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Abstract

End-of-life care for individuals with dementia can be complicated and difficult for clinicians, families and the patient. This paper examines the current literature on end-of-life practices for individuals with dementia and discusses emerging trends to help inform clinicians about factors that influence end-of-life care for individuals with dementia. Research articles highlight nursing home care, hospice and palliative care, and decision-making as major themes influencing end-of-life care, and suggest recommendations for clinicians in improving practice in these areas.

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End-of-life decisions are difficult for many families facing the death of a loved one. Dementia creates additional burden in an already complex decision-making process. Instead of making end-of-life decisions with the explicit consent of their loved one, individuals and families must make decisions for a person who is drastically different than the person they cared for initially. Dementia is a challenging disease to face during the end of a patient's life for many reasons, including: prolonged and unpredictable course of illness, intensity of care required, and the presence of behavioral disturbances (Givens, Lopez, Mazor, & Mitchell, 2011).

Dementia is an umbrella term used to describe the cognitive changes that stem from several different underlying disorders affecting speech, behavior, movement, and of course, memory (Craig, Meiland, Passmore, & Dröes, 2010). Because dementia has multiple causes, estimates for how many individuals are living with dementia are difficult to ascertain. The 2011 Alzheimer's Association Report estimates that some 5.4 million Americans currently live with Alzheimer's disease (Alzheimers Association, 2011). Research suggests that by 2050, there will be more than 13 million Americans living with dementia (Elliott, Gessert, & Peden-McAlpine, 2009).

Although, dementia manifests itself differently across, and even within, each of the aforementioned disorders, current research in end-of-life care focuses on the group as a whole (Craig et al., 2010). This paper examines the current literature on successful end-of-life practices for individuals with dementia, as well as pointing out areas of care that may need improvement. Emerging trends in research and practice helps to inform clinicians about factors that influence end-of-life care for individuals with dementia.

Methods

Eleven scholarly articles surveying the current trends in end-of-life care for individuals with dementia were reviewed. Search terms included: "End-of-life," "dementia," "nursing home," "advanced directive," "palliative care," "hospice care" and/or "decision making" using PubMed. All identified articles are research-based, published within the last five years, and relevant to the topic of end-of-life care of individuals with dementia.

Results

Nursing Home Care

Nursing homes are very common settings of care for individuals with dementia; 90% of individuals with dementia are cared for in a nursing home and 70% of those individuals die there (Givens et al., 2011). Although nursing homes have become the primary site of care for patients with advanced dementia, families and caregivers often report dissatisfaction with the care provided in these institutions (Engel, Kiely, & Mitchell, 2006). Researchers are working to determine the factors that affect the quality of care of nursing home residents and their families (Engel et al., 2006).

Research suggests that nursing home admission is a locus of stress for residents and their families (Givens et al., 2011). Several factors mitigate this stress. For example, Engel et al. (2006) found that residents and their families experience greater satisfaction when more time is spent discussing advanced directives upon admission. In addition, increasing emotional support and education regarding prognosis can decrease stress during admission (Givens et al., 2011). Thus, providing better communication increases caregiver satisfaction and decreases stress related to nursing home admission (Givens et al., 2011).

The quality of patient care is another factor af-

fecting satisfaction with nursing home care at the end-of-life, especially when, as Givens et al. (2011) found, families report patient care is inadequate. Specifically, surrogates who choose feeding tubes are less satisfied with their care, and the majority of proxies regret their decision to insert a feeding tube after the fact (Engel et al., 2006). Engel et al. (2006) suggest that better pain and comfort measures correlate with greater satisfaction.

Additional research also identifies specific areas of care that could be improved to increase satisfaction with patient care. Research has shown that nurses' role in feeding decisions in nursing homes is ambiguous. Nurses feel that they lack sufficient knowledge about the risks and benefits of feeding tubes, and nurses are often unsure about their moral obligations in feeding decisions (Lopez, Amella, Mitchell, & Strumpf, 2010). Engel et al. (2006) contends that specialized care units with staff specifically trained in the care of persons with advanced dementia increases resident and family satisfaction with the patient management.

Palliative and Hospice Care

Hospice and palliative facilities allow individuals to "die with dignity" by providing "medical care, pain management, and emotional spiritual support for people who are dying" as well as bereavement support for their families (Alzheimer's Association, 2011). Although palliative and hospice care models were initially designed to serve patients with advanced cancer, individuals with dementia can also benefit from these services (Torke et al., 2010). Torke et al. (2010) conducted interviews with 80 staff members of hospice care facilities, and noted that 96% of interviewees agreed with the statement "I think that palliative care is effective in patients with dementia," however, no rationale for this finding was provided (Teno et al., 2011). Teno et al. (2011) found that families of persons with dementia who received hospice and palliative care services reported fewer unmet needs and concerns with quality of care, rated the quality of care higher, and indicated better quality of dying than those without hospice services.

Further research demonstrates areas of need for individuals with dementia that could be improved by adding hospice or palliative care (Engel et al., 2006; Torke et al., 2010). Nursing home residents with advanced dementia are less likely to have advanced directives and more likely to undergo aggressive in-

terventions at end-of-life than terminal cancer patients (Engel et al., 2006). Torke et al. (2010) also concur that caregivers of individuals with dementia have a high level of need, including need for respite services, assistance with caregiver burden and behavioral symptoms (Torke et al., 2010).

Despite the purported benefits of hospice care, only 21% of hospice care institutions enroll patients with a primary diagnosis of dementia (Torke et al., 2010). Although underutilized in the dementia population, use of hospice care is increasing (National Hospice and Palliative Care Organization [NHPCO], 2011). In 2010, thirteen percent of hospice admissions come from individuals with dementia (NPHO, 2011). This figure has increased two percent from the previous year, which was the second largest increase in admissions rates among primary diagnoses groups (NPHO, 2011). Similarly, there is low utilization of palliative care services by individuals with dementia (Birch & Draper, 2008).

Research highlights several barriers for individuals with dementia to receiving hospice and palliative care. First, current reimbursement mechanisms for palliative and hospice care providers present a huge obstacle to enrolling patients for these services (Torke et al., 2010). Torke et al. (2010) attribute the lack of awareness of hospice and palliative care services by both the families and referring providers as another major barrier to access of services by individuals with dementia. These authors recommend focusing educational efforts on referring primary care providers and families rather than on palliative care providers (Torke et al., 2010).

Even for those who overcome roadblocks, hospice and palliative services that are available are not often ideal for patients suffering from dementia. Among 240 executive directors of hospice programs interviewed, 96% agreed that "patients with dementia often have unmet needs for palliative care," and 94% agreed that patients with dementia have untreated pain (Torke et al., 2010). To date, there is limited research that focuses on how to improve hospice and palliative care for dementia patients at the end-of-life.

Decision Making

When it comes to actually making decisions about end-of-life care, individuals with dementia are often excluded from the process. Research supports that patient's participation in end-of-life decisions depends on their cognitive status (Lindstrom, Gaston-

Johansson, & Danielson, 2010). An analysis of documentation from deceased patients across numerous municipalities in Sweden revealed that patients with dementia had very little information in their medical records about end-of-life care, while patients without dementia had significantly more information about their wishes and symptoms (Lindstrom et al., 2010). In order to preserve patient autonomy and improve end-of-life care for individuals with dementia, investigators recommend finding innovative ways to include these patients in their own care but did not expand on how to accomplish this (Lindstrom et al., 2010).

When individuals with dementia are not able to participate in their own end-of-life decision-making, the burden falls on families and caregivers. Black et al. (2009) conducted interviews with surrogate decision makers to determine how individuals made end-of-life decisions for their loved ones. The results indicated that 59% of individuals had completed an advanced directive, 56% discussed preferences for end-of-life care and 38% had done both (Black et al., 2009). However, some individuals had done neither and instead relied on “knowing the person and his/her values” or “information obtained from others” (Black et al., 2009).

Some researchers were able to demonstrate that families used elders’ life stories to frame their decisions for care when the individual’s wishes were not known (Elliott, Gessert, & Peden-McAlpine, 2009). It was suggested that in the absence of a patient’s explicit directives, it is acceptable for healthcare providers to use “narrative-ethics” as a method for determining a family’s perspectives and priorities in end-of-life decision-making (Elliot et al., 2009). Black et al. (2009) urge health care providers to assist patients and families by encouraging advanced care planning, discussion of dying, helping individuals to identify goals for the end-of-life, and providing information to support treatment decisions consistent with the patient’s wishes.

Conflict can occur when making end-of-life decisions for a loved one. Elliott, Gessert, & Peden-McAlpine (2007) interviewed family members to determine the causes of conflict in end-of-life decision-making, and identified that less conflict occurs when one person or a couple assumes a primary role in decision-making (Elliot et al., 2007). Decisions about transitions, such as entrance into nursing home care, often create a source of conflict for families (Elliott et al., 2007). When this type of conflict existed, manag-

ing the conflict became the focus for the family rather than the care of the individual with dementia (Elliott et al., 2007).

The well-being of the surrogate decision maker also affects the care of end-of-life dementia patients. Vig and colleagues (2007) interviewed fifty surrogates about factors that helped and hampered how they made medical decisions for a loved one. Four general factors that influenced the outcomes of the surrogates’ decisions were discussed: “surrogates’ characteristics and life circumstances,” “surrogate social networks,” “surrogate-patient relationships,” and “communication and surrogate-clinician communication and relationship” (Vig et al., 2007). Surrogates’ characteristics and life circumstances that affected their well-being included: previous surrogate decision-making, successful coping strategies, support from outside sources, proximity to the individual with dementia, and finances (Vig et al., 2007). Surrogates relied on social networks to validate their choices, and found these helpful in their decision-making processes (Vig et al., 2007). Characteristics of surrogate-patient relationships and communication seemed to also influence surrogates’ decision-making and well-being, and these included understanding and knowing the patient’s medical condition needs (Vig et al., 2007). Finally, the surrogate-clinician relationship played an important role in surrogate decision-making. When interviewed about end-of-life experiences, surrogates reported that availability of the clinician to answer questions and offer support, getting frank information, making treatment recommendations and receiving reassurance about decisions improved their experience (Vig et al., 2007). Additionally, the involvement of too many clinicians in patient’s care hindered surrogates’ decision-making ability (Vig et al., 2007).

Discussion

Health care providers should be knowledgeable of current research trends about care for individuals with dementia and consider existing research to inform and assist patients and their families with end-of-life decisions. This review highlights nursing home care, hospice and palliative care, and decision-making processes as major themes influencing end-of-life care for patients with dementia.

Given that nursing homes have become more important in end-of-life care for individuals with dementia (Givens et al., 2011), clinicians should ensure that these services are used appropriately and effec-

tively. The transition into a nursing home can be a stressful time for an individual with dementia and their caregivers (Givens et al., 2011). As such, clinicians should provide emotional support for both the patient and caregivers, and initiate discussions about goals of care upon admission, including the discussion of advanced directives. While progress is currently being made to ensure accessible and reimbursed services for individuals with dementia, improvements in end-of-life care in nursing homes are still needed (Engel et al., 2006). When possible, specialized dementia units should be the preferred placement for individuals with dementia residing in a nursing home (Engel et al., 2006). To be advocates for patients and their caregivers, nurses should be more knowledgeable about nutritional support (e.g., enteral feeding practices), and play a more proactive role in facilitating feeding decisions (Lopez et al., 2010).

Hospice and palliative care provide viable options at the end-of-life for patients with dementia. These options for care should be discussed with caregivers and families earlier in the course of a patient's illness (Alzheimer's Association, 2011; Torke et al., 2010). It is also critical for healthcare providers to decrease the barriers to end-of-life care by increasing their knowledge of hospice and palliative care service and by managing the high level of caregiver stress associated with the care of patients with dementia, (Torke et al., 2010). Researchers and health care providers should also work toward improving existing hospice and palliative care services for individuals with dementia (Torke et al., 2010). Research must focus on how to deliver more comprehensive hospice services to individuals with dementia, and effective ways to relieve symptoms associated with dementia and improve the quality of life in all health care settings.

When patients cannot participate in their end-of-life care decisions, families and caregivers must step into a decision-making role by relying on advanced directives, previous discussions about end-of-life; in the absence these guides, decision-makers must use former, life stories, and third-party information (Lindstrom et al., 2010; Elliott et al., 2009; Black et al., 2009). Health care providers should assist individuals to express their thoughts about end-of-life preferences for care by beginning conversations early at the time of diagnosis, by involving family members and caregivers, and by completing advanced directives (Elliott et al., 2009; Black et al., 2009). When family

members are involved, health care providers should help avoid conflict by suggesting that one person in the family assume the role of the primary decision maker. Additionally, healthcare providers should recognize that transitions, such as nursing home admission, can often become a source of family conflict and should be prepared to manage caregiver needs at crucial points in the decision-making process (Elliott et al., 2007).

It is also important for clinicians to ensure that the primary decision maker receives adequate support. Supporting surrogate decision makers involves assessing their current emotional or mental health status, and most importantly for the clinician, maintaining a positive surrogate-clinician relationship (Vig et al., 2007). There are several factors that affect a positive surrogate-clinician relationship. Clinicians must be available to answer questions and offer support, provide the surrogate with frank and accurate medical information about the individual with dementia, make treatment recommendations, and provide reassurance to the surrogate regarding their decisions (Vig et al., 2007). Since it has been shown that having too many clinicians involved in the care of a patient may cause conflicts (Vig et al., 2007), one case manager or primary identified health care provider should be assigned to work with a surrogate in these cases.

Conclusion

Overall, more research is needed to enhance the understanding of the factors that affect end-of-life care for individuals with dementia and their families. Researchers should focus on improving nursing home management, increasing access and quality of palliative care, and improving models to assist patients and families in decision-making at the end-of-life.

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