Addressing Social Isolation and Loneliness of People Living With Dementia and Their Caregivers

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Introduction

The National Alzheimer's and Dementia Resource Center (NADRC) developed this resource at the request of the Administration on Aging within the Administration for Community Living (ACL). ACL funds the NADRC to provide expert technical assistance to ACL and its grantees. Through the NADRC, ACL makes Alzheimer's disease and related dementias program information, tools, and trainings available to the Alzheimer's Disease Programs Initiative (ADPI) grantee community and the general public. This resource is intended to support the work of ACL's ADPI grantees and others who are dedicated to addressing social isolation and loneliness in people living with dementia and their caregivers. The NADRC's full array of dementia-related information, resources, and tools can be found at https://nadrc.acl.gov/.

Social isolation and loneliness can have a profound impact on a person's physical and mental health, especially older adults' (Centers for Disease Control and Prevention [CDC], 2021; National Institute on Aging [NIA], 2019), and are more widespread than many other major health issues including smoking, diabetes, and obesity (Office of the Surgeon General, 2023). They are distinct but interrelated concepts. Social isolation is measured by the size of a person's social network, proximity of social network members, and frequency of contact with others (Administration for Community Living [ACL], n.d.-a; Lydon et al., 2022; NIA, 2021; Yu et al., 2021). Loneliness is defined as the perceived discrepancy between a person's expectations of the quantity or quality of relationships and their lived experience. Loneliness is also described as the distressing feeling of not belonging and being alone or separated from others (ACL, n.d.-b; Lara et al., 2019; Lydon et al., 2022; NIA, 2021; O'Rourke et al., 2021; Victor et al., 2020; Yu et al., 2021).

In the United States, nearly a quarter of community-dwelling adults aged 65 years and older are socially isolated, and 43% of adults over age 60 report feeling lonely (NASEM, 2020). One study found that 4% of community-dwelling older adults were considered severely socially isolated (Cudjoe et al., 2020). Addressing social isolation and loneliness has become a priority for policymakers. U.S. Surgeon General Vivek Murthy described loneliness as an invisible epidemic and launched a National Strategy to Advance Social Connection (Office of the Surgeon

General, 2023; Scheimer & Chakrabarti, 2020). ACL launched the [Commit to Connect](#) initiative to combat social isolation and loneliness, emphasizing that human connection is "essential to our health and well-being" (ACL, n.d.-a), and CDC added loneliness to its "How Right Now" communications campaign designed to promote and strengthen emotional well-being and resiliency (CDC, n.d.).

The Unique Impact of Dementia on Social Isolation and Loneliness

Older adults are at increased risk for social isolation and loneliness because they are more likely to live alone, face the loss or dispersal of family and friends, be diagnosed with a chronic illness, and experience sensory impairments like hearing loss (CDC, 2021; Lara et al., 2019; NIA, 2021). A dementia diagnosis can also increase the risk of social isolation and loneliness compared to other diagnoses. A total of 6.7 million Americans ages 65 and older are estimated to be living with dementia in 2023, and this number is projected to double by 2060 (Alzheimer's Association, 2023). Approximately one-third of people living with dementia report feeling lonely, and two-thirds of people living alone with dementia report feeling isolated (Eades et al., 2016). Studies indicate that without regular social contact, a person may experience an acceleration of their dementia symptoms (Curelaru et al., 2021; Domenicucci et al., 2022). Reduced social interactions may also contribute to a decreased quality of life for both people living with dementia and their caregivers (ACL, 2021; Yu et al., 2021).

Over 40% of caregivers of people living with dementia experience moderate to severe levels of loneliness and social isolation (Victor et al., 2020). These caregivers experience greater stress and burden than caregivers of people with other conditions (Hoel et al., 2022). People living with dementia disproportionately require more assistance with daily activities than people with other conditions (Alzheimer's Association, 2023). This has important implications because caregivers of people living with dementia have a greater need for the assistance and support of people from their social network to help provide care (Jutkowitz et al., 2020). However, caregivers may find it difficult to ask for support because of the stigma associated with dementia or a concern that the person living with dementia will not accept help.

Living With Dementia

It is difficult to capture the experience of living with dementia because it varies based on a range of factors including age of onset, type of dementia(s), rate of progression, availability of services and treatment options, availability of support system, and connection to others. Despite these varied experiences, significant milestones throughout the dementia journey can contribute to feelings of loneliness and isolation.

Early Changes and Getting a Diagnosis

A person might experience a broad range of symptoms in the early stages of dementia such as difficulty remembering important events, concentrating, or completing tasks that used to be easy. Neurologic symptoms such as tremor, rigidity, or other movement issues can be attributed to some types of dementia. Symptoms such as moodiness and irritability, social withdrawal, and personality changes may have a direct impact on interpersonal relationships (American Psychiatric Association, 2013; Association for Frontotemporal Degeneration [AFTD], n.d.; Lewy Body Dementia Association [LBDA], 2019). Unfortunately, people experiencing the aforementioned symptoms may delay getting a diagnosis out of a fear of what others will think, concerns about the future, the perception that there are no treatments available, or the belief that they will not get the support they need (Gamble et al., 2022). During this time of uncertainty and reluctance to get a diagnosis, a person may withdraw from others and experience feelings of loneliness (LBDA, 2019).

Getting an accurate diagnosis requires access to a trained provider who can conduct a comprehensive evaluation; the process can sometimes take many years, especially for younger onset individuals (AFTD, n.d.; LBDA, 2019). In the early stages, frontotemporal dementia and Lewy body dementia are frequently misdiagnosed as either another dementia, such as Alzheimer's disease, or a psychiatric condition. Most people initiate the diagnostic process with their primary care physician (PCP), yet studies have shown low rates of detection among PCPs. Providers may be reluctant to diagnose because of concerns of causing potential harm and distress to the person (Gamble et al., 2022). Both the person being diagnosed and the caregiver may feel frustrated and alone while waiting for a diagnosis and available treatments.

Adjusting to a Dementia Diagnosis

After receiving a diagnosis of dementia, many individuals express feelings of powerlessness, hopelessness, and shame, causing them to conceal the diagnosis and avoid social interactions (Czech et al., 2019). At the same time, family and friends may not know how to interact with the person living with dementia and instead ask about them through a spouse or adult child. The person living with dementia may feel even more isolated and alone if people avoid speaking to them directly (Graham, 2022). They may also feel socially excluded in public situations when people make false assumptions, patronize, or discriminate against them based on negative stereotypes depicting the most severe symptoms of dementia (Cherry & Barton, 2019). This social exclusion is important to overcome because studies have demonstrated that inclusion can boost self-confidence, personal autonomy, and well-being for a person living with dementia (Niedderer et al., 2022).

Coping With Dementia Symptoms

Dementia symptoms can interfere with social connection and the ability to participate in daily activities. Apathy is a common dementia symptom, making it difficult for a person to have the motivation to get up, go out, and be involved in meaningful activities (CaringKind, n.d.). People living with dementia also have fewer opportunities to be with other people if they no longer work. Dementia symptoms may also impact a person's ability to walk or take transportation without assistance. The progression of dementia symptoms can be unpredictable, and a person may struggle more on some days than on others. In social situations, a person living with dementia needs to know they have support and understanding to openly discuss their symptoms to maintain healthy relationships (LBDA, n.d.). Activities that are tailored to the person's abilities promote social connection and can help the person cope with the losses associated with dementia (Hoel et al., 2022; Niedderer et al., 2022).

Communication With Others

A person living with dementia may withdraw socially if they are having difficulty following conversations or understanding what is going on around them (CaringKind, 2022). These communication challenges can result in family members and friends also withdrawing if they feel that their interactions are not meaningful (Czech et al., 2019). Given the symptoms of

dementia, a person may need to structure time for staying in touch with family, friends, and neighbors (Alzheimer's Orange County, 2022) using a method that works for them such as meeting for coffee or talking on the phone. Engaging in regular social interaction can make a difference on the person's overall quality of life (Birt et al., 2020; Rai et al., 2022).

The Experience of Dementia Caregiving

There are noted positive aspects of dementia caregiving, such as increased connection between the person living with dementia and the caregiver and a sense of accomplishment, purpose, and growth for the caregiver (Yu et al., 2018). However, caregivers have reported feeling simultaneously enriched and stressed by the caregiving role (Roberts & Struckmeyer, 2018). Being aware of the unique challenges that caregivers of people living with dementia experience can help organizations better address social isolation and loneliness for this group.

Impact of Disease Progression

Dementia is a progressive condition, and worsening symptoms for the person living with dementia can make it increasingly challenging for caregivers to find time for social activities. Although the trajectory of dementia is different for everyone, most caregivers can expect the person they are caring for to gradually decline over a period of years (Effa, 2022). Disease progression leads to increased caregiver burden over time (van den Kieboom et al., 2020) because people living with dementia often require more supervision and have more intense care needs as time goes on (Haro et al., 2014). Caregiver loneliness and feelings of isolation have been shown to increase as dementia advances (Carbone et al., 2021; Roberts & Struckmeyer, 2018).

Reduced Social Support

The demands of caregiving can make it more difficult for a caregiver to reach out to friends and family. At the same time, others may believe that caregivers lack the time, energy, and interest to maintain relationships as their responsibilities increase. This cycle can be detrimental because caregivers with insufficient social support are more likely to feel overwhelmed and stressed (Giebel et al., 2020; Hanna et al., 2022; Savla et al., 2021). Both

caregiver stress and burden are linked to increased loneliness in caregivers (Grycuk et al., 2022; Victor et al., 2020).

Dementia caregivers may not feel comfortable participating in social activities with the person they are caring for, and the demands of care could limit their own participation. They may also find that people pull away after a dementia diagnosis. One study found that caregivers of people living with dementia are at risk of social network deterioration (Davies et al., 2019). New caregivers have reported that their relationships with family and friends changed when the person they were caring for was diagnosed with dementia (Steenfeldt et al., 2021). The COVID-19 pandemic magnified dementia caregivers' isolation from family, friends, and coworkers (Chyu et al., 2022). These findings are important because caregivers who are isolated and lonely tend to feel more burden than those who feel socially connected (Sung et al., 2023), while caregivers who perceive that they have adequate social support are better able to cope with challenges, manage stress, and provide care (Lai & Thomson, 2018).

Feelings of Loss and Grief

Dementia caregivers often experience feelings of loss and grief throughout the disease process. Ambiguous loss, or the sense of loss that occurs when the person living with dementia is still physically present, can be particularly complicated for caregivers (Alzheimer's Society, n.d.). These feelings may be triggered for caregivers as the relationship they have with the person they are caring for becomes less reciprocal, and the caregiver turns from a partner to a caretaker (Steenfeldt et al., 2021). Physical loss or death often comes with a sense of closure; ambiguous loss is unique because there is no closure, which can make it feel like an experience that others cannot understand or empathize with and may strain a caregiver's relationship with others (Boss & Yeats, 2014). Similarly, the grief a caregiver feels during the disease process while the person living with dementia is still alive has been associated with social isolation in caregivers and poor physical and mental health outcomes (Park & Galvin, 2021). Both ambiguous loss and grief can contribute to feelings of isolation because of the social stigma surrounding grief before someone has passed away (Large & Slinger, 2015).

Measuring Social Isolation and Loneliness

The first step to addressing social isolation and loneliness for people living with dementia and their caregivers is identifying whether or not they are experiencing it. Tools exist to screen for social isolation and loneliness and to measure the impact of the programs designed to address it.

Risk of social isolation can be objectively measured. The Upstream Social Isolation Risk Screener, for example, is used to identify risk of social isolation for adults living in the community (Smith et al., 2020). The Multidimensional Scale of Perceived Social Support measures whether a person has support from family, friends, and significant others, and the Lubben Social Network Scale-5 assesses how a person feels about the support they receive (Veazie et al., 2019).

Measures of loneliness typically assess a person's perception of how connected or alone they feel. Simply asking a person directly if they feel lonely is an easy and effective way to ascertain loneliness in older adults, but it can be difficult to frame this question in a positive way (Campaign to End Loneliness, n.d.; Veazie et al., 2019). A question like this can be added to intake assessments delivered by service professionals. Volunteers, such as home-delivered meals drivers, or other gatekeepers who regularly see people living with dementia and their caregivers can also be trained to ask this question of participants and connect them to appropriate services. The De Jong Gierveld Loneliness Scale, UCLA Loneliness Scale Version 3, and Campaign to End Loneliness Measurement Tool are all validated tools used to assess perceptions of loneliness in older adults (Campaign to End Loneliness, n.d.; Veazie et al., 2019).

Tools specifically relevant to people living with dementia and their caregivers are also available. The Dementia Crisis to Thriving scale, for example, includes social isolation as one of 13 domains with which a person living with dementia may require assistance over time (Weaver & Samia, 2016). Service providers can use this tool to monitor a person's social interactions and identify whether they are vulnerable to social isolation and require intervention. The BRI Social Isolation Scale measures social isolation resulting from caregiving responsibilities but can also be modified for use in people living with dementia (Bass et al., 2019; Hughes et al., 2021). The

Engagement and Independence in Dementia Questionnaire is intended for people living with dementia and includes a subscale on social support (Hughes et al., 2021; Stoner et al., 2018). The Social Functioning in Dementia Scale assesses the social networks of people living with dementia (Hughes et al., 2021; Sommerlad et al., 2017). The NADRC resource [Evaluating Dementia Services and Supports: Instrument Resource List](#) (Hughes et al., 2021) includes a list of measures of social wellness with links to relevant research, sample questions, and tips for what to consider when choosing an evaluation instrument.

Person-Centered Approach to Service Delivery

Once social isolation or loneliness is identified, it is important to address that need based on the person's unique circumstances. Offering a service or program that is not a good fit for an individual living with dementia or providing a referral without considering how a person will access it can exacerbate feelings of social isolation and loneliness. Choosing an appropriate program requires an understanding of the person's preferences and strengths and the characteristics of the program. Practitioners should take into consideration the purpose of the program (e.g., communicating, learning skills, building a sense of belonging), the way in which it is delivered (e.g., in person, virtual, phone-based), and format (e.g., group-based, one-on-one, dyadic) (Lydon et al., 2022), and those variables should be matched with the person's goals and skills.

Geographic location can significantly impact social isolation and loneliness. The availability of programs and resources may vary based on where an individual lives, as can access to transportation to get to those programs. Technology can help facilitate communication and social engagement for people who have a hard time leaving the home or getting to programs in person. For example, computers, smartphones, and tablets host commonly used platforms that support social interaction (Domenicucci et al., 2022). These can include applications for messaging (e.g., Facebook messenger, WhatsApp), video conferencing (e.g., Facetime, Zoom, Skype), and social media (Faieta et al., 2022). These tools proved particularly helpful during the COVID-19 pandemic and continue to be of use when a person cannot physically attend a gathering (Faieta et al., 2022). However, the use of technology may be limited by cost, ease of

use, ongoing assistance needed to maintain devices, and internet connectivity (Rai et al., 2022). The gap between those who have access to technology and those who do not—known as the "digital divide"—can exacerbate feelings of disconnection and isolation if this is the only option provided for participation.

Language and sensory impairments, such as aphasia, hearing, and vision loss, should also be considered when designing accessible social engagement programs for people living with dementia and their caregivers. Individuals experiencing these challenges may have more limited ability to engage in social activities and maintain relationships with others. Providing program adaptations, tools, and strategies that support easier social interactions may prove important in addressing social isolation and loneliness. These include items like hearing and mobility aids (Curelaru et al., 2021) and accessible public spaces (Long et al., 2020). Offering supports such as these could help improve the effectiveness of interventions meant to improve social isolation and loneliness.

Delivering Programs to Address Social Isolation and Loneliness

There is no one-size-fits-all solution to delivering programs and services to people living with dementia and their caregivers. Programs that address social isolation and loneliness should be carefully considered and chosen to meet the needs of those they are serving. Some of the most common types of programs for addressing social isolation and loneliness are group-based support and learning, arts-based interventions, friendly visitor and call programs, respite programs, and care consultation. Each of these program types has shown promising results in improving social isolation and loneliness for people living with dementia and their caregivers. The National Resource Center for Engaging Older Adults ⧉ also has a Social Engagement Innovations Hub ⧉ that houses details on social engagement programs for older adults and can be sorted to find programs specifically relevant to people living with dementia. Service providers can make the biggest impact for the people they serve when they provide programs that fit people's needs and build on their strengths.

Support Groups, Group Education, and Memory Cafés

Participating in group activities can increase feelings of social support and decrease loneliness for older adults, including those living with dementia and their caregivers (Dam et al., 2016; Masoud et al., 2021; Poscia et al., 2018). The main goal of group-based support and learning is to increase feelings of belonging or acceptance among participants. Other common objectives include improving knowledge or skills and providing opportunities for enjoyment and stimulation. Group activities can be formal interventions or less structured gatherings. Examples include support groups, structured education or training, and memory cafés. Groups should be assembled based on similar experiences, interests, or disease progression.

Support groups are often one of the first types of assistance offered to people living with dementia and their caregivers. The goal of a support group is to allow people living with dementia and their caregivers a space where they can feel less alone and express themselves without judgment (Roberts & Struckmeyer, 2018). They provide people with an opportunity to meet with and learn from others who have a shared experience. Support groups can be facilitated by professionals, peers, or both and can be held virtually, in person, or hybrid. They may be structured around a specific topic or rely on the flow of conversation. Some support groups are specifically created for people who have a certain experience. For example, they may be exclusively for caregivers of people with a certain type of dementia or for people who are newly diagnosed. Research has shown that support groups may reduce social isolation if a person attends regularly for several months, especially for those who start with significant feelings of loneliness (Dam et al., 2016). One qualitative study found that support from peers helps people living with dementia and their caregivers build community, makes participants feel like they are helping each other, and has positive social and emotional impacts (Keyes et al., 2016). Another study found that peer support helps reduce unmet needs and increases knowledge and resiliency related to dementia (Whelan et al., 2020).

Structured group education or training has also been shown to improve social isolation and loneliness. Structured group education and support facilitated by professionals over the course of several weeks can help caregivers and people living with dementia find acceptance with their

diagnosis and find value in disclosing a diagnosis to allow for increased social support (Whelan et al., 2020). Structured educational offerings build skills and understanding and a sense of community for the participants (Donovan & Blazer, 2020; Span, 2017; Torres, 2020). Bringing together groups of similar people for moderated discussions, peer support, and skills enhancement may lessen social isolation and loneliness even if that is not an intentional outcome of the program.

Memory cafés are social gatherings of people living with dementia and their caregivers. The purpose of a memory café is to provide a place where people living with dementia and their caregivers can come together without fear of judgment or stigma because of their common experience with the disease (Jewish Family & Children's Services, n.d.; Masoud et al., 2021; Soltzberg & Ordóñez, 2019). The model is flexible and allows for organizations to modify their delivery of memory cafés to fit the needs and interests of those they are serving, from where they are held to what language they are delivered in. Memory cafés have a strong emphasis on creating opportunities for socialization to decrease the isolation that can come with a dementia diagnosis (Goyer, 2022). Studies have shown that memory café participants have increased feelings of connectedness, community, acceptance, and belonging, and that the feelings were stronger for in-person cafés than virtual (Greenwood et al., 2017; Masoud et al., 2021). Memory cafés provide critical peer support for the caregivers who attend, allowing them to learn from the experiences of other caregivers around them (Greenwood et al., 2017).

The memory café model inspired Florida Atlantic University (FAU) to create Tête-à-Tête for its Haitian Creole–speaking community members using ADPI funding (Soltzberg & Ordóñez, 2019). Tête-à-Tête gatherings provided opportunities for people to meet without fear of stigma, learn more about dementia, and gain access to culturally competent services. FAU partnered with a faith-based organization to implement Tête-à-Tête, and church staff and congregants played a significant role in its success. A member of the congregation who was a nurse practitioner became a natural liaison between program staff and the congregation because of her lived experience and knowledge of the language spoken by the Haitian Creole community. A translator was also an integral part of providing culturally relevant services. FAU found that assessing the needs of the participants via survey helped them tailor the program to

fit this community. They collaborated with a native speaker who understood the local culture to create and deliver the program. Bringing the program directly to the community in person and ensuring that materials were culturally and linguistically competent also helped FAU overcome barriers that traditionally limited services this community received, including a fear of engaging with health systems or community services because of immigration status, language barriers, low literacy, and accessing transportation. More than 300 participant encounters occurred through Tête-à-Tête gatherings, and over 90% of participants reported improved quality of life, increased knowledge, and improved socialization because of Tête-à-Tête (FAU, 2019).

Pima Council on Aging (PCOA) is also implementing memory cafés in the community through its ADPI grant (PCOA, 2023). PCOA empowers community-based organizations and volunteers to host and run the memory cafés in ways that fit the needs of their clients and communities and support these organizations through training and ongoing technical assistance. They currently support two organizations in the delivery of memory cafés—one in a rural community and one that is specifically focused on LGBTQI+ inclusivity. Both are held in person, although PCOA also has the capacity to support virtual delivery of memory cafés. More than 100 people living with dementia and their caregivers have attended at least one memory café, and caregivers have reported increased feelings of social support (PCOA, 2023).

Arts-Based Programming

Evidence suggests that arts-based programming can have positive outcomes for older adults, including people living with dementia and their caregivers. Participation in these programs can increase feelings of social inclusion, engagement, and self-esteem; reduce feelings of depression; and improve overall well-being and quality of life (Bourne et al., 2020; Poscia et al., 2018; Whelan et al., 2020). More frequent engagement in arts programs has been associated with lower odds of loneliness (Lim et al., 2020). These programs are particularly impactful for people living with dementia, as "the creative, imaginative, and emotional parts of a person [living with dementia] often remain relatively strong" (Social Care Institute for Excellence, 2020) even when other skills and abilities have diminished. Arts-based programs can

tap into the strengths of people living with dementia when communication and cognition become challenging.

Arts-based programs fall into three main categories: performing arts, literary arts, and visual arts (Bourne et al., 2020; Ward et al., 2021). Although some programs focus on one type of art activity (e.g., music), others are multisensory and combine elements of the performing, literary, and visual arts. One key driver of impact is that the program being delivered has an intended outcome of improving health and wellness outcomes for participants (Ward et al., 2021). This sort of program, called participatory art programming, is different from art therapy because it is delivered in the community rather than in a clinical setting, often with trained artists as opposed to therapists. It is also different from typical arts and crafts activities because it is focused on the outcomes of the participant rather than the successful creation of a product or craft (Ward et al., 2021). These arts programs are beneficial to people living with dementia because they emphasize a person's strengths and focus on staying in the moment rather than relying on a person's prior knowledge or skill (Ward et al., 2021).

Performing arts include activities like participation in a choir or theater group and often have an element of sharing the final product with others. Music-based programs can be used to improve mood and quality of life for people living with dementia and may improve communication (Soufineyestani et al., 2021). Several studies suggest that participation in a choir or other singing group improves social isolation for people living with dementia (Harris & Caporella, 2014; Thompson et al., 2021). Participants have noted that these kinds of programs help create a sense of belonging, build relationships, and foster connections (Faw et al., 2021). People who participate in these performance groups who do not have dementia leave with a better understanding of the disease and reduced unease when interacting with someone living with dementia (Harris & Caporella, 2014).

Literary arts programs involve elements of storytelling, poetry, writing, and reading. Storytelling is commonly used in programs for people living with dementia. It can help improve communication skills, build social connections, and promote self-esteem leading to reductions in social isolation and loneliness for people living with dementia (DeVries et al., 2019). Activities

that have elements of shared reading have also been found to increase social engagement, improve communication, and benefit overall mental health (DeVries et al., 2019).

Visual arts bring people together to view or create art. These programs can increase communication and self-esteem among people living with dementia and enhance social connections and engagement for both people living with dementia and their caregivers (Whelan et al., 2020). Museum-based programs in which the person living with dementia and their caregiver simultaneously view and discuss art have shown positive results for caregivers, including increased social interaction and connections with others, reduced feelings of social isolation, and an increased sense of belonging (Kinsey et al., 2021). They have also been shown to improve communication between people living with dementia and their caregivers while participating in the program (Hazzan et al., 2016).

Opening Minds through Art (OMA) is an intergenerational visual arts program in which people living with dementia are paired with volunteers to create art. Each session lasts approximately 1 hour over the course of 12 weeks. Participation in the program has led to improved well-being for people living with dementia, including increased social interest, engagement, and pleasure (Sauer et al., 2016). Senior Services, Inc. (SSI) is implementing OMA in Winston-Salem, North Carolina, through their ADPI grant(SSI, 2023). They provide sessions at an adult day program and in the home. They also offer OMA sessions to people living with dementia as a form of respite if their caregiver is attending a support group. The sessions are in person and are structured to accommodate the person living with dementia's mood and abilities that day. The volunteer is present to assist the person living with dementia through each step of the art-making process, and time is built in for people to share their artwork with others at the end of the sessions. SSI has modified its implementation of OMA to meet the needs of its participants and to fit its organizational capacity. SSI is providing OMA both in a group setting and one on one. OMA was designed to include college students as volunteers, but SSI offers the opportunity to volunteers of any age. They are also training family caregivers and home health aides to deliver the program to people living with dementia in their homes.

Friendly Visitor and Call Programs

Friendly visitor and telephone reassurance programs are common activities offered by aging network providers (Gould & Basta, 2013). Both offer older adults with opportunities for one-on-one social interaction by providing them with a visit or brief check-in from a volunteer. Friendly visits are typically in-person visits done with an older adult in their own home but can also include social outings or events (Elder Network, n.d.). Telephone reassurance or call programs are brief check-ins or conversations done over the phone. The frequency and duration of each service depends on the needs and preferences of the person being served.

These kinds of programs are particularly helpful for people who are living alone, including those living alone with dementia (O'Hara, 2021). They not only help with social isolation but may also provide a sense of security for the person and their caregiver because they know someone is looking out for them on a regular basis (Shepherd's Center of Northern Virginia, n.d.). Volunteers who are visiting or calling people living with dementia receive specialized training on the best ways to engage them and when to ask for assistance or report changes to program staff. One study showed that receiving training on the basics of dementia allowed friendly visitors to better understand participant needs and communicate with people living with dementia (Rosebush et al., 2021). Caregivers also felt more comfortable with the friendly visitor when they knew the visitor had dementia training (Rosebush et al., 2021). Although typically done in person, friendly visits can also be impactful when done virtually. Studies have found that virtual friendly visits led to increased social interactions and decreased loneliness and depression for people living with dementia (Curelaru et al., 2021; Pepin et al., 2019). These programs can also be beneficial to caregivers. Another study found that caregivers who participated in a friendly visitor program (one-on-one visits with a peer volunteer over 6 months) had an improvement in perceived social support (Smith et al., 2018). There was also improvement in depression and loneliness, and qualitative reports noted decreases in social isolation (Smith et al., 2018).

Similar to a friendly visitor program, a telephone reassurance or social call program assigns a volunteer to call a person living with dementia at a regularly scheduled time as a way to both

check in on the person and reduce isolation. Volunteers are trained not only on the program format, but also on special considerations for communicating with people living with dementia and available resources if there are questions or concerns (Corley et al., 2017; Feldman et al., 2022). Studies have shown improvements in the loneliness of older adults, including those living with dementia, who participate in call programs (Feldman et al., 2022; Lee et al., 2021b), including high levels of satisfaction from program participants.

Motion Picture Television Fund (MPTF's) expanded its telephone-based social connectivity program to provide weekly calls to people at risk of or living with dementia using an ADPI grant (MPTF, 2022). These weekly calls were designed to be more than a friendly check-in. The calls were used to encourage engagement and conversation with people living with dementia who were at risk of loneliness. Volunteers providing these calls went through specialized training with a focus on dementia beyond what MPTF typically provides to volunteer callers. Training covered a basic overview of dementia, communication techniques for people living with dementia, and ways to engage people living with dementia, such as finding creative topics of conversation. Volunteers were specifically trained in how to spur conversation and encourage reminiscence and storytelling. They were also trained to identify possible elder abuse and other areas of concern, such as food insecurity, and how to report these concerns to program staff.

Participation in the program was associated with a significant increase in the number of social contacts the person living with dementia reported in the previous week. Qualitative outcomes were also positive, with participants reporting that they looked forward to the calls and felt supported by the caller (Zarit & Heid, 2022). MPTF found this program to be both low cost and high impact for people living with dementia who were at risk for social isolation.

Respite Programs

Respite care provides short-term relief to caregivers, including caregivers of people living with dementia (NIA, 2017). Respite is regularly scheduled care and can be provided in the home or at a facility (NIA, 2017). The goal of respite is to provide the caregiver with a set period of time to do things they enjoy or take care of their own needs without focusing on the responsibilities of caregiving. Research has shown that respite helps caregivers build their own

resiliency, which can lead to better health outcomes for the people living with dementia as well (Roberts & Struckmeyer, 2018).

Caregivers report increased isolation as their caregiving responsibilities increase, or because they are uncomfortable leaving the person they are caring for with someone else (Family Caregiver Alliance, n.d.; Roberts & Struckmeyer, 2018). Professionals often suggest that caregivers seek out and accept respite care, either from a paid service provider or family and friends depending on their comfort level (Family Caregiver Alliance, n.d.). Respite can help caregivers reconnect with the interests they had before they took on caregiving responsibilities, leading to reduced social isolation (Lee et al., 2021a).

Adult day programs provide "services to adults who need supervised care in a safe place outside the home during the day" such as meals, social activities, therapeutic activities, and personal care (National Adult Day Services Association, 2023). In addition to providing respite to caregivers, some adult day programs include support groups, educational programs, and counseling for caregivers (Fields et al., 2014). One study showed that adult day programs are a preferred form of respite for caregivers because it provides the caregiver physical separation from the person they are caring for so they have time to focus on themselves (Lee et al., 2021a). Day programs also decreased social isolation for caregivers and improved perceived social support (Vandepitte et al., 2016).

Adult day programs can specialize in serving people living with dementia (NADSA, 2023) and can have a significant impact for both people living with dementia and their caregivers. Day program attendance has been associated with reduced social isolation for people living with dementia (Du Preez et al., 2018). Caregivers of people living with dementia have indicated that benefits of day programming include an opportunity for the care recipient to socialize (Du Preez et al., 2018). Research has also shown that when people living with dementia participate in adult day programs, it positively impacts their caregivers' mood and well-being because they are provided a break from dealing with the behavioral and psychological symptoms of dementia (Bangerter et al., 2021).

MAC, Inc. created the Life Bridges social model day program through their ADPI project as a source of respite for caregivers and an opportunity for socialization, care, and support for people living with dementia (MAC, 2023). The program, delivered in rural Maryland, is person-centered and has a focus on music, dance, and exercise. It is delivered in person and provides opportunities to participate in arts, physical activities, cognitive games, and more. MAC, Inc. has been able to partner with graduate students from the University of Maryland Eastern Shore to provide physical therapy services and intergenerational socialization opportunities.

Middle Alabama Area Agency on Aging's (M4A's) volunteer-based respite program—Anchor Community Respite Ministry—is located in a faith-based organization in Birmingham, Alabama (M4A, 2023). This day program, funded through an ADPI grant, is designed to promote cognitive stimulation, social engagement, and physical health for people living with dementia. It also seeks to engage caregivers through social connection, emotional support, and education. This program was originally designed to be in person. However, it went virtual for several months during the COVID-19 public health emergency. During COVID-19, M4A continued to engage people living with dementia and their caregivers in a variety of innovative ways, including organizing parades to drive past participants' home to celebrate a theme or delivering craft kits and holding virtual meetings as a shared time to assemble the craft. M4A's respite program makes in-person programming available 2 days per week for 4 hours a day.

Care Consultation

Care consultation is an in-depth and person-centered process in which a person living with dementia, their caregiver, or both, identifies needs, sets goals, and receives individualized resources and assistance. It is more comprehensive than information and referral services or general education. Care consultation is centered around a formal needs assessment, the formation of a care plan, the provision of services based on that care plan, and ongoing support and follow-up (Alzheimer's Association, n.d.). As dementia progresses, the needs and priorities of the person living with dementia and their caregiver may change. The process of care consultation is flexible enough to meet needs as they arise. Care consultation can also be delivered in a variety of ways—in person, over the telephone or videoconferencing, or via email

(Bass et al., 2014). The crux of care consultation is the provision of personalized coaching and support based on an assessment of needs. Improvements in feelings of isolation and support are the result of the participant identifying them as needs or concerns, intentionally working on a plan to better the outcomes, and receiving ongoing support and coaching to reach goals (Mittelman, 2017). If a caregiver or person living with dementia does not identify social isolation or loneliness as a need, the impact of care consultation may not show up in those areas. If and when they do identify that need, coaching is available related to communicating a diagnosis with others, asking for help, and building or expanding social networks.

BRI Care Consultation^TM (BRI CC) is a structured platform that allows organizations to provide coaching to both caregivers and people living with dementia focused on "accessing community and family resources, quality information, and emotional support" (Best Practice Caregiving, n.d.). These coaching sessions are typically done via phone or email, and coaching is tailored to the needs of the person living with dementia and their caregiver based on an assessment. Unlike other interventions, BRI CC does not have a set number of sessions and can continue for as long as the caregiver or person living with dementia needs support based on regular reassessment (Bass et al., 2016). This intervention has been shown to improve social support for both the caregiver and the person living with dementia (Best Practice Caregiving, n.d.).

MemoryLane Care Services (MLCS) in Ohio used ADPI funds to begin implementing BRI CC in their adult day center. MLCS enrolled 103 people living with dementia and their caregivers into BRI CC, including 27 people living alone with dementia (MLCS, 2022). Community partners, including health care entities, social services, aging services, and disabilities providers, served as key referral sources. Each case had an average of 12 action steps created to address identified needs, and MLCS provided ongoing contact and consultation via telephone, email, and mail. They found significant reductions in social isolation for people living with dementia because of the program, despite being implemented during the COVID-19 pandemic. Because of this impact, MLCS continued providing BRI CC to individuals in the community and participants of the MLCS adult day services program after their grant ended.

Sustainability

It is likely that no organization wants to discontinue a program that has successfully decreased social isolation and loneliness for people living with dementia and their caregivers because they have not considered how to sustain it early on. Several key factors are important for organizations to think through when deciding which programs can be sustained beyond a grant funded pilot program, including client and community needs, organizational capacity, program characteristics, and long-term costs and marketing (Menne & Bass, 2020).

Key elements of sustainability from within an organization include staff and client buy-in, interest, and ability. Organizations must be aware of and responsive to the needs of their clients and communities. Knowing whether there is demand for a service and how clients might access that service can help ensure that an organization is offering programming that will be utilized by the community. Providing successful programs requires an understanding of the client and community. It also requires appropriate staffing. Consider if staff have the time and skills required to provide a new program. If not, partnering with other organizations or volunteers that do have that capacity could be beneficial. Pima Council on Aging, for example, trains other organizations to provide memory cafés using their own staff and volunteers. Organizations should also be aware of what others in their community are already offering and refer to them if it makes the most sense. They may be able to fill a gap in available services or partner with others who are already doing the work. A sustainable program does not duplicate work unnecessarily.

It is important to measure the outcomes being achieved or maintained by a program. Organizations should consider the outcomes they intend to impact and use programs that have demonstrated efficacy for those outcomes. Although the exact design of a program may need to be altered or modified based on the specific population served, lessons learned from others who have implemented similar programs can offer valuable points of consideration before and during implementation. Knowing the outcomes of interest, measuring those outcomes, and demonstrating the impact a program has on a client or community is a powerful driver of sustainability. MemoryLane Care Services was able to show that BRI CC made a statistically

significant impact on social isolation and loneliness for people living with dementia and used those data to help secure funding from the local Area Agency on Aging to continue providing the service.

Funding sources are another integral part of sustainability. Even if a program starts with grant funds or a donation, that funding will not last forever. The possibility of reimbursement through programs such as Medicare or Medicaid, private insurance, and sliding scale fee-for-service can help support secure and sustainable funding. Additional support from philanthropic giving, nonprofit organizations, and other private foundations can play a crucial role in the long-term sustainability of interventions. Senior Services, Inc. plans to sustain OMA in part by hosting art shows and selling the artwork created by people living with dementia during OMA sessions. Motion Picture Television Fund has been able to sustain and expand their telephone-based connectivity program using money from the Small Business Innovation Research program. They now support other organizations in the development of their own call programs.

Conclusion

Dementia can have a significant impact on the lives of the people who are living with it and those who support them. Given the prevalence of social isolation and loneliness in this group, it is critical to provide programs and services that help mitigate the negative consequences. Decreasing social isolation and loneliness can help improve a person's well-being, quality of life, and resilience and have a positive impact on physical and mental health outcomes.

Service providers can offer a wide range of activities to people living with dementia, caregivers, or both if they are struggling with social isolation or loneliness. Given the diverse experiences and needs of individuals, no one program is going to be a perfect match for every person. What is right for someone at one point in the disease may not be appropriate at another at the same or different point. It is important to consider a person's preferences and strengths when deciding what might be the best fit for them. Taking a strengths-based, person-centered and sustainable approach can ensure that the needs of people living with dementia and their caregivers are served long term.

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