

Medical Decision-Making in Advanced Dementia from the Family Caregiver Perspective: A Qualitative Study

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Abstract : Advanced dementia is a progressive terminal brain disease that is accompanied by a syndrome of difficult to manage symptoms and complications that eventually lead to death. The management of advanced dementia poses major challenges to family caregivers who act as patient health care proxies in making medical treatment decisions. Little is known, however, about how they manage advanced dementia and how their treatment choices influence the quality of patient life. This prospective qualitative study examines the key medical treatment decisions that family caregivers make while managing advanced dementia. The term 'family caregiver' refers to a relative or a friend who is primarily responsible for managing patient's medical care needs and legally authorized to give informed consent for medical treatments. Medical decision-making implies a process of choosing between treatment options in response to patient's medical care needs (e.g., worsening comorbid conditions, pain, infections, acute medical events). Family caregivers engage in this process when they actively seek treatments or follow recommendations by healthcare professionals. Better understanding of medical decision-making from the family caregiver perspective is needed to design interventions that maximize the quality of patient life and limit inappropriate treatments. Data were collected in three waves of semi-structured interviews with 20 family caregivers for patients with advanced dementia. A purposive sample of 20 family caregivers was recruited from a senior care center in Central Florida. The qualitative personal interviews were conducted by the author in 4-5 months intervals. The ethical approval for the study was obtained prior to the data collection. Advanced dementia was operationalized as stage five or higher on the Global Deterioration Scale (GDS) (i.e., starting with the GDS score of five, patients are no longer able survive without assistance due to major cognitive and functional impairments). Information about patients' GDS scores was obtained from the Center's Medical Director, who had an in-depth knowledge of each patient's health and medical treatment history. All interviews were audiotaped and transcribed verbatim. The qualitative data analysis was conducted to answer the following research questions: 1) what treatment decisions do family caregivers make while managing the symptoms of advanced dementia and 2) how do these treatment decisions influence the quality of patient life? To validate the results, the author asked each participating family caregiver if the summarized findings accurately captured his/her experiences. The identified medical decisions ranged from seeking specialist medical care to end-of-life care. The most common decisions were related to arranging medical appointments, medication management, seeking treatments for pain and other symptoms, nursing home placement, and accessing community-based healthcare services. The most challenging and consequential decisions were related to the management of acute complications, hospitalizations, and discontinuation of treatments. Decisions that had the greatest impact on the quality of patient life and survival were triggered by traumatic falls, worsening psychiatric symptoms, and aspiration pneumonia. The study findings have important implications for geriatric nurses in the context of patient/caregiver-centered dementia care. Innovative nursing approaches are needed to support family caregivers to effectively manage medical care needs of patients with advanced dementia.

Keywords : advanced dementia, family caregiver, medical decision-making, symptom management

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