

The Relationships Between Family Primary Caregiver Characteristics and Satisfaction With Hospice Care, Quality of Life, and Burden

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Purpose/Objectives: To examine relationships between family primary caregiver characteristics and satisfaction with hospice care, quality of life (QOL), and burden.

Design: Exploratory, quantitative.

Setting: Five hospice organizations in Eastern Washington and Northern Idaho.

Sample: 44 primary caregivers of patients enrolled in hospice for more than two weeks.

Methods: Telephone surveys measured primary caregivers' satisfaction with hospice care, QOL, and burden. Demographic, personal, and situational characteristics were compiled. Multivariate regression techniques were used to identify caregiver characteristics that explained the most variation in satisfaction with hospice care, QOL, and burden.

Main Research Variables: Satisfaction with hospice care, QOL, and burden.

Findings: Being retired, being a wife or daughter, patient diagnosis, per diem rate paid to the hospice organization, county population and density, length of time in hospice, and length of time as a caregiver were significantly related to satisfaction with hospice care, QOL, and burden. Age, sex, education level, occupation, income, patient functional status, and social support were not related to these variables.

Conclusion: Although caregivers reported satisfaction with hospice care, the caregiver role negatively affects their QOL and they are burdened. "At-risk" caregivers are still working, have been providing care for a long time, and live in a rural locale.

Implications for Nursing Practice: These findings create a profile of "typical" and "at-risk" primary caregivers and support the role of hospice to care for family caregivers.

The trend toward home care for people who are dying is part of a social movement to improve end-of-life care in this country (Field & Cassel, 1997; National Public Radio, 1997). Nationally, 17% of deaths occur at home (Babcock, 1998), and western states report rates approaching 33% (Tolle, 1998). In a national study of the care of terminally ill patients, Emanuel et al. (1999) found that 96% were living at home and 96% of the primary caregivers were family members. More people would choose to die at home but are unable to because families have two concerns: the caregivers' burden and their ability to provide care (Fried, van Doorn, O'Leary, Tinetti, & Drickamer, 1999).

Key Points . . .

- ▶ The typical family caregiver of a dying loved one is an elderly wife who provides personal care and is responsible for care of the home in a setting of limited social and financial resources.
- ▶ Although satisfied with hospice care, caregivers report a diminished quality of life and significant burden.
- ▶ "At-risk" caregivers are those who have not retired, have been providing care for a long time, and live in a rural locale.

Although many people prefer to die at home in the company of loved ones and hospice care in the United States usually is directed toward that end (Field & Cassel), a "good death" at home depends on the well-being of the person who steps forward to assume the role of primary caregiver (Emanuel & Emanuel, 1998; McMillan, 1996; Schumacher, Stewart, & Archbold, 1998; Siegel, Raveis, Houts, & Mor, 1991; Yang & Kirschling, 1992). For this reason and because caregivers have their own needs, care of the patient and family unit is a foundational tenet of hospice care.

Hospice care providers need information about how to optimally use their resources to assist family caregivers. However, research to guide those decisions is not well developed. The purpose of this study was to examine relationships between combinations of demographic, personal, and situational characteristics of family primary caregivers and their satisfaction with hospice care, quality of life (QOL), and burden. This article addresses three questions: Who are the "typical" caregivers? What is their satisfaction with hospice care, QOL, and burden? What is the profile of "at-risk" caregivers who may need extra help from hospice?

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