

Journal Watch

Palliative family caregivers' accounts of health care experiences: The importance of "security"

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Abstract: When providing care for a loved one with a terminal illness, family members often look to health care providers for guidance and expertise. The objective of this study is to explore family caregiver accounts of their experiences within the health care system and with individual providers.

METHODS: A thematic analysis of secondary qualitative data was performed. Data are from a subsample of bereaved and current family caregivers (N = 31) in a prior study of coping in end-of-life cancer situations. Data from these participants referring to experiences with health care providers was thematically coded and the concept of "security" was used as an analytic lens to facilitate conceptual development and exploration.

RESULTS: Considered together, the findings can be viewed as manifestations of a need and desire for security in palliative family caregiving. Specifically, family caregivers' accounts illustrate the importance of feeling secure that health care services will be provided by competent professionals; feeling secure in their timely access to needed care, services, and information; and feeling secure in their own identity and self-worth as a caregiver and individual. In addition, the findings suggest a conceptualization of security that extends beyond trust in individuals to include a generalized sense of institutional trust in the health care system.

SIGNIFICANCE OF RESULTS: The concept of security moves beyond description of individual satisfaction or dissatisfaction with health care to identify a common, foundational need underlying such evaluations. Further empirical research is needed that explicitly focuses on caregivers' experiences of security and insecurity in the domains identified in this article. This will contribute to theory building as well as assist in identifying the causes and consequences of security.

Strengths:

1. Drawing from subjective experiences, this study identifies the need for security as a common theme among caregivers and illustrates the specific dimensions of security that family members seek (**competence** of care, **access** to care, and **respect** for self-identity and worth).
2. Relatively narrow selection criteria (caregivers currently providing care at home to adult family members with advanced cancer, life expectancy <6 mos, PPS 50% or less)

resulting in fairly homogenous population (majority of caregivers retired, female, and spouse to patient).

Weaknesses:

1. The study uses secondary analysis of pre-existing qualitative data to address new questions (in order to minimize responder fatigue), but doesn't provide details or specific examples.
2. Limited number of male caregivers in the study; this may mean concerns specific to this population may not have been identified in the analysis.
3. N=31. A larger population size would be of benefit in future studies for sub-population analysis, ie: male vs female caregiver needs, different ethnic backgrounds, variability in needs according to age of patients and caregivers.

Relevance to palliative care: Family members of palliative patients have various psychosocial needs to help them cope with end of life experiences. An underlying theme of "security" is common to many of these needs. Being aware of the different aspects of "security" can help health professionals provide reassurance to caregivers. One identified requirement is the need for trust and confidence in both individual health professionals as well as the system as a whole. This theme is particularly relevant given the present economic climate and public uncertainty about the restructuring of our health care system.