

Knowledge about Dementia: Why Should Family Caregivers Know that Dementia is a Terminal Disease?

Authors : Elzbieta Sikorska-Simmons

Abstract : Dementia is a progressive terminal disease. Despite this recognition, research shows that most family caregivers do not know it, and it is unclear how this knowledge affects the quality of patient care. The aim of this qualitative study of 20 family caregivers for patients with advanced dementia is to examine how the caregiver's knowledge about dementia affects the quality of patient care in the context of healthcare decision-making, advanced care planning, and access to adequate support systems. Knowledge about dementia implies family caregivers' understanding of dementia trajectories, common symptoms/complications, and alternative treatment options (e.g., comfort feeding versus tube feeding). Data were collected in semi-structured interviews with 20 family caregivers. The interviews were conducted in person by the author and designed to elicit rich descriptions of family caregivers' experiences with healthcare decision-making and the management of common symptoms/complications of end-stage dementia as patient healthcare proxies. The study findings suggest that caregivers who recognize that dementia is a terminal disease are less likely to opt for life-extending treatments during the advanced stages. They are also more likely to seek palliative/hospice care, and consequently, they are better able to avoid unnecessary hospitalizations or medical procedures. For example, those who know that dementia is a terminal disease tend to opt for "comfort feeding" rather than "tube feeding" in managing the swallowing difficulties that accompany advanced dementia. In the context of advance care planning, family caregivers who know that dementia is a terminal disease tend to have more meaningful advance directives (e.g., Power of Attorney and Do Not Resuscitate orders). They are better prepared to anticipate common problems and pursue treatments that foster the best quality of patient life and care. Greater knowledge about advanced dementia helps them make more informed decisions that focus on enhancing the quality of patient life rather than just survival. In addition, those who know that dementia is a terminal disease are more likely to establish adequate support systems to help them cope with the complex demands of caregiving. For example, they are more likely to seek dementia-oriented primary care programs that offer house visits or respite services. Based on the study findings, knowledge about dementia as a terminal disease is critical in the optimal management of patient care needs and the establishment of adequate support systems. More research is needed to better understand what caregivers need to know to better prepare them for the complex demands of dementia caregiving.

Keywords : dementia education, family caregiver, management of dementia, quality of care

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