0002-7977-4302
Michelle Simmons Counseling Group, USA

ABSTRACT

This chapter focuses on the support that treatment teams can provide to informal caregivers of people with cancer, from the time a diagnosis is made through grief counseling after death. Written through the lens of one informal caregiver's experience of caring for a spouse with cancer for 4 years before, during, and after the COVID-19 pandemic, the chapter describes current practices in the fields of palliative care and grief counseling for supporting informal caregivers in the disease process. The authors identify gaps in support for informal caregivers experiencing the disease's emotional, physical, social, and financial impacts. Using a family-centered care model, they recommend support for sustaining informal caregivers as they navigate this experience. They offer a vision for future improvements to this aspect of cancer care.

DOI: 10.4018/979-8-3693-5400-1.ch005

INTRODUCTION

Informal caregivers, such as spouses, partners, family members, and friends, provide essential support to cancer patients during their illness and treatment. Informal caregivers' tasks and support needs change throughout the illness depending on the patient's health care and psychological needs (Romito et al., 2013). From the time of the initial diagnosis through the advanced stages of the disease, informal caregivers provide support by accompanying the patient to appointments, helping with medication management and nutrition during treatment, providing psychological support for coping with the uncertainty of the disease, and providing personal care in the last stages of the disease (Berry et al., 2017; Romito et al., 2013). These are all key supports, and they are provided by people who are not medically trained to manage the disease process, symptoms of cancer, and treatment side effects. Although the burden of cancer is heavy, many informal caregivers step into the role willingly and without hesitation because of the love they have for the person. Recognizing their needs and supporting these informal caregivers helps the medical team achieve its goals for the patient (Berry et al., 2017).

Often, the services provided by palliative care teams are patient focused, as opposed to holistic, and family centered. Although informal caregivers are included in the process and the decisions made, the focus is almost exclusively on the patient's needs. When informal caregivers' needs are addressed, it is often within the context of the patient–caregiver dyad (Romito et al., 2013). However, recent studies have suggested that better benefits and outcomes could come from intervening with informal caregivers on an individual basis (Berry et al., 2017; Romito et al., 2013). Although many nonprofit organizations designed to support patients with cancer have begun to expand their services to focus on individualized informal caregiver needs (Romito et al., 2013), this trend has not been prominent within health care provider settings. Berry et al. (2017) proposed a model that refocuses the work of palliative care teams on the well-being of both the patient and the informal caregiver, instead of exclusively on the patient, thus creating more holistic cancer care that benefits the informal caregiver by not depleting their capability to respond to the patient's changing medical and emotional needs. This increases their self-efficacy and maintains a higher level of emotional well-being (Berry et al., 2017).

Informal Caregivers' Needs

Informal caregivers must take on the task of caring for the patient and often also must take over household responsibilities that the patient themselves formerly managed. This is often referred to as the *caregiver burden* (Applebaum & Breitbart, 2013, and it creates stress for the caregiver. Informal caregivers often exhibit more distress and anxiety than the patients do (Sklenarova et al., 2015). They often have needs related to managing the disease process and caring for their loved one that remain unmet, and often the number of these unmet exceeds the patient's (Sklenarova et al., 2015). This is not surprising given that most palliative care teams are patient focused, and the informal caregiver provides support and information to the team to assist with patient treatment. However, unmet caregiver needs affect both their own and the patient's and quality of life (Kim & Carver, 2019). They can also have long-term health consequences for the informal caregiver. Informal caregivers may have requests and needs they prefer to address outside of the patient's presence. However, in most health care settings medical staff interact with informal caregivers and patients together (Romito et al., 2013), thus closing off avenues of

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