



Caregiving for People with Non-Alzheimer's Dementia

Issue Brief

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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.

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Research Summit on Dementia Care: Building Evidence for Services and Supports

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Introduction

As the population ages, the number of people with dementia is expected to increase significantly (National Institute on Aging [NIA], 2016). The term *dementia* refers to a decline in cognitive ability, marked by changes severe enough to interfere with the person's daily life and activities, such as memory and language loss, difficulty with problem-solving and reasoning, and behavioral changes (NIA, 2016; National Institutes of Health [NIH], 2013). Although many people consider the terms *Alzheimer's disease* and *dementia* to be synonymous, there are numerous diseases and disorders that can cause dementia (Alzheimer's Disease Education and Referral Center, 2013). Recent estimates suggest that 13.9 percent of adults age 71 or older in the United States have dementia and that 20 to 40 percent of people with dementia have a disorder other than Alzheimer's disease (NIH, 2013; Plassman et al., 2007).

In recent years, research on Alzheimer's disease has increased significantly, but there has been less focus on other types of dementias. Because less is known about these other dementias, under- and misdiagnosis is common, treatment protocols are lacking, and it is not clear how best to support people with these dementias and their caregivers (Lancet, 2015; Galvin, Duda, Kaufer, Lippa, Taylor & Zarit, 2010a; Merrilees & Ketelle, 2010; Nunnemann, Kurz, Leucht, & Diehl-Schmid, 2012; Shinagawa et al., 2015; Taylor & Yardley, 2014; Ulfacker, Edmondson, Onyike & Appleby, 2016; Zweig & Galvin, 2014). This paper examines what we know about caregiving as it relates to the three most common causes of dementia after Alzheimer's disease: frontotemporal dementia (FTD), Lewy body dementia (LBD), and vascular dementia.

Overview of Frontotemporal Dementia, Lewy Body Dementia, and Vascular Dementia

Although there are some similarities between Alzheimer's disease and other dementias, there are also significant differences in the symptoms and progression of each form of dementia that create unique experiences for family caregivers. For example, people with FTD may have intact memory, unlike those with Alzheimer's disease, but demonstrate pronounced personality and emotional changes (Merrilees & Ketelle, 2010). FTD is also more likely to affect people under the age of 65, presenting distinct logistical, financial, and emotional challenges for families (Lima-Silva et al., 2015; Merrilees & Ketelle, 2010). People with LBD experience symptoms like hallucinations, delusions, and sleep disturbance much earlier in the disease than people with Alzheimer's, and these symptoms can be particularly challenging for caregivers (Galvin et al., 2010a; Karantzoulis & Galvin, 2011). The level of impairment is also greater earlier in LBD than in Alzheimer's disease, placing a more significant responsibility on caregivers (Gill et al., 2013; Leggett, Zarit, Taylor & Galvin, 2010). Vascular dementia tends to involve less memory impairment in the early stages than Alzheimer's disease but greater problems with attention and executive functions such as planning, abstract thinking, and behavioral control. There is also more variation in symptoms with vascular dementia, and the onset can be more abrupt than with Alzheimer's disease (Karantzoulis & Galvin, 2011; Paturel, 2013).

Studies suggest that many cases of dementia are caused by more than one type of brain change or disease, or "mixed dementia" (NIH, 2013; Schneider, Arvanitakis, Leurgans, & Bennet, 2009). In one study of community-dwelling people diagnosed with probable dementia,

about 45 percent were diagnosed with mixed dementia (Schneider et al., 2009). Most commonly people with mixed dementia have both Alzheimer's disease and vascular dementia (NIH, 2013; Sachdev et al, 2014; Schneider et al., 2009). Alzheimer's disease and LBD also co-occur regularly; up to 80 percent of people with LBD are thought to have Alzheimer's disease as well (Karantzoulis & Galvin, 2012; Leggett et al., 2010). Mixed dementia makes it more difficult to understand each form of dementia and its specific impact on families. The common occurrence of mixed dementia also complicates the process of obtaining an accurate diagnosis, getting targeted treatment, and educating patients and families on what to expect (NIH, 2013).

Like caregivers of people with Alzheimer's disease, caregivers of people with non-Alzheimer's dementias require support throughout the course of the disease. However, little research has been conducted on caregiving specific to non-Alzheimer's dementias. Much of the existing research on caregiving and dementia is either limited to Alzheimer's disease or does not specify the type of dementia being studied, potentially overlooking or conflating caregiving issues that may differ significantly by type of dementia. Differences in age of onset, symptoms, dementia progression, comorbid conditions, and the knowledge level of medical professionals can all contribute to distinct caregiving challenges and therefore require dementia-specific caregiving research. This research could explore which characteristics of each dementia cause the greatest challenges for caregivers and test specific interventions that may be effective in addressing these challenges (Mueller, Ballard, Corbett, & Aarsland, 2017; Nunnemann et al., 2012).

Gaps in knowledge about specific dementias and about appropriate instruments to assess for non-Alzheimer's dementias also preclude understanding of caregiving issues. For instance, there is little information about prognosis and cognitive decline in LBD or on the progression of FTD (Caceres et al., 2016; Mioshi, Bristow, Cook & Hodges, 2008; Mueller et al., 2017). Researchers and providers need to know which assessment tools to use in diagnosis and in studying dementia progression. For example, the Mini-Mental Status Examination is not sensitive enough to detect cognitive changes in early LBD; one study recommends the Montreal Cognitive Assessment as a better measure for this form of dementia (Mueller et al., 2017; Taylor & Yardley, 2014). A systematic review of dementia assessment instruments identified measures that are best suited to specific domains such as attention or executive function, but also concluded that more information is needed on the quality of different instruments for assessing different dementias (Bossers, van der Woude, Boersma, Scherder & van Heuvelen, 2012).

Frontotemporal Dementia

FTD is the most common type of dementia in people under the age of 65. It is typically diagnosed between ages 50 and 60, which presents specific challenges, such as difficulty managing family and workplace responsibilities (Caceres et al., 2016; Lima-Silva et al., 2015; Merrilees & Kettelle, 2010; Nunnemann et al., 2012). FTD accounts for up to 10 percent of all dementia diagnoses and is characterized primarily by changes in behavior or language (Diehl-Schmid et al., 2013; Merrilees & Kettelle 2010; NIH, 2013).

There are several sub-types of FTD. The behavioral sub-type is most common and is marked by a decrease in empathy for others, including family members; socially inappropriate behavior such as eliciting arguments with people in public; repetitive behaviors such as clapping or humming; loss of insight into the changes in their own behavior; and only subtle cognitive decline (Association for Frontotemporal Degeneration [AFTD], n.d. [b]; Chow, Pio, & Rockwood, 2011; Diehl-Schmid et al., 2013; Merrilees & Kettelle, 2010). Other sub-types of FTD include semantic dementia and progressive nonfluent aphasia, both of which involve loss of language skills (Merrilees & Kettelle, 2010; Mioshi et al., 2013). The progression of FTD varies widely, but as the disease progresses, symptoms of all FTD sub-types tend to occur (Mioshi et al., 2013; NIH, 2013; Onyike & Diehl-Schmid, 2013).

Symptoms That Affect the FTD Caregiving Experience

Some of the hallmark symptoms of FTD, including erratic and socially inappropriate behaviors and emotions, personality changes, communication problems, and lack of self-awareness, can make coping difficult for caregivers (Nunnemann et al., 2012; Riedijk et al., 2006; Wong et al., 2012). These symptoms are different from Alzheimer's disease, where memory loss is experienced early in the disease process and behavioral and personality changes typically are not experienced until later in the disease progression (Riedijk et al., 2006). A study by Diehl-Schmid et al. (2013) found that personality changes, including aggression, lack of manners, and lack of empathy, were particularly burdensome for FTD caregivers. Behavioral symptoms are also associated with feelings of burden in FTD caregivers, and FTD caregivers are more likely to be depressed and stressed than caregivers of people with Alzheimer's disease (Caceres et al., 2016; Lima-Silva et al., 2015; Nunnemann et al., 2012). Initially, changes in personality or behavior may be mistaken for depression or other psychiatric conditions, and language changes are often wrongly attributed to Alzheimer's disease or stroke (Merrilees & Kettelle, 2010; Ulfacker et al., 2016). These common misdiagnoses can make it harder for caregivers to understand the person with FTD's behavior and personality changes and exacerbate caregivers' feelings of anger, frustration, or hopelessness (Nunneman et al., 2012; Shinagawa et al., 2015).

Other characteristics of FTD also affect caregivers' experiences. Sleep disruptions affect about 85 percent of people with the behavioral sub-type of FTD, according to one study (Merrilees et al., 2014). Caregivers report their own related sleep disturbances, and this reduced sleep is correlated with higher rates of caregiver depression (Caceres et al., 2016; Diehl-Schmid et al., 2013; Merrilees et al., 2014; Riedijk et al., 2006). Conversely, some people with FTD sleep more than usual, which may give caregivers some respite (Caceres et al., 2016). Caregivers must also become vigilant about the safety of the person with FTD early during the disease, limiting access to dangerous items such as knives, household cleaners, or unattended stoves or ovens (Merrilees & Ketelle, 2010). The increased need for supervision correlates with caregiver strain (Diehl-Schmid et al., 2013).

The significant care needs of people with FTD lead some families to seek institutional care, but caregivers of people with FTD often experience greater difficulties with this process than caregivers of people with Alzheimer's disease. Identifying a long-term care facility that is

equipped to care for younger people with the behavioral issues of FTD can be a challenge (Merrilees & Kettelle, 2010; Nunneman et al., 2012). Aggression, for example, can be difficult for facility staff to manage, because people with FTD tend to be younger and therefore stronger than people with other dementias (AFTD, n.d. [c]). Riedijk et al. (2006) found that placing a family member in an institution can be associated with great psychological distress for FTD caregivers; the researchers speculated that there may be little social support for this decision among family members and friends who do not understand FTD and its caregiving challenges.

Support Needs and Resources for FTD Caregivers

The young onset of FTD, coupled with lack of public awareness and information on how to manage the dementia, can leave FTD caregivers feeling isolated and stressed. Spouses of people with FTD may feel disconnected from their peers as they cope with dementia and perhaps leave the workplace at a young age; spouses and other family members alike may feel their social network does not understand the changes in behavior and personality experienced by the person with FTD, which can contribute to feelings of embarrassment, isolation, and shame (Diehl-Schmid et al., 2013; Ducharme, Kergoat, Antoine, Pasquier & Coulombe, 2013; Nunnemann et al., 2012; McFarland, 2010).

FTD caregivers need social and emotional support from health care providers, family and friends, and other FTD caregivers (Caceres et al., 2016; Diehl-Schmid et al., 2013; Shinagawa et al., 2015). Support groups are one resource that caregivers have found beneficial; because many caregivers are still working, groups that meet in the evening may be more accessible (Caceres et al., 2016; Chow et al., 2011; Nunneman et al., 2012; Shinagawa et al., 2015). Caregivers may also cope by educating others about FTD or reminiscing about times prior to the person's FTD diagnosis (Caceres et al., 2016).

Caregivers of people with FTD also report greater difficulty locating information compared to caregivers of people with Alzheimer's disease (Riedijk et al., 2006). Health care providers often do not have adequate training or education to assist families in managing behavioral symptoms common in FTD (Caceres et al., 2016). Few community-based or long-term services and supports can adequately respond to the needs of FTD patients (Shinagawa et al., 2015). This inadequate support system is illustrated by a German study where 89 percent of families caring for someone with FTD were referred to local Alzheimer's organizations for services and support, but the services did not meet the specific needs of FTD patients and their caregivers (Nunneman et al., 2012). FTD caregivers want education and information about the basics of FTD, its symptoms, and how to coordinate care (Caceres et al., 2016; Diehl-Schmid et al., 2013). They have suggested that a centralized source of information on legal, financial, medical, and social issues related to FTD, including respite care and communication skills, would be valuable (Chow et al., 2011).

The AFTD was founded in 2002 to address gaps in both informational and emotional support. It offers caregivers information about FTD and links to local caregiver support groups where available; however, many states do not have local groups, according to the AFTD website.

It also runs telephone support groups and provides links to other online FTD caregiver forums to facilitate communication and sharing among affected families (AFTD, n.d. [a]).

Lewy Body Dementia

LBD affects about 1.5 million older adults and makes up 10 to 30 percent of dementia cases (Galvin, Duda, Kaufer, Lippa, Taylor & Zarit, 2010b; Leggett et al., 2010; Zweig & Galvin, 2014). The term *LBD* encompasses two related diagnoses: Parkinson's disease dementia (PDD), and dementia with Lewy bodies (DLB). Both PDD and DLB are caused by Lewy body proteins in the brain, but PDD begins with the movement difficulties that are characteristic of Parkinson's disease, while DLB usually starts with symptoms such as sleep problems and hallucinations (NIH, 2013). As these two types of LBD progress, they eventually display the same combination of cognitive, physical, and psychological symptoms, including hallucinations, depression, fluctuating attention and concentration, difficulty solving problems, visuospatial problems such as getting lost in a familiar place or difficulty driving, REM sleep behavior disorder which involves acting out dreams physically, slow movement, falls, and tremors (Galvin et al., 2010b; Leggett et al., 2010; Mueller et al., 2017; NIH, 2013; Zweig & Galvin, 2014). In the later stages of LBD, symptoms can resemble Alzheimer's disease, but in the early stages, people with LBD are more likely to experience hallucinations, sleep problems, and language loss, such as difficulty finding words, and are less likely to have memory loss compared to people with Alzheimer's disease (Levy & Chelune, 2007; Mueller et al., 2017; Zweig & Galvin, 2014). Although the literature is somewhat mixed, people with LBD also seem to show more early impairment in functional abilities and decline more rapidly than people with Alzheimer's disease, creating greater dependence on caregivers (Galvin et al., 2010a, 2010b; Gill et al., 2013; Karantzoulis & Galvin, 2011; Killen et al., 2016; Leggett et al., 2010; Mueller et al., 2017).

Obtaining an LBD Diagnosis and Managing Care

People with LBD and their caregivers often have difficulty obtaining a diagnosis and finding doctors and long-term care providers with the expertise to care for them. Common cognitive screening tests cannot distinguish LBD from Alzheimer's disease, and some early LBD symptoms like hallucinations and tremors contribute to misdiagnoses of a psychiatric disorder or Parkinson's disease (Taylor & Yardley, 2014). On average, it takes four physician visits for patients to receive the correct diagnosis, and in a survey of almost 1,000 LBD caregivers, half indicated that they visited at least three doctors and had more than 10 physician visits in the year prior to receiving a diagnosis (Galvin et al., 2010a; Zweig & Galvin, 2014).

Even after receiving a diagnosis, 77 percent of LBD caregivers reported difficulty finding a doctor to help manage the dementia (Galvin et al., 2010a). Being prescribed the wrong medications can be harmful to the person with LBD. For example, antipsychotics may be prescribed for the hallucinations that are common to LBD, but these medications can cause a serious reaction or even death in people with this type of dementia (Mueller et al., 2017). Conversely, people with LBD seem to respond better to cholinesterase inhibitors than do people with Alzheimer's disease; at least one study has demonstrated reduced rates of nursing home admission for people with LBD who are taking this type of medication (Galvin et al., 2010b;

Rongve, Vossius, Nore, Testad & Aarsland, 2013). This increases the importance of working with a physician well versed in LBD treatment protocols. However, finding such a physician can be difficult. People with LBD and their caregivers often encounter health care professionals who are unfamiliar with LBD and thus may not offer the appropriate clinical approach (Lewy Body Dementia Association [LBDA], 2010).

Even when working with a specialist, managing LBD is complicated. People with LBD generally experience a mix of physical, cognitive, and psychological symptoms, and treating one symptom can make another one worse (Galvin et al., 2010a; Taylor & Yardley, 2014; Zweig & Galvin, 2014). Multiple health care providers may be involved, necessitating many appointments and treatments that LBD caregivers help manage. In a survey of LBD caregivers, 58 percent reported difficulty coordinating medical care and more than half were seeing two or more doctors for LBD-related issues (Galvin et al., 2010b). All of this requires an extra level of care, monitoring, and advocacy by the caregiver.

Some research suggests that people with LBD are admitted to nursing homes sooner than people with Alzheimer's disease, although the evidence is inconclusive (Mueller et al., 2017; Rongve et al., 2014). Greater physical and cognitive impairment and associated caregiver burden early in the dementia may contribute to earlier institutionalization. The symptoms of psychosis that are often present are also associated with earlier nursing home placement (Mueller et al., 2017; Rongve et al., 2013). Zweig & Galvin (2014) suggest that although the decision to institutionalize may be necessary, it may also be particularly difficult for LBD caregivers, who are aware that many providers are not well versed in LBD and who may be concerned about whether a family member will receive the appropriate medications and care.

Symptoms That Affect the LBD Caregiving Experience

Many studies of Alzheimer's caregiving have examined caregiver depression and burden and have considered which factors make caregiving more challenging. The severity of behavioral and psychological symptoms and the level of dependence related to daily activities both appear to correlate with feelings of caregiver burden (Beinart, Weinman, Wade & Brady, 2012; Mohamed, Rosenheck, Lyketsos & Schneider, 2010). Although less research is available on LBD caregiving, the evidence suggests that these same factors are important and may explain why levels of caregiver burden appear to be higher with LBD than with Alzheimer's disease (Killen et al., 2016; Leggett et al., 2010; Mueller et al., 2017). Zweig and Galvin (2014) report that people with LBD display more behavioral symptoms than people with Alzheimer's disease, even when the level of cognitive impairment is the same. Depression and apathy, which are associated with feelings of caregiver burden, are both common in people with LBD (Galvin et al., 2010a). The hallucinations and delusions that are typical even in the early stages of LBD are also challenging for caregivers. Sometimes the delusions, which tend to persist, relate to a spouse being unfaithful or a family member being an impostor, which can create additional stress for already challenged caregivers (Mueller et al., 2017; Zweig & Galvin, 2014). Sleep problems, which affect about half of people with LBD, impact caregivers as well (Galvin et al., 2010a, 2010b; Mueller et al., 2017). In one survey of LBD caregivers, sleep problems were closely associated with caregiver burden (Galvin et al., 2010a).

Finally, people with LBD may need considerable support with daily activities even early in the disease. In a survey of 962 LBD caregivers, 60 percent reported that the person with LBD needed help with activities of daily living such as bathing and eating, and 90 percent said they needed help with instrumental activities of daily living such as managing finances and shopping (Galvin et al., 2010a). This functional dependence correlates with higher levels of caregiver burden (Galvin et al., 2010a; Leggett et al., 2010).

Support Needs and Resources for LBD Caregivers

In a recent survey of LBD caregivers, half reported receiving no informational support at the time of diagnosis (Killen et al., 2016). Caregivers expressed a need for information about disease prognosis, symptoms, and progression (Galvin et al., 2010a; Killen et al., 2016; LBDA, 2010; Taylor & Yardley, 2014). One survey of 125 LBD caregivers asked about the types of information and supports that would be most useful. The most agreed-upon needs were for basic information about LBD, how to cope with changing behaviors, learning what approaches have worked for other caregivers, managing communication challenges, and ways to address sleep disturbances. Respondents also indicated a need for information and support in relation to hallucinations, fluctuations in symptoms, medications, worry or anxiety, memory problems, and agitation (Killen et al., 2016). A directory of physicians specializing in LBD diagnosis and treatment and nursing homes skilled in LBD care would also be valuable (LBDA, 2010).

Caregivers have affirmed the importance of talking to others who are dealing with LBD in their relatives (Galvin et al., 2010a; Killen et al., 2016). In a survey of 611 caregivers by the LBDA, 86 percent reported feeling “somewhat” to “very” isolated (Leggett et al., 2010). LBD caregivers may also experience a lack of emotional support from others because they are in a situation that is not understood well (LBDA, 2010). LBD caregivers also contend with the stigma associated with psychiatric symptoms such as hallucinations and delusions (Leggett et al., 2010; Liu et al., 2017; Mueller et al., 2017; Zweig & Galvin, 2014).

The LBDA was formed in 2003 to raise awareness and to provide information and support to affected families. It supplies informational materials, links caregivers to local LBD support groups where available, maintains an online forum where caregivers can exchange information on a variety of LBD topics, and provides caregivers with individualized information and support via e-mail and phone.

Vascular Dementia

Vascular dementia is responsible for about 20 percent of dementia cases in people over age 65; it also frequently co-occurs with Alzheimer’s disease (Alzheimer’s Association, 2016; Hunter et al., 2015; Pilon et al., 2016; University of California San Francisco [UCSF], 2010). About one-quarter to one-third of people who have a stroke will develop dementia; these are often small strokes that go unnoticed but that cause cumulative damage resulting in dementia (Paturel, 2013; UCSF, 2010; “What’s causing your memory loss?”, n.d.). Men and African Americans are at higher risk for vascular dementia, as are smokers and people with high blood pressure, heart disease, diabetes, and alcoholism (Paturel, 2013; UCSF, 2010). Brain imaging tests such as MRIs can help accurately diagnose this form of dementia (UCSF, 2010). Managing

comorbid conditions like diabetes, high blood pressure, and high cholesterol, all of which increase the risk of additional strokes, may slow the progression of dementia (Paturel, 2013; UCSF, 2010). Therefore, proper diagnosis has the potential to positively impact both people with vascular dementia and their caregivers.

Symptoms of vascular dementia are similar to those of Alzheimer's disease, but the progression is different. Vascular dementia usually advances more slowly than Alzheimer's disease and in a "stair step" fashion, with sudden worsening of symptoms after each subsequent stroke, while in Alzheimer's disease the progression generally happens more quickly and steadily (Gill et al., 2013; Paturel, 2013; Pilon et al., 2016; UCSF, 2010). Vascular dementia symptoms can vary considerably based on the location and severity of the brain damage from each stroke (Paturel, 2013; Sachdev et al., 2014). For example, depression is linked to left-brain strokes, impulsivity is linked to right brain strokes, and frontal lobe injury is associated with loss of empathy (American Stroke Association [ASA], 2008).

Obtaining a Vascular Dementia Diagnosis and Managing Care

The criteria for diagnosing vascular dementia are not well defined, and the similarity between vascular dementia symptoms and those of Alzheimer's disease can contribute to misdiagnosis (Alzheimer's Association, 2008; Paturel, 2013; UCSF, 2010). One study examined Medicare costs for people with vascular dementia or Parkinson's disease and found that an initial incorrect diagnosis of Alzheimer's disease led to significantly higher medical costs from hospitalization, ER and skilled nursing facility use, physician visits, and use of durable medical equipment; these costs subsequently decreased once a correct diagnosis was made. It is not clear why costs were higher for those who were misdiagnosed, and the study did not examine out-of-pocket costs for patients and their families, but it is reasonable to presume that family caregivers often bear some of the burden of these unnecessary expenses (Hunter et al., 2015).

People with vascular dementia are significantly more likely than people with Alzheimer's disease or people without dementia to experience other cardiovascular conditions such as heart disease, congestive heart failure, high blood pressure, diabetes, and heart attack and are also more likely to have kidney disease and chronic pulmonary disease (Fillit & Hill, 2002). Decreased levels of strength and balance associated with these comorbid conditions can contribute to greater dependence on caregivers (Pilon et al., 2016). Managing multiple health conditions means that caregivers often coordinate care with several health care providers, requiring time, attention, and sometimes financial burden.

Symptoms That Affect the Vascular Dementia Caregiving Experience

Some researchers have found that, compared to Alzheimer's disease, people with vascular dementia experience more aggression, depression, anxiety, and apathy; other studies have reported no difference or less aggression and anxiety (Ballard et al., 2000; Cerejeira, Lagarto, & Mukaevtova-Ladinska, 2012; D'Onofrio et al., 2012; Kuo et al., 2014). These mixed findings may be attributable to differences in the location and severity of brain damage among people with vascular dementia (Paturel, 2013). In some cases, agitation, combined with

confusion and loss of impulse control, may lead the person with vascular dementia to lash out physically at a caregiver (UCSF, n.d.).

Researchers have also reported mixed findings when considering how caregivers are affected by the person with vascular dementia's changes in mood and behavior. D'Onofrio et al. (2014) reported that caregivers of people with Alzheimer's disease experience greater burden than those of people with vascular dementia. Another study reported that burden is greater for vascular dementia caregivers early in the dementia progression but is greater for Alzheimer's disease caregivers later in the disease (Kuo et al., 2014; Vetter et al., 1999). It is not clear whether these mixed findings are attributable to variation in symptoms among people with vascular dementia or whether the different results relate to how the studies were designed.

Support Needs and Resources for Vascular Dementia Caregivers

Little information is available on the specific support needs of vascular dementia caregivers. There appears to be no organization focused on serving this specific population. The ASA provides resources for people who have had strokes and their caregivers, but there is little information on the ASA website about dementia, even though many people develop dementia after strokes. The UCSF website (2017) provides some general coping strategies for vascular dementia caregivers; these tips are similar to those provided to Alzheimer's caregivers. A 5-year consortium was recently launched by NIH to focus on development of biomarkers for vascular dementia. This research effort is aimed at better understanding the cognitive impairment caused by stroke and may eventually lead to improved support for vascular dementia caregivers (National Institute of Neurological Disorders and Stroke, 2017).

Conclusion

Although all dementia caregivers share similar needs for information, support, and caregiving skills, certain characteristics of non-Alzheimer's dementias are unique and require specialized approaches and supports. Early symptoms of FTD and LBD can be quite different from the hallmark memory loss associated with Alzheimer's disease, and therefore the experience of caregivers can also be different. The common co-occurring physical conditions, such as heart disease with vascular dementia or motor problems with LBD, can also present different challenges for people with non-Alzheimer's dementias and their caregivers.

To better understand and meet the needs of non-Alzheimer's dementia caregivers, information and support to help manage behavioral symptoms, personality changes, and physical health challenges of people with non-Alzheimer's dementias is needed. Virtually no research has been conducted on the specific experiences and needs of people with vascular dementia and their families and how these may differ from the experiences of people with Alzheimer's disease. Longitudinal studies with larger sample sizes are needed to better understand the prognosis and progression of FTD and LBD, including research on the experience of caregivers over the course of these non-Alzheimer's dementias (Caceres et al., 2016; Mueller et al., 2017; Shinagawa et al., 2015). As this type of research progresses, health care providers need to be informed of developments and of the resources that may be available to patients and families.

In addition to research on dementias and how they progress, much more needs to be learned about the supports and services that can best help caregivers. It is not known whether the same types of training and support that are helpful to Alzheimer's caregivers will also be beneficial to caregivers of people with other dementias, how they might be adapted, or what new and different types of services might need to be developed. Randomized controlled trials could test specific interventions with defined populations. Future research could also focus on coping strategies to determine those that are most effective (Roche, Croot, MacCann, Cramer & Diehl-Schmid, 2015; Wong & Wallhagen, 2014). With greater attention and resources devoted to answering these types of questions, caregivers for people with all types of dementias can be better prepared to provide the care and support that will be increasingly necessary.

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