Helping Family Caregivers of Individuals With Dementia

Cognitive changes not only affect older adults, but also impact family members caring for these individuals. Approximately 75% of the estimated 5.4 million individuals with Alzheimer's disease and other dementias in the United States are cared for by family caregivers (Boltz, Chippendale, Resnick, & Galvin, 2015). Family caregivers are often the ones who are notified when there is a diagnosis of dementia. In the United States, only 49% of individuals with dementia were notified of the diagnosis by their medical provider, compared to 93% of family members who were informed (Holroyd, Turnbull, & Wolf, 2002). After their family member receives a diagnosis of dementia, family caregivers often report feeling helpless and powerless (Boltz et al., 2015).

Studies show that the demands of caregiving usually come at the cost of increased caregiver stress and morbidity and poorer quality of life. Factors associated with psychological morbidity (e.g., strain, anxiety, depression) on dementia family caregivers include being female, being a spousal caregiver, additional stressful life events, poor physical health, decreased quality of relationship between caregiver/care recipient, and the presence of behavioral and psychological symptoms in the individual with dementia (Bolz et al., 2015). Identifying and addressing needs of family caregivers is just as important as addressing care recipients’ needs. Nurses in long-term care are in a unique position to build family- and resident-centered plans of care that incorporate strategies to support residents and their family caregivers when there is a diagnosis of dementia.

CREATING A FAMILY- AND RESIDENT-CENTERED PLAN OF CARE

First, identify what family caregivers know about the disease and whether there are any misconceptions. Often, residents and family members have had negative or frightening experiences with other individuals with dementia (Lee & Weston, 2011). Because most family caregivers perceive inadequate support from health care providers in managing dementia-related problems, report strain, and have low confidence in managing caregiving (Jennings et al., 2015), nurses can often help provide education and resources. In addition, support and consultation programs are necessary for family caregivers of individuals with dementia at all stages, as these caregivers may be less than optimally prepared (Novais, Dauphinot, Krolack-Salmon, & Mouchoux, 2017). Understanding what family caregivers know, providing education on the disease and what
to expect, and addressing misconceptions is an important first step.

Second, identify the needs of family caregivers. Older adults in long-term care settings may have multiple health conditions, but not all are associated with significant challenges. However, for individuals with challenging comorbidities, family caregivers may need help with changes in behavior, memory, physical disability, and mood. A study exploring family caregivers found that family caregiving activities were related to patients’ (i.e., residents’) stage of dementia (Huang et al., 2015). For individuals with mild dementia, family caregivers provided assistance with transportation and housekeeping. For individuals with moderate dementia, family caregivers provided assistance with transportation, housekeeping, mobility, and protection from different forms of abuse and neglect, such as financial exploitation and self-neglect. For individuals with severe dementia, family caregivers provided assistance with personal care, mobility, protection (as stated above), transportation, and housekeeping (Huang et al., 2015).

Nurses can help facilitate family care conferences that outline the assistance being provided by family caregivers, assess whether family caregivers are willing and able to provide assistance, and identify and offer resources depending on the need. Different services and interventions need to be designed for family caregivers of individuals with dementia according to their specific needs at different stages of dementia (Huang et al., 2015).

Third, create a family- and resident-centered plan of care that includes:

1. The identified needs of family caregivers and how they will be met: Engaging social workers may be helpful, as they can identify additional resources such as caregiver support groups, counseling services, and fiduciary service providers. In addition, nurses can also inform family caregivers of online resources available, such as Alzheimer’s Association, Dementia Action Alliance, LeadingAge, and Pioneer Network, all of which can be great sources of information.

2. The goals and priorities in the care of the resident (Lee & Weston, 2011). Ask family caregivers and residents about their goals, whether they are feasible, and how they can be accomplished (Behrens et al., 2018).

3. Outline family caregivers’ preferred method of communication: Do they prefer telephone calls or e-mails? What is their availability? Do they have an identified back-up person(s) for when they are unavailable?

4. Identify a contact person knowledgeable about the plan of care to whom family caregivers can reach out when they have questions or need assistance. Identifying another person will ensure help is provided in an efficient manner.

As the perceived needs of caregivers evolve with disease progression and transition in their care recipients, caregivers’ needs should be regularly assessed, taking into account their need for information, coping skills, support, and service (Novais et al., 2017). The process for making adjustments should involve open and honest communication to foster a relationship of trust among the resident, family caregiver, and care team.

In summary, caregiving for individuals with dementia presents unique and extreme challenges associated with caring for someone with cognitive and behavioral impairment. Family caregivers in these roles may struggle with numerous needs when there is cognitive decline in a loved one. Identifying and addressing family caregivers’ needs and providing ongoing education and support are important steps in building a family- and resident-centered plan of care.

Nurses in long-term care settings have the unique skillset necessary for building and implementing this type of plan.

REFERENCES


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The author has disclosed no potential conflicts of interest, financial or otherwise.

doi:10.3928/00989134-20180808-01