

Factors Influencing Proxy Healthcare Decisions for Patients' with Terminal Alzheimer's Disease

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Alzheimer's disease poster

Purpose: Alzheimer's disease (AD), a chronic terminal disease, progressively impairs cognitive function resulting in deterioration of intellect, memory, and personality. With disease progression, the proxy decision-maker becomes more involved in intervention choices and end-of-life care. Decision-making can be a difficult process for the family member. Health care decisions may not be based on patients' wishes or best practice guidelines. Proxy decision outcomes conceptually involve medical futility and quality of life and death. The purpose of this study is to examine factors that influence health care proxy decision-making for a family member during the terminal stage of Alzheimer's disease.

Method: The objectives of this quantitative, descriptive correlational study are to (a) compare differences between spousal and child decision-making and intervention choice for the loved one with Alzheimer's; (b) compare differences in gender-based healthcare decision-making for the loved one with Alzheimer's; and (c) examine the relationship between age, gender, familial position, income, background structure, interactional and contextual situation, and the perception of burden to the decision type (reward-seeking; punishment-avoidance; altruistic helping; distress reduction) and decision outcome (intervention non-invasive, intervention invasive or no intervention).

Sample and Setting: The sample will include family members who serve as the proxy decision-maker for patients with terminal stage Alzheimer's disease. The proxy decision-maker is limited to the spouse, son, or daughter of the patient with diagnosed AD. Inclusion criteria require the proxy decision-maker be able to read and write in English and reside within a 50-mile geographic area of the AD patient's residence. The AD patient must reside in a long-term care facility and score within the severe dementia level on the global deterioration scale (GDS). The brief cognitive rating scale (BCRS), a companion instrument to the GDS, will be used to assess the AD patient dementia level. A sample size of 114 proxy decision-makers will be obtained from long-term care facilities located in a major urban city and three rural cities within a southeastern state. A demographic data proxy questionnaire and intervention history questionnaire will be completed by the proxy decision-maker. Demographic data and intervention history of the AD resident will be collected through medical record review. The proxy will complete The Elder Image Scale and the Family Caregivers' Motives for Helping Scale. This study is incomplete at this time.

Discussion: This study integrates two theories derived from nursing and social psychology to define this study's framework. These are the Family Caregiving Dynamics theory and the Motivation-to-Help theory. Knowledge gained from this study will help proxy decision-makers and healthcare professionals gain a better understanding of how difficult decisions are made during the terminal stage of Alzheimer's disease. This knowledge will facilitate opportunities for nurses and physicians to provide and promote therapeutic support to proxy decision-makers during the decision-making process.