



Research on Care Needs and Supportive Approaches for Persons with Dementia

Background Paper

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Additional information can be found at the Summit website (<https://aspe.hhs.gov/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers>) or the National Alzheimer's Project Act website (<https://aspe.hhs.gov/national-alzheimers-project-act>). The opinions and views expressed in this report are those of the authors. They do not necessarily reflect the views of HHS, the contractor or any other funding organization.

Introduction

More than 5 million Americans have dementia, and the number of people with Alzheimer's disease, the most common cause of dementia, is projected to increase to 13.8 million by 2050 (Hebert et al., 2013; National Institute on Aging [NIA], 2016). As the disease progresses, individuals with dementia become more dependent on others for assistance with daily activities. Ultimately, in advanced dementia, people with the disease need assistance with basic tasks, such as eating. People with dementia receive care from paid and unpaid caregivers, in some cases relying on public and private programs. This paper focuses on research related to care and support for people with dementia.

Care Needs of Persons With Dementia From Early to End Stage

Dementia reduces a person's cognitive function and ability to perform routine activities; it also is often associated with challenging behaviors (Alzheimer's Association, 2016; NIA, 2016). As dementia progresses, an individual will eventually require assistance with activities of daily living (ADLs) (e.g., eating, grooming, mobility) and instrumental activities of daily living (IADLs) (e.g., meal preparation, shopping, financial and medication management) (Karon et al., 2015). Additional medical and nursing care may also be required to manage coexisting medical conditions, multiple medications, incontinence, and mobility devices (Reinhard, Levine, & Samis, 2012). As people with dementia require more assistance to meet their needs, their quality of life may be negatively affected (NIA, 2017).

The psychosocial aspects of dementia often include depression, anxiety, and strain on family relationships (Powers et al., 2016; Riley, Burgener, & Buckwalter, 2014). People with dementia can also experience stigma associated with their dementia diagnosis (Alzheimer's Association, 2008; Riley, Burgener, & Buckwalter, 2014). Few studies include people with dementia expressing their experience with the disease and those that do include the perspective of people with dementia typically have small sample sizes and include only those with mild to moderate symptoms (Powers et al., 2016). Some studies found that people with dementia want to maintain their sense of personal identity and quality of life; they wish to retain independence by continuing daily tasks and by participating in decisions about their future to the extent possible (Alzheimer's Association, 2008; Dawson et al., 2012; Powers et al., 2016).

Some subgroups of people with dementia, such as those with young-onset dementia, who are living alone, and people who also have intellectual and developmental disabilities, may have specific care needs.

- *Young-onset dementia*--It is estimated that about 4 percent or 200,000 of the more than 5 million Americans with dementia have young-onset dementia--dementia that is diagnosed earlier than age 65 (Alzheimer's Association, 2016). Obtaining a diagnosis of dementia can be difficult for people who are under age 65. Some signs of dementia, such as personality and behavior changes, may be misdiagnosed in younger people because dementia is not always expected (Greenwood & Smith, 2016; Harris & Keady, 2009; Hunt, 2011). The diagnosis itself can elicit feelings of loss and fear, and the stigma of the disease may lead people with young-onset dementia to be hesitant to disclose their diagnosis (Greenwood & Smith, 2016; Harris & Keady, 2009). Many people with young-onset dementia are employed at the time of diagnosis, but advancing symptoms of dementia including loss of judgment and the inability to plan may ultimately lead them

to leave or lose their jobs and their income. In addition, those with young-onset dementia may lose their sense of identity and participation in meaningful activities as they leave the workforce, refrain from driving, and change their role to become a dependent family member (Greenwood & Smith, 2016; Harris & Keady, 2009; Hunt, 2011). As the disease progresses, people with young-onset dementia are at risk of social isolation because family and friends may not understand the diagnosis and resources for people with dementia, such as adult day care, are often geared to older populations (Greenwood & Smith, 2016; Harris & Keady, 2009; Hunt, 2011).

- *People with dementia who live alone*--In 2011, using a broad definition of possible and probable dementia, more than 30 percent of people with dementia in the community age 65 and older were living alone, according to an analysis of the National Health and Aging Trends Study (Amjad et al., 2016). Only including people with a narrower definition of probable dementia, 13 percent of people with dementia were living alone (Gould et al., 2015). Many people with dementia who live alone are at risk for self-neglect, which is when a vulnerable adult is unable to perform basic self-care, including obtaining food, clothing, or shelter and managing physical and mental health care needs (National Center on Elder Abuse, 2015). In addition, people with dementia who live alone have been reported to have significantly more unmet needs than people with dementia who live with others, particularly in the areas of looking after their home, preparing food, self-care, and accidental self-harm (Miranda-Castillo, Woods, & Orrell, 2010). Other concerns related to people with dementia who live alone include malnutrition, medication nonadherence, wandering, responsiveness to emergencies, and social isolation (Gould et al., 2015). At times, people with dementia living alone will resist interventions, deny or underestimate the severity and importance of their cognitive deficits (Tierney et al., 2004; Wilkins et al., 2014), and have little or no awareness regarding their circumstances (Dong et al., 2010; Lehmann et al., 2010; Wilkins et al., 2014), thus placing them at greater risk for adverse outcomes.
- *People with intellectual and developmental disabilities and dementia*--Research shows that age-related health problems among people with intellectual disabilities are generally like those in the general population, including the development of dementia in later life (Heller et al., 2010; May & Kennedy, 2010; McCallion et al., 2013). It is also well established that adults with Down syndrome are at high risk for developing Alzheimer's disease in middle age, but the risk of dementia for people with other intellectual disabilities has not received as much research attention (Ball et al., 2008; McCarron et al., 2014; Strydom et al., 2010, 2013). Some early signs of dementia in those with Down syndrome, such as changes in personality, behavior, and speech, vary from early dementia symptoms in the general population (Ball et al., 2008; Strydom et al., 2010). Neurological symptoms, such as seizures and myoclonus--the sudden, involuntary jerking of muscle--may also occur to a greater extent in people with Down syndrome and Alzheimer's disease than the general population with the disease (Ball et al., 2006; Urv, Zigman, & Silverman, 2010). Like others with dementia, the amount and type of services people with intellectual and developmental disabilities and dementia need will change over time as their symptoms become more pronounced (Jokinen et al., 2013). However, greater emphasis may be placed on ensuring that care is stress free, predictable, and consistent to manage challenging behaviors and distress in people with intellectual and developmental disabilities and dementia (British Psychological Society, 2015). Unlike people with dementia in the general population who often remain at home through the early stages of the disease, adults with intellectual and developmental disabilities and dementia who live on their own may need to move to formal community residential

settings, such as small group homes, to better address their needs (Janicki, 2011; Jokinen et al., 2013; Strydom et al., 2009).

Research on Care and Support for People With Dementia

Although most evidence-based treatments and care practices related to dementia focus on family caregivers, there are supports and programs available focused on directly assisting people with dementia in their care needs (Maslow, 2012). The section below describes some of the care practices and support programs available for people with dementia.

Person-centered Care for People With Dementia or Their Proxy

Person-centered care for people with dementia emphasizes the importance of caring for all aspects of a person's well-being--social, mental, emotional, and spiritual needs in addition to diagnoses and physical and medical needs. Psychosocial aspects of dementia, such as depression and anxiety, may be addressed by using person-centered care, which focuses on all needs, including mental and emotional requirements. One of the key aspects of person-centered care is shared decision-making, but many families and service providers do not adequately incorporate people with Alzheimer's disease into the care planning and decision-making process (Hamann et al., 2011; Lines, Gould, & Wiener, 2014). This lack of involvement occurs despite the ability of persons with mild to moderate dementia to express preferences related to their health care, daily care and activities, and place of residence (Feinberg & Whitlatch, 2002; Menne, Tucke, Whitlatch, & Feinberg, 2008; Mozley et al., 1999; Tyrrell, Genin, & Myslinski, 2006).

Programs for People With Dementia Who Live Alone

Gatekeeper programs train community members such as mail carriers, utility workers, bank tellers, and other persons who interact with people in their daily work to identify older people who may be at risk for harm and to refer at-risk adults for assessment and service delivery. Through this training, community workers may be able to identify people who have diminished abilities to complete previously routine tasks, including collecting their daily mail, or IADLs, such as managing their finances. One gatekeeper program, Senior Reach in Colorado, found that older adults served by the program demonstrated significant improvements in several areas including improved functioning, increased optimism about the future, decreased emotional disturbance, and improvements on the Geriatric Depression Scale (Bartsch & Rodgers, 2009). In another program, registered nurses were trained to work with local health professionals and community service providers to increase awareness of the signs and symptoms of dementia and to obtain needed services for people with dementia and their families (Hall, Bossen, & Specht, 2001).

Law enforcement personnel encounter people with dementia in a variety of situations including reports of missing persons, neighbor complaints, traffic violations, claims of fraud or theft, suspected elder abuse, and domestic violence. Progressive memory loss and cognitive changes because of dementia pose significant challenges and can affect an individual's ability to think clearly and respond appropriately. The International Association of Chiefs of Police (IACP) developed a 1-day training--the IACP Alzheimer's Initiative--which provides training on intervention strategies. The training includes four modules that address the basics of Alzheimer's disease and related dementias, approaches for interacting with individuals who have dementia and warning signs, search and rescue techniques specifically tailored for people with dementia who are missing, and local community services that can provide follow-up

support. The IACP also hosts a website with resources and materials for educating law enforcement about issues related to dementia (Gould et al., 2015).

Early Stage Programs

Programs that educate people with dementia and their care partners about the disease and focus on maintaining abilities may assist people in the early stages of dementia. Memory clubs focus on providing information about dementia, improving communication between the caregiver/care recipient dyad and confidence related to future planning decisions, and enhancing feelings of support. In one study of three memory clubs in Minnesota, participants with dementia who were less cognitively impaired were more likely to report increased confidence about conducting daily tasks (Gaugler et al., 2011). In another study--a randomized controlled trial of a 9-week Early Stage Memory Loss support group--participants with early-stage dementia had significant improvements in quality of life and decreased depressive symptoms compared to the study's control group (Logsdon et al., 2010).

Late Stage Programs

Alzheimer's disease is a terminal illness. In the late stages, people with dementia need comprehensive care. Comfort Matters™ is a comfort-focused and person-directed approach to care for people with dementia at any stage of dementia, including the end of life. The program teaches long-term services and supports staff, medical providers, and families about the palliative approach to dementia care with the goal of improving the person's quality of life by relieving physical pain, behavioral symptoms, and stress (Wiener et al., 2016). Several improvements in care have been noted for people with dementia who participate in Comfort Matters™ compared to those who do not participate, including fewer prescription medications, less use of the hospital and emergency department, and no use of physical restraints (Alonzo et al., 2015).

The Namaste Care Program for nursing home residents who cannot participate in regular nursing home activities because of advanced dementia or earlier stages of dementia with agitation is conducted 7 days a week and is staffed by trained nursing assistants. Individual one-on-one activities include the playing of soft music and sensory experiences, such as soaking hands in warm lavender-scented water and providing comfort using stuffed animals. One study of the Namaste Care Program found that program participants who had limited social interaction experienced decreases in some indicators of delirium and reduced need for anti-anxiety medications (Simard & Volicer, 2010).

Research Needs and Challenges

Relatively few nonpharmacologic therapies have been tested in multiple large randomized controlled studies or have shown consistent results (Alzheimer's Association, 2016). Most dementia-focused evidence-based treatments and care practices that have been evaluated target family caregivers as opposed to people with dementia (Maslow, 2012). Researchers note a lack of programs and services for people with dementia who live alone or who are in the early or late stages of the disease (Gaugler et al., 2011; Gibson & Richardson, 2016; Maslow, 2012). Maslow (2012) identifies several other topics requiring additional research, including nonpharmacological treatments for those with non-Alzheimer's type dementia or young onset dementia, and for people with dementia from various racial and ethnic groups. Additional research is also needed on behavioral symptoms, the underrecognition and underdiagnosis of dementia, and how to coordinate medical and nonmedical care. Future research would also

benefit from stronger methodology and evaluation criteria (Gaugler et al., 2011; Minnesota Evidence-based Practice Center, 2016).

Conclusion

The care needs of people with dementia change throughout the course of the disease, thereby requiring caregivers to modify the assistance they provide. Further complicating care for people with dementia are the unique care needs of those in various circumstances, such as living alone or having a dual diagnosis of intellectual and developmental disabilities and dementia. Some programs exist to help address the care needs of people with dementia as opposed to their caregivers, but more research is needed.

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