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“Best Kept Secret”: Perspectives from Adult Day Care Staff

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Abstract

“Best Kept Secret”: Perspectives from Adult Day Care Staff

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The aims of this project were three-fold: explore through semi-structured interviews with adult day care staff members their perceptions on transitioning individuals with dementia to more supportive care; describe the impact of COVID-19 on adult day care centers; explore staff members’ understanding of Washington State policies on adult day centers and determine if this knowledge varies among the positionalities. It was found that staff members are used as a supportive resource during times of transitioning the individual with dementia, and COVID-19 has resulted in a shift of increased responsibilities of the caregivers, which led to many adult day care clients being transferred to more supportive care. The majority of adult day care staff were not familiar of Washington State policies affecting adult day care centers, but this varied by positionality. Future studies should use this as a preliminary study for understanding the supportive services offered by adult day care staff.

Introduction

Dementia is an imminent public health issue and is a fatal neurological condition which involves the loss of cognitive functioning, the possible loss of behavioral functionality, and often presents itself in various forms.¹⁻² There are two classifying categories of dementia—neurodegenerative and non-neurodegenerative. Alzheimer’s Disease is the most recognized form of neurodegenerative dementia and affects an estimated 5.8 million Americans aged 65-years-and-older; this translates to 1 in 10 people having Alzheimer’s Disease in the USA.³⁻⁴ While not an exhaustive list, non-neurodegenerative forms of dementia include vascular dementia, normal pressure hydrocephalus, and vitamin deficiency.³ Having a positive family history of Alzheimer’s Disease, limited education, head injury or mild cognitive impairment, age, risk factors for cardiovascular disease, lack of social engagement, and the inherited Apolipoprotein E (APOE) ϵ 4 gene are risk factors for Alzheimer’s Disease.⁵⁻⁹ The Alzheimer’s Association has calculated with the current trajectory, a new case of Alzheimer’s Disease will develop every 33 seconds by the year 2050⁸ and was the 6th leading cause of death in the United States in 2018 with an estimated 122,019 people killed from this disease.⁴ A review of dementia research conducted in 2018 stated dementia should be classified as a disorder or syndrome consisting of various causes with eventual lead to cognition decline in daily functioning.³ Signs of dementia vary by cause, but the disorder most commonly presents with memory loss, loss of autonomy, poor judgement, repeating questions or answers, wandering, losing items, personality, and mood changes.¹⁰ While there is currently no medical cure for dementia, treatment consists primarily of providing greater levels of supportive care as the disease progresses.

Background

Dementia

There are multiple causes of dementia which indicates that dementia is a syndrome rather than a single disease. It is helpful to think of dementia as consisting of two categories—neurodegenerative and non-degenerative; non-degenerative dementia is a “potentially reversible” form of dementia.^{3,11} Subcortical dementia is a non-degenerative form of dementia and is characterized by depression, forgetfulness, and the slowing of intellectual processing.¹² Neurodegenerative dementia includes frontotemporal dementia, Lewy Body, and one of the more commonly forms of dementia, Alzheimer’s Disease.^{6, 13-14} Alzheimer’s Disease is quickly growing in the United States, and the expected number of people living with Alzheimer’s Disease in 2050 is estimated to be 14 million.⁴ Due to longer lifespans, the global prevalence of dementia is around 8-10% in developed countries compared to 7% in poorly developed countries.³ The increase in the number of people living with dementia has led to an increased demand for services. Primary care physicians report there is currently an unmet need for the demand of services for those affected by dementia, and in order to meet this demand for services by 2050, a 200% increase of geriatricians will be needed.⁴ Family and friends are known as informal caregivers and data show these informal caregivers contributed more than 18 billion hours of unpaid care in 2019, which equates to over \$244 billion in monetary free labor.⁴

While there is no cure for dementia to date, there are ways to lessen the effects of dementia for both the individual and caregiver. Certain medications, such as cholinesterase inhibitors, N-methyl D-aspartate antagonist, vitamins E and C, NSAIDs, and therapeutic treatments are potential methods of mitigating the symptoms of dementia.^{6, 15-17} There are

currently no treatments that have shown to be effective at altering the progression of dementia; therefore, the treatment of dementia primarily focuses on providing more supportive care.

It is well-documented that caring for individuals with dementia affects the caregiver.^{6-8, 14, 18-19} Caregivers are often left to provide support or find resources for the increased care of the individuals with dementia, such as transitioning these individuals into supportive care.²⁰ Consequently, it is important to understand these transitions in care to better meet the needs of the individuals with dementia and their caregivers. For individuals with mild to moderate forms of dementia, adult day care centers can serve as a form of respite care for both the caregiver and individual with dementia – this allows both parties to have time away from the other to socialize, retain independence, and relax.⁶ Transitioning into and utilizing more supportive care is important for both caregivers and the individuals with dementia, and it is important to better understand their priorities to better support these transitions.

The focus on adult day care centers grows out of research from the Decision-Making in Alzheimer's Research (DMAR) project, a 5-year National Institute on Aging study investigating decision-making processes and preferences in individuals with Alzheimer's Disease and their caregivers around transitions in receiving more supportive care.²¹ This project seeks to understand how the values and preferences of the individuals with dementia and their caregivers may differ and change over time as dementia progresses.²¹⁻²² This thesis project, which began in 2020, grew out of initial DMAR interviews in which adult day care facilities and their staff members were identified as important sources of supportive care. It is important to determine whether staff members have direct involvement with the process of transitioning the individual with dementia into a more supportive setting. For example, other studies have examined the impact of adult day care services on the client (individual with dementia) and the time to nursing

home, but there has not been a focus on the adult day care staff members' involvement on caregivers' decision-making and if this has influenced the client's time to nursing home placement.²³ In addition, given the timing of this project, the PI sought to understand the policies surrounding COVID-19 and its effect on the use of adult day care centers.

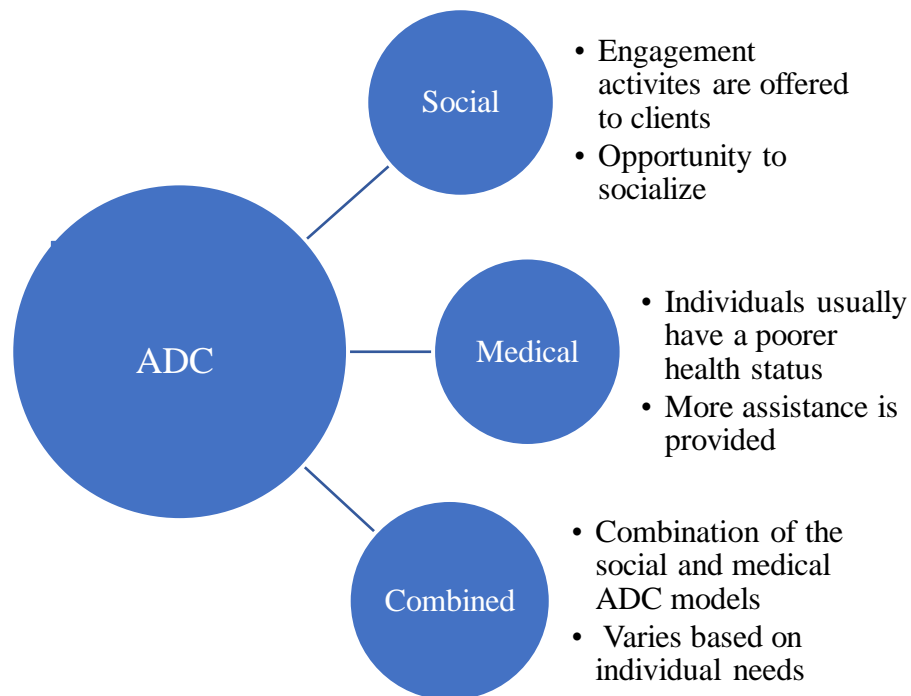
Adult Day Care

First seen in the literature in the 1970s by Rathbone-McCuan, Weiler et al., and Weissert, there are presently over 7,500 adult day services centers (ADSC) located throughout the United States.²⁴⁻²⁶ Adult day services include adult day care*, which can also be referred to as adult day services or as adult day health services.²⁷⁻³¹ Adult day care is a form of long-term care that may provide day services, such as health monitoring and medical care, nutrition, socialization, and therapeutic care to older adults with various physical and mental impairments.^{28, 32-35} Another form of adult day services is adult day *health* services which typically include more structured health services for individuals with greater physical and mental needs.²⁷ Originally, adult day care centers were developed for frail or vulnerable individuals and referred to as Models I-III.³⁶ Model I provides therapeutic services and is closely connected to a nursing home or rehabilitation center; Model II provides social and supportive services transportation and is associated with a general hospital; Model III is considered a special-purpose model, which serves a particular group of people (blind, veterans, dementia).²⁵ In the United States, there are three main models of adult day care—medical, social, and combined (see Figure 1).^{20, 25, 30} Each model can be dementia-specific or have a variation of supporting individuals diagnosed with dementia. The medical model tends to serve individuals with poorer overall health and is usually referenced

* For the purpose of this paper, the term *adult day care* will be used to describe an operating business servicing older adult by providing day-time socialization activities.³⁰⁻³¹

by greater caregiver burden or more hired help.²⁰ According to the National Adult Day Services Association, 80% of adult day centers have a nursing professional, 50% of centers have a social work professional, and 60% have case management services.^{28, 32} While the focus of this paper will be on adult day care in the US, countries like Sweden and Taiwan also have adult day care centers. The adult day care centers in these countries are different in the staff, structure, and services.³⁷⁻³⁸ A study in 1998 compared US adult day care centers to centers in Sweden and found that US adult day centers were more costly and had more formal admission processes; however, adult day centers in the US had more hours of operation and were open for more days during the week.^{37, 39}

Figure 1: Models of Adult Day Care Centers in the United States^{20, 25, 30}



Adult Day Care and COVID-19

Starting in March 2020 with the onset of the Coronavirus Disease (COVID-19) pandemic, in-person businesses, such as adult day care centers, reduced their hours or closed. The closure of adult day care centers greatly limited the interaction of individuals with dementia and staff members due to social-distancing measures. Little is known of the extent that adult day service staff members, caregivers, and people with dementia have been impacted in the United States, but researchers have begun to study the pandemic's effects on individuals with dementia. In 2020, Tsugawa et al investigated awareness around COVID-19 and resulting depressive tendencies among people living with severe Alzheimer's Disease. The study examined the depressive scores based on the Mini-Mental State Examination and Geriatric Depression Scale and understanding of COVID-19 from 126 individuals with mild, moderate, or severe Alzheimer's Disease at one memory clinic in Japan. This study found individuals with moderate to severe Alzheimer's Disease had lower depression scores and did not fully understand COVID-19.⁴⁰ Based on these results, the researchers recommended that for individuals with mild to moderate dementia, priority should be given to prevention of their cognitive decline and functional independence; however, for those with mild dementia, it could potentially be more useful to address reducing psychological stress and preventing depression.⁴⁰ Another study conducted in England interviewed those providing unpaid help and people living with dementia regarding COVID-19's impact on services the individuals living with dementia utilized. The study found three consistent themes from the interviews: loss of control, uncertainty, and adapting to the new "normal."⁴¹ With loss of control came faster deterioration, and many caregivers stated the disease had progressed faster since the COVID-19 lockdown.⁴¹ While adult day care centers provide respite care for both the caregivers and individuals with dementia,

elderly individuals utilizing an adult day care center are also exposed to other individuals, staff members, and other outside sources who may carry respiratory illnesses, such as COVID-19.

COVID-19 has impacted not only the day-to-day function of people with Alzheimer's Disease and related dementias (ADRD) but also their caregivers and the services used. Therefore, it is vital to understand what state level policy changes have been revised and implemented on the daily care of this particular group of people due to COVID-19. COVID-19 has forced a shift from in-person adult day care to home-based care regardless if the individual with dementia and caregiver were ready for the transition.⁴² People were told to avoid large gatherings, increase hand washing, and were expected to maintain a six-foot social distance in order to prevent the spread of COVID-19.⁴³ Some long-term facilities and adult day care centers were expected to close due to the stringent regulations from the COVID-19 pandemic, and at the beginning of 2021, it was estimated that approximately 20 long-term facilities in Washington State would potentially close in the next 18 months.⁴⁴ Before COVID-19, the industry was already attempting to find financial support due to the low reimbursement rate of Medicaid, but the addition of the decreased number of individuals utilizing adult day care due to COVID-19 caused these facilities to lose nearly \$234 million dollars since the beginning of the pandemic.⁴⁴

Understanding policies affecting adult day care centers regarding the staff members and transitioning ADRD individuals in and out of the adult day care center will allow for a better understanding of what policies can be revised or adapted post-COVID-19 to address the needs of people suffering with ADRD. It is equally important to determine the current level of understanding about policies among adult day staff care members to better gauge staff involvement with the administrative tasks of adult day care. By gaining this insight, a better idea of how staff members are involved with the decision-making regarding the adult day care can be

understood. Additionally, it is important to understand how COVID-19 directly impacted policy for both private and public adult day care centers, especially with caregivers being laid off or having to work remotely.

Washington State Policies

While adult day care centers do provide important services, not every individual with dementia is eligible for assistance with public adult day care. The Washington State Legislature has determined the eligibility criteria for who can and cannot receive a Medicaid waiver for public adult day care services in Washington through Washington Administrative Code (WAC) 388-106-0805.⁴⁵ While Washington State does not require licensing of adult day services, it does require adult day care centers that seek Medicaid reimbursement comply with certain codes.⁴⁶ For public adult day care centers in Washington State, WAC 388-71-0752 states administrators must be on site during the hours of operation, and if they are unavailable, a program director must be designated at the location.⁴⁷ WAC 388-71-0752 also states a registered nurse or at least one person certified in cardiopulmonary resuscitation (CPR) and first aid is required to be onsite whenever individuals are attending adult day care.⁴⁷

Federal Policies

Some individuals may receive a waiver through Medicaid to use at adult day care but certain restrictions exist.⁴⁸ The Program of All-Inclusive Care for the Elderly (PACE) is a Medicaid and Medicare program that covers certain services for individuals who meet certain requirements, such as being at least 55 years old, living where PACE programs are offered, needing a certain level of care, and being able to live safely in the community with PACE assistance.⁴⁹ While an

individual does not need to be enrolled in both Medicaid and Medicare (or either) to join PACE, Medicaid covers the long-term care portion of the PACE program, but Medicare does not cover this portion or the premium for Medicare Part D drugs.⁴⁹

Role of Finances

In some U.S. states, adult day care services are considered an alternative to long-term care. Adult day care services have the potential to slow down the transition from in-home care to transferring into a nursing home, which can help save both the family and healthcare system money.^{35, 50}

Zelman et al calculated adult day care centers spend an average of 6 hours per work day with an individual, which equated to an hour cost of \$5/hour in 1991.⁵¹ When Weissert et al researched the three different types of adult day care models in 1989, the average cost was \$30 for 6-hours of care; the average 2007 cost for services was \$61 for an average of 8-10 hours a day.^{25, 52-54} As of 2021, the average cost of adult day care is between \$61 to \$70 a day consisting of 6 to 8 hours, but this amount can range from \$25 to \$100 depending on the location, services offered, and hours of care used.⁵⁵⁻⁵⁶ Staff members at adult day care centers spend 8-10 hours per day on average with ADRD individuals, indicating the important role staff members play in coordinating the daily routines of care for these individuals during the week.^{28, 53} Staff members working at adult day care centers, who interact with ADRD individuals on a daily or weekly basis, are in a position to share clinical information that can be used in clinical providers' decision making. Such information may include changes in mood, behavior, mental status, family or caregiving support, and medication adherence.²⁸ Adult day care centers that are federally funded through Medicaid are required to collect information on the health changes of

the individual;^{28, 35, 57} however, the level of information required to be collected varies from state to state.²⁸

Cost of Care

Access, cost, and quality appear to be the trifecta or “Iron Triangle” in defining what constitutes as a ‘good’ outcome in healthcare.⁵⁸ As of 2020, the average cost of caring for those with Alzheimer’s Disease was estimated to be \$305 billion.⁴ Davis et al (2018) determined the cost of healthcare involving Alzheimer’s Disease is projected to be over \$1.1 trillion in 2050, and postulated that by delaying mild cognitive impairment due to Alzheimer’s Disease, a decrease in long-term care costs and an increase in life expectancy could possibly be seen.^{8, 59} Delaying the onset and progression of dementia, specifically Alzheimer’s Disease, by five years with a hypothetical treatment could reduce the cost of care by \$83 billion.⁵⁹ In 2020, it was estimated Medicare and Medicaid would contribute \$206 billions in payment reimbursement to help offset some of the cost of Alzheimer’s Disease.⁴

Regardless of the type of insurance, one of the current goals of health care is to increase the quality of care. Adult day care centers are noted to address the emotional, social, and physical competence levels of individuals. A study conducted by Schmitt et al found that attending adult day health was associated with quality improvements in physical and emotional-roles inevitably improving the quality of life of the individuals in comparison to those not participating in an adult day health center.³⁵ As staff members spend time with ADRD individuals, they are privy to the day-to-day and week-to-week changes in the individuals. As mentioned previously, one study argues that another potential avenue of increasing the quality of health of individuals with dementia would be allowing the staff members to share information

that is relevant to care transitions and changes in mental or physical status with the individual's provider.²⁸ This step in health care coordination has the potential to increase the quality of healthcare received; however, there is currently inconsistency on the services offered in day care centers due to differences in service models.^{28, 60}

Unresolved Questions

With the rate of dementia cases expected to increase in the coming years, it is important to answer how support services can better serve both the caregiver and individual with dementia. COVID-19's impact has left many unknowns on how businesses will recover from being closed or having reduced operation hours. Adult day care staff who provide supportive care are often key stakeholders in the decision-making process. By understanding staff members' involvement with the client's transition into more advanced care, researchers and policy makers can create tools to assist with decision making and develop or modify policies to support caregivers to better align their decisions with person-centered care for the person with dementia. To accomplish this, more knowledge is needed on factors that influence the decision process for seeking more advanced care in addition to understanding the impact of COVID-19 on the decision to utilize adult day care services. Understanding the perspectives of staff members working at adult care centers in encouraging or discouraging more supportive care, such as enrolling in more days at adult day care or transitioning into a nursing home, could help bridge this gap in knowledge. It is also important to examine the staff members' knowledge of state-required policies on adult day cares to help bring to light the involvement of staff members in decision-making around policy within an adult day care center.

Research Questions

1. How are adult day care staff members utilized by caregivers of individuals with dementia in decision making regarding transitioning to more supportive care?
2. In what ways did staff members' roles change as a result of COVID-19?
3. How much knowledge do adult day care staff members have of Washington State requirements, such as reimbursement policies and required certifications, affecting adult day care? Does this knowledge vary among the positionality of staff members?

The steps toward these goals are to: 1) explore through semi-structured qualitative interviews with staff members working at three Western Washington adult day care centers their perceptions of the decision-making of caregivers and the person with dementia on receiving more skilled care, 2) describe the perceived impact of COVID-19 on adult day care centers and how this pandemic has affected caregiving decisions regarding the transitions of care for people with dementia, 3) Explore staff members' understanding of Washington State policies on adult day centers, reimbursement policies and certifications required to work or volunteer at the adult day care center; understand if this knowledge varies among the different positions of the staff members. The goals will be achieved through the following three specific aims:

Aim 1. Explore through semi-structured qualitative interviews with staff members working at three Western Washington adult day care centers their perceptions of the decision-making of caregivers and the person with dementia on receiving more skilled care.

By understanding the responsibilities of the adult day care center staff members and their involvement in the decision-making of the club members, the transition process regarding the person with dementia to more skilled care will be better understood.

Aim 2. Describe the perceived impact of COVID-19 on adult day care centers and how this pandemic has affected caregiving decisions regarding the transitions of care for people with dementia.

Describe how COVID-19 has impacted the operability of adult day care centers, including how the staff members' roles have been affected. By understanding how the COVID-19 pandemic has affected the roles of the staff members, a better understanding of what resources available to the caregivers can be understood.

Aim 3. Explore staff members' understanding of Washington State policies on adult day centers, reimbursement policies and certifications required to work of volunteer at the adult day care center; understand if this knowledge varies among the different positions of the staff members.

Identify the current understanding of adult day care staff members on Washington State policies that affect individuals with dementia and staff members. By understanding and utilizing the staff perceptions of lessons learned from COVID-19's impact, present future beneficial policy recommendations that will be better understood by adult day care staff members.

Reflexivity statement

The PI would like to acknowledge personal involvement with dementia and its effects on caregivers and the individuals with dementia. While the PI has not utilized adult day care centers as a caregiver, the PI presents a unique perspective on what may prevent people from using these services.

Materials and Methods

Study Design

The design for this study was based on a phenomenological approach, which focuses on the experiences of staff members from three local adult day care companies in Western Washington—Old Friends Club, Senior Social, and Elderwise. Phenomenology aims to capture the everyday lived experiences of the person; therefore, the design was appropriate for this study.⁶¹⁻⁶² Obtaining insight from adult day care staff members through interviews allows for a better understanding of the subjective experiences of staff members. Observing adult day care centers would not provide the same information when compared to the level of insight gained from interviewing staff members. The information obtained through the interviews will better determine if adult day care center staff members have a role in assisting caregivers in transitioning their loved ones to more supportive care. The combination of three adult day care centers served as a way gain input from a sufficient number of day care staff to analyze patterns and investigate themes in the interview data. Prior to recruitment for the study, approval for conducting the interviews was sought through the University of Washington's Human Subjects Division and obtained exempt status. This student research project was supported through a

collaborative project stipend awarded by the Northwest Center for Public Health Practice (NWCPHP).⁶³

Study Sites

Old Friends Club is an adult day care center first established in 2015 with over four Western Washington locations in Bellevue, Carnation, Kirkland, Issaquah/Sammamish. In order to hear from a sufficient number of day care center staff, participants were recruited from two other separate adult day care centers. Staff members from Senior Social and Elderwise were asked to participate in the study. Mercer Island's Parks and Recreation manages the Senior Social and is similar in the activity structure of Old Friends Club according to the director of Old Friends Club. Senior Social was established on Mercer Island in 1994 as a social adult day center.⁶⁴ The second adult day care center, Elderwise, is located in Western Washington with partnering facilities around the Puget Sound. Elderwise was initially started in 1997 and operated multiple locations around Seattle pre-COVID-19.

Study Subjects

Staff members from the Old Friends Club were contacted via e-mail and asked to participate in the study. This study used a purposive sampling approach and interviewed staff members recommended by the director of the Old Friends Club and director of Elderwise. Criteria for eligibility included being employed or previous volunteer experience at the Old Friends Club, Senior Center, or Elderwise for at least 1-month as well as having direct experience interacting with members of the adult day care and their caregivers. The anticipated number to be studied in order to reach data saturation was between 5-10 total staff members based on the initial interview

with the director of Old Friends Club. Data saturation refers to the point in the data collection process when no new ideas or themes are being discovered from the data; in essence, it is the point when no new material is being discovered.⁶⁵⁻⁶⁶ Policy workers from the Leading Age of Washington organization and Full Life Care were interviewed to discuss current Washington State policies on public adult day care centers and were also based on the recommendation of the director of Old Friends Club.

Data Collection

An interview guide for this study was developed based on the Decision-Making in Alzheimer's Research (DMAR) project²¹ and revised after the pretest interview with the director of the Old Friends Club was completed. Due to COVID-19 regulations and to protect the safety of the participants and researchers, interviews were conducted through videoconferencing using Zoom, an online media conferencing application. Potential participants were screened for eligibility over the telephone or by Zoom videoconferencing. After reviewing the consent form with the participant, verbal informed consent for both the participation and the recording of the interview were obtained before the beginning of the interview. The collection of names of the interviewees was for consent purposes only. For interviews of staff members without access to Zoom, a FaceTime call was scheduled and audio recorded. A participant identification number was given to each interviewee, and interviews were de-identified from any mention of the names of other staff members or those to whom the staff members referred (i.e., clients or caregivers).

The participant's demographic information including age, gender, schooling, and ethnicity were collected at the beginning of the qualitative interviews of the Old Friends Club, Senior Social, and Elderwise staff members. The interview questions for the adult day staff

members can be seen in Appendix A. Upon completion of the study, each staff interviewee received a thank you gift in the form of a prepaid Visa gift card in the amount of \$25, and the director of Old Friends Club received \$50 for the referrals and introductions of staff members from local adult day care centers. Interviews were recorded and encrypted to the researcher's local hard drive using Zoom's recording function and individually transcribed. Half of the interview voice recordings were transcribed verbatim by the researcher and the other half were transcribed using an online artificial intelligence transcription software, Simon Says.⁶⁷ The transcription was reviewed for each transcript and edited based on the audio recording to ensure accuracy.

Data Analysis

A preliminary codebook consisting of primary codes, multiple secondary codes, and tertiary codes (n=113) was created using the transcript with the richest data.^{62, 68} The preliminary codebook and 13 transcripts were entered and uploaded into Dedoose qualitative software for analysis, and all transcripts were read, analyzed, and coded in Dedoose. A secondary coder assisted to achieve reliability of the codes as well as serve as an objective reviewer. The first transcript was analyzed independently by two coders, and a Dedoose training test consisting of 35 excerpts was completed by both coders to determine the overall inter-rater reliability (Kappa) for the first transcript. The two coders met to review the codes from the preliminary codebook, discuss discrepancies, achieve consensus, as well as condense the codebook during this process (n=94). The coders analyzed the second transcript independently and a Kappa score was calculated using the Dedoose training test, and following this, the coders met to discuss discrepancies and revise the codebook. The codebook was revised an additional time (total of 85

codes), and this version was used by the two coders to code the remaining transcripts (Appendix B). Revising and condensing the codebook was an important part of the data analysis process because it allowed the two coders to delete, merge, and reach consensus on code application. This improved the usage of codes used between the two coders. To emphasize this process, the coders met every third transcript to discuss any discrepancies, come to a consensus on codes, as well as calculate the overall Kappa score from a new Dedoose test. For the informational interviews from Leading Age of Washington and Full Life Care, the two coders analyzed the transcripts together and came to a consensus throughout the coding process.

After all transcripts were coded, codes were sorted to one or more of the research questions, and code counts were used from the private adult day cares to determine the high frequency code counts (>40 counts) and extensiveness of codes (seen in 2 or more transcripts). Transcripts were read again, and horizontalization* was completed on transcript excerpts from private adult day cares to determine the experiences of the staff members.⁶⁹⁻⁷¹ After the significant excerpts were determined from the previous step, clustering of similar experiences was completed, and this allowed for themes and subthemes to be determined.⁶⁹ A final read through of the excerpts based on the themes and subthemes was done, and an overall theme from the data was found. A thematic map for the data was created (see Appendix C), and the green ovals represent the main themes, the blue rectangles represent the subthemes found in the transcripts, and the orange rectangle is the overall theme for the study.

* Horizontalization is when all transcripts are read thoroughly, and significant excerpts are identified so equal weight is given to the participants' statements. This helps to group identified themes that are related to the research question(s).⁶⁹⁻⁷¹

Convoy Model

The Convoy Model of Social Relations framework was employed to help understand the importance of adult day care centers for both the individual with dementia and the caregiver. The crux of this model is that social support is an important factor in an individual's well-being (Figure 2).⁷²⁻⁷³ An individual identifies with and has multiple social relationships throughout their lifetime. From friendships forming in childhood years to a social network in older adult years, socialization is an important part of a person's life course because it not only facilitates interaction (support) between individuals, but it helps with reducing stress. The Social Convoy Model of Social Relations framework acknowledges a person has multiple people within their social realms who come in and out of their "circle" throughout their lifetime.⁷²⁻⁷⁴ One aspect of this framework has a person place people into three concentric circles throughout the duration of their life: close, closer, and closest as seen in Figure 3.⁷²⁻⁷⁴ The structure, function, and qualities of a person's relationship, or social convoy*, is influenced by personal and situational factors the person experiences and helps to explain common experiences among people as well as unique differences.⁷²⁻⁷⁴

* The term *convoy* is based on a person's cohort in which one learns, lives, and receives social support.⁷²⁻⁷⁴

Figure 2: Convoy Model of Social Relations Framework⁷²⁻⁷³

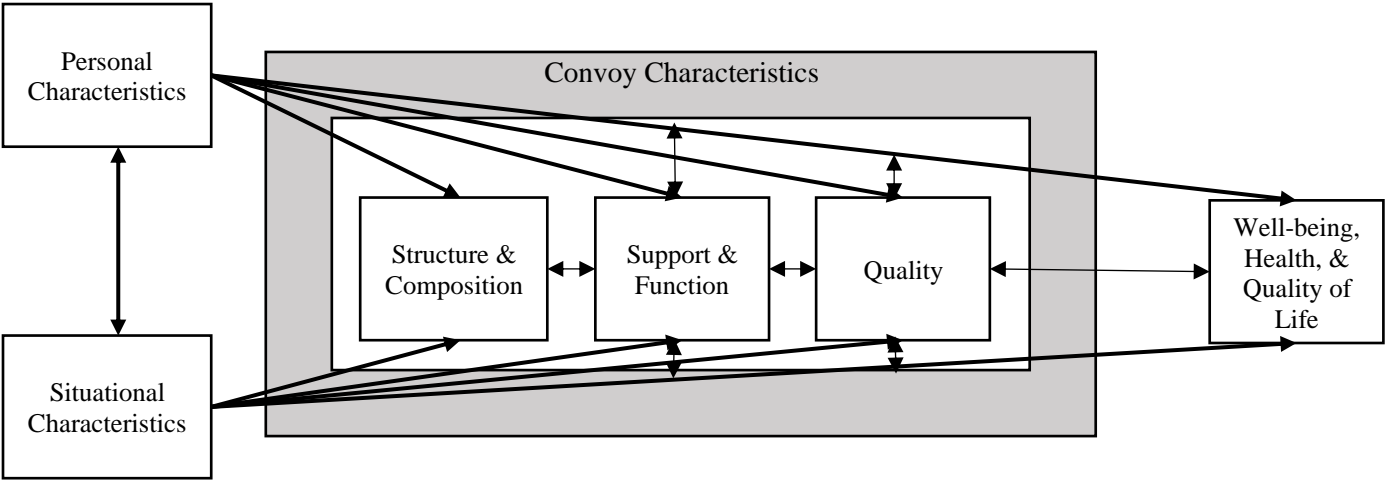
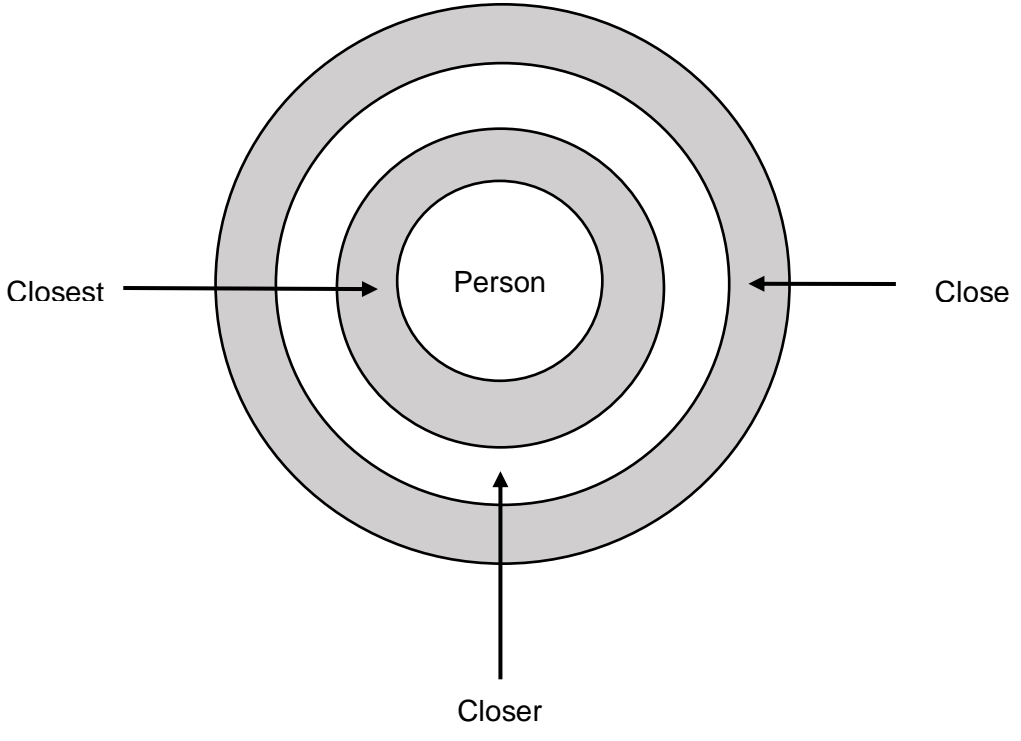


Figure 3: Illustration of a Person's Convoy Based on the Convoy Model of Social Relations⁷²⁻⁷⁴



Results

Summary Section

In total, thirteen interviews were completed among staff from the Old Friends Club, Senior Social, Elderwise, Leading Age, and Full Life Care, and the interview length ranged from 45 minutes to 120 minutes. The three private adult day care centers interviewed varied in the participants interviewed and clientele demographics. From the private adult day care interviews completed, the age range was from 23-years-old to 75-years-old. All interviewees identified as non-Hispanic/Latinx females and held at least a high school degree. Interviewees had worked at Old Friends Club, Elderwise, or Senior Social for at least 3 months before the interview and had previous work experience at another adult day care or long-term care facility. Participants were asked to discuss the center characteristics and demographics of the clientele at the adult day care center, and the average of the results can be seen in Table 1. The age range of the clients at all three adult day care centers was between 50 and 90-years of age with the majority of clients having some form of dementia. Other average client demographics included having middle income and identifying as White or Asian.

Average OFC Client Characteristics	Age range	Education/Socio economic (Low, Middle, High)	Ethnicity⁷⁵ (Perceived group of belonging)	Disease
	Late 50s to mid 80s	Highly educated; middle income	White, Pacific Islander	Mild to moderate Dementia, Parkinson's, traumatic brain injury, no dementia
Average EW Client Characteristics	Age range	Education/Socio economic	Ethnicity⁷⁵ (Perceived group of belonging)	Disease
	Late 50s to mid 90s	Highly educated; middle to high income	White, Asian	Moderate to late-stage dementia, physically limited
Senior Social Client Characteristics	Age range	Education/Socio economic	Ethnicity⁷⁵ (Perceived group of belonging)	Disease
	Late 50s to mid 90s	Middle income	White, Asian	No data

Table 1: Characteristics of adult day care centers used in current project including the average age, socioeconomic status, and ethnicity of clients attending adult day care.

The results of the Dedoose training tests from the two coders can be seen in Table 2. The Kappa Score from the first two transcripts were lower than the rest of the Kappa scores due to the two coders revising the codebook and redefining the code definitions. While the Kappa scores for the 5 training tests were deemed “weak” according to the interpretation of Cohen’s Kappa, the two coders discussed any discrepancies with the code application or definition before coding the next transcript.⁷⁶

Test	Kappa Score
1	0.26
2	0.17
3	0.35
4	0.37
5	0.42

Table 2: Kappa scores from five Dedoose training tests

Aim 1 Results: Staff Members' Perceptions Regarding More Supportive Care

The goal of Aim 1 was to better understand the perceptions of adult day care staff members regarding the decision-making of caregivers transitioning their loved ones to receive more supportive care. Aim 1 addressed the first question: what is the role of adult day care staff members in supporting caregivers of individuals with dementia in decision making. Through the analysis of the data collected by the semi-structured interviews, adult day care staff described providing a general and specific support system to both the caregiver and client during times of transitioning the client in or out of adult day care. One example of this is when staff members offered for both the caregiver and client to visit the day care before deciding to join. Staff members explained this procedure:

“Well I can say that for anybody transitioning into the club, you know the process was, what I observed, was that they would come and attend with their caregiver at first, and for the caregiver to be a part of the group...So again, they were really welcome to come and stay to make that transition a little bit easier.” (ID#5)

“...[S]o if... a caregiver is interested in the program for their family member, or potential member, they come in and sit in for an hour or two and then. They'll both be together, the member and caregiver or potential member, and then the caregiver will go off and kind of talk about what's going on with the program supervisor or director of Old Friends Club. They'll talk to them and just see like, oh, like this is kind of how it goes. This is what we suggest and what are you experiencing? And then the potential member will be alone with us other members and a program assistant program director.” (ID#7)

The perception of the staff was that these initial encounters with the caregiver and client created a smoother transition into this type of supportive care by providing the future client the opportunity to get to know other individuals and staff members while their caregiver was still near them.

Potential clients and individuals already attending adult day care are able to experience a variety of engagement activities, such as socialization opportunities, and this helps to provide clients with a sense of belonging and purpose at the adult day care center. As seen in the following quotes, staff members encourage socialization between the clients that help foster a community with one another:

“I mean, I’m sure you may have heard this from other staff members, but we kind of call that the long hello, which was basically just nobody was in a hurry. Everybody’s happy to be there. We’re just having tea. We don’t have you know, we don’t have a schedule to adhere to. I mean, we usually started art around eleven o’clock, but, you know, we just talk. And it was wonderful because it was such a relaxed conversation.” (ID#10)

“We spend, you know, it’s an hour meeting, and...there were times we checked in for half an hour just and, you know, where we don’t have much of an agenda. And we’re just like, well, how is everybody coping and what are you doing and what, you know?” (ID#9)

“Yeah. They [clients] loved it [adult day care], it was amazing. And then when one of them would get sick, they would ask, and you know, it was amazing to the family that they would remember. They’re like, ‘How do they, how do they remember that person?’ And I’m like, ‘Because they shared stories with each other that now connect, you know. Even though it’s a new person they remember ‘Oh well, she lived in Hawaii like me.’” (ID#3)

After the morning conversations, staff members facilitated activities among the clients, such as physical movement, musical entertainment, art, or board games, to help bring in a range of movement and intellectual stimulation. One staff member from Old Friends Club developed a game to help engage individuals with dementia and encourage them to think of memories from long ago:

“...[W]e often will play...a game called Shake Loose a Memory...[cards remind everyone of] things that even people living with dementia will remember, ‘cause they’re way back memories, and some of those conversations really, you know, take off from those questions...[Y]ou get to know everybody a little bit more, and if it’s a new person just visiting, you can spend a little extra time pulling information and getting to know them a little bit and making them feel special. When people feel special, they want to go back to that place.” (ID#1)

“Yeah, singing and exercise to do some physical movement...A lot of conversation. And so it’s kind of trying to. Get all the kind of different pieces of human and like the social connection and then the physical kind of moving and feeding the body with food and then you know singing, and then the painting is kind of that creative expression time.” (ID#6)

Attending adult day care helps to promote and support the clients’ independence and ideas through the engagement of other people and can provide a sense of belonging by engaging with other people with similar ailments.

Staff members also serve as a resource to the caregivers by discussing the client’s functionals at daycare, serving as a facilitator in conversations between caregivers, and providing information about transitioning the client to more supportive care. Functionals of the client mostly include activities of daily living (ADLs) but can sometimes include instrumental activities of daily living (IADLs). ADLs are personal hygiene, dressing oneself, eating, mobility, and transferring, and IADLs often include cooking, cleaning, managing finances, and transportation.^{8, 77} Discussing the client’s functionals with their caregivers allows for both the caregiver and staff member to watch for patterns or changes in behaviors through the utilization of program notes:

“I guess families will ask us, maybe this is a different question, but families will ask us you know how the person is in the program, and we do keep good tabs with families on functionals, you know how they’re doing in the program.” (ID#9)

“... I think it’s really important to be able to have that personal relationship with them over a course of time. Um, because you can’t meet someone and know what their needs are. You, you have to get to know them to see their patterns and each person is so unique.” (ID#3)

One of the most important ways staff members serve caregivers is by offering respite care. Adult day care allows for both the caregiver and the client to have time away from one another, which allows the caregiver to gain back some independence and freedom. When asked what the caregiver would do when their loved one was at adult day care, one staff member received the following response:

“And I got a variety, you know, ‘Oh I’m going to take a nap,’ ‘I’m going to be able to sleep.’ This one lady says, ‘I’m going to vacuum in the nude.’ [laughs] And to her that meant total freedom. It was the first time in five years that she would have, a, some consecutive hours of free time. And that’s, to me, that always kind of like shows that, uh, it gives her time to take a breath.” (ID#2)

Staff members mentioned they received job satisfaction knowing they were able to help provide respite to both the caregiver and client, but staff also received satisfaction from providing support. Caregivers would reach out during the time their loved one was utilizing adult day care but also after transitioning had occurred, and staff members would also help facilitate conversations between clients, which in turn would help form friendships:

“...[I]t was about a year later that he called me and said, you know, ‘Something’s going on, and I don’t know what to do and what can I do?’ So he’s not, she has not been part of the program for over a year, and he’s reaching out to us cause. I mean that felt pretty good.” (ID#1)

“You always try to hook them up with somebody that they’re going to connect to in that group, you know, that’s not you because it makes them want to come back. I mean, they have their friend, you know, that they want to go see and hang out with...I love that program. It’s best thing I’ve ever seen... I loved it because I felt like they trusted us and that says a lot. Like if you trust someone to ask their opinion. Like we were basically family, you know.” (ID#3)

These examples help to glean the overall satisfaction from utilizing adult day care for the staff members, the caregivers who use the staff as a resource, and the clients.

Staff members stated a major impact of transitioning the client out of adult day care was the caregiver’s ability to care for their loved one. Through the data collected, staff members

discussed how caregivers communicate the feeling of exhaustion and burnout of caring for their loved ones but also the guilt associated with transitioning their loved one into more supportive care:

“...[L]ike the caregiver came to me and just told me everything that was happening like. How they're no longer being able to take care of themselves, let alone their family member. And I'm like yes, hard and probably time you find more help because then you guys are just exhausted.” (ID#7)

“I had one lady that, um, couldn't place her husband because she could not bear the thought of being able to have the freedom to go to the store if she wanted to, and he would no longer have that freedom.” (ID#2)

“A lot of times especially a significant other, um, they feel, of course an obligation. They married this person 30, 40 years ago, and they've been through a lifetime together, and they don't want to give up on them.” (ID#3)

Staff members can help mitigate the feelings experienced by the caregivers by listening and having an empathic presence. Staff also discussed how they provided support by facilitating conversation between caregivers:

“They [caregivers] talk to each other, exchanged numbers. You know, they just naturally, you know, make a little community. Because, you know, they were there, they're all in the same boat and they, you know, they just had a nice connection.” (ID#10)

“We had periodically offered caregiver support groups, and we were getting ready to offer that again because we had this caregiver support person, who had lots of that kind of experience. We also would offer, you know. Through that caregiver support, one on one help with planning for the future; making sure people had their POLST if they didn't have it and understood why those are important.” (ID#1)

These conversations would sometimes lead to the formation of a support system and be a way to address the caregiver's feeling of guilt and help advise what could be done next regarding transitioning.

Another avenue of support provided by staff members was through providing social connections to decrease the social isolation that both the clients and caregivers experience. Community organizations offering resources for caregiver support and activities for individuals

with dementia, such as Momentia, were mentioned in the interviews. By providing these services to the dementia community, a sense of connection and support was provided for the caregivers. Caregivers and clients need different levels of support when it comes to transitioning to a higher level of care, such as support from family or friends, as well as financial support. Staff members reported that both the caregivers and clients start to feel isolated if there is lack of support especially when there is disagreement between family members regarding the care of the individual with dementia:

“...And also, how much family support they have...Um, when caregivers have to fight family at the same time and, you know, family members....The family member’s already gone, and the family member’s like, ‘I don’t understand what mom’s talking about...he seems fine.’ And so you’re just fighting that as well...” (ID#1)

Staff members mentioned how primary caregivers have to explain to other family members how the dementia is progressing in their loved one, and this can sometimes be met with denial as seen in the above quote. Family support is important for both the caregiver and client, so when one member of the family is reluctant with accepting the disease progression, it can lead to a feeling of isolation. Caregiver isolation can also occur when the caregiver is hesitant to acknowledge the decline of their loved one. Primary caregivers may be overwhelmed, burnout, or feeling guilty due to the level of decline in their loved one, which may cause them to become feel isolated and lonely:

“I understand that, you know, guilt is such a huge part in trying to, you know. You can’t be guilty that he has this disease because you didn’t cause it. You can regret it, but, you know, you can’t be that guilty...They [caregivers] won’t take vacation because they feel guilty.” (ID#2)

Staff members described that as the dementia progresses, caregivers begin to feel more isolated, and the resulting tendency is for the caregivers to not want to acknowledge the decline. Not acknowledging the level of decline can serve as a barrier to the caregiver seeking more

supportive care and also serve as a barrier to utilizing adult day care services; therefore, this has a direct effect on the client's socialization with others.

While a theme of providing general support was described among the staff members interviewed, more specific support was described around transitions of care. Staff members at adult day care centers serve as a separate set of eyes and support when both the client and caregiver utilize the day care services, and staff help to reiterate what the caregiver may be seeing at home. Offering a supportive presence when the caregiver is thinking of transitioning the individual with dementia to more supportive care is an important part of the staff member's job:

“So a lot of times just having someone that knows you and knows your family and you trust them, saying, ‘Hey, you’re making the right decision. It’s time, you know, you’re doing what’s best for them by putting them in long-term care because at this point, you’re harming both of you, you know, it’s not good for you, it’s not good for them.’” (ID#3)

Caregivers would sometimes ask what the staff members were seeing from their loved one during adult day care and when it would be a good time to transition the client to more supportive care. Staff members would discuss the level of care the client required at the adult day care and if the adult day center was meeting the client's needs:

“Um, they [client] no longer were benefiting then it was time to really talk to the family about them not being appropriate for that setting and looking at a different level of care. So, that would be the first, you know, thing to consider when transitioning would be, you know, their level of in the disease process their level of care.” (ID#2)

“I mean, the decision-making process that we're involved in has more to do with whether they can stay in Elderwise or not...I mean, people might informally ask something, but the, you know, the guidelines for if somebody should stay in Elderwise or not have to do with, for example, if they have social graces.” (ID#9)

If the adult day care center was not able to meet the needs of the client, staff members would talk to the caregiver about transitioning the client out of the center. In some severe cases, staff members would have to give a time limit to transitioning the client to more supportive care:

“I would probably start advising if I was seeing some kind of or maybe of an assistant, would start mentioning some behavioral type things that we were noticing. So they would get another perspective. And so I think some in some of those cases maybe that determined for them or added to their repertoire of their what they thought the person needed. So they got reaffirmation from us that would maybe inspire another transition.” (ID#8)

“I mean, I saw that a couple of times, where the caregiver was ready, you know, it was just it was too much for them to be, you know, managing their the care recipient's schedule and their own, and it was time for them to put them in a place where they felt like they got everything under one roof every day, which was heart breaking because we also had people that we loved and didn't want to go, but of course understood that the responsibility was getting too much for the caregiver.” (ID#10)

“And we would typically give the caregiver at least a month's notice saying, here's what's going on, you know, and in fact, you know, checking in with them as the progression happened.” (ID#10)

Often, this conversation would prompt the staff member to ask how the caregiver was doing as an individual and if they were spending more time as a caregiver:

“If you're spending more time being the caregiver, literally a caregiver, and you're not spending time being their child or their spouse then you need to take a look at it because anybody can do that physical. Anybody can do the hygiene, anybody can, you know, do the feeding. Not anybody else can be their spouse.” (ID#2)

Staff members mentioned that when it is time to transition to a higher level of care, adult day cares help both the client and caregiver to have an easier transition:

“Yeah, it was great to know that this [adult day care] was kind of like, you know, kind of like a perfect steppingstone. It was never meant to be long term. It's really a way that, um, these day care centers are a wonderful way to transition to higher level of care.” (ID#2)

When the decision had been made to transition the individual with dementia out of adult day care, staff members would provide resources in the community, such as previously mentioned Momentia, and also suggest:

“[W]e might suggest that somebody else we know did well there or whatever. But we you know, we know resources in the community we, we refer people, you know, to support groups or to places care managers that actually that's their jobs.” (ID#9)

For the client's last day at the adult day care center, the staff members would have to decide to acknowledge the client's departure or if it would be better to not bring the transition up in conversation:

"I guess it depended on the person and their personality because sometimes something was done where they didn't know it was happening...If it was a sensitive situation, we may not have done much to be involved with it. So the person might have left without us really saying a formal goodbye if they would handle that situation better. But, you know, there would be the other side of the coin where somebody knew they were...for more normal reasons, they were leaving. And, you know, there might we could have had a party for them or, you know, made more recognition, really depended on the person. You had to kind of play with the story." (ID#8)

Throughout the duration of the client's time at adult day care, caregivers and staff members communicate with one another on how the client's disease is progressing, the social engagement of the client, and reiterate what the caregiver may be seeing at home; therefore, to answer to the first question for Aim 1, the interview findings indicate that adult day care centers provide support for clients and caregivers by serving as an important resource in transitioning to more supportive care.

Aim 2 Results: COVID-19's Impact on ADCs and Care Transitioning

The purpose of Aim 2 was to describe and understand the perceived impact of COVID-19 on adult day care centers as well as to understand how the roles of the adult day care staff members changed as a result of COVID-19. In some instances, staff members' roles switched to remote positions (through Zoom activities) while some of the roles completely dissolved:

"Yeah. Most of us have kind of moved on, I think. The program director that trained me and like you know he was moved here to be part of Old Friends Club and to open another branch in Seattle, he went back to Tennessee you... and he's doing something totally different...COVID taught us very quickly that we were not essential you know, and it's a scary thing." (ID#3)

Each interviewed participant noted a change in their role as a result of the COVID-19 pandemic. Before COVID-19, staff members were able to provide in-person interactive games, music, and exercise activities for the clients during their time at the adult day care center, but due to COVID-19 regulations, in-person activities at the adult day care centers ceased. After closing for a few months, Elderwise found a way to operate three virtual social resources over Zoom—MiniWise, ElderZoom, and ArtWise:

“One is called ElderZoom, which was the group that we had when we met in person. We just kept on going with that. And then another one is called Miniwise, which is kind of based on that ElderZoom group, but new people, you know, new people to the group... And then with the ArtWise, when we first started this out, there was just a lot of brainstorming about how we could do art, you know, that art part of what we used to do in person, how can we do that over Zoom?... We had to make art kits, you know, had to get the word out. And a lot of the people that are in the ArtWise group are people that used to meet in person.” (ID#10)

While some of the Zoom activities have helped to engage the individuals virtually, the amount of support needed by caregivers increased due to COVID-19. There has been an increased responsibility for the caregivers to manage taking care of their loved one without the respite care they once had before.

“The caregiver is now doing the part of the job that we used to do in person, which is help prompt the person who has dementia to do the art.” (ID#10)

For the individuals with dementia who were able to have a caregiver assist with virtual activities, it allowed for their support circle to continue to exist; however, for those who were not able to utilize Zoom, these social interactions with other members came to an end.

The majority of adult day care centers were closed in early March of 2020, which left the caregivers to make a decision of keeping their loved one at home or transitioning them to more supportive care. Almost all of the interviewed adult day care staff stated that since the beginning

of COVID-19, they have heard of a number of their clients transitioning to more supportive care due to disease progression or passing away:

“But yeah, it definitely made people once we closed up for the pandemic, people were making more decisions to put people in assisted, their loved one, in an assisted living.” (ID#8)

“I’m afraid they that most of our folks, will, not all, but most of our fol-folks will have declined to the point where they won’t probably be able to return.” (ID#1)

“He [caregiver] went from feeling like he had a team to now it was all on him you know, and I could see it in his face that he felt super guilty, you know. He was telling me that she had an appointment to like actually go [transition into more supportive care] within the next week or two and like you could see it in his face that he was super disappointed like he thought that he would have more time, and he should have by all rights.” (ID#3)

“Now I know that many because the program shut down, um, most all of the people that were coming to the programs have now placed their loved ones, so, um, they don’t have the choice and, you know. So it’s made a huge difference in the participants’ [individuals with dementia] lives because they’ve really been turned upside down. Many had to place them right away, um, not just having that respite.” (ID#2)

“Things are happening either they're going into care or passing away or you know whatever, it's overwhelming being on Zoom, so whatever it is so in that respect we're not reaching the people who were in our program and not reaching other people.” (ID#4)

However, when interviewed, the directors from these centers were still trying to share resources in the community to help keep the individuals with dementia engaged and caregivers supported during this time. Old Friends Club has been sharing community resources through e-mails, and a former employee of Senior Social is currently teaching weekly online classes during COVID-19. These resources offered to the community have helped reach both local and national clients due to the majority of the services being held online. Both directors from Old Friends Club and Elderwise have used the time during COVID-19 to look at the future of their adult day care centers and plan to incorporate more communities of color, different faiths and perspectives, as well as bring funding back to the local communities. Staff members mentioned:

“...[W]e’re creating this toolkit that we will give to other organizations as well as giving them support and ongoing training, um, so that it can be led by the community members that they’re, the same community that they’re serving, so you build more, you can build trust more quickly, you can build rapport more quickly because the people that are leading the program are represent that community...So where we were adding one per year prior, we would like to see by the end of 2023, we, we want to see 18 programs up and running.” (ID#1)

“So it was kind of coincided really nicely with COVID because she was able to release the book and she’s been working on some education programs, sort of just teaching how the program works and the philosophy of it so that it can be used in other facilities outside of just our organization.” (ID#6)

These future plans will help support more caregivers and clients from different neighborhoods and faiths by increasing the presence of adult day cares in these communities.

COVID-19 has impacted the services and utilization of adult day care centers, and consequently, the support staff members provide for both the client and caregiver. The roles of the staff members have either dissolved or shifted to offer virtual activities through Zoom; therefore, the answer to the second research question is that staff members are not able to fully perform their previous role, which has resulted in an increase of the caregiver’s responsibility in taking care of their loved one.

Aim 3 Results: ADC Staff Members’ Awareness of Policies

The purpose of Aim 3 was to explore the understanding of staff members regarding Washington State policies and requirements to work or volunteer at the adult day care center. By interviewing staff members with different positions, another goal was to determine if the knowledge around policy varied among the different positions of the staff members. Staff members were not sure of all of the requirements to work at adult day care centers, but some mentioned being asked to complete a background check and be certified in CPR. Overwhelmingly, the staff members

interviewed reported not knowing what policies, including reimbursement policies, affected the adult day care center or not wanting to take part in policy discussion:

“I don't, honestly, know anything about the policies except for like resident rights for being in long term care.” (ID#3)

“I do not. I try to avoid anything policy wise [laughs]” (ID#5)

“I am not sure with this kind of program...” (ID#7)

Two of the three adult day care directors were familiar with the requirements for the operation of the adult day care pre-COVID-19 and reimbursement for these services; however, some other staff members were more cognizant of policies post-COVID-19 due to the prohibition of in-person gatherings:

“We I mean, that that's it's kind of a funny thing because in Washington State and the city of Seattle, we don't need a special license. We need a business license, and we don't need any licensing. (ID#12)

“[COVID-19 policies assisting private adult day care] None at all. No, yeah.” (ID#1)

In terms of required forms on the adult day care clients, staff members stressed the importance of having a Physicians Orders for Life-Sustaining Treatment (POLST) form:

“We had, we would take a POLST. We wanted the POLST...it's something you go over with the physician, and it's signed by the physician...So the POLST is two pages. It's one sheet, front and back that says, you know, is there a DNR, are you full code? You know and then it goes into all the longer-term autobiography kind of thing. What we wanted to know is, are you full code or are you do you have a DNR? And so, would keep that on file.” (ID#1)

“But yes, that [POLST] is part of our intake.” (ID#12)

“They did a POLST form. So we knew if they wanted CPR or not.” (ID#9)

The staff members involved with the administration of the adult day care center expressed a sense of freedom through not utilizing Medicaid funding to support their centers. Many

conveyed there was a certain cost with accepting Medicaid money, such as jumping through multiple hoops and red tape to deal with the regulations:

“Well, I tell you what, we do not fall under any state guidelines. We are not under any state regulations because the adult day guidelines are there only for people that take state funds. And we tried to go through that route, but there were too many requirements that we couldn't meet as far as, you know, trained staff, you know, having social workers available and so forth...but we don't have any state regulations.” (ID#9)

While extra funding would be beneficial to the operation costs of the adult day care centers, most of these costs are covered by program fees, grants and donations; however, this does limit those individuals who are able to afford the fees of the adult day care:

“[U]p to 2.0 [adult day care version of Old Friends Club], it was a combination of program fees, grants, and individual donations. We were very fortunate, program fees covered about 75% of our, um, uh expenses. Moving into 2.0, uh we want all of that, all of those program fees to stay in the communities where the programs are held. So, the core Old Friends Club is going to be shifting to solely grant, um, and donation. And sponsorships. We take sponsorships that sort of thing. Um, so yeah, it's shifting [laughs].” (ID#1)

Staff members at the adult day care and outside organizations would work together to support the adult day care center through donations, fundraisers, and scholarships, which could help sponsor a membership for an individual:

“We do offer scholarships, and I couldn't tell you exactly what percentage that would be.” (ID#4)

“[W]e also offered a scholarship program, so we had a couple who were sponsored that, you know, they didn't pay their tuition or whatever they just were able to come because we had someone sponsor them.” (ID#3)

By involving community organizations, this provided a sense of connection and support to both the caregiver and client. As mentioned before, the staff members report that their real love and satisfaction is met through taking care of their clients and supporting their caregivers. This would often help prompt the staff members to work with the caregiver and client regardless of their income level.

When the staff members of Leading Age and Full-Life Care were interviewed, two participants had different experiences and views compared to the information gathered from the private adult daycares. When asked how COVID-19 has impacted adult day care centers across Washington, some adult day care centers were allowed to legally remain open:

“So none of our programs stayed open. It was the other adult day health program from other agencies that we were hearing that stayed open during this time. Yeah, so at our location we actually had a partnership with or have a partnership with Providence. We were providing other PACE clients adult day health services. We know that they've stayed open during this whole time. So that's how I know they are. But other programs we're hearing that had PACE remained open, so.” (ID#13)

Medicaid reimbursement was discussed during the interviews, and it was found that Medicaid was paying Full-Life Care during this time of COVID-19:

“But I think one of the policies that has come out of the state, which I've been really grateful for, is we've been receiving retainer payments during this time, which have been super helpful... There isn't money lost because we couldn't reach out to the caregiver or let's say someone has COVID and they aren't responding to our calls because they have COVID. That has been a great thing that has come out of the whole pandemic... The retainer payments are not our full rate, it's about 70%, but it's better than zero. It has helped a lot.” (ID#13)

New COVID-19 policies have resulted in private adult day care centers becoming unable to operate in person. Staff members working at both the private and public adult day care centers knew of COVID-19 policies affecting in-person gatherings; however, many private adult day care staff members did not know what policies directly impacted adult day care centers. For the third research question, it was found that the majority of the staff members did not know of Washington State requirements or reimbursement policies affecting private adult day care centers, but this knowledge varied among the staff members, such as the directors of the adult day care centers.

Discussion

This study illustrates the importance of adult day care staff members as a resource for caregivers looking to transition the individual with dementia into more supportive care. One of the main goals of adult day care centers is to offer the client and caregiver support when transitioning to or from the adult day care center. Staff members also help to address and meet the needs of the client and caregiver throughout the duration of their time at the center. Staff members also provide the clients with a sense of belonging by assisting with activities and conversations that may illicit fond memories of a simpler time, while also providing respite to the caregiver.³⁵ The Convoy Model of Social Relations theory helps to understand how important the friendships formed between the adult day care clients are to the client. As a person ages, other people in this person's life will have different levels of social support, and role changes will occur (i.e., child becomes caretaker of parent); this leads to the changing of the person's circle composition and shift in roles.⁷²⁻⁷⁴ Engagement activities provide an opportunity for clients to reminisce and share memories, which in turn helps to promote new connections between the clients. When staff members help facilitate these encounters, the client is able to have some sort of independence in what memories are shared with the new friends. These new networks formed are important to a person's social convoy by creating affective, affirming, and aiding connections or "transactions."⁷²⁻⁷⁴ Staff members serve an important role in the client's social convoy when clients utilize adult day care by offering social support through checking in with the client and making sure they are comfortable. When the staff members are able to build rapport with the client, this allows the client to feel comfortable and safe. Staff members have the opportunity of serving as a separate set of eyes to help watch for disease progression or any unmet needs of the

client. Staff members help to provide a safe and enriching community for the clients and serve as a support system for both the clients and caregivers.

It is important to acknowledge how COVID-19 has completely reshaped supportive care for the adult day care client and caregiver. The inability for the caregivers and clients to utilize the staff members at adult day care has had a direct influence on the social convoys of these individuals through the relationships of family and friends being removed as well as the isolation COVID-19 has caused. The support received from the staff members and other caregivers is not the same as it was pre-COVID-19, and without this resource, their social relationships with other caregivers from the adult day care have suffered.⁷⁴ While the adult day care centers are able to share supportive resources through e-mail, caregivers and clients are still disconnected from one another due to COVID-19 restrictions. From the interviews, it was found that clients utilizing adult day care as well as their caregivers form strong bonds with one another. While the quality of these relationship may vary, these daily socialization networks formed helped to lessen both the caregiver and client's stress as well as promote the general wellbeing of a person.⁷³⁻⁷⁴ Since the closing of in-person gatherings of the majority of adult day care centers, the perception of staff was that due to the cognitive decline or death of these clients from the lack of socialization, it is highly unlikely some clients will be able to utilize these adult day care centers once they reopen. These results align with the COVID-19 deterioration discussed in the study by Giebel et al (2020).⁴¹ Some of these same staff members have had to look for other jobs as a result of the adult day care centers closing.

The majority of the staff interviewed did not know of any policies that the adult day care center needed to follow or abide by with the exception of the adult day care center directors. All participants had knowledge of COVID-19 closure policies which affected adult day care

utilization, but many participants did not know of reimbursement policies. Staff members mentioned the importance of the POLST form, which helps to give the individual with dementia control of their end-of-life choices.⁷⁸ These forms do not take the place of a living will or other necessary form but serves as an active written medical order for the desire of CPR or other life prolonging actions.⁷⁸

Even though public adult day care centers have been reimbursed by Medicaid, with financial assistance from the government come certain trade-offs for the adult day care center. For those who can afford the program fees, this population is able to utilize adult day care services. While some adult day care services may offer scholarships, not everyone can afford to pay to go to one of these private centers. Without financial assistance, low-income individuals and their caregivers are at a disadvantage of this source of respite. Staff from the adult day care centers interviewed mentioned the importance of community involvement including donations and grants received to help fund the day care center, but in order to allow low-income communities to utilize these services, policy makers may have to intervene and mandate all adult day care centers accept Medicaid clients. This would result in changes to the current structure of private adult day care, such as having to pay for health monitoring, nursing services, social services and other positions to be considered a Medicaid-endorsed center, which these private Washington adult day care centers may not be willing to make.⁴⁶ It is important for adult day care staff members to be involved in their community as a grassroots effort to spread the word about the benefits of adult day care centers for the individuals with dementia and serve as a resource for the caregivers when it is time to transition the individuals.

Currently adult day care centers serve approximately 286,300 individuals on any given day.⁷⁹ By using the new toolkits Old Friends Club and Elderwise are planning to implement in

the coming years, this will allow for more populations to be reached. Community health workers could be one avenue of getting the community more involved by explaining the benefits of adult day care to these communities especially in low-income areas. In one example, promotores were used to increase colorectal screening in low-income populations.⁸⁰ Including community health workers would be one successful way of bridging different communities, which in turn would allow for different cultures to be studied and a better understanding of these social convoys to be had.⁷³⁻⁷⁴

Limitations

This study had a small sample size (n=13) from three adult day care centers in Western Washington and two public organizations discussing publicly funded adult day care centers. All of the participants were female and White, which could limit the generalizability of the results. As mentioned in the positionality piece, the researcher for this study has previous exposure to some facets of dementia. While this previous knowledge of dementia allowed the researcher to have prior knowledge of certain aspects of dementia care, it is important to acknowledge the unintended bias during the interviews, which could have led to biased answers or bias in interpreting the results.

Conclusion

The purpose of this research study was to understand the involvement of adult day care staff members in the decision-making process of transitioning people with ADRD into more supportive skilled care. Additionally, this study was used to illustrate how caregivers can use staff members as a resource to make a more well-rounded decision on person-centered care that

will help prolong the person with dementia's individuality and dignity.^{20, 81} This study found that adult day care staff members serve as a supportive resource for both the individual with dementia as well as the caregiver before, during, and after transitioning out of adult day care. COVID-19 impacted the availability of this supportive resource by prohibiting in-person gatherings and has resulted in an increase of caregiver responsibilities. This has led to some of the adult day care clients being prematurely placed in more supportive care. The perception of staff was that due to the cognitive decline of these clients from the lack of socialization, it is highly unlikely some clients will be able to utilize these adult day care centers once they reopen. Lastly, the majority of the staff interviewed did not know of any policies that the adult day care center needed to follow or abide by with the exception of a few staff members. A window of opportunity has been created to revise state policies in order to better address the necessity of adult day care in the lives of both the individual with dementia and their caregivers.⁸² In future studies, it would be useful to seek a more diverse range of participants to be interviewed to help strengthen these preliminary findings.

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APPENDIX A

Interview Guide

Part I: Background

Basic questions about the interviewee

1. What is your position title at the Old Friends Club or Elderwise?
2. How would you identify your gender?
 - a. Female
 - b. Male
 - c. Other
3. What is your age?
4. What is the highest level of school you have completed or the highest degree you have received?
 - a. Less than high school degree
 - b. High school degree or equivalent (e.g., GED)
 - c. Some college but no degree
 - d. Associate degree
 - e. Bachelor's degree
 - f. Graduate degree
 - g. MD, JD, or PhD
5. How do you describe your ethnicity?
 - a. Hispanic / Latino, or
 - b. Not Hispanic / Latino
6. How long have you worked here?
 - i. Where did you work prior to working here?
 - b. Have you held any other position while working here?
7. Would you explain more about what your job duties are?
 - a. What are your day-to-day duties?
8. What other job titles/positions are at the Old Friends Club or Elderwise?
9. Who makes up the general population at the Old Friends Club or Elderwise?
 - a. Low-income? High-income?

- b. Certain demographics?
- 10. What services do you offer at the Old Friends Club or Elderwise?
 - a. For the club members?
 - b. For the caregivers?

Part II: Decisions regarding transitions in care [Aim 1]

1. Could you tell me a little bit about your experience with these sorts of transitions and decision-making processes, and what your role has been?
 - a. How do you interact with the caregivers?
2. Are you involved with any decision making about transitioning to more advanced care that are made by:
 - i. The caregivers?
 1. [PROBE] Do you feel like you understand and could describe the factors that caregivers consider in these decisions?
 - ii. The people with dementia?
 1. [PROBE] Do you feel like you understand and could describe the factors that persons living with dementia consider in these decisions?
3. Can you tell me more about a specific decision-making process you were involved with and the key factors that were weighed in making the decision?
4. What are some examples of potential factors that have impacted the decision for transitions in care?
 - a. What potential factors do you see most often?
 - i. Are those with mild impairment allowed to make decisions at the Old Friends Club or Elderwise?
 1. What decisions are they asked to make?
 - ii. What about those with moderate impairment?
5. In your experience, when do older adults with dementia and their caregivers most need assistance with decision making about transitions to more supportive care?
6. What are some of the ways you try to better understand what people prefer?
 - a. Can you tell me some of the ways of how you address peoples' wants?
7. What are some of the ways you transition members into the club?

- a. What is the routine for accepting a new club member?
 - b. When do you feel that people with dementia should transition into this type of care?
8. While Old Friends Club or Elderwise is open, what are some of the ways you influence the decision processes of the members?
- a. How do you ensure the club members' preferences are met when members do not agree with each other?
9. What are some ways you ensure the members' preferences are met when members do not agree with their caregiver?
10. How do you transition the members out of the club?
- a. What are some of the ways you voice your opinions or offer a supportive presence with the transitioning of members out of the club?
 - b. When do you feel that people with dementia should transition out of this type of care?
 - i. Are there circumstances when you feel members should be transitioned out?
11. Have you dealt with conflicting preferences between older adults with memory loss and their family members/caregivers? If so, can you tell me about it, and how you have dealt with it?

Part III: COVID-19 Impact [Aims 2 and 3]

1. How has COVID-19 impacted the services you provide to the members?
 - a. How has it impacted your ability to remain open?
 - i. How are you able to legally operate during COVID-19?
 1. What regulations are in place to help the center remain open?
 - b. How has it impacted your work?
2. How did the COVID-19 Phases impact Old Friends Club or Elderwise?
3. Can you recall what Phase I looked like at your center?
 - a. What changes happened in Phase II?
4. What new regulations have you had to accommodate?
 - a. What policies do you have to abide by?
 - i. How are these impacting the services you can provide?

- b. Are people better understanding what happened and why?
- 5. What are you doing to ensure a smooth transition into the new COVID-19 regulations?
- 6. How has COVID-19 impacted transitioning clients in and out of adult day centers?
 - a. Have caregivers reached out for help in making transition decisions?
 - i. What are some of the questions they are asking you regarding transitions of care?
 - b. What are some of the ways caregivers ask for your input in transitioning members to more advanced care?
 - i. How has this changed since the beginning of COVID-19?
- 7. What are your thoughts on policies of supporting adult day care during this time?
 - a. What policies are in place to protect the staff members?
 - i. The club members?

Part IV: Current Local and State Policies on ADC [Aim 3]

- 1. What is your understanding of policy regulations on the local or state level regarding day centers for people with dementia?
 - a. Any state policy regulations that affect staff members directly?
 - b. Any certifications staff members need to have?
- 2. How many times a week can adult day centers be utilized?
 - a. Can the service be used at multiple locations?
- 3. What records are kept surrounding members' information?
 - a. HIPAA?
 - i. Consent forms
 - b. Advanced directives
 - c. Wills
 - d. Others?
- 4. How is the Old Friends Club or Elderwise reimbursed for their services?
 - a. Medicaid
 - b. Medicare
 - c. Other
 - i. Out-of-pocket
 - ii. Grant funds

iii. Local support

5. What local, state, or COVID-19 policies have been most beneficial to staff members?

a. What policies protect staff members and the decisions they make or recommend?

Part V: Referral

1. Do you work or have worked with other staff members at the Old Friends Club who would be willing to participate in this study?
2. Would you be willing to do an e-mail or virtual introduction?

APPENDIX B

Final Codebook

Topic	Parent	Child	Definition
1.0 COVID-19	1.1 Caregiver support during COVID-19		Participant mentions caregiver support or connection during COVID-19
	1.2 COVID-19 changes affecting adult day care	1.2a Ability/inability to remain open (in-person)	Participant discusses the operability of adult day care in person
		1.2b Future plans	Participant mentions future plans after COVID-19 is over
		1.2c Other changes	Other changes due to COVID-19 including new opportunities, mask use, hand washing, placement of client, passed away, etc
		1.2d Virtual communication	Participant discusses the use of Zoom services (or other virtual communications) for activities
	1.3 Understanding COVID-19		Participant mentions client or caregiver understanding (or uncertainty) of what COVID-19 is or how long it will last
2.0 Important quotes			Important quotes or examples
3.0 Placement before or after adult day care	3.1 Adult family home		Participant discusses client was in adult family home before coming or after coming to adult day care
	3.2 Assisted living		Participant discusses client was in assisted living before coming or after coming to adult day care (i.e., Aegis)
	3.3 Home		Participant discusses client transitioning to home or other family member's home
	3.4 Other placement		Participant discusses client was transitioned or placed somewhere else

4.0 Policies	4.1 Certifications	4.1a CPR	Participant mentions CPR certification staff members need to work at adult day care
		4.1b Other certifications	Participant mentions other certifications staff members need to work at adult day care
	4.2 Information on clients	4.2a Other forms	Other forms kept on clients at adult day care (including suggestions)
		4.2b POLST	Participant discusses POLST forms stored on clients (physician's orders for life-sustaining treatment)
		4.2c Program notes	Participant discusses program notes kept on clients
	4.3 Medicaid		Participant mentions Medicaid bureaucracy, support, or finances
	4.4 Other policies		Other policies discussed which are needed, followed, or recommended in adult day care settings (i.e., mandatory reporting)
	4.5 Washington State		Participant discusses (mandatory or non-mandatory) Washington State policies (WAC codes)
5.0 Potential factors resulting in transitioning (or not transitioning)	5.1 Caregiver		Participant mentions reason for transition was due to burnout, health of caregiver, level of care needed for client, guilt, desire to keep client at home, etc.
	5.2 Client health	5.2a Behavioral changes	Participant mentions changes in behavior (declining or improving), progression of dementia, etc resulting in transition
		5.2b Other changes	Participant mentions reason for transition was due to social changes, physical changes, environmental changes, or other disability of client
	5.3 Other reason		Participant mentions other reason for transitioning (or not)

6.0 Preferences	6.1 Conflict		Participant discusses conflict between client and someone else before, during, or after day care
	6.2 Ensuring preferences are met		Participant discusses an event when the preferences of the client were met and how the preferences were met
	6.3 Preferences not being met		Participant discusses an event when the preferences of the client were not met and remained unmet
7.0 Reimbursement	7.1 Donation		Participant discusses finances paid through donation
	7.2 Grants		Participant discusses finances paid through grant awards
	7.3 Other reimbursement		Participant discusses other forms of reimbursement used to fund the adult day care
	7.4 Private health insurance		Participant discusses finances paid through insurance reimbursement
	7.5 Program fee		Participant discusses finances paid by program fees
8.0 Staff members involvement with transitions	8.1 Transitioning to/from activity at adult day care		Participant discusses their involvement when transitioning client to or from a different activity what factors were discussed
	8.2 Transitioning to/from adult day care		Participant discusses their involvement when transitioning client to or from adult day care and what factors were discussed
9.0 Structure of adult day care	9.1 Adult day care model		Participant mentions model of adult day care (i.e., social)
	9.2 Barriers to attending		Participant mentions reason why caregiver may not utilize adult day care is due to stigma, uncertainty, finances, or other barriers
	9.3 Benefits of services provided	9.3a Caregivers	Participant mentions providing assistance to caregiver

		9.3a.1 Other services or benefits to caregivers	Participant mentions other services provided to caregiver
		9.3a.2 Support	Participant mentions providing information to caregiver (i.e., could be information about dementia, other facilities, or additional caregiving support) or participant discusses how they provide emotional support to caregiver (including empathy)
		9.3b Clients	Participant discusses services or activities provided to clients
		9.3b.1 Community	Participant discusses a sense of community and/or connection among clients (i.e., feeling like family or friends)
		9.3b.2 Engagement activities	Participant mentions activity was provided at adult day care (i.e., music, art, exercise, food)
		9.3b.3 Other services or benefits to caregivers	Participant mentions other services provided to client (i.e. helping with isolation; providing empathy)
		9.3b.4 Socialization	Participant mentions clients conversing and interacting with one another
	9.4 Business hours, days, size, and locations		Participant mentions how often adult day care was/is operating
	9.5 Satisfaction		Participant mentions self, client, or caregiver expresses satisfaction of adult day care (wanting to come back, job satisfaction, etc)
	9.6 Staff roles	9.6a Activity facilitator	Participant mentions adult day care has a lead (or co-lead) activity (program) facilitator
		9.6b CNA	Participant mentions adult day care has a CNA
		9.6c Other staff roles	Participant mentions adult day care has other role(s)
		9.6d Program assistant	Participant mentions adult day care has a program assistant

		9.6e Program/Activity director	Participant mentions adult day care has program (or activity) director (or coordinator)
		9.6f Volunteer	Participant mentions adult day care has a program volunteer
	9.7 Success stories		Participant mentions a success story of client attending adult day care
	9.8 Training		Participant mentions adult day care training for staff members

APPENDIX C

