

Alzheimer's Disease and Social Engagement: A Comparative Examination of Memory Care Facilities in Massachusetts

Julia Ward



A senior thesis

submitted in partial fulfillment

of the requirements for the Bachelor of Arts degree of

Sociology with Honors

Boston College
Morrissey College of Arts and Sciences
April 2023

ALZHEIMER’S DISEASE AND SOCIAL ENGAGEMENT: A COMPARATIVE EXAMINATION OF MEMORY CARE FACILITIES IN MASSACHUSETTS

Julia Ward

Advisor: Alyssa Goldman, Ph.D.

Abstract

People’s needs for social engagement vary over the life course. Social engagement for individuals residing in memory care facilities is an important topic to research because this population benefits greatly from active participation in the communities in which they reside. This study examines the following research questions: To what extent does the facility in which adults with Alzheimer’s disease reside impact their social ties? How do the facilities differ in facilitating social engagement? I interviewed ten memory care facility employees across seven facilities in Massachusetts and found patterns in visitation for family members and friends of Alzheimer’s residents and social engagement for residents in memory care. Individual factors that affect visitation include family dynamics and disease progression. Structural factors that affect visitation include geographic location and religion. These findings are useful to inform policy and recognize increased opportunities for social engagement as an opportunity for facilities to slow disease progression.

TABLE OF CONTENTS

Introduction	6
Literature Review	10
Theory	13
Industrial	13
Cost of Care	14
Neighborhood	14
Indoor Built Environment	16
Disability	19
Methods	22
Sample and Recruitment	22
Survey and Interview	23
Ethics	25
Analysis	26
Results	27
Sample Descriptions	27
Demographic Survey Data	27
Facility Descriptions	29
Interview Themes	33
Patterns in Social Engagement	33
Patterns in Visitation	39
Discussion	47
Interpretation of Results	47
Limitations	49
Conclusion	50
References	51
Appendix	56

LIST OF TABLES

TABLE 1. CHARACTERISTICS OF INTERVIEW PARTICIPANTS (DATA FROM QUALTRICS SURVEY).

TABLE 2. INTERVIEW TOPICS FOR MEMORY CARE FACILITY EMPLOYEES.

TABLE 3. KEY FEATURES OF FACILITIES (DATA FROM QUALITATIVE INTERVIEWS).

TABLE 4. PROPORTION OF RESIDENTS THAT PARTICIPATE IN SOCIAL ENRICHMENT ACTIVITIES AND NEED ENCOURAGEMENT (DATA FROM QUALITATIVE INTERVIEWS).

ACKNOWLEDGEMENTS

This project would not have been possible without the support and help of many people. I would first like to thank the ten participants who provided their valuable insight for this research project.

I would like to thank my thesis advisor, Professor Alyssa Goldman, for her continuous support. I am so thankful that I took your Introduction to Sociology for Healthcare Professions course my sophomore year of college, for your passion for sociology and research inspired me to pursue a sociology major. I have had the incredible opportunity to assist you with research as your undergraduate research fellow, and I am so grateful that I was able to complete this project of my own under your guidance. I cherish your insight and motivation throughout this process. I would also like to thank Professor Moorman and Professor Schor for their guidance and immense help.

Lastly, I would like to thank my mom and my sister, Nicole, for their constant love, motivation, and support.

INTRODUCTION

The number of Americans with Alzheimer's dementia is projected to grow from a current six million to thirteen million by 2050 (Alzheimer's Association 2022). According to the Alzheimer's Association, the proactive management of Alzheimer's and other dementias can improve the quality of life of affected individuals and their caregivers. Staying socially, physically, and mentally active can reduce the risk of cognitive decline and dementia by participating in activities that are meaningful to the individual with dementia, maintaining a sense of self identity and relationships with others, and having opportunities to connect with others living with dementia (Alzheimer's Association 2022). Memory care facilities are likely to affect patterns of social engagement, including patterns in visitation amongst residents and their caregivers. In fact, *The Lancet* Commission on dementia prevention, intervention, and care suggest that addressing these modifiable risk factors may prevent or delay up to forty percent of dementia cases (Livingston 2020). According to the National Health and Aging Trends Study, greater satisfaction among family members providing dementia caregiving was associated with more emotional support from family members and friends (Leggett 2020). A plethora of research has also proven the connection between cognition and social networks, for social engagement is associated with a preservation of cognitive functioning in older adults (Sharifian et al. 2019). Specifically, among an older population of individuals with Alzheimer's disease,

those with a large social network size demonstrated less impaired cognitive performance (Bennet et al. 2006).

Alzheimer's disease is a complex brain disorder in which memory, thinking, and behavior progressively deteriorate in older adults. While Alzheimer's disease is not curable, myriad studies suggest that social ties play an important role in slowing the progressive decline in cognitive function that is associated with this type of dementia (Hsiao 2018). The medicalization of disability within society also relates to the experience of residents within memory care facilities, for it can be interpreted in two contrasting perspectives: the memory care facility as fundamentally a home, or fundamentally a place to receive medical care. Memory care facilities play an important role in the development of an individual's social ties, for residing in this environment permits connectivity with other residents and lessens social isolation. According to the Centers for Disease Control and Prevention (2020), social isolation was associated with an approximate fifty percent increased risk of dementia. Therefore, the importance of social connection is crucial for individuals transitioning into a new environment of a memory care facility or assisted living residence. In these environments, the establishment of social connectivity amongst residents who may not have a family member or friend visitor promotes their well-being and offers increased opportunities for social engagement. Thus, for those experiencing social isolation or a disruption in pre-existing social networks, the facilities provide a unique social environment in which residents can benefit from supportive services or spaces for socialization (Mauldin et al. 2021).

Geographic location plays a significant role in the maintenance of social networks and physical proximity permits social interaction. Individuals residing in long-term care

facilities, therefore, have increased access to social tie maintenance when the facility is proximal to individuals within their social networks. Schafer and Sun (2022) emphasize that adult children are key providers of emotional support for aging parents; however, there is limited contemporary research examining how spatial separation can shape the place of children in the lives of their aging parents. It is crucial to delve into this idea that distance complicates relationships, especially for those residing in long-term care. The researchers also found that factors such as high socioeconomic status enable access to communication technologies, which can provide greater access to social tie maintenance.

With my combined interest in Alzheimer's disease, social networks, and health care accessibility, I have chosen to develop the following research questions: To what extent does the facility in which adults with Alzheimer's disease reside impact their social ties? How do the facilities differ in facilitating social engagement?

I hope to extend the research in this field with my unique focus on memory care facilities throughout Massachusetts, for little research has examined access to social ties and the association amongst environmental characteristics of memory care facilities, social connectivity, and Alzheimer's disease in older-aged adults. This research is especially relevant to the circumstances of the COVID-19 pandemic and its complications in patient care modes due to necessary social distancing and healthcare precautions instituted by numerous long-term healthcare providers. I predict that the location and cost of the memory care facility in which Alzheimer's disease patients reside impact the quality and quantity of their social ties. I believe that facilities located in urban areas of Massachusetts, as opposed to suburban, will have greater access to social opportunities. Similarly, I believe

that facilities with high living costs provide a greater number of opportunities for social programming.

LITERATURE REVIEW

Generally, research suggests that social networks and health are interdependent (Smith and Christakis 2008). In regard to Alzheimer's disease and social ties, a community-based longitudinal study found that an extensive social network seems to protect against dementia (Fratiglioni et al. 2000). Importantly, via their investigation of the association between the incidence of dementia and various social network components in a cohort of noninstitutionalized individuals with good cognition, the researchers found that a poor or limited social network increased the risk of dementia by sixty percent. More recent studies have displayed similar results: having a larger social network was associated with decreased risk of mild cognitive impairment or conversion to dementia in a nationally representative cohort of residents aged sixty-five and up in the United States (Zhang, Natale, and Clouston 2020). This study was one of the first to examine social network structure and dementing processes on a national scale. Abbott and Pachucki (2016) examined social network characteristics indicative of social integration (network size, quality, centrality, and isolation) and their associations with dementia special care unit residents' overall well-being and cognition. By measuring residents' relative centrality, the researchers were able to measure integration, for high closeness centrality, or how close an individual is to all others in their network, was correlated with being well integrated. These significant findings within structural aspects of their coresident relationships suggest that health indicators of quality of life and cognitive function tend to cluster in social networks,

reinforcing the idea that dementia residents' quality of life is in part linked to relationships with others (Abbott and Pachucki 2016). Park et al. (2010) recognize the importance of meaningful social interactions within assisted living residences. By examining how social engagement is experienced among residents of assisted living, these researchers found that relationships within the assisted living residence lacked desired qualities of close social ties with family and long-term friends because of the total institution characteristics, where delivery of medical care is more important than the "home" aspect. These individual and organizational characteristics of resources, size, and resident mix were found to affect the residents' social context as well as their opportunities for social interactions, for residences with larger settings had more opportunities for social programming than smaller residences. Social engagement was organized by the perspective of time and loss, barriers to and resources for social engagement, and strategies to develop or modify relationships (Park et al. 2010).

Furthermore, the effects of the COVID-19 pandemic have exacerbated social isolation in adults with Alzheimer's disease and related dementias, and decreased opportunities for social interaction have had detrimental effects on this vulnerable population (Curelaru et al. 2021). These researchers demonstrate that social interactions are correlated with increased quality of life for people with dementia. Most important, however, is the finding that engagement and communication with visitors have been proven to provide contentment for people with Alzheimer's disease residing in long-term care facilities (Curelaru et al. 2021). Akin to Curelaru et al., Ferdous (2021) recognized that COVID-19 has impacted those living in memory care facilities. The high percentage of pandemic deaths in long-term care facilities (38% nationally and 60% in Massachusetts)

has changed our perception of the relevance of facility characteristics in potentially facilitating or inhibiting social interactions for people with Alzheimer's disease and has influenced our understanding of facility visitation and social network size (Girvan 2021). Importantly, Ferdous (2021) assesses the relationship between the physical environment and the prevalence of social interaction, which this researcher considers an essential therapeutic intervention for older adults with or without Alzheimer's disease and related dementias. For example, the researcher highlights that the creation of outdoor spaces with accessible paths for walking creates an opportunity for visitors to spend time with residents outdoors. Ferdous (2021) also highlights the important statistic that the CARES Act will provide a payment of 50,000 USD to Medicare-certified long-term care facilities with six or more certified beds to address the challenges directly linked to the pandemic. With an aim to provide evidence-based, interdisciplinary spatial design concepts, interventions, and action plans, Ferdous (2021) found that future memory care facilities should recognize these aspects to help minimize social isolation in older-aged adults with Alzheimer's disease. By not limiting social and community activities, this encourages residents of memory care facilities to be more active and mitigate loneliness.

THEORY

Industrial

The variations in cost and coverage of different long-term care facilities may create disparities in the availability and quality of social engagement opportunities and care for residents. Medicare covers some, but not all, costs of care in a memory care facility: While Medicare and Medicaid cover \$206 billion, or 64%, of the total health care and long-term care payments for individuals with Alzheimer's or other dementias, out-of-pocket spending entails \$81 billion, or twenty-five percent of total payments (Alzheimer's Association 2022). In the state of Massachusetts alone, the annual cost of assisted living costs \$78,000 and a private room in a nursing home costs \$162,425 (Genworth 2023). These costs are much higher than national averages of \$54,000 for assisted living and \$108,405 for nursing homes (Genworth 2023). The high costs of long-term care in Massachusetts may limit who can afford to reside in a facility and the types of services offered. Thus, opportunities for social engagement and visitation at facilities are influenced by the continuous rise in costs of this industry.

According to the National Investment Center for Seniors Housing & Care, memory care is the fastest-growing sector of the senior housing market, with the number of units doubling over the past decade (Crouch 2019). In 2022, the total payments for all individuals with Alzheimer's or other dementias were estimated to be \$321 billion (Alzheimer's Association 2022). Researchers also consider the nursing home industry in the context of

social welfare—as part of the health care system or as a component part of a broad set of industries dealing with aging (King 2020).

Cost of Care

An assessment of the economic impact of illness on society is necessary and can be applied to better understanding the costs of caring for individuals with dementia. Leniz et al. (2021) emphasize that health care costs increase at the end of life and that that long-term facility and hospice care costs are among the highest direct cost components for dementia care. Further, because long-term care services are so expensive, researchers found that dementia puts patients and families at a greater risk for high levels of out-of-pocket spending (Delavande et al. 2012). This is in part because Medicare and private insurance coverage for services such as long-term care are limited. High expenditures associated with the costs of long-term care are important to recognize because it can be a significant financial burden for families already faced with the challenges associated with a dementia diagnosis. There will be more individuals who require care in the future, and it is necessary to ensure that long-term services and support is not only accessible but affordable for all people.

Neighborhood

Sharkey and Faber (2014) apply a theoretical model of the relationships between individuals within residential contexts to interpret how institutional mechanisms, peers and networks, and access to opportunities influence the lives of residents. Memory care

facilities are likely to be subject to the various impacts of the neighborhood in which they are located, for the facilities are a place for residents to interact and use the space in a salient way. Importantly, institutions including care facilities have been neglected in the literature on neighborhood effects despite their centrality to social and economic life within communities (Sharkey and Faber 2014:565). The researchers highlight that existing literature focuses on compositional characteristics of neighborhoods rather than institutions that are present within communities. By applying the latter to memory care facilities, it acknowledges that these facilities are more than merely a neighborhood characteristic – they are an integral part of the community whose residents are valued members of the community. With this understanding comes a recognition that residents should be supported and included in the communities in which they live.

Neighborhood effects should not be isolated from social contexts including families, for they are linked. Sharkey and Faber (2014) suggest that the effects associated with changing one's neighborhood can lead to different effects on children. Akin to this perspective, a change in neighborhood for an individual with Alzheimer's can bring about a change in family dynamics. Neighborhoods play a crucial role in preventing or reducing disengagement for those with a dementia diagnosis; in fact, residents often define themselves according to the places they live and spend time (Ward et al. 2018). For example, if an individual chooses to live in a specialized care facility within their local neighborhood, this can promote opportunities for visitation and maintenance of their ties to family and friends that live nearby. Further, residing in a neighborhood that has access to resources and social engagement opportunities can support individuals with dementia and promote their well-being. It is imperative for care facilities to be recognized in their

respective communities to promote residents' inclusion, integration, and access to social ties.

Similar to Sharkey and Faber, Small and Adler recognize that a neighborhood “is not merely the sum of its physical features” (Small and Adler 2019:114). Small and Adler (2019) theorize that physical space plays a central role in the formation of social ties through the mechanism of spatial propinquity, defined as proximity between actors. While these researchers focus on tie formation, this general mechanism can be applied to my research on tie maintenance because spatial context influences social interaction opportunities. As highlighted by Small and Adler (2019), sociologist Simmel frames proximity in a way that understands how physical distance can impact the psychological and emotional relations between people. Applying Simmel's framework to the context of residents in memory care is essential because it recognizes the impact of physical distance on social relationships including friendships, marriage, and family relations; therefore, when facilities are in close physical distance to the homes of residents' loved ones, it can facilitate social tie maintenance and support for residents.

Indoor Built Environment

The way an indoor environment is built impacts health outcomes and can shape opportunities for social engagement. For example, Bromley (2012) found that designing hospitals with features of “ample space, homey environments, and hotel-like services” project feelings of healing and humanness in patients. This idea of humanizing spaces is also important in memory care facilities, for a space can promote feelings associated with home such as comfort and familiarity for Alzheimer's residents. Therefore, when residents

feel more “at home” in their environment, they may be more likely to engage with other residents and participate in social programming activities. The future of medicine is “shaped by expectations and normative models of care imported and translated into the buildings of the present, which are themselves often articulated with reference to past forms of clinical practice and the spaces within which they were forged” (Martin et al. 2015:1018). This is important because the architecture of healthcare not only illustrates patients as consumers, but it actively shapes changes within these built environments. Therefore, by examining architectural work in this way, it demonstrates that the design of memory care facilities can play an important role in facilitating opportunities for social engagement.

With a focus on spatial and environmental design in long-term care, Ferdous (2019) identified four key characteristics that affect residents’ social interaction: the physical environment and setting; accessibility, legibility, and layout; the social environment and network; and staff-resident ratio and care philosophy (Ferdous 2019:957). All four of these characteristics impact opportunities for social interaction that can be informed by my research. The physical environment of care facilities, including unit size and scale, is seen as a leading factor in influencing social interaction because the physical environment can impact a resident’s mood or behavior (Ferdous 2019). The researcher also highlights that mealtime intervention, access to the outdoor environment, and small-scale homelike settings all positively influence social interaction and engagement. Importantly, Ferdous (2019) recognizes that “design of both the indoor and outdoor environments influences the residents’ activities and interactions” (Ferdous 2019:954). Akin to the aforementioned architectural research by Martin et al. (2015), Ferdous emphasizes that the floor plan of

care facilities should be designed in a way that is straightforward to promote residents' spatial orientation, privacy, and autonomy. Arranging furniture in a conversational pattern can also stimulate social interaction (Ferdous 2019). Significantly, "frequent social interaction is associated with higher quality of life" for dementia residents, and this promotes their engagement in active, expressive, and social activities (Ferdous 2019:955). Ferdous (2019) found that both design and staff involvement play a role in enhancing social integration in casual living and activity areas near bedroom or kitchen spaces, promoting an understanding that the "socio-human environment is perceived to be more important than the physical environment" (Ferdous 2019:955). The creation of a therapeutic physical environment with qualities of legibility, familiarity, autonomy, and sensory stimulation also promotes social interaction (Marquardt et al. 2011). Most significant to my study is the finding that "get-togethers with family, friends, or neighbors are associated with a higher level of quality of life for elderly people with dementia" (Ferdous 2019:955). As highlighted by Smit et al. (2014), long-term care facilities with more active atmospheres "supported social interaction via the environment" and "having more activity programs is preferable." Furthermore, Ferdous (2019:956) suggests that taking a person-centered approach in dementia care can "reinstate the confidence of the residents" especially because dementia and Alzheimer's disease "change a person's ability to think, act, and interact with the surrounding social environments."

Presence of staff also plays a crucial role in promotion of psychosocial well-being of dementia residents, for they support patient well-being in their creation of a homely environment (Ferdous 2019). This is significant to my research because I believe that staff play a central role in promoting social engagement for residents who may need

encouragement to remain engaged in social programming. Because Ferdous (2019) solely addressed people with dementia in long-term memory care settings in their research, these findings are especially relevant to my study. Research by Hackett et al. (2019) shows that among those already diagnosed with Alzheimer's disease and related dementias, there are further declines in social engagement for these individuals post-diagnosis. This suggests that cognitive changes associated with dementia and disease progression negatively affect social engagement (Hackett et al. 2019).

Evans, Waller, and Bray (2022) highlight the need to establish policies and practices, and, more generally, the importance of environmental design to improve the well-being of people living with dementia. The researchers suggest myriad solutions to implement to increase accessibility within the indoor built environment of care facilities: guidelines to reduce the risk of falls, accessible bathrooms with familiar fittings and good signage, increased sensory stimulation and access to the outdoors, and eating spaces in any setting to provide opportunities for people with dementia to participate in food preparation and serving (Evans et al. 2022:91). Therefore, improving the indoor environment of memory care facilities can improve the quality of life for residents, especially by creating distraction-free spaces for socializing with visitors.

Disability

As suggested by theory pertaining to the indoor built environment, providing a positive social environment for people with dementia is necessary. Similarly, Blackman et al. (2003) highlight that the needs of people with dementia are informing the design of residential homes, but the issue of accessibility to public spaces and amenities in these

environments remains. According to Blackman et al. (2003), the social model de-medicalizes disability and politicizes it as a social issue about universal rights; even though both physical impairment and dementia are increasing in aging societies, little focus has been given to the relationship between psychological capacities and the organization of space (Blackman et al. 2003:359). Further research on the medicalization of progressive diseases akin to Alzheimer's is, therefore, critical. Interestingly, the researchers highlight that the progression of dementia is described in stages, but the individual experience is non-linear. The individuality of a person with dementia is also important to consider; their individuality is "constituted through interactions with others in possibly unconnected moments of time" (Blackman et al. 2003:361). However, despite disability status, all individuals are embedded within networks of social relations. These relations are necessary, for they are sometimes the "one constant in an emotional world threatened by losses" in a world where their dementia causes disorientation and memory loss (Blackman et al. 2003: 362). The researchers define an accessible, dementia-friendly environment as one that is calm and familiar, allowing the residents to have both emotional and physical support. Blackman et al. (2003) propose the 'open city' design, which emphasizes the importance of establishing a functional outdoor environment for people with dementia. An accessible environment for people with dementia would be beneficial to avoid unnecessary confusion and disorientation that the external environment creates when the design does not reflect their needs. Importantly, Blackman et al. (2003) reiterate that there is a new culture of dementia care that regards people with dementia as service users who should be able to participate in shaping their care, necessitating the need for the creation of barrier-free environments for these individuals. Not only would the creation of an accessible

environment promote the autonomy and health status of people with dementia, but it would not exclude them from society and necessary social interaction. It is commonplace for dementia care to be oppressive, for individuals are often subject to disempowerment through decisions made for them (Blackman et al. 2003:360). This emphasizes the need for an establishment of respectful and trusting relationships for those who care for people with dementia. Nevertheless, this research is crucial because a person with dementia's orientation to place, level of social disturbance, and level of apathy depend on the quality of care provided (Blackman et al. 2003:367).

METHODS

SAMPLE AND RECRUITMENT

To answer the aforementioned research questions, I examined the differences in social connections by focusing on access to social engagement and how this access varies by characteristics of memory care facilities. I interviewed and surveyed employees at various assisted living residences with memory care throughout Massachusetts. I analyzed data from interviews and surveys conducted between February 2023 and April 2023 with ten memory care facility employees (Table 1). I used convenience and snowball sampling methods to recruit participants for this study. Generally, the qualitative interviews with staff of memory care facilities investigated the types of social enrichment activities offered, why patients do or do not obtain visitors, and what kind of factors may shape who obtains more or less visits. Each subject was asked to both participate in a phone interview and respond to a brief online survey. These surveys collected the demographic information of participants.

I also arranged to have representatives of memory care facilities send recruitment communications to their staff members. The representatives used email to send these communications. Conflicts of interest were avoided by obtaining consent from all participants after I explained my study and my involvement as a student researcher and

Boston College Alzheimer's Buddies volunteer to them. If participants wanted to withdraw from the study, they could at any time without consequence. These communications spoke in the voice of the representative of a memory care facility, and they included a link to the survey as it would appear on Qualtrics. Upon clicking the link, the subject would encounter the informed consent language of the study.

Existing data from the Commonwealth of Massachusetts on assisted living residences throughout Massachusetts guided my recruitment process (<https://www.mass.gov/assisted-living>). This data provided a list of 267 assisted living residences sorted by location. I used this resource to contact various facilities via phone. I began data collection in ten memory care facilities within Boston (Back Bay, Brighton, Dorchester, Jamaica Plain, Mission Hill, Roxbury, South Boston, and West Roxbury), and I expanded my data collection to include facilities outside of the city. These include twenty-six facilities in suburbs near Boston College's campus (Brookline, Cambridge, Dedham, Framingham, Needham, Newton, Westwood, Wellesley, and Watertown). My final sample included ten participants who were employed at seven assisted living residences with memory care in Boston, Brookline, Dedham, and Needham.

SURVEY AND INTERVIEW

If individuals indicated their consent to participate in the study, they were routed to a brief online survey designed to obtain basic demographic information, and, thereafter, participated in an interview either via Zoom or over the phone. In the interview,

participants were asked to elaborate upon topics pertaining to visitation in memory care facilities, namely about challenges or factors that influence visitation.

If a memory care facility employee agreed to take part in the study, they were asked to respond to a series of questions in Table 2. I asked each participant twelve questions (see Appendix). These questions were selected to gain a greater understanding of the social enrichment activities offered at the facility, what the residents' engagement is with these activities, and what factors may influence visitation for residents with Alzheimer's disease and related dementias. Table 2 details the interview topics gathered from the perspectives of memory care facility employees. All information collected was linked to research data and protected health information, if necessary.

Table 2. Interview topics for memory care facility employees.

Visitation Characteristics

What factors shape visitation

Visitation hours of the facility

Average number of visits per resident

How many residents obtain few visits (<1 per week)

Types and Amount of Social Enrichment Activities

Types of Activities

Number of Activities

Observations of Social Enrichment Activities

Why some residents participate in activities more/less than others

In person or virtual activities

Resident engagement with activities/eagerness to participate

Observations of Visitation

Why some residents obtain more visits than others

Why some residents obtain no visits

Accommodating visitation

General Information about Facility

Number of residents with AD or dementia

Specialized unit for AD (yes/no)

ETHICS

Upon selecting the Qualtrics link in the recruitment email, subjects would land immediately on the informed consent verbiage in Qualtrics, where they would read the verbiage and indicate whether they consent or decline to participate. If subjects consented to participate, they would be prompted to provide their name and email address, complete the online survey, and then read instructions on the next steps for scheduling an interview. All participants were over the age of eighteen and did not require consent from a parent or legal guardian. Immediately before starting the recording of my interviews, I obtained from each subject confirmation that they consent to record. Additionally, because it is unlawful in Massachusetts to record people's voices without their consent, immediately after starting to record, I asked the subject to repeat their consent for the record.

I collected identifiable information from various assisted living residences with memory care throughout Massachusetts. These facilities provide live-in care for patients diagnosed with Alzheimer's disease or dementia. The identifiable information includes the name of the memory care facility, the location of the facility, how many people at the memory care facility have Alzheimer's disease or related dementias, visitation hours of the facility, services provided at the facility, and the cost of the facility. The identities of the

employees and names of facilities in which I conducted interviews are not disclosed within this research project, for I solely compared data pertaining to visitation and social engagement across these institutions. All names of memory care employees are pseudonyms, and all facility names are de-identified.

I have received Institutional Review Board approval from Boston College (23.077.01). I have also completed Human Research (Social/Behavioral Research) through CITI Program training.

ANALYSIS

All interview data was transcribed using Otter.ai software, and I used content analysis to sort and interpret my interview results. Based on analyses of interviews and surveys, I discovered patterns in visitation and social programming offerings across various facilities in Massachusetts. The major themes that emerged from this analysis include family dynamics, disease progression, and geographic location. Interview data was sorted amongst these themes to demonstrate how these factors affect social engagement for residents in memory care.

RESULTS

SAMPLE DESCRIPTIONS

DEMOGRAPHIC SURVEY DATA

Table 1 details the characteristics of interview participants. This data was obtained from a Qualtrics survey. Ten participants across seven facilities in Massachusetts completed the survey and interview process. This sample consisted of a diverse group of occupations, including three memory care directors, two caregivers, one art therapist, and other professions including one guest services manager, one program supervisor, one hospitality aide, and one director of community relations. The average number of years that a full-time memory care facility employee worked was fifteen and the average number of years that a part-time memory care facility employee worked was one. The sample consisted of four white women, three white men, one African American woman, and two Latino men. Seven participants completed a bachelor's degree or more and three participants completed some college or trade school. Four participants are single or never married, four are married or in a domestic partnership, and two are divorced or separated.

Table 1. Characteristics of interview participants (data from Qualtrics survey). *Note:* * depicts the value is an average.

Position	N
Full-time memory care facility employee	8
Part-time memory care facility employee	2
Years Worked in Long-Term Care	
Full-time memory care facility employee	15*
Part-time memory care facility employee	1*
Per diem memory care facility employee	0
Occupation at Facility	
Memory Care Director	3
Caregiver (Wellness Nurse, 911 Paramedic)	2
Art Therapist	1
Other (Guest Services Manager, Program Supervisor, Hospitality Aide, Director of Community Relations)	4
Age	
18-24 years old	2
25-34 years old	1
35-44 years old	3
45-54 years old	2
55-64 years old	2
65-74 years old	0
75 years or older	0
Sex	
Male	5
Female	5
Other	0
Ethnicity	

White	7
African American	1
Latino or Hispanic	2
Asian	0
Native American	0
Native Hawaiian or Pacific Islander	0
Other	0
Education	
Less than high school	0
High school or GED	0
Some college or trade school	3
Bachelor's degree or more	7
Marital Status	
Single, never married	4
Married or domestic partnership	4
Widowed	0
Divorced/Separated	2

FACILITY DESCRIPTIONS

Table 3 depicts the key features of the facilities where I interviewed, including the employment title of the staff I interviewed, the number of residents with Alzheimer's disease or related dementia, a description of social activities and programming, whether the facility is located in an urban or suburban area, and the location of the facility relative

to Boston. This data was obtained and summarized from qualitative interviews. Some fields are estimates provided by interviewees. My sample consists of seven assisted living residences with memory care. Three of these facilities are located in an urban area of Massachusetts and four facilities are located in a suburban area of Massachusetts. Facility 1, an urban facility located in Boston, has the greatest number of residents with Alzheimer's disease or related dementias relative to other urban facilities 2 and 3. Facility 6, a suburban facility located six miles outside of Boston, Massachusetts, has the greatest number of residents with Alzheimer's disease or related dementias relative to other suburban facilities 4, 5, and 7. The description of social enrichment activities offered is verbatim from answers provided by memory care facility employees. The number of activities offered per day is based upon activity calendars provided to me by the interviewees. There was a wide variety in cost of each facility, with facility 7 being the most expensive and facility 3 costing the least; however, these values may differ depending on room size and level of care needed.

Table 3. Key features of facilities (data from qualitative interviews). *Note: * depicts an estimate across 136 apartments (assisted living apartments and memory care), ** depicts an estimate across 82 apartments (assisted living), *** depicts an estimate across memory care, and – depicts that the interviewee did not report a value.*

	Facility 1	Facility 2	Facility 3	Facility 4	Facility 5	Facility 6	Facility 7
Staff Interviewed	Director of Community Relations	Director of Memory Care	Wellness Nurse	Program Supervisor; Guest Services Manager; Director of Memory Care	Director of Memory Care; Hospitality Aide	Art Therapist	911 Paramedic
Number of Residents with AD/dementia	75*	18	6**	19	23	40	30***
Capacity for memory care	–	–	–	25	28	44	36
Description of Social Activities from Staff Interviewed	health, wellness, music, art, word games	social and crafts, live entertainment, trips to the beach or park, a lot of interactive time	planting, bingo, board games, movies, happy hour	exercise, household task sorting, planting, food activities, social activities, movie nights with popcorn, tea party, singalongs, travelogue, storytelling and poems, chair ballet, televised worship;	fitness programs, intergenerational programs, cognitive games, art programs, daily fitness groups, pet therapy, volunteer program, entertainment, word games, lectures, slideshow presentations, arbitrary travel, baking,	cognitive programming, music programs, music therapy, live concerts, arts programming, seasonal crafts, open art studio program, museum trips, scenic drives, visitation of historic	enrichment activities, collective movie nights, social dinners in a common area that looks like a restaurant, communal-type activities

	social, experiential, therapeutic, creative and artistic, emotional and spiritual, sensory, and physical; bowling, arts and crafts, entertainment, social baking groups, sensory stimulation, musical entertainment, singalongs, trivia, word fun						
	cooking, food demos, magicians and outside entertainers, spiritual services; piano concerts, entertainment, animal visits, cooking demonstrations, art lectures, movies, ballets and operas, exercise						
	sites in Boston, exercise, simple stretching, Zumba, yoga, personal training, dance therapy, social and recreation, bowling, social hour, gardening and horticulture, manicures						
Number of Activities Offered Per day	7-10	7-8	5-9	5-8	7-8	11-12	12-18
Urban/ Suburban	Urban	Urban	Urban	Suburban	Suburban	Suburban	Suburban
Location	Boston	Boston	Boston	21 miles outside Boston	17 miles outside Boston	6 miles outside Boston	21 miles outside Boston
Approximate cost per month	\$9,000-\$10,000	\$8,000	\$4,000-\$5,000	\$8,000	\$10,000	\$9,000	\$12,000

INTERVIEW THEMES

Various themes emerged from data gathered from qualitative interviews. In terms of visitation hours, all seven facilities have no restrictions on visitation hours and there was a theme of a “home” aspect. In terms of social enrichment activity participation, the main themes that emerged included a transition from assisted living to memory care or from home to a facility, the stage of dementia, and the personality of the resident. Increased and decreased visitation varied by myriad factors, including individual factors and structural factors. Individual factors include family dynamics and health of the resident. Structural factors include geographic location, logistics, and religion.

PATTERNS IN SOCIAL ENGAGEMENT

All seven facilities offered an array of social enrichment activities for residents in memory care. There was little variation in the types of activities offered across each facility; however, there were notable differences in the number of activities offered per day. Facility 7 offers the greatest number of social programming activities per day, between twelve and eighteen, and facility 4 offers between five and eight, the lowest range of activities. This is a notable finding given both facilities are located in the same neighborhood.

There was also variation in the proportion of residents that take part in social enrichment activities, as summarized in Table 4. Facility 1, the facility with the largest number of residents with Alzheimer’s disease and related dementias, and facility 7, the most expensive facility, had the greatest proportion of residents that participate in social enrichment activities. Facilities 2 and 3 have the lowest proportion of residents participating in activities. All facility employees agreed that residents need encouragement to participate in social programming.

Table 4. Proportion of residents that participate in social enrichment activities and need encouragement (data from qualitative interviews). *Note: * depict values that are averages.*

	Facility 1	Facility 2	Facility 3	Facility 4	Facility 5	Facility 6	Facility 7
Proportion of residents that participate in activities	80-90%	50%	65%	73.3%*	77.5%*	75-80%	80%
Do residents need encouragement (Y/N)	Yes	Yes	Yes	Yes	Yes	Yes	Yes

While 100% of memory care facility employees believed that some residents need encouragement, there were differences in reports of how eager or engaged residents are to participate across the seven memory care facilities. For example, employees from facilities 1 and 7 believe that residents are eager to participate whereas employees from facilities 2 and 3 believes that residents are not engaged or eager.

“So the residents that are in memory care participate all the time. ... They go to every single one [activity].” (Shirley, director of community relations, facility 1)

“I think the majority of the patients do tend to look forward to it [participating].” (Ben, 911 paramedic, facility 7)

In contrast, Bob, memory care director at facility 2, states that only *“about 25%”* and Dan, wellness nurse at facility 3, states that *“probably a third of the residents”* are engaged or eager to participate.

Furthermore, interview data revealed a variety of reasons why residents may need encouragement to participate in social programming, including their disease progression, their transition to the facility in which they reside, the time of day, or their relationship to staff.

Disease Progression

Disease progression, which hinders residents’ cognition, serves as a reason why some need encouragement to participate in social enrichment activities:

“Some need encouragement. Some just genuinely enjoy activities, but you have some better and different because everyone's in different stages and levels here so everyone's different cognitively.” (Rebecca, memory care director, facility 4)

“I would imagine, obviously, more difficult cases like some depending on what stage in the disease process they are, they're more difficult to rouse. Some of them are, you know, entirely in their own world and just don't interact whatsoever.” (Ben, 911 paramedic, facility 7)

Transitioning to Memory Care

Employees from facility 2 and facility 5 agree that the transition to memory care can be a reason why residents may need encouragement to participate:

“I think goes back to how they’re adjusting to living in the unit overall.

Some people take a lot longer and, you know, they’re going to be a little bit

less excited about being engaged.” (Anna, hospitality aide, facility 5)

“Residents need encouragement. Especially new residents. They tend to,

you know, stay in their apartments. And so, we encourage ... whether it’s

me, or the assistants, or the aides to go in and guide them out and sit with

them ... just work directly one-on-one with them until they get established

and familiar and, you know, make friends until they become comfortable.”

(Bob, memory care director, facility 2)

The transition from assisted living to memory care or from home to memory care can be difficult for elderly populations. Given the shift in their environment and their new home, this serves as a reason why newer residents may need additional support or encouragement in comparison to their peers.

Time of Day

The time of day is also an important factor to consider, for it can impact the residents’ participation in social programming activities:

“It’s [participation] going to vary a bit throughout the day and different

days of the week. ... So I would say by about 10:30 we really see the bulk of

people that are up and engaged. And again after lunch, there’s one or two

folks that like to take a nap. And then by the later afternoon, it kind of depends. I see the attendance in groups can rebound but again sometimes at the end of the day people are just really tired so a few might go back to their apartments. They might want some quieter time at that point of the day.” (Stacy, art therapist, facility 6)

The time of day plays a major role for residents with Alzheimer’s disease and related dementias, given they may experience sundowning in later hours of the day. Emotions associated with sundowning such as agitation and confusion can impact the residents’ eagerness to participate in social programming. Interestingly, a memory care facility employee of facility 5 believes that engagement varies by both disease progression and time of day:

“There are different levels throughout the days. Throughout the day, for instance, we’ll have residents that are engaged throughout all programs. Then we’ll have some residents that are a little bit more cognitively impaired, who need a little bit extra support.” (Jack, memory care director, facility 5).

Relationship with Staff

Lastly, a crucial factor to consider in terms of engaging residents with Alzheimer’s disease and related dementias is the staff-resident relationship. The relationship between the resident and staff plays an important role in the residents’ eagerness to participate in social enrichment activities:

“It’s definitely with encouragement. It’s who is encouraging them too. If there’s like a certain aide that the resident feels very comfortable with,

they're more adept to come for an activity if that resident assistant is with them because they feel comfortable and they might not know who they are, but they know the feeling that they're giving them, so they feel comfortable and more adept to come to activities." (Jessica, guest services manager, facility 4)

When memory care residents are comfortable with staff, they are more likely to be eager to participate in social enrichment activities.

PATTERNS IN VISITATION

Visitation Hours

Prior to conducting interviews, I hypothesized that visitation hours would vary across different memory care facilities; however, interview results revealed that this was not the case. Interestingly, all seven facilities did not have any standard visitation hours. Rather, family members or friends of residents could visit the facility at any time. This was clearly demonstrated across multiple interviews:

“They [family members and friends of residents] can visit at any time. It's really up to them. They can come anytime they want. Generally, people with dementia kind of do better in the morning and early afternoon. But there's no restriction to our visiting hours.” (Stacy, art therapist, facility 6)

“We don't have any sort of visitation hours it's, you know, always open.”
(Anna, hospitality aide, facility 5)

“We don't have a certain set time for visitation hours. Families are allowed to visit their families at any time.” (Rebecca, memory care director, facility 4)

“They can come and go as they please. 24 hours a day. Seven days a week. We don't have visiting hours.” (Bob, memory care director, facility 2)

Another interesting theme that was brought to light when inquiring about visitation hours of the memory care facility was a notion of “home:”

“So it's their home so anyone can come and visit whenever they'd like, it could be 11pm it could be 5am. They can come and go as they please.”

(Jessica, guest services manager, facility 4).

This memory care facility employee provides intriguing insight that connects to existing interpretations of facilities, namely in the “home” aspect. As I examined earlier, the consideration of a facility as fundamentally a home rather than a place to receive medical care is necessary.

Increased/Decreased Visitation

While interview results revealed that there are no restrictions in visitation hours in my sample of memory care facilities, I found that there are myriad factors that contribute to an increase or decrease in visitation. These can be broken down into individual factors (family dynamics and health) and structural factors (geographic location, logistics, and religious/cultural reasons). The aforementioned factors explain why some residents in memory care obtain more or less visits than others.

Individual Factors

Individual factors that affect visitation include family dynamics, personality of the resident in memory care, and disease progression. These were the most discussed factors across all ten interviewees.

Family dynamics affect visitation. This is clearly demonstrated throughout multiple interviews with memory care facility employees:

“I think it has to do with caregiver guilt. I think it has a lot to do with the people who are visiting, if they know how to have a successful visit with

somebody with Alzheimer's or somebody with dementia. There are ways that you can visit that are positive. There are ways that you can visit them that are negative. And then also depending on the person, some people especially once they have integrated into a community and are comfortable, it's easy for their loved ones to come and go. ... It just takes skill to visit with somebody with Alzheimer's. And I think it has a lot to do with the relationship between family members or friends and family with the people with Alzheimer's." (Stacy, art therapist, facility 6)

"Could be family dynamics. Sometimes family members have a broken relationship, and some family members will help make sure that their family is taken care of but that emotional connection is something that's in the past." (Jack, memory care director, facility 5)

"We do have a couple of residents that don't have any children, and I have noticed if they don't have children, their visits are a lot less frequent if it was like a niece or a nephew. So, I think that would be our biggest thing is that if they don't have children, they're definitely not in there as much." (Jessica, guest services manager, facility 4)

"I think every family dynamic is different. So there's people who call their mom every day as is and there's people who talk to their mom once a month. ... And then the existing family dynamic pre diagnosis. Just how the family or friends or, whoever is going to be visiting, how they interacted with the person before." (Anna, hospitality aide, facility 5)

“I just don't think ... some people don't have enough family or friends to come see them and some do.” (Rebecca, memory care director, facility 4)

“Predominantly those family dynamics, you know, people who are those difficult cases and you talk to them, and they really don't respond to you. Those are very difficult folks to have conversations with, and I do think a lot of family members no matter how much they love them, they struggle to see the family member like that.” (Ben, 911 paramedic, facility 7)

Family dynamics were found to be the main factor that influences visitation. The relationships between the resident and their family members can either promote visitation or prompt its decline.

In addition to family dynamics, the personality of the resident in memory care can also impact the frequency of visitation for family members and friends:

“There's all kinds of interpersonal relationships that, you know, adult children have with their loved ones. I mean, personality changes, you know, can be affected. You know, there's some people when they go through memory disorders that you know, nice people become mean, mean people become nice. You know, some people don't know how to deal with it. They have a coping mechanism. Other family members are in denial. They find it frustrating.” (Shirley, memory care director, facility 1)

Personality changes become more pronounced in severe stages of Alzheimer's disease. There are many emotions associated with having a loved one residing in a memory care facility and this can be a challenge for families to navigate, resulting in an impact in visitation.

Dementia progression is another factor that was found to influence visitation within memory care facilities:

“You hate to say it, but with the progression of the disease, I think some people, the kinder parts of themselves come out and then some people unfortunately, their behavior does kind of change in more of a negative direction. And I think it is a lot harder for those people's family members to come and visit them. It's hard to come see your mom when she's number one, not acting like herself, but then number two, just being kind of nasty. Unfortunately, I think that does affect visitation.” (Anna, hospitality aide, facility 4)

Disease progression is a common factor, for memory care facility employees agree that residents in earlier stages of the disease are likely to obtain more visits compared to residents who are in more severe stages.

“I think as people go through, you know, a progression in their diseases, visitation rates decline.” (Shirley, director of community relations, facility 1)

“I think the less progressed dementia residents tend to get more visitors.”
(Bob, memory care director, facility 2)

Structural Factors

Across all ten interviewees, a key theme that emerged was that geographic location of the facility can be a common barrier to visitation in memory care.

“It could be geographic. It could be just guilt. It could be a lot of things. A lot. I mean, some people feel obligated to come you know, other people

actually want to come. But, it really varies a lot.” (Shirley, director of community relations, facility 1)

“You know, some residents no longer have family and friends living or they live far away. That’s predominantly the reason why they wouldn’t get visitors.” (Bob, memory care director, facility 2).

“You know, some people don’t live nearby. And some people have busy lives and kids and things like that, that just prevents them from getting here as often as they’d like, you know.” (Dan, wellness nurse, facility 3)

“I would say somebody whose family is out of state for one thing. That’s probably the biggest factor is the distance. I really think it’s location, family in the area. If a visitor is somebody who’s also working full time, that changes things. If the visitor is the primary person who comes is also elderly, they’re limited by you know, their own challenges, driving at night, that kind of thing.” (Chris, program supervisor, facility 4)

“Location is probably just logistically the biggest one.” (Anna, hospitality aide, facility 5)

“I think logistics is number one, like who’s close.” (Stacy, art therapist, facility 6)

“Proximity of family and what their day to day life looks like, you know.”
(Ben, 911 paramedic, facility 7)

Geography can impact visitation because family members who do not live in close vicinity to the memory care facility may not be able to visit as frequently. Interestingly, despite the

distance, memory care facilities such as facility 5 ensure that their residents with out-of-state families maintain social contact:

“Pretty much everybody has a visitor unless their loved one is in a different state or a different country. That's the only time. But we accommodate that by using Zoom. We do Zoom calls with their loved ones. So, if they can't be here physically, they'll be here virtually.” (Jack, memory care director, facility 5)

Technology can certainly benefit individuals residing in memory care, for it connects residents with family members or friends who would not have otherwise had the opportunity to interact with them.

A third theme is religion and culture. Out of ten interviews, one interviewee discussed religious and cultural factors as having an influence on the frequency of visitation for residents in memory care:

“Oh, some people are just not going to leave their side. You know, they're just not. This is, you know, the last of their parent or loved one, and they couldn't possibly abandon them at, you know, this point. There's a lot of, you know, religious and cultural things as well. ... Oh, you know, there's some people like, you know, Jews, you know, never want anybody to die alone. So, if there's a chance that you know, is, you know, a Jewish family, they will stay there until they pass away and until the body is picked up. Where, you know, other families may just say you know, there's nothing I can do and leave.” (Shirley, director of community relations, facility 1)

This is a unique finding given that no other participant mentioned the important role of religious and cultural factors in frequency of visitation.

There were other factors that influence visitation but were highlighted less frequently by interviewees. For example, the time of day plays a role in visitation, for family members and friends of residents who work standard nine to five hours may have more free time for visitation over the weekend. Furthermore, inclement weather can influence visitation. Overall, there are a variety of factors that influence visitation in memory care facilities. While there were a vast number of potential themes that affect visitation, I found that the main individual factor is family dynamics, and the primary structural factor is geographic location.

DISCUSSION

INTERPRETATION OF RESULTS

The findings of this study support existing research pertaining to Alzheimer's disease and social engagement. Park et al. (2010) highlight that residences with larger settings have more opportunities for social programming. This is clearly portrayed in my research, for facilities 6 and 7 have the greatest amount of social programming activities offered per day, at 11-12 and 12-18, respectively. These two facilities also have a larger capacity for memory care when compared to other suburban facilities 4 and 5. The cost of care across all seven facilities varied; however, the most expensive facility per month offered the greatest amount of daily social programming activities.

My findings associated with family dynamics contrast with existing theory pertaining to neighborhood effects. Sharkey and Faber (2014) suggest that changes in an individual with Alzheimer's neighborhood can bring about changes in family dynamics. However, my findings suggest that despite an individual with Alzheimer's transition into memory care, their existing family dynamics play a role in whether they obtain visits. It is not the neighborhood that changes these dynamics, for the dynamics remain the same pre-diagnosis. Small and Adler (2019) state that theory from Simmel emphasizes that physical distance impacts the relations between people. This supports my findings around

geographic location in that residents who have family members or friends residing nearby the memory care facility obtained more frequent visits. However, I found that social engagement opportunities were also facilitated via technology platforms including Zoom for family members that lived out-of-state or did not live in close proximity to the memory care facility.

Existing theory pertaining to the indoor built environment highlights that designing spaces as “homey environments” can shape opportunities for social engagement (Bromley 2012). This supports my findings in the idea of space and visitation. Multiple memory care facility employees in my sample recognized that the memory care facility was the home of the resident. When seeing the facility as a home rather than as merely a place to receive medical care, there is an increase in visitation for residents. Further, Ferdous (2019) emphasizes the importance of staff involvement in enhancing social integration. This is congruent to my finding that staff-resident relationships play a pivotal role in a resident with Alzheimer’s disease or related dementias’ engagement with social programming activities.

Importantly, Blackman et al. (2003) state that a calm and familiar environment are key aspects of an accessible and dementia-friendly space. This connects to my findings in that when residents were more comfortable in their spaces, they were more engaged and eager to participate in activities. I also found that newer residents had more difficulty and were less eager to participate in social enrichment activities. However, over time, as these individuals became more familiar with their surroundings, their eagerness to participate increased.

LIMITATIONS

This study had several limitations. One major limitation was the small sample size and inability to obtain complete insight on some interview questions. Some data, such as current facility capacity, was missing despite existing data from the Commonwealth of Massachusetts on assisted living residences throughout Massachusetts, for this resource contains data from November of 2022. There was also a great variety in responses within the same facility, which may be attributed to years of experience working in memory care or whether an individual is employed full-time or part-time. Further, my research is limited in that results are not generalizable due to the small sample sizes of seven facilities and ten employees. It is also necessary to highlight that because of high turnover in this field, to obtain perspectives from individuals who are with Alzheimer's residents over an extended period of time and have a solid sense of their social lives is difficult. Throughout the recruitment process, one participant exclaimed that they were leaving their occupation and two other participants shifted roles within the same facility. Interviews had to be rescheduled on multiple occasions due to unexpected conflicts that arose within facilities. Another limitation of this study was the inability to include a sample of family members and friends of Alzheimer's residents despite my creation of an IRB-approved flyer for their recruitment. Inclusion of interview data from this population would have strengthened my results.

CONCLUSION

The population is aging at a rate that is at an all-time high. There are going to be a great increase in individuals needing to reside in long-term care facilities in the future. Furthermore, the incidence of Alzheimer's disease and related dementias is continuing to increase. With this knowledge, this research project is so important because social engagement can improve the well-being and slow the decline of aging individuals. Importantly, socially engaging with people on a regular basis and taking part in activities that are stimulating are linked to better health outcomes across the life course.

My research was conducted solely in the state of Massachusetts and had sample sizes of ten memory care facility employees and seven facilities. Future research should explore additional insight from a greater number of employees in memory care. Future research should also expand to include samples in states other than Massachusetts. The results of this research and the continuous rise in Alzheimer's disease in aging populations suggest that policy efforts should address the imperative need to increase social engagement opportunities in all memory care facilities across the world. After all, as stated by a memory care facility employee, *"socialization is the best treatment we have for Alzheimer's right now."*

REFERENCES

- Abbott, Katherine M. and Mark C. Pachucki. 2016. "Associations between Social Network Characteristics, Cognitive Function, and Quality of Life among Residents in a Dementia Special Care Unit: A Pilot Study." *Dementia* 16(8):1004-19.
- Affairs, Executive Office of Elder. "Assisted Living." *Mass.gov*, (<https://www.mass.gov/assisted-living>).
- "Alzheimer's Association | Alzheimer's Disease & Dementia Help." (<https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>).
- Bennett DA, Schneider JA, Tang Y, Arnold SE, and Wilson RS. 2006. The effect of social networks on the relation between alzheimer's disease pathology and level of cognitive function in old people: A longitudinal cohort study. *The Lancet Neurology*, 5, 406–412. 10.1016/S1474-4422.
- Blackman, T., Mitchell, L., Burton, E., Jenks, M., Parsons, M., Raman, S., and Williams, K. 2003. The accessibility of public spaces for people with dementia: A new priority for the 'open city'. *Disability & Society* 18(3):357-371.
- Bromley, E. 2012. Building patient-centeredness: hospital design as an interpretive act, *Social Science & Medicine* 75(6):1057-66.
- Genworth. "Cost of Long Term Care by State: Cost of Care Report." (<https://www.genworth.com/aging-and-you/finances/cost-of-care.html>).
- Centers for Disease Control and Prevention 2020. "Social Determinants of Health and

- Alzheimer's Disease and Related Dementias.”
- (<https://www.cdc.gov/aging/disparities/social-determinants-alzheimers.html>).
- Crouch, Michelle. “What Is Memory Care and How Much Does It Cost?” AARP.
- (<https://www.aarp.org/caregiving/basics/info-2019/memory-care-alzheimers-dementia.html>).
- Curelaru, Aurora, Sarah J. Marzolf, Jean-Claude K. G. Provost, and Helen H. H. Zeon. 2021. “Social Isolation in Dementia: The Effects of Covid-19.” *The Journal for Nurse Practitioners* 17(8):950-53.
- Delavande, Adeline, Michael D. Hurd, Paco Martorell, and Kenneth M. Langa. 2012. “Dementia and out-of-Pocket Spending on Health Care Services.” *Alzheimer's & Dementia* 9(1):19-29.
- “Does Medicare Cover Memory Care Facilities?” MemoryCare.com. Retrieved May 23, 2022 (<https://www.memorycare.com/does-medicare-cover-memory-care/>).
- Evans, S.C., Waller, S. and Bray, J. 2022. “Designing inclusive environments for people living with dementia: how much do we really know?” *Working with Older People* 26(2):89-96.
- Ferdous, Farhana 2019. “Positive social interaction by spatial design: a systematic review of empirical literature in memory care facilities for people experiencing dementia.” *Journal of Aging and Health* 32(9):949-961.
- Ferdous, Farhana. 2021. “Redesigning Memory Care in the COVID-19 Era: Interdisciplinary Spatial Design Interventions to Minimize Social Isolation in Older Adults.” *Journal of Aging & Social Policy* 33:4-5, 555-569.
- Fratiglioni, Laura, Hui-Xin Wang, Kjerstin Ericsson, Margaret Maytan, and Bengt

- Winblad. 2000. "Influence of Social Network on Occurrence of Dementia: A Community-Based Longitudinal Study." *The Lancet* 355(9212):1315-19.
- Girvan, Gregg. "38% Of Covid-19 Deaths in Nursing Homes & Assisted Living Facilities." Medium, FREOPP.org. Retrieved September 25, 2021 (<https://freopp.org/the-covid-19-nursing-home-crisis-by-the-numbers-3a47433c3f70>).
- Hackett, Ruth A., Andrew Steptoe, Dorina Cadar, and Daisy Fancourt. 2019. Social engagement before and after dementia diagnosis. *English Longitudinal Study of Ageing* 14(8):e0220195.
- Hsiao YH, Chang CH, and Gean PW. 2018. Impact of social relationships on Alzheimer's memory impairment: mechanistic studies. *J Biomed Sci.* 25(1):3.
- King, L. 2020. How Government Created and Shaped the US Nursing Home Industry. *Critical Sociology* 46(6):881-897.
- Leggett AN, Meyer OL, Bugajski BC, and Polenick CA. 2021. Accentuate the Positive: The Association Between Informal and Formal Supports and Caregiving Gains. *J Appl Gerontol.* 40(7):763-771.
- Leniz, Javiera et al. 2021. "Exploring Costs, Cost Components, and Associated Factors among People with Dementia Approaching the End of Life: A Systematic Review." *Alzheimer's & Dementia: Translational Research & Clinical Interventions* 7(1).
- Livingston G, Huntley J, Sommerlad A, Ames D, Ballard C, Banerjee S, et al. 2020. "Dementia prevention, intervention, and care: 2020 report of the Lancet Commission." *Lancet* 396(10248):413-46.

- Martin, D., Nettleton, S., Buse, C., Prior, L., and Twigg, J. 2015. "Architecture and health care: a place for sociology." *Sociology of health & illness* 37(7):1007-1022.
- Mauldin RL, Fujimoto K, Wong C, Herrera S, Anderson KA. 2021. "Social Networks in an Assisted Living Community: Correlates of Acquaintance and Companionship Ties Among Residents." *J Gerontol B Psychol Sci Soc Sci.* 13;76(7):1463-1474.
- Marquardt, G., Johnston, D., Black, B. S., Morrison, A., Rosenblatt, A., Lyketsos, C. G., and Samus, Q. M. 2011. "Association of the spatial layout of the home and ADL abilities among older adults with dementia." *American Journal of Alzheimer's Disease & Other Dementias* 26:51-57.
- Park, Nan Sook, Sheryl Zimmerman, Kathleen Kinslow, Hae Jung Shin, and Lucinda Lee Roff. 2010. "Social Engagement in Assisted Living and Implications for Practice." *Journal of Applied Gerontology* 31(2):215-238.
- Sass, James. 2000. "Emotional labor as cultural performance: The communication of caregiving in a nonprofit nursing home." *Western Journal of Communication*, 64(3):330-358.
- Schafer, Markus H. and Haosen Sun. 2022. "There at Any Distance? Geographic Proximity and the Presence of Adult Children in Older Europeans' Core Discussion Networks." *Social Science Research* 102:102643.
- Sharifian N, Manly JJ, Brickman AM, Zahodne LB. 2019. "Social network characteristics and cognitive functioning in ethnically diverse older adults: The role of network size and composition." *Neuropsychology* 33(7):956-963.
- Sharkey, P., and Faber, J. W. 2014. "Where, when, why, and for whom do residential

- contexts matter? Moving away from the dichotomous understanding of neighborhood effects.” *Annual review of sociology* 40:559-579.
- Small, Mario L. and Laura Adler. 2019. “The Role of Space in the Formation of Social Ties.” *Annual Review of Sociology* 45(1):111-32.
- Smit, D., Willemse, B., de Lange, J., and Pot, A. M. 2014. “Wellbeing-enhancing occupation and organizational and environmental contributors in long-term dementia care facilities: An explorative study.” *International Psychogeriatrics* 26:69-80.
- Smith, Kirsten P. and Nicholas A. Christakis. 2008. “Social Networks and Health.” *Annual Review of Sociology* 34(1):405-29.
- Ward, R., Clark, A., Campbell, S., Graham, B., Kullberg, A., Manji, K., Rummery, K., and Keady, J. 2018. “The lived neighborhood: understanding how people with dementia engage with their local environment.” *International Psychogeriatrics* 30(6):867-880.
- Zhang, Yun, Ginny Natale, and Sean Clouston. 2020. “Social Network Structure and Dementing Processes.” *Alzheimer's & Dementia* 16(S7).

APPENDIX

Memory Care Facility Employee Interview Questions

1. How many people at the memory care facility where you work have Alzheimer's disease?
2. What types of social enrichment activities are provided at the memory care facility? How many of these activities are there at the memory care facility? These can include (but are not limited to) volunteer programs, recreational activities, religious services, book clubs, physical activity, outdoor activities, card games, etc.?
3. What proportion of residents would you estimate take part in the aforementioned social enrichment activities?
 - a. How engaged/eager are residents to participate? Do some need encouragement?
4. What proportion of social enrichment activities provided by the facility would you say are in-person interaction or virtual?
5. Why do you think some people participate in social enrichment activities and others do not?
6. What are the visitation hours of the memory care facility (for friends and family of residents)?
7. Can you describe to me the type of resident that does not get visitors?

8. On average, how many visits and/or visitors would you estimate that residents with Alzheimer's get per week? How many residents are getting very few visits and/or visitors?
9. Why do you think some Alzheimer's residents get more visitors than others?
 - a. Are there any Alzheimer's residents that get no visitors? Why do you think this is the case?
10. What do you think affects visitation? What factors do you believe shape increased visitation? Decreased visitation?
11. In what ways can the memory care facility better accommodate visitation? Or if you think the facility already does accommodate visitation well, are there other things that you think could be done either within or outside of the facility to encourage visitation/social connection for residents with Alzheimer's disease?
12. Do you have any additional questions for me?

Family Member/Friend of Alzheimer's Resident Interview Questions

1. How many years has your family member/friend been residing in the memory care facility?
2. How did you meet/how do you know the individual residing in the memory care facility?
3. What factors did you consider when selecting a memory care facility for your family member/friend to reside in?
4. What are the visitation hours of the memory care facility?
5. How often do you visit the resident? How long do you spend with the resident during visitation? How long does it take to get to the facility? What means of transportation do you use to get to the memory care facility?
6. Outside of visits, do you interact with the resident? And if so, how? This can be done virtually, via email, phone, letter, etc.
7. How do you make decisions about visitation? What are your opinions on the importance of visitation?
8. Do you think that the memory care facility can better accommodate visitation? If so, how?
9. Do you have any personal circumstances that affect your ability to visit your family member/friend residing in the memory care facility (i.e. non-standard work hours, lack of child care, accessibility to transportation, etc.)?
10. How often does your family member/friend participate in social enrichment activities that are provided at the memory care facility in which they reside? These can include (but are not limited to) volunteer programs, recreational

activities, religious services, book clubs, physical activities, outdoor activities, card games, etc.

11. Do you know whether your family member/friend has social interaction with anyone else outside of the facility, and if so, how often? For example, frequency of visits with other family members/friends?
 - a. What kinds of factors either within the facility or outside of the facility make visitation more or less challenging for friends/family?
12. Do you believe that in-person or virtual interactions are more beneficial for your family member/friend that resides in the memory care facility? And why?
13. Do you have any additional questions for me?