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Review Article

Meeting the Informational, Educational, and Psychosocial Support Needs of Persons Living With Dementia and Their Family Caregivers

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Abstract

Background and Objectives: Meeting the unique and changing needs of individuals living with Alzheimer's disease and their family caregivers can be very challenging given the dynamic and often unpredictable nature of the disease. Effective programs are available to help families manage the challenges they will face.
Research Design and Methods: This article first describes the educational, information, and support needs of individuals living dementia and their family caregivers across all stages of Alzheimer's. Next, we describe the variety of services and program models targeted to the needs of individuals living with Alzheimer's disease or other types of dementia and their families.
Results: These programs can help ensure that person- and family-centered care is maintained from time of first symptoms through end-of-life.
Discussion and Implications: We end with our recommendations for maintaining person- and family-centered care through the provision of targeted information, education, and support to individuals and their families.

Keywords: Alzheimer's disease, Person-centered care, Psychosocial, Social support

The prevalence of dementia has increased dramatically over the past decades. Likewise, there is a growing need for quality education and support programs to help individuals living with dementia, family caregivers, and professionals (Black et al., 2013; Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010). Families are often unprepared to confront the complex emotions and challenges that often accompany a dementia diagnosis. Individuals living with dementia and their care partners also face obstacles to effective communication and when trying to manage the changing levels of care and decision making that are required over time. As individuals living with dementia are diagnosed earlier and more accurately, we can expect more families to enter the social service system earlier in the disease process. In preparation, it is imperative that adequate person- and family-centered systems, programs, and resources are in place to address the unique needs of individuals living with dementia and the family members who care for them.

Whether an individual is in the midst of a diagnostic process, or has received a diagnosis, the terms dementia and memory loss are often presented in a manner synonymous with inevitable deficit and decline and thus, can be stigmatizing (Harman & Clare, 2006). Due to a lack of understanding of the diagnosis and poor access to quality information, education, and support, individuals living with dementia often begin their adjustment to their diagnosis by being told that they cannot or should not do certain things, such as driving or continuing to work. Family caregivers, with their limited understanding of the disease, have difficulty making sense of the changes the individual living with dementia is experiencing (Robinson, Clare, & Evans, 2005).

An estimated 25% of individuals with dementia are living alone with no one to care for them (Alzheimer's Association, 2016). For others, family caregivers are often involved with their care from the onset of symptoms, through diagnosis, relocation to skilled care, and end-of-life. Caregivers can be spouses, partners, adult children, parents, other relatives (siblings, aunts, nieces/nephews, in-laws, and grandchildren), friends, or neighbors. According to the Alzheimer's Association (2016), in 2015, over 15 million family caregivers provided over 18.1 billion dollars of unpaid care. Negative health effects for caregivers are widely documented in the literature and include higher levels of depression, compromised physical health, and decreased quality of life (Etters, Goodall, & Harrison, 2008; Perkins et al., 2012; Pinquart & Sörensen, 2007).

When an individual living with dementia can no longer make decisions for him/herself, it is not uncommon for the caregiver to begin to make decisions on their behalf. In turn, for the individual living with dementia, the window of opportunity to be an active participant in their own care begins to close (Menne & Whitlatch, 2007; Whitlatch & Feinberg, 2003). Ultimately, the core of the individual's identity can be lost (Maslow, 2013). As the symptoms of dementia other chronic conditions progress, care partners often begin to provide help with instrumental activities of daily living (IADLs) such as shopping, making appointments, and providing transportation. Eventually, caregiving demands increase and ultimately care partners are providing assistance with personal activities of daily living (PADLs, e.g., bathing, dressing, and toileting), oftentimes with no backup plan in place if the caregiver becomes ill or can no longer provide care (Pearce, Forsyth, Boyd, & Jackson, 2012).

Many qualitative studies report a clear need for greater support after receiving a dementia diagnosis for both the individual living with dementia and their family caregiver (Bunn et al., 2012). In addition to not knowing what types of supports exist, families face many challenges to receiving this desperately needed education and support. Many in need of help experience difficulty in knowing which sources of information are accurate and of good quality; many also suffer a lack of knowledge of and guidance on how to access them (National Academies of Sciences, Engineering, and Medicine, 2016).

The purpose of this paper is to describe the broad categories of educational, information, and support needs of individuals living dementia and their family caregivers across the three stages of Alzheimer's (i.e., early, middle, and late stages). Further, we will provide a description of specific services and program models that have been developed and tested (i.e., evidence-based), thus ensuring individuals living with Alzheimer's disease or other types of dementia and their families have the most effective person- and family- centered support available to them. Lastly, we will present updated practice recommendations that summarize the most current knowledge and person- and family- centered strategies in education, information, and support programs and services for individuals living with dementia and their family caregivers.

Developing Evidence-based Person-Centered Programs

Research findings increasingly document that education, information, and psychosocial programs and support can contribute to the quality of life of both care partners, improve mental health outcomes for caregivers, and delay relocation to long-term care settings for individuals with dementia (see review by Smits et al., 2007). Evaluations of these programs vary greatly; some have an established evidence base documenting their effectiveness while others have very little research supporting their design, evaluation, and efficacy (see also Wiener et al., 2016 for additional information on Models of Dementia Care). Throughout this paper we provide descriptions of programs that take a person- or family-centered perspective and have a documented evidence base confirming their effectiveness. For our purposes, here we follow the definition of an established evidence-base practice model developed as part of the Hartford Foundation funded project "Decision Support Tool for Dementia Caregiving Programs." The work group for this project has compiled a list of the latest nonpharmacological, evidence-based programs for persons with dementia and their caregivers (Maslow, 2016). The original criteria for designation as an evidence-based practice model includes the following (adapted from Maslow, 2016):

(a) use in an evaluation of a community-based population;
(b) the intervention is nonpharmacological;
(c) the intervention has positive outcomes in at least one U.S.-based randomized control trial (RCT);
(d) positive outcomes for the person with dementia, the family caregiver(s) or both;
(e) outcomes are reported for the person with dementia and the family caregiver(s);
(f) has been or is being replicated/translated at least once in the United States.

Programs that meet these six criteria are designated as evidence-based practice models. As well, we note the translation status of each program per Maslow (2016).

Education and Information

Education and information about dementia can include a variety of topic areas such as information about disease progression, pharmacological options, risk factors (genetic and environmental), stress management for both care partners, managing behavioral and psychological symptoms of dementia (BPSDs), and available and appropriate services. Access to the various types of information, education, and appropriate services across the different stage of Alzheimer's can vary, with evidence suggesting that caregivers find it most difficult to access information in the early stages (Lilly, Robinson, Holtzman, & Bottorff, 2012; for information about the stages of Alzheimer's visit http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp). To be most useful, information for both the individual living with dementia and caregiver must target their current needs and situation rather than take a "one size fits all" approach (Etters et al., 2008; Lauriks et al., 2007; Van Mierlo, Meiland, Van der Roest, & Dröes, 2012). Information presented "off time", that is, when the individual living with dementia or care partner is not ready to hear it, could cause unnecessary stress for either person (Orsulic-Jeras, Whitlatch, Szabo, Shelton, & Johnson, 2016).

However, appropriate and accurate education and information about the disease is "[u]ndisputably effective" (p968; Sörensen, Duberstein, Gill, & Pinquart, 2006) and has significant positive effects on burden, depression, and subjective well-being. Selwood, Johnston, Katona, Lyketsos, & Livingston (2007) note that education alone is not enough to improve outcomes, unless presented in conjunction with other strategies targeted to the unique needs of the individual living with Alzheimer's, the caregiver, and broader family. These authors note in their review that mental health improved for care partners who learned behavioral management techniques individually (as opposed to in group settings), and learned coping strategies (individually or group-based delivery format).

Other types of information that are useful for individuals living with dementia and care partners address the future care needs of the individual, and decision making around how these needs will be met as the disease progresses. Understanding future care needs is another type of information critical for families who have accepted the disease and understand its progression. They are ready to plan for the future and willing to discuss decisions together. Practitioners can support these families by providing a safe, open, and nonjudgmental environment that facilitates discussion about what the individual living with dementia values for their care (e.g., not being a burden, being safe) and who they want to help them once they need assistance (Orsulic-Jeras et al., 2016). Care partners who understand their relative's care values can make more informed decisions about care as the disease progresses. These decisions are critical to ensuring person- and family-centered care throughout the course of dementia because they reflect the individual's and caregiver's values and preferences for care (Whitlatch & Feinberg, 2003). Planning for incapacity is very important to individuals living with dementia and their family caregivers as they face legal and financial decisions about many aspects of their lives. Targeted legal and financial information is also very important to individuals living with dementia and their care partners as they try to manage their resources in order to ensure that their housing, support, health, social, and financial needs are met. In addition, it is critical for practitioners to provide guidance about how to recognize and avoid financial scams and other exploitive efforts that target vulnerable older populations.

Support Options

In addition to meeting the education and information needs of families, professionals have numerous options for providing or referring families to appropriate supportive services and programs across the disease trajectory.

Support Groups

Support groups have been found to be helpful to families in decreasing isolation and increasing social support (Chien et al., 2011; Logsdon, McCurry, & Teri, 2007). Support groups encourage care partners and individuals living with dementia to share personal experiences and learn from others, while fostering engagement and socialization. Groups can be led either by a professional or peer, can target the individual living with dementia and/or the family caregiver, and bring together similar kin groups of attendees (e.g., spouses, adult children, men, women, etc.). Web-based, online, and phone groups rather than in-person support groups are also available in some communities (Berwig et al., 2017; Topo, 2009). Research on the effectiveness of support groups is mixed (i.e., no strong evidence base) with some studies showing great gains by participants and other studies showing less promise (Pinquart & Sörenson, 2006).

Counseling

Families report positive outcomes from their experiences meeting individually with counselors, social workers and other clinicians who provide individual, dyadic, and family counseling and/or psychotherapy (Vernooij-Dassen, Joling, van Hout, & Mittelman, 2010). Examples of this type of support include cognitive behavioral therapy, psychodynamic therapy, and other techniques designed mainly to help deal with BPSDs in the middle to late stages (see section below). Individual and family counseling protocols are often one element of a multicomponent intervention (see Multi-Component section below).

Respite

Respite is a service primarily designed to provide a break or time away from caregiving as a strategy for ensuring that care partners gets relief from their care responsibilities. Respite can be provided by a professional, friend, or family member who provides companionship and/or supervision for the individual or takes him/her out of the home. Ideally, respite provides the care partner the opportunity to run errands, exercise, visit with friends or family, or engage in other pleasant or enriching activities that promote caregiver self-care and improve well-being. Likewise, home health workers or aides provide respite when they care for the individual because they provide supervision during their visit. Adult day programs provide a safe and enriched environment for individuals living with dementia while simultaneously providing respite for the care partner who may use the time to go to work. In addition, caregivers who take advantage of adult day programs show improved outcomes such as increased levels of the beneficial stress hormone DHEA-S (Zarit et al., 2014). Again, the evidence base documenting respite's effectiveness is mixed with few studies using a RCT.

Care Coordination Programs

Care coordination programs (also referred to as Case Management, Care Consultation, Managed Care, Collaborative Care, and Care Counseling) provide information, coaching, and emotional support to family caregivers and, in some cases, the individual living with dementia. These programs can be conducted online, by phone, or in-person, and are designed to provide education and information about the disease, referral to appropriate programs, recommended strategies for coping with stress, advice about self-care, and care planning. Care coordination can provide regular assessment of the individual's and caregiver's strengths and changing needs, and offer strategies for coping with new stressors. This model of support, assessment, and reassessment is in-line with recommendations put forth by Fazio et al. and Molony et al. (this issue) which focus on the importance of adjusting practices based on the individual's and caregiver's changing needs and preferences.

Multicomponent Interventions

Multicomponent interventions include more than one treatment modality such as information and education, individual and family counseling, support groups, and self-help training. In their review of multicomponent programs, Brodaty and Arasaratnam (2012) discuss that multicomponent programs that included a combination of skills training, education of the caregivers, activity planning, environmental redesign, caregiver support, caregiver self-care, or exercise for the caregiver can significantly reduce BPSDs.

Alternative Therapies

Also available to individuals with dementia and their family care partners are alternative therapies such as yoga, meditation, life review, physical exercise, aromatherapy, bright light, music, and art. A number of research studies show promising findings for the use of alternative therapies (Douglas, James, & Ballard, 2004) including improved caregiver depression, anxiety, and perceived self-efficacy (Waelde, Thompson, & Gallagher-Thompson, 2004). Music interventions are available to families across the three stages of Alzheimer's with promising findings reported for decreased anxiety and reduced agitated behaviors for the individual (Lin et al., 2011; Sherratt, Thornton, & Hatton, 2004; Sung, Lee, Li, & Watson, 2012). While both the individual with dementia and his/her care partner are often encouraged to participate, research suggests that outcomes are stronger when the caregiver plays a more active role in the program through role playing and other interactive exercises (Pinquart & Sörensen, 2006).

Education, Information, and Support Interventions Across All Stages of Alzheimer's Disease

Early Stage of Alzheimer's Disease

A diagnosis of Alzheimer's or other dementia brings about many significant and unexpected life changes. One significant change is the transition from a familial relationship between two caring individuals (such as spouse or adult child) to that of a ***care dyad***. Thoughts about what lies ahead can become overwhelming for the person who is transitioning into the role of care partner. Care partners often experience stress during this postdiagnosis period due to a lack of information and knowledge about the diagnosis, and limited access to formal resources and support (Ducharme et al., 2011; Robinson et al., 2005).

The initial or early-stage postdiagnosis is often characterized by few visible symptoms of the disease. The individual living with Alzheimer's is still quite independent and does not require much if any assistance. However, challenges with daily tasks combined with the fear of future impaired functioning can threaten the individual's self-identity, future independence, and perceived views and expectations of normal aging (Clare, 2003; Harman & Clare, 2006; Steeman, Tournoy, Grypdonck, Godderis, & De Casterlé, 2013).

Early-Stage Education and Information

The need for information and education about the disease, symptoms, treatment, and prognosis are high during this stage (Peeters et al., 2010; Van Mierlo et al., 2012). Programs and resources are needed to help newly diagnosed and early-stage individuals living with Alzheimer's and their families cope with the impact of the disease. However, individuals and care partners may have different information needs as they begin to accept the diagnosis and seek out information about symptoms, progression, and treatment options. In addition, readiness to receive information and support may vary within a family and, in turn, may impact the willingness and/or ability of family members to accept help (Orsulic-Jeras et al., 2016).

Information about services is often less emphasized during this early stage because the individual's level of need for personal assistance is minimal. However, research shows that when asked to look back to the early stages of their relative's dementia, later stage caregivers believe they would have benefited from receiving relevant information earlier on (Boots, Wolfs, Verhey, Kempen, & de Vugt, 2015). In addition, retrospectively, some care partners felt that being introduced earlier to information that was hopeful or empowering would have helped them be more open to asking for help. This early-stage paradox creates a challenge in trying to support early-stage families who often struggle to accept changes due to fear of stigma.

Online Resources

One of the largest unmet needs reported by care partners of individuals living with early-stage dementia is the lack of high quality and available information, education and support services that are tailored to meet the unique needs of families, rather than take a "one size fits all" approach (Gaugler & Kane, 2015; Rudzicz & Polgar, 2016). One strategy for addressing the unique needs of families is to provide an assessment that ensures that a comprehensive picture of the individual's and care partner's needs, preferences, and strengths is obtained. See Molony et al. (this issue) for more information about assessment and care planning.

Care to Plan Tool. The Care to Plan Tool is one example of a needs assessment that generates a tailored support recommendation (Gaugler, Reese, & Tanler, 2016). Although the Care to Plan tool shows positive feasibility and acceptability for care partners, it remains unclear how the use of the tool affects *outcomes* for individuals living with dementia and care partners. However, although there is no established evidence base for Care to Plan, preliminary findings show promise in linking tailored support that could potentially improve the care planning process for both care partners. Care to Plan has not undergone any translational studies to date.

Early-Stage Support Options

The early stage of Alzheimer's provides a unique opportunity for the individual and caregiver to learn more about available resources that can help them in the future. Supportive services that provide transportation, delivery of groceries and meals, and access to technology (e.g., mobile phone, internet, on-line shopping) can be helpful in preserving the autonomy of the individual living with dementia.

Support Groups

A growing body of research has documented the effectiveness of early-stage support groups (Logsdon et al., 2010). There are existing support groups developed for early-stage families in many, but certainly not all, communities. Challenges exist with service delivery of these programs, mainly around engaging families in rural and minority communities as well as involving both care partners. Organizations such as the Alzheimer's Association have been successful in establishing both staff and volunteer-led support groups that serve individuals living with dementia *and* their care partners. Although few early-stage support groups have undergone rigorous evaluation, a handful of studies have been conducted. These studies have found a decrease in isolation, increase in social support, and ability to accept the diagnosis, cope with symptoms, improve quality of life, and enhance family communication (Logsdon et al., 2007; Logsdon et al., 2010; Snyder, Jenkins, & Joosten, 2007). Memory Club, one example of an early-stage dyadic group intervention, has showed promise in supporting both care partners (Gaugler et al., 2011; Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004). With time set aside to work together as well as separately, Memory Club participants are given the opportunity to have discussions about their care situations as well as plan for the future. The group format encourages Memory Club participants to create and maintain a community of supportive peers which is critical to the well-being of both the individual living with dementia and care partner. Although many early-stage groups are available in the community and some have reported positive outcomes, few translational studies exist that support their effectiveness in community settings.

Technology-Based Supports

Internet-based interventions offer support for families in an efficient and cost-effective way (Boots, Vugt, Knippenberg, Kempen, & Verhey, 2014; Lauriks et al., 2007). Online support interventions include health coaching, counseling, stress management, and specific caregiver support. In addition, telecare and telehealth interventions are used to facilitate the delivery of health information and care options from a distance using a variety of technologies (Lorenz, Freddolino, Comas-Herrera, Knapp, & Damant, 2017). These types of interventions can assist with care management when there are multiple family members who are providing care from a distance.

Telehealth interventions have also been found to improve coping skills for care partners of individuals living with Alzheimer's (Chi & Demiris, 2015). In addition, telehealth interventions can be effective in reaching isolated populations, specifically rural individuals living with Alzheimer's and their care partners (Clancy Dollinger & Chwalisz, 2011). Despite these promising findings, many telehealth programs (home telehealth in particular) face barriers to sustainability due to a variety of programmatic challenges (e.g., lack of person- or family-centered outcomes, evidence of cost effectiveness; see Radhakrishnan, Xie, & Jacelon, 2016). Funding of technology-based programs through client payment and/or government subsidies is also challenging although family caregivers report being willing to pay privately for services that support family members with dementia (Schulz et al., 2016).

Overall, telehealth, online, and other technology-based programs have the potential to broaden the reach of support for families facing the challenges of Alzheimer's who might otherwise not have access to useful and timely resources. Note: Many interventions mentioned in this paper have technology-based and/or telehealth components that are not described here but will be identified in other sections. Although a handful of telehealth interventions have shown promising results, none to our knowledge have conducted translational studies to date.

Care Planning for the Future

Families in the early stage can benefit from discussions about future care and values for care as they plan for the time when the individual living with dementia is no longer able to voice his or her preferences (Orsulic-Jeras et al., 2016). Thus, knowing the individual living with dementia is crucial to person- and family-centered care in the early stage if his/her voice is to be heard and honored through the later stages.

SHARE Program. Other than a few of the early-stage dyadic support groups, few interventions exist which are designed to elicit discussions that clarify *both* care partners' values and preferences for care and develop a future plan of care based on these preferences. One exception is the SHARE Program (Support, Health, Activities, Resource, and Education; formerly referred to as Early Diagnosis Dyadic Intervention; Whitlatch, Judge, Zarit, & Femia, 2006). SHARE takes advantage of the unique opportunity in early-stage Alzheimer's when the individual with dementia can assume an active role in discussing care values and preferences for the future. The core of this intervention centers on the individual's care values and preferences, and the care partner's perceptions of those care values and preferences Whitlatch, Heid, Femia, Orsulic-Jeras, Szabo, & Zarit (in press). After the individual's care values and preferences are understood, the SHARE protocol works with the individual living with dementia and caregiver to develop a plan of care for the future (Orsulic-Jeras et al., 2016). SHARE's proactive approach focuses on empowerment and self-efficacy for both care partners with a strong emphasis on giving the individual living with Alzheimer's a voice in planning their own care. Allowing care partners the opportunity to hear, acknowledge, and validate the individual's preferences gives them a starting point from which to frame discussions on decision making and future care planning. This strategy helps to build a network of support and identify opportunities for meaningful engagement.

SHARE has been translated multiple sites across the United States and also in the Netherlands. Adaptations of the SHARE intervention include persons with chronic conditions, heart failure, and SHARE in a group setting.

Driving Safety for Individuals Living with Alzheimer's Disease

One of the greatest threats to the autonomy and personhood of an individual living with Alzheimer's is losing the ability to drive (Snyder, 2005). Individuals living with Alzheimer's often rely on the support of family and/or friends to assist in making decisions about driving safety (Carter et al., 2015). In turn, families seek help from professionals, but often find that professionals are also unprepared to give driving advice (Adler, 2010; Stern et al., 2008). Physicians report feeling that they are unprepared to offer families legal advice on driving cessation, even though they are often the first professional contact families reach out to for driving advice (Perkinson et al., 2005). To address this significant deficiency in the early-stage service system, several organizations have developed literature to provide education to families regarding driving safety and when it is time to "put away the keys." The Alzheimer's Association Dementia and Driving Resource Center is an online tool that provides information and suggestions about how to discuss driving safety with care partners and persons living with dementia (http://www.alz.org/care/alzheimers-dementia-and-driving.asp).

Despite the availability of printed educational material for families about driving, research suggests that simply providing reading material may not be adequate for informing families about how and when to limit and ultimately stop the individual from driving (Stern et al., 2008). As a result, several psychoeducational driving groups have been developed by researchers in order to provide more support to families (Meuser, Carr, Berg-Weger, Niewoehner, & Morris, 2006; Stern et al., 2008; Zarit et al., 2004). Windsor and Anstey (2006) discuss various interventions developed to provide support to families after driving cessation. In addition, families could benefit from information about senior transportation options in their communities as an alternative to the person living with dementia continuing to drive and risk hurting him/herself or others. Understanding and accepting the individual's changing reality and identity can be challenging to the individual, care partner, and family and friends, but it is essential to providing person- and family-centered care that reflects the individual's preferences and values for care.

Middle Stage of Alzheimer's: Increased Need for Care and Support

During the middle stage of Alzheimer's, individuals living with dementia begin to require more assistance with IADLs such as shopping, housekeeping, taking care of finances, food preparation, taking medication, using the telephone, and accessing on-line resources. As the disease progresses, individuals living with Alzheimer's also require help with more personal activities (PADLs) such as bathing, dressing, toileting, eating, and grooming.

The increasing dependence of the individual for help with IADLs and PADLs often brings about higher levels of stress and burden for the caregiver. The need for supportive services and help from other family/friends becomes high during the middle stage. Discussions about changing living arrangements and possible relocation in the future may be initiated by the caregiver or other family members, or more commonly, are made reactively as a result of an unexpected emergency or crisis that occurs for either care partner (e.g., severe fall, unexpected health crisis).

Middle-Stage Education and Information

Similar to the needs of families in the early stage of Alzheimer's, the information and education needs of families in the middle stage is significant. Information and education are most effective if targeted to meet the unique needs of each family. In their meta-analysis of over 100 studies of dementia caregiver interventions, Pinquart & Sörensen (2006) note that education has a positive and significant effect on burden, depression, subjective well-being, the individual's symptoms, ability and knowledge. The individual living with dementia's increasing dependency and changes in behaviors (e.g., wandering, agitation, sexual disinhibition) during the middle stage of Alzheimer's can be stressful and exhausting for the caregiver. Thus, in addition to needing information about the disease and its progression, families in the middle stage can be helped by learning how to manage the individual with dementia's unpredictable and changing behaviors. Programs that help families to manage BPSDs are described below (see also Sörensen et al., 2006 who provide additional description of caregiver need and potential interventions and resources that could be useful.)

Middle-Stage Support Options

As noted, growing evidence indicates that psychosocial programs and support can contribute to the quality of life of both care partners, improve mental health outcomes for caregivers, and delay relocation to long-term care settings for individuals with dementia (see review by Smits et al., 2007). Evaluations of these programs vary greatly; some have an established evidence base documenting their effectiveness and others have very little research supporting their design, evaluation, and efficacy (see also Wiener et al., 2016 for additional information on Models of Dementia Care). Next, we provide descriptions of middle-stage programs that take a person- and family- centered perspective many of which have a documented evidence base confirming their effectiveness.

Management of BPSDs

One of the most distressing symptoms of dementia are the BPSDs that first surface during the early stage of Alzheimer's and reach their peak in number and intensity during the middle or late stage. Currently, there is neither consensus nor an established evidence base concerning the techniques that are universally effective for helping family caregivers to manage and cope with BPSDs. Yet, promising practices do exist. In their review of psychological interventions for caregivers, Selwood et al., 2007 found that behavioral management techniques taught to individual care partners rather than groups of caregivers decreased caregiver depression over both the short- and long-term. Individual and group strategies for coping with BPSDs decreased distress and depression over the short- and long-term. Teaching "principles" was found to be less effective than learning and practicing what to do (i.e., role playing and problem solving) when working with specific behaviors. Nonpharmacological interventions are available to manage wandering specifically although the effectiveness in decreasing wandering behaviors is not universal (see Robinson et al., 2006 for a review). Mounting evidence indicates that nonpharmacologic interventions to help caregivers manage BPSDs can be as effective as or more effective than pharmacological strategies in reducing BPSDs (Brodaty & Arasaratnam, 2012) and decreasing the caregiver's negative reactions to the behaviors.

Advanced Caregiver Training (ACT). This evidence-based program helps care partners to recognize and manage BPSDs. Behaviors can be caregiver based, individual living with dementia based, and/or environmentally based (Gitlin, Winter, Dennis, Hodgson, Hauck, 2010a, b). Sessions provide education, strategies to improve communication, and information about the importance of physical and mental engagement for both care partners. The ACT intervention has been fully translated to date.

Caregiver Skill Building. The Caregiver Skill Building program (CSB) is designed to help caregivers manage and cope with BPSDs by learning about the causes of these behaviors and how to respond in an optimal manner (Farran, Gilley, McCann, Bienias, Lindeman, & Evans, 2007). This 5-week group intervention also provides telephone support weekly for 7 weeks. The program first addresses simpler and less distressing BPSDs and then moves on to those that are more upsetting. Group booster sessions (6 and 12 months) and phone contacts are also available as needed. The effectiveness of CSB is not firmly established and no translational studies have been conducted to date.

Care Coordination Programs

As noted, care Coordination programs provide information, coaching, and emotional support to family caregivers and, in some cases, the individual living with dementia.

Benjamin Rose Institute Care Consultation. BRI Care Consultation is an evidence-based phone-delivered coaching and support program (Bass et al., 2014). BRI-CC helps caregivers to develop an action plan that recognizes the family's personal strengths and resources, and draws upon resources in the community and available through their health plan. This person- and family- centered program is delivered in partnership with Alzheimer's Association chapters and a managed care health system or a Veteran's Administration Medical Center. BRI Care Consultation provides information, referral, and guidance for both care partners and improves access to medical and nonmedical services. Moreover, critical to BRI Care Consultation are the on-going interactions with Care Consultants that encourages regular re-evaluation of referrals, changing information needs, and family support that can inform changes to the dyad's action plan. Numerous translational studies have been conducted.

CarePRO Care Partners REACHING OUT. This evidence-based group intervention empowers family caregivers of individuals living with Alzheimer's disease through education, skill building, communication, and self-care strategies (Coon et al., 2016). Research indicates the feasibility of CarePro and high levels of "caregiver perceived benefit." (p.9; Coon et al., 2016). English and Spanish versions of CarePRO are available. Currently translational studies are underway in Arizona and Nevada.

Dementia Care Consultation. A dementia care consultation intervention based in the community for family caregivers (Fortinsky, Kulldorff, Kleppinger, & Kenyon-Pesce, 2009). Care consultants meet individually with caregivers and persons living with dementia over 12 months to develop and adjust care plans. Referring primary care physicians receive copies of care plans and incorporate them as needed. Preliminary RCT findings are promising (e.g., delayed relocation to skilled living environments, increased caregiver efficacy, lower depression, and decreased caregiver burden). We are aware of no translational studies that have been conducted to date.

New York University Caregiver Intervention (NYU-CI). This multicomponent evidence-based intervention teaches spouse caregivers how to manage the stress of providing care for individuals living with Alzheimer's disease (Gaugler, Roth, Haley, & Mittelman, 2008; Gaugler, Mittelman, Hepburn, & Newcomer, 2010; Mittelman et al., 1993). Treatment modalities for the caregiver include education about the disease, referrals to services, individual and family counseling, support groups, and telephone counseling. Originally developed for spouse caregivers, NYU-CI is also available for adult child caregivers. NYU-CI has been shown to delay the decision to relocate the individual into a skilled care environment for spouse and adult child caregivers (Mittelman et al., 1993). Numerous translational studies for the NYI-CI intervention have been conducted.

Powerful Tools for Caregivers. Based on the Chronic Disease Self-Management Program, Powerful Tools is designed to help caregivers develop the "tools" to maintain their health and lessen the stress of providing care (Kuhn, Hollinger-Smith, Presser, Civian, & Batsch, 2008). Six weekly classes help caregivers learn how to reduce stress, communicate their needs to family members and service providers, and address difficult emotions. Powerful Tools has an established evidence base, with numerous translational studies published to date.

Savvy Caregiver and Savvy Caregiver 2: Distance Dementia Caregiver Education Programs. Savvy Caregiver is a 12-hr psychoeducational evidence-based program (six 2-hr group sessions) that introduce family caregivers and caregiving professionals to the caregiving role, providing them with the knowledge, skills, and approaches to carry out the role, alerting them to self-care issues, and using problem solving skills to manage BPSDs (Kally et al., 2014; Lewis, Hobday, & Hepburn, 2010). Savvy 2 is advanced training (4 weeks) for caregivers who completed the initial program, but want added support and information to meet the challenges of more advanced dementia. Participants reported feeling more confident as caregivers and overall better communicators. The Savvy Caregiver program has conducted translational studies.

Skills2Care. The evidence-based Skills2Care program (formerly REACH ESP) is a home-based program for community individuals living with dementia and their family caregivers with the goal of reducing caregiver burden through: information about the disease, education about the impact of the home environment, and supporting caregivers to make environmental modifications (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2014). Five 90-min home visits and one 30-min telephone contact are conducted over 6 months. The Skills2Care program is fully translated.

Alternative Therapies

Alternative therapies are increasingly viewed as a viable option for providing support and coping strategies to individuals living with Alzheimer's and their caregivers. Music therapy has been found to increase levels of well-being, improve social interactions (Lord & Garner, 1993), and reduce agitation in individuals with dementia (Gerdner, 2000). Aromatherapy also has shown to be useful for individuals living with dementia and effective in reducing agitation, as well as better tolerated than neuroleptics or sedatives (see Douglas et al., 2004 for a review). Finally, Korn et al., 2009 have examined the effect of Polarity therapy on the well-being of American Indian and Alaska Native family caregivers.

Exercise provides health benefits to individual with dementia and their caregivers including reduced falls, improved mental health, improved sleep, mood, balance, gait, and decreased daytime agitation (Dawson, Judge, & Gerhart, 2017; King et al., 1997). Additional studies show varying results where weekly exercise plus phone support did not lead to improvements in depression, anxiety, or burden (Castro, Wilcox, & O'Sullivan, Baumann, & King, 2002). However, the RDAD program (Reducing Disability in Alzheimer's Disease; Menne et al., 2014; Teri et al., 2003) has shown very positive results and has published numerous translational studies. RDAD consists of 12 1-hr sessions in the home which helps promote exercise and physical activity in persons living with dementia and their caregivers. Moreover, caregivers learn approaches for managing BPSDs which is associated with a decrease in unmet needs (Menne et al., 2014).

Overall, these alternative programs embrace a person- and family- centered philosophy because they provide ongoing support and meaningful engagement, and help build caring and engaging relationships. In addition, they respond to and, in turn, target the unique needs of individuals living with dementia, their caregivers, and other family members. More research is needed, however, to identify the most promising modalities (For additional information about Alternative Therapies that enhance person- and family-centered care see Scales, Zimmerman, & Miller, this issue)

MultiComponent Interventions

Multicomponent programs for individuals living with middle-stage dementia and their caregivers show encouraging results. This model of support is especially effective for positive outcomes (e.g., delaying relocation of individuals with dementia to long-term care settings) if participants are “exposed to all components” (Brodaty & Arasaratnam, 2012).

Care of Persons With Dementia in Their Environment (COPE). The COPE program is a multicomponent evidence-based intervention that engages both care partners to support the strengths of the individual with dementia by reducing environmental stressors and enhancing caregiver skills (Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010). Treatment components include, but are not limited to: individual living with dementia deficits and capabilities, home environment, caregiver communication, caregiver-identified concerns, caregiver education about medications, pain, and reducing stress, and information about healthy activities. A translational study of the COPE intervention is currently underway.

Resources for Enhancing Alzheimer’s Caregiver Health (REACH 2). This home- and evidence-based program addresses five areas of caregiver stress: safety, self-care, social support, emotional well-being, and BPSDs (Belle et al., 2006; Lykens, Moayad, Biswas, Reyes-Ortiz, & Singh, 2014). Caregivers are provided training and counseling for 6 months (9 1.5-hr sessions). Intervention strategies include providing information, role playing, stress management techniques, problem solving, and telephone support. REACH 2 is delivered in-person, over the phone, and through structured telephone support group sessions. Lykens et al. (2014), note that their trial in Northern Texas (where REACH 2 was conducted in both English and Spanish) produced positive outcomes for caregiver depression and burden. Numerous translational studies on the REACH intervention have been published.

Advances in Technology

New developments in technology and web-based programs offer families innovative strategies for providing assistance and support to individuals and their care partners from a distance and managing their health care. Consumer Health Information Technology (CHIT) includes electronic technologies caregivers, individuals living with dementia and other family can access and interact with and that have the potential to use health and other personal information to tailor care plans, and individualize programs (Dyer, Kansagara, McInnes, Freeman, & Woods, 2012). A review of the use of CHIT by caregivers of adults with chronic conditions found that “on-line peer –support groups and chat rooms were both the most used and valued components of any website, application, or intervention” (page 2; Dyer et al., 2012). The authors note the importance of anonymity to these users as well.

In general, these online multicomponent interventions have the potential to improve knowledge, skills, and coping, while enabling meaningful engagement and caring relationships and support for caregivers and individuals living with dementia. They hold great promise for families in rural settings and those with additional chronic health conditions that do not allow them to leave their home. Moreover, individuals who are distrustful of institutions because of historical prejudice and injustice may feel more comfortable accessing support and services that are offered in a more confidential manner. In turn, a more supportive person- and family- centered environment is created which respects individual differences and supports families and individuals regardless of cultural background, sexual orientation, gender identity (Moone, Crogham, & Olson, 2016), and socioeconomic status.

Late stage of Alzheimer’s: Relocation to Assisted Living or Skilled Care and End of Life Care

Not different from families during previous stages of Alzheimer’s, families in the late stage have a significant need for information about the illness and its prognosis as well as support. Stress for both the individual living with dementia and the family caregiver can be high during this stage. Understanding how the disease will progress can help alleviate some of this stress because it helps families to know what to expect in the future and, in turn, prepare for the future. Referring back to earlier discussions about the individual’s care values and preferences could ensure that decisions made are in line with individual living with dementia’s earlier stated preferences for care (Orsulic-Jeras et al., 2016).

Late-Stage Education and Information

During the late stage, when the individual living with Alzheimer’s care needs become too great for the caregiver to manage, families often begin to consider whether to continue in-home care or relocate the individual with Alzheimer's to an alternate care setting (e.g., assisted living, skilled care). This decision can be very distressing to caregivers and individuals who may have not discussed the possibility of relocating to a care setting.

On the other hand, some families may have promised their relative that they would never relocate him or her to a long-term care setting. This promise can be unrealistic as the individual living with dementia's care requirements intensify and the caregiver's ability to meet these needs becomes increasingly challenging or even impossible. Yet, oftentimes caregivers do not understand that many individuals living with dementia are open to discussing the possibility of relocating to a long-term care setting if their care needs become too burdensome (Whitlatch, 2010). As a result, it is critical for families to have an understanding of available alternate living environments from assisted living and skilled care to hospice.

Late-Stage Support Options

Research indicates that the transition from home to skilled setting can be stressful for persons living with dementia and caregivers. Compared to their in-home caregiving peers, caregivers with relatives in skilled care environments report providing less hands on assistance (PADLs), and experience more guilt (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Caregivers who adopt manageable visiting routines are often better adjusted than caregivers who, for example, visit daily, stay for long periods of time, and continue to provide a significant amount of personal care (Aneshensel et al., 1995). Moreover, families often work to establish relationships with long-term care and assisted living staff with the hope that this will ensure that the individual living with dementia will receive the best care possible. Interventions that help caregivers and individuals with dementia adjust to the skilled care environment could help alleviate the stress of relocation (Gaugler & Kane, 2015). See article by Hirshman and Hodgson (this issue) which goes into great detail about transitions in care.

Regardless of whether or not the individual with dementia relocates to a long-term or supportive environment, his or her dementia will progress and the need for end-of-life care will become more salient. However, no matter the speed or course of progression to end-of-life, or whether the individual remains at home or relocates to a care setting, the educational and informational needs about care-related decisions are high as is the need for support for both the individual and caregiver. Shared decision making around end-of-life practices that are based on the individual's earlier stated preferences, are critical to ensuring person- and family-centered care.

Families during the final stage require significant support and can be helped by programs targeted to their unique needs as they enter into end-of-life and hospice care. As during the earlier stages of Alzheimer's, individual, dyadic, family counseling, and support groups can help alleviate the stress families feel during this time. Involving other family members/friends in care can be helpful to the individual with dementia and family caregiver by lessening their stress and isolation (Dening, Jones, & Sampson, 2013). Not all support is necessarily helpful or desired, and family members must respect the preferences of both the individual with dementia and caregiver. Yet, few programs exist which specifically target the unique needs of families facing end-of-life care for individuals with Alzheimer's disease.

End-of-Life Care

Throughout this paper, we advocate for the provision of education, information, educational materials, and support in the early stages of Alzheimer's. We encourage a focus on encouraging discussion of the individual's values and preferences for care with their caregivers when the individual's voice can still be heard (Dening et al., 2013; Orsulic-Jeras et al., 2016). One of the primary challenges of advanced Alzheimer's end-of-life care is the dependence upon family members to make critical health care decisions when the individual is no longer able (Caron, Griffith, & Arcand, 2005a). In addition, it is possible that if those early-stage supports are in place, individuals may be able to remain at home longer. However, in many family care situations, the individual's symptoms and health care needs are far too advanced to take advantage of the benefits of early intervention. Indeed, family caregivers are increasingly providing help with multiple and complex medical tasks (e.g., using monitors, providing wound care, managing multiple medications, preparing special diets; Reinhard & Levine, 2012), As a result, remaining at home may not be a viable option (Mittelman, Haley, Clay, & Roth, 2006).

Research indicates that a diagnosis of Alzheimer's or related dementia increases the likelihood of relocation to a skilled care setting (Gaugler, Yu, Krichbaum, & Wyman, 2009; Mittelman et al., 2006). Once the individual is living in a nursing home, the challenges for family caregivers include not knowing what role they should assume and how to obtain information about the individual's care (Caron, Griffith, & Arcand, 2005b). Thus, it is important to continue to provide counseling and supportive interventions to those caregivers who have chosen relocation to a skilled or supportive setting as the best option.

Palliative Care Approach

Evidence suggests that individuals with dementia receive less than adequate end-of-life care in comparison to those who are cognitively intact (Dening et al., 2013; Sampson, Ritchie, Lai, Raven, & Blanchard, 2005). Although many practitioners favor the option of providing palliative services for individuals living with dementia at the end-of-life, there are very few evidence-based interventions available (Jones et al., 2016). There is also recognition that a palliative approach is consistent with the principles of person- and family-centered care because it preserves the values and identity of the individual, even in the advanced stages (Kydd & Sharp, 2016). Thus, we strongly encourage that palliative approaches not only be considered for individuals living with dementia, but that future research focuses on the development of person- and family- centered interventions tailored to the unique strengths and challenges of living with and caring for an individual with Alzheimer's disease.

Advanced Illness Care Teams. Advanced Illness Care Teams (AICTs) help health care facilities to improve the quality of care for residents with advanced dementia (Chapman & Toseland, 2007). AICTs embrace a "holistic" approach for working with nursing home residents that focuses on four categories of wellness, including medical, meaningful activities, psychological health, and behavior. AICTs can help skilled facilities to improve planning and service delivery for residents before a crisis occurs. AICTs can also help staff increase their understanding of resident and family member/surrogate needs.

PEACE Palliative Excellence in Alzheimer Care Efforts. The goal of the palliative care PEACE program is to enhance end-of-life care of persons with dementia (Shega et al., 2003). PEACE focuses on advance planning, palliative care, person- and family-centered care, and family support. Individuals with dementia and their family caregivers discuss care options important for the optimal care of the individual with dementia. PEACE also works to integrate palliative care practices into primary care specifically within the geriatrics practice of the University of Chicago. Feedback from participants is provided to physicians which further enhances quality care. Initial feasibility and acceptability of the program is promising.

Residential Care Transition Module. Residential Care Transition Module is a six-session intervention designed to help families cope with the emotional and psychological stress associated with relocating a family member living with dementia into a residential care setting (Gaugler, Reese, & Sauld, 2015). Caregivers enrolled in the program reported less emotional distress at follow-up (4 and 8 months). Given the dearth of placement interventions, the promising findings suggest that psychosocial support can help families manage emotional distress associated with the relocation of an individual with dementia into a residential long-term care setting. The team is currently conducting an RCT with over 200 caregivers.

Concluding Remarks and Recommendations for Ensuring Person- and Family- centered Care Over the Course of Alzheimer's Disease

Individuals living with Alzheimer's disease and their families have unique information, education, and support needs that change as the symptoms of Alzheimer's progress. Practitioners working with these families need a variety of programs, tools, and materials to ensure that person- and family-centered care is maintained from the time of first symptoms through the late stages of Alzheimer's and end of life. This review has described the variety of education, information, and support needs of individuals living with dementia and their families across the disease continuum as well as the services and programs currently available to meet these needs (see Table 1. Resource List). This review highlights a variety of unmet needs and a lack of available and person- and family-centered evidence-based programming for families in the early and late stages of Alzheimer's. Likewise, we see that specific groups of

Table 1. Resource List

Disease condition	National organization(s)	Fact sheets
Alzheimer's disease	http://www.alz.org/	http://www.alz.org/alzheimers_disease_what_is_alzheimers.asp http://www.alz.org/alzheimers_disease_10_signs_of_alzheimers.asp#signs http://www.alz.org/alzheimers_disease_stages_of_alzheimers.asp
Creutzfeldt-Jakob disease	http://www.cjdfoundation.org/	https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Creutzfeldt-Jakob-Disease-Fact-Sheet
Dementia with Lewy bodies	https://www.lbda.org/	https://www.caregiver.org/dementia-lewy-bodies
Frontotemporal dementia	http://www.theaftd.org/	http://www.ftdtalk.org/factsheets/
Huntington's disease	http://www.hdsa.org/	https://www.ninds.nih.gov/Disorders/All-Disorders/huntingtons-Disease-Information-Page
Parkinson's disease	http://www.pdf.org/ http://www.parkinson.org/	http://www.parkinson.org/sites/default/files/PD%20Dementia.pdf
Vascular dementia		http://www.alz.org/dementia/vascular-dementia-symptoms.asp http://www.stroke.org/we-can-help/survivors/stroke-recovery/post-stroke-conditions/cognition/vascular-dementia

individuals and family caregivers have fewer information and support options available to them because of geography (i.e., rural areas and distance caregiving) or minority status (e.g., cultural background, LGBTQ, or other marginalized groups). Our review highlights the need for translation of proven research programs into practice in real world delivery systems (see Gitlin, Marx, Stanley, & Hodgson, 2015). We also find that many individuals and their families could benefit from technology-based programs that improve access to and acceptance of services and support. We also find that it is beneficial to have a clear understanding of the individual's preferences for the provision of their care. Understanding these preferences helps individuals and their families adapt to the changing symptoms and challenges they will likely face. Early planning could prevent future stress, enhance quality of life, and ensure person- and family-centered care for individuals living with dementia who might otherwise question whether their preferences were understood and would be honored in the future. While the number of evidence-based person-and family-centered services and supports is growing, there remain large gaps in programming which currently fail to meet the unique needs of individuals living with Alzheimer's disease and their families. We offer the following recommendations as a strategy for ensuring person- and family-centered care from time of diagnosis through end of life.

Information, Education, and Support Recommendations

1. Provide Education and Support Early in the Disease to Prepare for the Future

Intervening during the early stages creates opportunities to identify, meet, and, in turn, honor the changing and future care needs and preferences of individuals living with dementia and their family caregivers. Discussing the individual's care values and preferences early in the disease can aid in planning during the moderate and advanced stages, as well as at end of life. Early intervention gives individuals living with dementia a voice in how they are cared for in the future, while giving their caregivers piece of mind when making crucial care-related decisions.

2. Encourage Care Partners to Work Together and Plan Together

In recent years, interventions have been developed that bring together individuals living with dementia and their family caregivers, rather than working with each person separately. This person- and family-centered approach supports, preserves, and validates the individual living with dementia's care values and preferences while acknowledging the concerns, stressors, and needs of the caregiver. By discussing important care-related issues earlier on, the individual with dementia's desires and wishes for their own care will remain an important part of their caregiver's decision-making process as the care situation changes.

3. Build Culturally Sensitive Programs That Are Easily Adaptable to Special Populations

It is very important to design effective evidence-based programming that is sensitive to the unique circumstances of families living with dementia, such as minority, LGBT, and socially disadvantaged populations. However, many minority or socially disadvantaged families living with dementia do not seek out or accept support from non-familial sources. Highlighting multicultural issues when training professionals and providing guidance for reaching out to these special populations will lead to more effective programs that embrace the unique needs of all care partners.

4. Ensure Education, Information, and Support Programs are Accessible During Times of Transition

There are many transitional points throughout the disease trajectory that have variable effects on both care partners. For example, transitioning from early to middle to late stage often introduces new symptoms and behaviors that, in turn, increase care partners' questions and concerns about what to expect in the future. Progression through the various stages of dementia also brings about other types of transitions, such as changes in living arrangements or care providers (i.e., from in-home to nursing home care). Providing education, information, and support that honor the individual with dementia's values and preferences during these transitions will be reassuring to caregivers as they make hard choices on behalf of the individual living with dementia.

5. Use Technology to Reach More Families in Need of Education, Information, and Support

Supportive interventions and programs that use technology (such as Skype, Facetime, etc.) to reach those in need of services are expectedly on the rise. As technology continues to advance and become more accessible and reliable, delivering programs using electronic devices (computer, table, and smart phone) could help reach more families. These programs would be especially useful in rural communities where caregivers and individuals living with dementia are often isolated with little access to supportive services.

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Conflict of Interest

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