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TITLE: DAY CARE FOR PEOPLE WITH DEMENTIA--THE IMPORTANCE OF  
COMMUNICATING A SAFE AND UNCRITICAL ENVIRONMENT TO CLIENTS AND  
FACILITATING STIMULATING ACTIVITY

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Submitted to the graduate faculty of the University of Stirling

Stirling, Scotland

2005

## **ABSTRACT**

Exploratory case studies investigated the day care benefit from the multiple perspectives of the person with dementia, caregiver, and day care worker. The routines, daily processes, and factors promoting benefit were reported. The day care client was also queried to explore their ability to contribute useful information about their care environment.

The adult day care is primarily a social occasion for its clients, who enjoy the benefits of companionship and interaction. Day cares were differentiated by the environmental features: worker:client ratio, size, suitability of the site for intended purpose, quality of client-worker relationships, and quality of the activities offered. The quality of each of these features is an important component in the day care environment. All components at their highest quality are not necessary for the environment to be beneficial.

The most important factors contributing to day care quality were workers who (1) communicated safety to the client through a relaxed, uncritical environment, and (2) facilitated client stimulation through activity and personal interaction, satisfying the clients' basic needs to be safe and occupied.

This evaluation was comprised of: two sets of case studies. Each evaluation was concurrently conducted and consistently designed. Participant observation and survey were the primary methods of data collection. Informed consent was sought from day care clients with dementia, family caregivers, and day care workers.

## Acknowledgements

The completion of this doctoral thesis is a hallmark of my educational endeavors and serves as a symbol of endurance, perseverance, and dedication to individuals suffering from a dementing illness and that I believe they can have an improved existence.

I appreciate the day care managers for giving me access to their facility and their clients, without which the research could not have occurred. I appreciate the employees, volunteers, the people with dementia, and their families for making me feel welcome. I would also like to thank my darling daughter, Eva, for whom I do all things.

## TABLE OF CONTENTS

<b>ABSTRACT</b>	<b>3</b>
<b>TABLE OF CONTENTS</b>	<b>5</b>
<b>CHAPTER I</b>	<b>7</b>
<b>Introduction</b>	<b>8</b>
Statement of the Problem	8
Significance of the Study	9
<b>CHAPTER II</b>	<b>10</b>
<b>Literature Review</b>	<b>11</b>
What is Dementia?	11
Prevalence of Dementia	14
Who Needs Adult Day Care?	14
The Effect of Adult Day Care on the Person with Dementia	14
The Stressed Caregiver and Day Care's Effect	16
What Components of Day Care Make it Beneficial?	17
The Use of Proxy Reporters in Dementia Research	17
<b>CHAPTER III</b>	<b>20</b>
<b>Method of Inquiry and Analysis</b>	<b>21</b>
Choosing the Case Study Method	22
Analysis	26
Owning My Perspective	29
Ethical Considerations	31
Definition of Terms	31
<b>CHAPTER IV</b>	<b>33</b>
<b>An Exploration of Adult Day Care, Its Benefits for Persons with Dementia, and Their Study Contribution</b>	<b>34</b>
Introduction	34
Methodology	35
Participants and Facilities	40
Results	46
Table 1	57
Clients,' Caregivers,' and Day Care Workers' Perspectives of The Benefits of Day Care	57
Analysis	58
Discussion	59
Day Care Benefits	59
Conclusions	72
<b>CHAPTER V</b>	<b>74</b>
<b>An Exploration of Four Day Care Environments</b>	<b>75</b>
Introduction	75
Methodology	76
Results	84

Four Day Care Environments. Four Day Care Interventions	84
Analysis	94
Case Narratives	94
Measures	94
Client Vignettes	94
Discussion	94
Comparing Environmental Features of Day Cares A, B, C, and D	94
Conclusions	101
<b>CHAPTER VI</b>	<b>102</b>
<b>Final Conclusions</b>	<b>103</b>
<b>Tell Me That I'm Safe and Give Me Something to Do</b>	<b>103</b>
<b>Adult Day Care Clients Are Good Reporters on Their Care Environment</b>	<b>105</b>
<b>REFERENCES</b>	<b>107</b>
<b>APPENDICES</b>	<b>117</b>

## CHAPTER I

## **Introduction**

At current estimates, 5-8% of the entire population over 65 has a form of dementia. This prevalence range doubles every 5 years above age 65 (Neurology Forum, 2001). It is estimated that by the year 2025, the worldwide prevalence of dementia will have reached 34 million (Alzheimer's Society, 2001). The culmination of these statistics is a population that is top-heavy with elderly, a significant proportion of whom will have a dementing illness.

Formal services available to assist individuals with dementia and their families include in-home respite, adult day care, and overnight respite. However, informal care is more prevalent. It has been estimated that 70%-80% of health and social services for elderly are provided by family, friends, and neighbors (Marshall, 1988). In the UK, three-quarters of people with dementia are not institutionalized, and instead live alone, with family, or with friends (Holden & Woods, 1995). Although low utilization of formal services has long been a concern of public health officials, caregiver utilization of community services may be on the rise (Toseland, et al., 2003). Adult day care for people with dementia has become a popular service for family caregivers who need assistance, yet want to remain close and involved with their family member.

Adult day care is a community-based, supervised, daytime care program offering planned activities, and health care monitoring for dependent, and often cognitively impaired, elders living at home. It is an environmental intervention comprised of multiple variables that may be manipulated. It is a significant intervention, yet, it is based on little empirical support (Hall & Buckwalter, 1987).

## **Statement of the Problem**

The extent that people with dementia attending adult day care actually benefit is not fully understood. Many research projects report positive findings in those who have attended



day care. The source of the benefit is unknown. Many research projects have queried family caregivers and day care workers, no research projects have asked the person with dementia if they benefited and why.

### **Significance of the Study**

The multiple variables comprising the intervention that is day care may be manipulated. The physical, social, and emotional environment may be modified to meet the needs of the population (Roberts & Algase, 1988; Hall & Buckwalter, 1987; Latwon, 1980). However the intervention is based on little empirical support (Hall & Buckwalter).

- There are few publications focused on the variables within a day care that are responsible for the benefit to the person with dementia.
- There are also incomplete publications describing the operations at day care and the environment.
- There are no publications on day care benefits where the person with dementia was a reporter.
- There are few publications involving the person with dementia in the research process and none specifically investigating their ability to contribute to research.

The components of the day care intervention need exploration and description. The person with dementia may be a data resource that needs to be explored for their potential to contribute to research goals.

Any gains in knowledge will suggest where improvements may be made in the day care environment and possibly in data gathering techniques with people with dementia. Improvements in care may have implications for better well-being, quality of life, functionality, cognition, and relationship with the family caregiver and day care worker.

## CHAPTER II

## Literature Review

### What is Dementia?

“Dementia is the loss of intellectual functions (such as thinking, remembering, and reasoning) of sufficient severity to interfere with a person’s daily functioning. Dementia is not a disease itself but rather a group of symptoms that may accompany certain diseases or conditions. Symptoms may also include changes in personality, mood, and behavior. Dementia is irreversible when caused by disease or injury but may be reversible when caused by drugs, alcohol, hormone or vitamin imbalances, or depression” (Alzheimer’s Association, 1998).

It is the most characteristic disease of old age. The dementias of the aged are defined broadly as brain damage with an inevitable, progressive degeneration. The cognitive degeneration results from anatomical and biochemical degeneration (Wattis & Church, 1982, p. 37) in the form of sick and dead neurons. The two most prevalent types of dementia are Alzheimer’s disease (AD) and multi-infarct dementia (MID). Alzheimer’s disease is thought to be the most common form of dementia afflicting middle-aged and older persons (Holden & Woods, 1995). It appears in half of all hospital patients dying of dementia (Wattis & Church, 1982, p. 74), and is found in half of the elderly population with dementia when examined post-mortem (Holden & Woods). Post-mortem examination includes identification of the characteristic senile plaques and neurofibrillary tangles that are required for a conclusive diagnosis of AD. The amount of plaques and tangles is positively correlated with the severity of intellectual and behavioral deterioration (Blessed, Tomlinson, & Roth, 1968; Wilcock & Esiri, 1982). These same plaques and tangles have been found in the brains of normal, older

adults examined at autopsy. Thus, a significant number of plaques and tangles are required to cause impairment (Holden & Woods, 1995).

The etiology of the brain deterioration is uncertain. Causal theories of AD are: genetic; virological; toxicological; and aging (Reisberg, Ferris, Schneck, de Leon, Crook, & Gershon, 1981), but it is most likely "...the result of an accumulation of experiential insults and genetic predispositions" (Scherer, 1994), which does not rule out the many potential causes but includes them. The impairment presents as a gradually progressive and steady decline that is both cognitive and behavioral. Women are slightly more likely to develop the disease than men, even when allowing for the higher proportion of elderly females in the population (Wattis & Church, 1986, p. 74).

The second most common form of dementia is multi-infarct dementia (MID), or arteriosclerotic, causing localized deterioration in blood deprived brain tissue. It is caused by tiny, successive strokes, also called strokelets. It presents as a progressive decline in a sudden, stepwise fashion that is both cognitive and behavioral.

Dementia may be caused by factors other than anatomical and biochemical degeneration, such as exposure to a diet high in aluminum, head injury causing a loss of consciousness, and infective agents called prions (viruses behaving in an unconventional manner having an extremely long incubation period). The dementias are likely a group of related syndromes with many subtypes and varieties of patterns in its manifestations or are many different diseases with similar clusters of symptoms all having a neurological etiology (Khachaturian, 1992). Conversely, Kitwood (1990) suggested that 70% of the discrepancy between dementia and neurological pathology is unsubstantiated and that findings suggest that factors other than neurological damage, such as the psycho-social environment, play an important role in the etiology and prognosis of dementia.

Alzheimer's disease and MID cause emotional problems that include: agitation, depression, restlessness, aggression, delusions, paranoia, amnesia, and loss of drive and motivation. Most (70%-90%) dementia patients will experience some of such problems during the course of the disease (Swearer, Drachman, O'Donnell, & Mitchell, 1988; Teri, Larson, & Reifler, 1988; Teri, Borson, Kiyak, & Yamagishi, 1989). Physical problems include inability or compromised ability to: remain oriented to time-place-person, care for one's self, work, think abstractly, follow directions, perform activities of daily living (i.e., bathing, cooking), perform instrumental activities of daily living (i.e., driving, balancing a checkbook, washing clothes), access short-term memory, reach previous range of movement, apply clothes in the correct order, and speak.

Behavioral manifestation of the disease is varied. A person may forget to eat or bathe, and how to dress and toilet himself. He may forget simple social etiquette, becoming rude and aggressive or overly friendly and trusting. A lack of insight regarding these changes is common. Persons with dementia may view themselves as suffering no significant problems in activities of daily living, health, or family relationships, while professionals and family members view them as having problems in almost every area of life (Reifler, Cox, & Hanley, 1981). Further debility may result from a loss of confidence, loss of social skills, loss of skills through disuse, and depression. Depression is common and may be caused by the continued failings of the person with dementia, which in turn may cause excess disabilities, such as loss of energy and interest in life (Cotrell & Schulz, 1993). Depression is more likely to be associated with a decline in functional status that is independent of cognitive status (Pearson et al., 1989).

## **Prevalence of Dementia**

This is a growing population. Prevalence rates are increasing as people live long enough to develop the disease, and as the longevity of people with the disease increases since it has become a less rapidly fatal condition due to medical advancements (Blessed & Wilson, 1982). The average age for developing dementia is 82.3 with an average survival time of 4.5 years (Helmer, Joly, Letenneur, Commenge, & Dartigues, 2001). At current estimates, 5%-8% of the entire population over 65 has a form of dementia with the prevalence of dementias among persons 65 and over doubling every 5.1 years (Neurology Forum, accessed 8/10/01). It is estimated that by the year 2025, the worldwide prevalence of dementia will have reached 34 million (Alzheimer's Society, 2001).

## **Who Needs Adult Day Care?**

The primary purposes of day care are twofold: to provide day respite for family caregivers so they are able to continue supporting their relative as long as possible; and to provide an environment for the person with dementia that is safe while meeting needs for socialization, and recreational, physical, and cognitive stimulation (Diesfeldt, 1992; Hunter, 1992). Most people with dementia will need high quality or specialty care at some point in the disease process, and often, around the clock for a number of years. When possible, the government and families want community care options to assist some of the hours in a day that people with dementia require care.

## **The Effect of Adult Day Care on the Person with Dementia**

Studies exclusively relying on caregivers' and day care workers' proxy reports of benefits for people with dementia suggest that exposure to day care programs can have positive effects on the person with dementia. The following studies are based on caregiver or

worker reports. Adult day care reportedly impacts people with dementia by improving their interest in activities (Jones & Munbodh, 1982), well-being (Wimo, Wallin, Lundgren, Rönnbäck, Asplund, Mattson, & Krakau, 1990), mood (Archibald, 1993; Curran, 1996; Gotlieb & Johnson, 1995), emotional problems (Sands & Suzuki, 1983), behavior (Zarit, Stephens, Townsend, & Greene, 1999), and quality of life (Wimo, Mattsson, Krakau, Eriksson, & Nelvig, 1994).

Wimo, Wallin, Lundgren, Rönnbäck, Asplund, Mattson, and Krakau, (1990) assessed the well-being of people with dementia through the interview of 45 caregivers and 47 day care workers at a psychogeriatric day care hospital. The caregivers' interview questions focused on the impact of day care on their well-being and on the well-being of their family member with dementia. For the workers, the concept of well-being focused on their judgment of the emotional status of the person with dementia. Caregivers and workers reported increased well-being for both the person with dementia and the caregiver.

Sands and Suzuki (1983) evaluated a day care program for people with dementia that was based on milieu therapy, which asserts that the environment (including worker/worker and patient/worker interactions) must be structured in a particular way to maximize patient independence. The goal of this program was for the workers to meet the "normal human needs" of the people with dementia. In practice, this meant that the day care was organized to meet the needs of the person with dementia for stability, structure/orientation, constancy in personnel, communication assistance, recognition, self-esteem, meaningful relationships/activities, and personal space. The facility accommodated on average 20 people with dementia daily with a range of 17-26. The program was operated by five full-time workers with the educational qualifications: PhD in developmental psychology (1), BA in human services/gerontology (3), and no formal training (1). Volunteers contributed 10 hours daily. The resulting worker:client ratio was 1:5. The day care was located in a closed middle

school with five rooms and a non-enclosed yard. The people with dementia were separated into homogenous groups for certain activities in order to meet the needs required of the differing deficits. Family caregivers reported improvements in their family member primarily in the area of emotional problems, with occasional reports of improved cognitive functioning.

Curran (1996) investigated an adult day care run by a voluntary organization that accommodated 15 people with dementia 5 days a week for 5 hours a day. The study goal was to evaluate the impact of the day care on people with dementia by asking their family caregiver to describe behavioral changes since day care attendance began. Almost half of the caregivers reported improvements in the mood and/or behavior of their family member that they attributed to day care attendance. These improvements were maintained in the majority of the day care attendees for 9 months.

### **The Stressed Caregiver and Day Care's Effect**

The problems of the person with dementia effect the caregiver, which has a reciprocal, negative effect on the caregiver's ability to care for the person with dementia (Colerich & George, 1989). Problems frequently experienced as a result of the caregiving role are increases in burden, stress, anxiety, and depression (Barnes, Raskind, Scott, & Murphy, 1981; Diemling and Bass, 86; Drinka, Smith, & Drinka, 1987; Haley, Brown, & Levine, 1987).

Most of the literature on day care for people with dementia that has evaluated the effect on the family caregiver found positive caregiver effects such as: caregiver respite (Campell & Travis, 1999), improved well-being (Wimo, et al., 1990; Zarit, Stephens, Townsend, & Greene, 1999), improved quality of life (Wimo et al., 1994), and lower levels of caregiving-related stress (Zarit et al., 1999), and strain (an important antecedent to depression and anger; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Zarit et al. (1999) found that caregivers whose family member attended day care experienced lower anger when



compared to controls at 3 month and 1 year follow-up. Reductions of perceived stress have been reported by other researchers (Gottlieb & Johnson, 1995). Caregivers have consistently reported gains in relief, and gains in support and information from other caregivers and day care workers (Sands & Suzuki, 1983). Conversely, researchers have found no significant reduction in caregiver psychological symptoms following day care use and found caregivers to be little better off than those about to receive day care assistance. Full-time, institutional care has been found to reduce caregiver distress (Wells, Jorm, Jordan, & LeFroy, 1990). The literature regarding a reduction in inpatient care following day care use is inconclusive (Ballinger, 1984; Woods & Phanjoo, 1991). One study found a reduction in the institutionalization in people with dementia who had attended day care (Wimo, Mattsson, Adolfsson, Eriksson, & Nelvig, 1992), while another found day care use served as an intermediary step for the caregiver prior to institutionalization of the family member (Zarit, Greene, Ferraro, Townsend, & Stephens, 1996).

### **What Components of Day Care Make it Beneficial?**

Benefits for those attending day care, the clients, are often reported. However, the specific components that make adult day care so beneficial to its clients are unknown. There have been studies suggesting the necessity of establishing a relationship with the client in order to provide effective care (Graham, 1999) and clients have reported that the primary reason for attendance was social interaction (Powell, Bray, Roberts, Goddard, & Smith, 2000). Are these components responsible for the benefits often reported in the literature by family caregivers and day care workers? This is unknown.

### **The Use of Proxy Reporters in Dementia Research**

There is a great deal of important research on the psychosocial effects of dementia and

the psychosocial effects of day care. Most of which is limited to a study of their impact on the caregiver (Cotrell & Schulz, 1993). There also is important research on the effects of adult day care on people with dementia, most relying on proxy reports from family caregivers and day care workers. Methods of treatment for psychiatric symptoms and behavioral problems associated with dementia have even been developed without any real involvement of the patient. The over use of proxies has led to a lack of representation of patients' needs in the evaluation and selection of care strategies (Cohen, 1991). Some literature has even concluded that people with dementia cannot be sampled for information. For example, in Wimo et al.'s (1994) analysis of the cost-effectiveness of day care for people with dementia in which QOL was also evaluated, the authors concluded that "Since it is very difficult or impossible to obtain an understanding of the patients' own views of quality of life, when demented people are analyzed, it is necessary to use the views of external observers." Similarly, in Wimo et al.'s (1990) evaluation of the impact of day care on people with dementia, the authors stated "that it was impossible to ask the patients themselves about the effects [of day care] on quality of life..." Williams and Rees (1997) used dementia care mapping to improve the quality of life of people with dementia "because of their inability to provide information about the care they receive." There are no publications regarding interview strategies or other methods for gaining information from people with dementia. Nowhere in the literature has it been established that people with dementia cannot provide useable information about their experiences in light of the disease.

The few studies that have included people with dementia as participators in the research are described. Bogardus, Bradley, and Tinetti (1998) conducted open-ended interviews designed to elicit goals for the patient's health care. The people with dementia were capable of providing perspectives of goals for their own health care. Powell, Bray, Roberts, Goddard, and Smith (2000) evaluated goal negotiation in three daytime care settings

and suggested that they had the potential to provide goals for the time they spent in day care. In Chenoweth and Kilstoff's (1998) study of the development of a therapy program for people with dementia at day care, the patients participated in the program design, implementation, and evaluation alongside family caregivers and day care workers. Although the involvement of the person with dementia was not a focus of the study, all participants were reportedly empowered by the research process and gained insight into their problems and into making decisions for future goals. The findings suggest the ability of the person with dementia to take an active role in the research process. Marzanski (2000) questioned people with dementia about their current awareness of the disease. The majority of the study participants who did not know their diagnosis provided the correct diagnosis or described their main symptoms. Most said they would like to know what was wrong with them. Those that did know their diagnosis said they would like to have more information about their disease (Battin & Marzanski, unpublished data, cited in Marzanski, 2000).

## CHAPTER III

## Method of Inquiry and Analysis

There were two main questions I wanted to answer:

(1) What occurs in the day care that promotes benefit in people with dementia; and,

(2) Can the person with dementia provide useable information in a research context?

Before undertaking this project I asked myself two questions, “How does one try to understand and explain the meaning of a social phenomenon without becoming part of it” and, “How do I become a part of an environment while causing as little disruption to the natural setting as possible?”

Finding answers to the research questions required exploration of the operations of day care environments and the people in those environments. I had no control of the contemporary behavioral events occurring in the environments nor did I have control of the people. I knew repeated exposure to the environments would be the primary means by which data would be collected. For it would provide the opportunity to collect a wealth of descriptive data about the environment and how day care functioned and how the people in that environment behaved in response. Repeated exposure also would allow the opportunity to gather information about how the day care benefited the people with dementia. This data could be compared to data gathered directly from the clients regarding *their* reports of how day care benefited them and may help me evaluate the quality of the data they provided.

So I needed to collect data many times in multiple locales. I needed to ask questions of the people with dementia. I needed to do all of this without effecting the usual functioning of the environments and without effecting the delivery of the intervention (day care) or how it was experienced by its clients. To accomplish this, data was gathered through observation and interview. The case study methodology allowed for both techniques. Case study also allowed for single- or multiple-case study and for the inclusion of qualitative data (Yin, 2003, p. 9).

The case studies of this thesis followed Yin’s (1994; 2003) case study methodology.

Yin's method was chosen because it was the most clearly described case study methodology found, contained specific steps for data collection, specific techniques to improve validity and reliability, and strategies to assist in data analysis.

### **Choosing the Case Study Method**

The case study is characterized by the unit of analysis—the case, rather than the topic of study (ERIC, 2002). As a research strategy, the case study comprises an all-encompassing method covering the logic of design, data collection techniques, and specific approaches to data analysis in efforts to understand its topic in context (Yin, 2003, p. 14). Case studies aim to understand complex social phenomena by retaining the holistic and meaningful characteristic of real life events. They are designed to bring out details from the viewpoints of *all* relevant participants and the interaction between participants. This characteristic provides a voice to the powerless and voiceless (Feagin, Orum, & Sjoberg, 1991) and is particularly relevant to the topics of this study where the research outcomes primarily effect people with dementia. The researcher develops a better understanding of informants' experiences and is able to better represent these experiences to her audience. Case study excels at promoting an understanding of a complex issue and can extend experience or add strength to what is already known through previous research (Yin, 1984).

Critics of this method believe that the intense exposure to the case necessarily biases the findings. There is also criticism of its rigor due to its historical lack of specific procedures to follow (Yin, 2003, p. 10) and the often inadequate descriptions of how a particular case study was conducted. Others believe that the study of a single or a small number of cases makes it difficult to generalize from one case to another. This assertion infers that a single case study is like a single respondent or subject (Yin, 2003, p. 33), whereas it is an expansive understanding of a phenomenon. The criticism of the case study's lack of generalizability may

wrongly encourage analysts to try to select representative cases to generalize their findings to. Instead, findings can be generalized to theory in the same way that experiments are generalized to theory (Yin, 2003, p. 37). Moreover, generalizations from experimental research are rarely based upon a single experiment. They are usually based upon multiple sets of experiments that have replicated the same phenomenon. The same approach can be used with multiple-case studies (Yin, 2003, p. 10).

### **Case Study Design**

Three types of case studies have been identified that differ with regard to accepted knowledge on the topic, research goals, and data collection techniques. The first type, the *exploratory* case study, regards topics where little is known or where an intervention has no clear set of outcomes. This type of research sometimes serves as a prelude to further research. The second type, the *explanatory* case study, regards causal investigations. The third type, *descriptive* case study, regards the description of real-life interventions. (Yin, 1994)

The explanatory-exploratory type was chosen because the purpose of each of these study types was in line with the thesis's research questions. The use of the explanatory strategy came from the need to determine what in the day care intervention was responsible for the benefit to the person with dementia. Use of the exploratory strategy came from the need to explore the potential of the person with dementia to provide useful information in a research context. Data preparation techniques and data collection tactics that improved the quality of the data were included in the research design. These tactics enhanced the study's validity and reliability (Yin, 2003, p. 34).

### **Preparation for Data Collection**

Yin (1994) recommended a series of steps in the preparation for data collection: (1)

The first step regards the skills desired in an investigator to produce good data. Good question asking, good listening, adaptability and flexibility, awareness of issues being studied, and lack of bias, are qualities required to bring about rich data with evidence to support it; (2) Investigator training refers to researcher awareness of relevant and important issues and of what data needs to be collected. Successfully defining the study questions to be asked and developing the case study design may exemplify the required knowledge to conduct the study. In multiple investigator studies, efforts should be made to ensure that all researchers are ‘on the same page’; (3) Developing a case study protocol serves as a reminder of procedures, facilitates the collection of relevant data in the appropriate format, and acts as an aid to anticipate problems. The protocol also enhances the replication logic of multiple-case studies; and (4) Conducting a pilot case study aids in refining data collection plans with respect to the content of the data and the procedures to be followed.

### **Data Collection Tactics Establishing Construct Validity and Data Reliability**

Three important data collection tactics were used to improve the quality of the data gathered and to enhance the study’s construct validity and data reliability (Yin, 1994):

- (1) *Multiple sources of evidence* were used to establish construct validity. Multiple sources provided multiple measures of the same phenomenon and were essential in establishing the legitimacy of findings. When information is collected from multiple sources and aimed at discovery of a certain topic or phenomenon, the data from the multiple sources corroborates one another, suggesting that the measures were indeed measuring the construct that they were intended to measure. This technique is also called triangulation of data or convergent lines of inquiry;
- (2) The development of a *case study database* was used to promote the



reliability of the study data. The database contains the raw data that led to the case study conclusions. The availability of the database allows other investigators to review the evidence directly, suggesting that if the study was repeated it would be consistent with the initial study's theoretical conclusions. The database also provides the opportunity for secondary data analysis independent of the original investigator.

- (3)
  - a. Maintaining a *chain of events* was used to establish a case study's reliability. This technique allows an external observer to follow the steps from research questions to evidence to conclusions, suggesting that if the study was reproduced the findings would support the study's theoretical conclusions.
  - b. Maintaining a *chain of events* was also used to establish construct validity because the linkages between events exemplify that the methods were appropriate to study the topic.

### **Primary Methods of Data Collection**

Survey and direct observation are the methods that provided the bulk of the data in these case studies. In both methods the researcher entered the world of those surveyed and observed. This means that the researcher's behavior was more likely to be constrained than the participants. This should be a positive to the quality of the data that was collected because it may be more genuine and less susceptible to researcher effects.

The survey is one of the most important sources for obtaining information. Yin described three types of interview: open-ended interview, focused interview, and formal survey. The open-ended interview is a guided conversation, rather than a structured query, and a majority of its questions are open-ended. The focused interview, while it may still be open-

ended, is more closely aligned with a certain set of research question. The duration of the focused interview is shorter than an open-ended interview and its purpose may be to corroborate previous findings. The third type of interview, the formal survey, is a set of structured questions that narrow the breadth of responses.

Overall, the interview is an essential source of evidence in case study research because most case studies are about human affairs that can best be understood if reported by and interpreted by specific interviewees who can contribute their insight. Interviews can help in the gathering of information that cannot be found elsewhere and can uncover other sources of information. Still, interviews provide only verbal information that is subject to bias, poor recall, miscommunications, and inaccurate articulation. For these reasons multiple data sources were used to corroborate interview data. (Yin, 2003, p. 89-92)

The method of observation provided the opportunity for the investigator to gather information on a phenomenon in context and the opportunity to gather a variety of types of information. Information may be gathered by direct observation, where the investigator assumes a passive role in the environment, or participant observation where the investigator is not a passive observer in the environment and participates to varying degrees in the phenomenon of study having the opportunity to perceive reality from the viewpoint of an insider. However, gaining access to the environment and researcher bias is sometimes problematic.

## **Analysis**

This is the most difficult aspect of the case study methodology, primarily because case study analysis is an area still in need of further development and an activity that will always require lots of human interpretation. Unlike statistical analysis, there is no specific recipe to follow to arrive at your findings. The investigator's style of rigorous thinking accompanied by

the presentation of sufficient evidence and consideration of alternative interpretations is primarily responsible for a quality analysis (Yin, 2003, p. 110). However, appropriate data preparation strategies can minimize analytical difficulties. Analysis is closely linked with the study design, and with a little forethought the study protocol can benefit analysis because it requires the layout, even though flexible, of the study from beginning to end, from research questions to data collection to data analysis. This task promotes the anticipation of potential problems in any of these areas. Other strategies are used during analysis to reduce the difficulties inherent in case study analysis. Without a strategy the data must be played with to develop a sense of what is important to the study and how it should be analyzed (Yin, 2003, p. 109-115). Three general strategies are described:

General analytical strategies. Three strategies are described:

- (1) The most frequently used analytical strategy is interpreting data in relation to the *theoretical propositions* that prompted the study. This strategy focuses attention on certain data, yet ignores other data. Use of propositions in analysis also helps organize the case study, defines alternative explanations, and provides a path to follow where causal relations are expected.
- (2) Describing *rival explanations* in the literature review and including strategies in the research design to test the rival explanations improves the confidence that can be placed on the findings. If this strategy is chosen, data collection of rival influences should be pursued with abandon as though one were trying to prove salience of other influences.
- (3) A *descriptive framework* is used to organize the case study and the analysis of data. This strategy is used in descriptive studies, but is also used when a descriptive approach may help to identify the causal links to be analyzed.

Analytical techniques. Specific analytical techniques can be used in conjunction with the general strategies already described:

- (1) *Data organization* techniques are helpful to put the evidence in some preliminary order. These techniques include: putting information into different arrays; creating a matrix of categories based on the data and placing data in the categories; creating visual displays of the data, such as flowcharts; tabulating the frequency of events; calculating means and variances for the tabulations; putting information in a temporal scheme such as chronological order (Miles & Huberman, 1994), and numerically coding case study events to organize the data so that it is conducive to quantitative analysis (Pelz, 1981, cited in Yin, 2003).
- (2) *Pattern matching* compares an empirically based logic with a predicted one, and when the patterns coincide internal validity is strengthened. In explanatory case studies, patterns may be made between the independent or dependent variables. This technique may be applied to descriptive case studies, but the predicted pattern of specific variables must be defined prior to data collection. (Yin, 2003, 120-122).
- (3) The goal of *explanation building* is to analyze the data by building an explanation of the case. It is primarily used with explanatory case studies but is also used with exploratory cases, the goal of which is to generate hypotheses and to develop ideas for further study. Explanation-building occurs in narrative form. It is a reiterative process often paired with theoretical propositions due to the imprecise nature of narratives (Yin, 2003, p. 120-122).
- (4) *Time-series analysis* is used to follow intricate patterns and trace changes

over time. This design is matched with either a theoretical trend, a rival trend, or another trend that threatens internal validity (Yin, 2003, p. 122-127).

- (5) *Logic models* stipulate complex sequences of events over time. These events are staged in repeated cause-effect-cause-effect patterns, whereby a dependent variable at one stage becomes the independent variable at the next stage and so on. A chain of observed events are matched to a chain of theoretically predicted events to support or challenge the model (Yin, 2003, p. 127-133).
- (6) The techniques of *cross-case synthesis* are the aggregation of findings across more than one study (Yin, 2003, p. 133-137).

### **Analysis of the Cases of This Thesis**

To organize the data, a descriptive framework was used in this explanatory-exploratory case study aimed at both (1) exploring phenomenon and generating hypotheses to develop ideas for further study and (2) investigating causal relationships. The explanatory strategy applied to the need to determine what in the day care intervention was responsible for the benefit to the person with dementia. The exploratory strategy applied to the need to explore the potential of the person with dementia to provide useful information in a research context.

Explanation building was used both (1) to analyze the environmental features benefiting clients, and (2) to explore the clients' potential to provide useful information.

### **Owning My Perspective**

After many years of education and work experience in the areas of sociology,

psychology, biology, and anthropology, I developed a perspective of human behavior in relation to environment. I believe people are constantly effecting one another's behaviors, habits, moods, dispositions, beliefs, and futures on both a massive and minor scale. The human organism is effected by everything that crosses its receptive threshold. Our minds filter everything prior to our conscious or unconscious awareness of an event. After information has been filtered, the organism then may respond. A response may be physical or cognitive, voluntary or involuntary, conscious or unconscious, immediate or delayed. Whatever it is, if it appears on our radar screen the human organism must respond to it even if that means just filing an experience away, or a momentary elevation in skin temperature, or a passive awareness of an event. The human animal is foremost a social being but is dependent on its biology for support. We are operating this body with its primitive biology (primitive drives) in a socially advanced world. We are enormously linked to other people and our identity is a reflection of our societies values and how we interpret ourselves in light of those values. Everything requires interaction with people. When it doesn't we are keenly aware of that fact.

I have worked in geriatric research for several years on projects in nursing homes and with family caregivers of people with dementia. However, my knowledge of adult day care was close to zero when I first started reading the literature. When I designed the study, I had no expectations of the day care workers and had not even thought much about their role in the environment.

My bachelor's degree is in Sociology. I have worked in academic health research or in healthcare environments for 10 years. I've been a crisis counselor, social worker, research assistant, and research project coordinator. My intimate experience with Alzheimer's disease is with my paternal grandfather, who died in a nursing home over 15 years ago. He didn't want to be in the nursing home. He wanted to be home. His death was slow and unhappy, and my belief is that it did not have to be.

## **Ethical Considerations**

People with dementia were not able to refuse to be observed. Some degree of their privacy may have been compromised in the process of conducting the research for this project. The risks to all the participants were no greater than those risks encountered in everyday life.

## **Definition of Terms**

Client. – Refers to any person over the age of 50 who has a medical diagnosis of dementia or a diagnosis consistent with a dementing disease (i.e., confirming the exhibition of the symptoms of dementia).

Day care worker. – A paid or volunteer member of the adult day care program, whether full- or part-time, whose duties include the care and supervision of people with dementia at an adult day care.

Day care. - A community-based, supervised, daytime care program for people with dementia aimed at providing their clients a safe environment while meeting their needs for socialization, and recreational, physical, and cognitive stimulation. A second aim is the provision of day respite for family caregivers (Diesfeldt, 1992; Hunter, 1992).

Family caregiver. – A family member of the person with dementia who has assumed the majority or the responsibilities for providing the care for the person with dementia.

Quality of life. - The cognitive perception of an individual's subjective sense of well-being stemming from satisfaction of needs (i.e., the sense that needs have been met) within the areas of life deemed important by the individual (Ferrans & Powers, 1992)

Social interaction. – Various forms of human communication, including talking, body and facial movements, gestures, eye-movements, facial expression, proximity, and orientation.

Satisfaction. - The perceived discrepancy between aspiration and achievement, ranging from the perception of fulfillment to that of deprivation (Campbell, 1981).



## CHAPTER IV

# **An Exploration of Adult Day Care, Its Benefits for Persons with Dementia, and Their Study Contribution**

## **Introduction**

When I first began learning about day care for people with dementia, I had a difficult time forming a mental picture of what day care was like and what happened there. In the literature, there were no descriptions of daily schedules or activities offered in day care, nor were there physical descriptions of the environment. There also was conflicting evidence on the benefits of day care attendance for the client and there was no information on what was causing the benefits. I also could not find any reports of benefits from the vantage point of the day care client, the person with dementia. Since there was no information on what was causing the benefit and no information on benefits from the client, I began to wonder if the person with dementia could provide useful information to answer these questions.

In order to find some answers, a collective case study was conducted to explore the day care environment, its daily processes, social environment, benefits to clients, the factors that made it beneficial, and the contribution of the person with dementia to our understanding of client benefits.

This evaluation of adult day care was comprised of two case studies, concurrently conducted and consistently designed. Participant observation and survey were the primary methods of data collection. MMSE score was reported to provide more information on the care requirements of the clients. Informed consent was sought from clients and day care sites were described.

## **Research Questions**

The following research questions were addressed by this project:

1. What are the benefits of day care according to the person with dementia and how does this differ among day care environments?
2. What are the benefits of day care according to the day care workers and family caregivers and how do they differ?
3. What are the daily processes of a day care and what is the social environment?
4. What components in the day care are responsible for promoting benefit in people with dementia?
5. To what degree can the person with dementia be a data reporter in this case study?
6. Can people with dementia provide consent to participate in research and should they be asked?

## **Methodology**

### Review Boards

The research proposal for this project was reviewed and approved by the Stirling University Psychology Department Ethics Committee, the three local Council Boards having jurisdiction over the regions where each facility was located, and by the two day care facility operators who managed the three facilities.

### Preparing for Data Collection

Investigator skills. This researcher has had 2 years of experience working as a research coordinator in an academic research institution with geriatric populations. She has also gathering data and counseled these populations. She has worked as a research assistant, social worker, crisis counselor, and as a benefits counselor for indigent hospital patients. Her undergraduate degree is in sociology.

### Study protocol.

## I. Introduction to the case study and research questions

### A. Introduction

- Areas were identified in the research literature where little information existed or did not exist at all. These areas regarded the operations of adult day care and the factors of the day care that promoted benefit to people with dementia. This study aims to explore the adult day care environment. There is also little information in the literature about the ability of the person with dementia to contribute to the research process. This will also be explored. It is hoped that this study will produce information that can be used to improve the experience of day care for the people with dementia, increasing benefit, and will also explore the ability of the person with dementia to participate in research.

### B. Case study topics (questions that need to be answered to address the research questions and how to get them answered)

- What is day care?
  - a. Answer based on observation and review of day care brochures stated goals
- What are the benefits of day care to the clients, the people with dementia?
  - a. Answer based on client, family caregiver, and day care worker surveys, and on observation
- How do the day care sites physical environments differ?
  - a. Answer based on observations, MOOS, and Environmental Recording Form
- What are the clients' reports of benefits and do they differ among sites?

- a. Answer based on client surveys
- Do the client benefits differ between sites?
  - a. Answer based on observations and survey reports from clients, family caregivers, and workers
- How do workers and family caregivers differ in reports of client benefits?
  - a. Answer based on family caregiver and worker surveys
- What are the day care benefits according to the family caregivers and workers and do they differ among sites?
  - a. Answer based on family caregiver and worker surveys
- What are the day cares' routines?
  - a. Answer based on observations
- What happens at day care that is beneficial or harmful to the clients?
  - a. Answer based on observation and client surveys
- How do the workers differ among sites?
  - a. Answer based on observational data, day care worker survey, and MMSE.
- What can the person with dementia contribute to this research project?
  - a. Answer based on client surveys, the triangulation of client reports (on topics such as reports of client and family caregiver benefits) gained at survey with the family caregiver and worker surveyed reports. Answer also based on the triangulation of clients' reports of day care benefits with observational data
- Can the client be queried?
  - a. Answer based on the accuracy of the information gained in

client surveys by triangulating them with worker surveys.

- Can a person with dementia provide their 'consent'?
  - a. Answer based on client responses to my attempts to gain their consent

## II. Data collection procedures

### A. Names of sites to be visited and contact persons

- All day care sites within a 45-mile radius of the researcher's university that included people with dementia or exclusively served those with dementia were asked to participate in the study.
- Site 1: located in Kirkintulloch, [name of contact person withheld]
- Site 2: located in Tullibody, [name of contact person withheld]
- Site 3: located in Alva, [name of contact person withheld]

### B. Data collection plan

- Data collection for 3 months due to start March 1, 1999; and due to end on or about end of June, 1999. The end date may vary by a few days in order to ensure that an equal number of days of data collection occurred in each day care, to allow for flexibility should a need for it arise that benefited the study, and to accommodate unexpected delays.
- Keep tab of days of the week and which hours were spent in each day care, cover all days and hours of operation
- Draft client consent-to-be contacted (pre-consent) letters to be sent to caregivers
- Get letter from site managers supporting study to be sent with pre-consent letter
- Mail consent letter and support letter to caregivers with return envelope

with postage

- Keep tab of who has been sent consent letters and who has returned them
- Take field notes while awaiting responses
- Gather day care brochures
- Complete the MEAP
- Complete the Environmental Recording Form during every visit
- Visit family caregivers to conduct survey and to obtain consent to contact their family member in the day care
- Survey clients at convenient times, workers can tell me when
- Survey workers later in study at convenient times, leave measure with them to complete
- Reminders: Fit into environment but interact as little as possible. The most important questions are the ones that are the focus of the research, not the ones on the survey questionnaire
- Log the data into tables to keep track of caregiver, client, and worker consent, surveys, and measures completed/received, and separated by day care location
- Log survey data for each participant into table
- Score measures, put score on right, top corner
- Type field notes
- Maintain the case study database well so that it is readily available for review

### III. Outline of case study report

#### A. Objects of studies' interest

B. Aim of study

C. Findings

#### IV. Case study questions

A. Adult day care operation and benefits

- What are the benefits of day care according to the person with dementia and how does this differ among day care environments?
- What are the benefits of day care according to the workers and family caregivers and how do they differ?
- What are the daily processes of a day care and what is the social environment?
- What components in the day care are responsible for promoting benefit in people with dementia?

B. Data reporting and consent of the person with dementia

- To what degree can the person with dementia be a data reporter in this case study?
- Can people with dementia provide consent to participate in this research?

Pilot case. A formal pilot case was not conducted. However, the researcher visited the day care closest the university daily for 1 week. This activity was aimed at collecting information to inform and refine my data collection techniques with respect to the content of the data and the procedures to be followed. I believe it served me well.

#### **Participants and Facilities**

Samples were drawn over a period of 3 months from three day care facilities in central Scotland. Only adult day care facilities that included people with dementia or exclusively



served those with dementia were contacted for study participation. A method of convenience sampling was implemented that included facilities located within a 45-mile radius of the researcher's home. Three eligible facilities chose to participate. Eligible participants were 20 male and female community-dwelling individuals with a physician's diagnosis of dementia who had attended day care at least once a week for at least 1 month, their family caregiver (20), and 22 day care workers (volunteers included). All participants and non-participants (those who did not consent to participate) were Caucasian. There was nothing unusual about the study sample.

Shortly after the study's start, it was discovered that two of the three day cares were operated and funded by the same non-profit organization, the same clients attended both sites, and the same day care workers, volunteers, and managers worked at both sites. The day care programs also operated identically, and client attendance and client:worker ratio was identical. These two sites were analyzed as one day care and were referred to collectively as Case 2.

### Consent

Informed consent was sought from clients, family caregivers, and day care workers. The consent procedure operated as follows: in order to gain consent, permission for the researcher to initially contact potential study participants had to be obtained by the day care managers by mail to protect caregiver confidentiality. Each caregiver received a letter from the day care manager that supported the research project. Accompanying the manager's letter was a brief description of the study from the researcher and a *pre-consent* form. This letter included a tear-off portion to be returned by mail in a pre-stamped envelope indicating either the caregiver's consent for contact information (name, address, and phone number) to be released to the researcher, or refusal for information to be released to the researcher. The researcher then phoned those caregivers who consented to be contacted. A meeting was

scheduled between the caregiver and researcher in the caregiver's home to discuss the study further and, if the caregiver agreed, obtain their consent to participate and their consent for their relative's participation (the person with dementia). The caregivers were given an information sheet that detailed the study and what their and their relative's involvement would entail.

Once consent was obtained from the caregiver for the client's participation, attempts were made to gain the client's consent/assent to participate. This took place in the day care. Clients were read an information sheet stating that they would be asked about the benefits of coming "here" or "to the club." They were then asked to provide a yes or no response to six consent questions. If the client seemed restless, the information sheet and the consent questions were not read aloud and the researcher asked the client if she could ask some questions about the club. If the client was not interested in this activity or did not like it, attempts to gain consent were ceased. Gaining the client's consent to participate and to answer questions would be attempted three times only. On two occasions the client surveys were ceased. In one instance, the client stated that he did not want to talk today and that he just wanted to go home (at the time of the survey the client was waiting for the day care van to take him home early). This survey was successfully completed the following week. On the second occasion that the survey was ceased, the client did not understand why I wanted to ask her questions and behaved in a worried, agitated fashion. The survey was re-attempted twice the following week unsuccessfully.

Special caution must be exercised when research involves a cognitively impaired population. In this type of research, it is common to retain consent from the family caregiver *only* for the inclusion of the client. However in this project, as described, efforts were made to include the client in the decision to participate. Attempts to gain patient assent function as a

systematic method of delivering project information to the client, which is the minimum amount of consideration that should be offered to a potential research participant.

All workers, including volunteers, were approached in the day care to gain their consent to participate. They also received an information sheet detailing the study and their involvement. If in agreement they completed a consent form.

Please refer to Appendix A to review all consent forms.

### **Participant Observations**

Observations were performed continuously over a 3-month period that totaled 64 days of observation that were divided equally among each day care. The Case 1 day care was observed on 32 occasions and the Case 2 day cares were observed on 32 occasions (16 at each of the two day care sites that had been grouped together for analysis). A visit to a day care lasted on average 5 hours. The majority of the time in the day care was spent observing the daily processes, clients, and care workers. The observations were overt, as the care workers and clients had been informed of the purpose of my presence. I interacted with the participants only casually and nondirectively, so that I would not alter the course of events. In between observations I surveyed and administered measures to the workers and clients. Field notes were kept and formal measures to record information were completed. I experienced no difficulties becoming included as an unobtrusive part of the environments.

### **Surveys**

Family caregiver. A face-to-face meeting was scheduled with each caregiver in their home. Each consenting family caregiver completed the survey. The time to complete the survey ranged was 28-110 minutes.

Client. During a face-to-face meeting with the researcher in the day care, each participating client completed the survey and several measures. Completion of the survey and measures ranged from 12-50 minutes.

Day care worker. The researcher met face-to-face with each consenting day care worker and volunteer to complete the survey. One measure, the Dementia Quiz, was left with the worker or volunteer to be completed and returned. The time required to complete the survey ranged from 5-30 minutes and averaged 10 minutes.

Please see Appendix B to review all participants' survey data.

### **List of Measures**

The Dementia Quiz (DQ). The DQ (Gilleard & Groom, 1994) was administered to day care workers to assess general knowledge about dementia. Scores were calculated according to the measure's instructions using the equation:  $\text{number of correct responses} - (\text{number of incorrect responses} / 3)$ . This is a 17-item, multiple-choice measure. Each question may be answered by choosing 1 of 5 responses: one response is correct, three responses are incorrect, and one response is *don't know*. Don't know responses are not scored. The maximum possible score is 17. There were several cases where a participant's response could not be accommodated by the Dementia Quiz's scoring directions, and so the responses were scored by the following method: when participants provided no response for a question, the question was coded as a don't know, which means that it was not scored. There were also instances where a participant provided two answers for a single question. These questions were coded as correct if one of the two answers was the correct response. There was one instance of a study participant earning negative points. This was scored as a 0, the lowest score according to the measure directions.

Demographic information. Client demographics were obtained from the day care

manager. Caregiver and worker demographics were obtained during the surveys.

Environmental Recording Form. This exploratory measure created for this study and completed via observation, was designed to record pertinent information, such as client:worker interactions, activities, dining routine, client opportunity for choice, etc. (Please see Appendix C to review.)

Survey. These surveys were developed for this study to elicit information about experiences with the day care service and participant perspectives related to its benefits. Please see Appendix D to review all survey forms.

The Mini-Mental State Examination (MMSE). The MMSE (Folstein, Folstein, & McHugh, 1975) was administered to clients to assess cognitive impairment. A score was calculated from the total number of correct responses. The sum represents a measure of cognitive impairment. The highest possible score was 30.

Multiphasic Environmental Assessment Procedure (MEAP). The MEAP (Moos & Lemke, 1984) was used to gather descriptive data on the facility, such as safety features, social recreational aids, and prosthetic aids.

Participant observations. The observations were conducted to gather detailed, in depth information on each day care and its processes, schedules, clients, and workers, in order to develop each case study.

Satisfaction with Day Care Services. This exploratory measure, developed for this study, was used to assess client satisfaction with the day care service. Each client was asked to rate how happy s/he had been with the day care service over the past 2 weeks by choosing descriptors ranging from *not happy at all* to *extremely happy* that had been assigned to a 7-point scale, with higher scores indicating greater satisfaction. The participant's response to this one question is the participant's score. (See Appendix E to review this form.)

See Appendix F for Rationale for Choice of Measures.

## **Results**

### **The Intervention: A Day at Day Care**

I have described the real-life context in which the day care intervention occurred and have described the intervention itself.

#### Case Study 1

The day care in Case Study 1 published brochures that described the goals and services of the day care. The intended audience of these brochures was the family caregiver. It described a private, for-profit service. Its goal was to “offer therapeutic activities and individualized services in a group setting for older adults with a variety of disabilities” and to provide “relief to the family.” Its targeted population was “adults (18 or older) who are dealing with strokes, Alzheimer’s disease, memory loss, developmental disabilities, confusion or head injuries.”

On full capacity days, which was most days, the facility’s bus completed two round-trips retrieving clients at home and delivering them to day care. One bus load arrived near 10 am and the other arrived near 11 am. Average attendance was 15. Worker-client ratio was 4:1. Morning tea was served immediately upon the arrival of the first bus load. When at capacity, morning tea was staggered in shifts separated by 30-60 minutes because only 12 clients could be seated in the dining room at once. After morning tea, clients were separated into one of two sitting areas. Criteria for separating clients was based on whether they were high-functioning or low-functioning. A worker explained that this separation occurred because “the more progressed upset the more intact.” Lunch occurred at noon. Clients were often seated at the dining table up to 30 minutes prior to serving lunch. On full-capacity days, lunch also was staggered in shifts separated by 35-60 minutes. Workers did not dine with the clients. Afterwards, clients were again separated between the two sitting rooms.

The activities for the two groups that followed morning tea and lunch varied. Half the members of the high-functioning group usually played cards or dominoes and required little from workers. Others listened to music or sat. Occasionally music was played on the karaoke machine, lyrics were provided, and the clients sang. Every 2 weeks, a fitness worker visited to instigate exercises that both groups of clients could do sitting or standing. Smoking was permitted in the high-functioning sitting room along with clients who were not smoking. Smokers from the other sitting room were brought in to smoke, then were returned to their sitting room.

The low-functioning group was quieter. There was usually very little activity. A video was usually played on the VCR and it was frequently a repeat. One worker commented, “They don’t remember, they forget” when referring to the many times clients had viewed an Al Jolsen musical. Craft activities were never offered although craft material was possessed by the facility. Workers usually did not attempt to engage clients in activities. The range of activities offered did not change throughout the 3-month duration of the study.

Most touching occurred when workers helped clients on or off the bus or were taken to the bathroom or dining room. Throughout the day there was little conversation between workers and clients. Topics included the weather, the tea, lunch, clients’ former work life, and former activities. For example, workers said, “I thought it was clearing up but I think it’s going to rain,” “You used to be a joiner, didn’t you?” or, “You used to speak pretty good Italian, [client’s name].”

The bus departed at 3 pm to take the clients home. Workers prepared the clients to leave between 2 and 2:45 pm, often putting coats on clients up to an hour prior to departure. If clients had been engaged in an activity, they stopped the activity and waited until they were loaded onto the bus.

I have described the typical routine at day care. What follows are specific examples.

Example 1: An energetic client, who was excited because she thought it was her birthday, asked to walk to the other sitting room because she believed her sister was there. Her requests and pacing continued for 30 minutes. No efforts were made to accommodate or calm her. After several attempts to open the heavy door to exit the room, she succeeded and proceeded to the other sitting room. Along the way a worker said sarcastically, “She’s not looking for anyone.” The client entered the sitting room said “hello” and returned to her sitting room, seemingly satisfied. When she entered the room another worker sarcastically asked her, “Where do you want to go now?”

Example 2: “I think they just like to be quiet, so that’s what we do,” commented a worker sitting with the lower-functioning group. Later, she played beanbag toss tic-tac-toe with the clients.

Example 3: A client exits the bus in the morning and remarks, “It is so good to see new faces.”

Example 4: Workers joked that a client could wait to go to the bathroom because she was wearing a diaper.

Example 5: Twice, the only wheelchair-bound client’s requests to be taken to the toilet were ignored resulting in his soiling himself and insisting that he be taken home. He was taken home early.

Example 6: Commonly clients stated that they were cold but received no response from workers.

Example 7: After lunch, clients went to their groups. There was no worker present in the lower-functioning group. A client asked other clients, “What are we going to do today?” The worker arrived 20 minutes late. The client asked him, “What are we going to do today?” He did not respond nor offer an activity.



Example 8: Workers routinely cut clients' food, taking utensils out of the hands of clients successfully cutting their own food.

Example 9: While the client's lunched in the dining room, two workers talked about their holiday plans, "I'll go to Tenerife or Greece. I don't know which is better." A client comments, "I've been to both. I like Greece. What part of Greece?" Workers continued talking without acknowledgment of the client's comments.

Example 10: After morning tea when clients were separated into sitting rooms, a client stated, "I've got to go to work." He repeated this every few minutes while walking around the room anxiously. The worker responded to this behavior by shutting the door so he could not leave and told him to sit down.

Example 11: A client who usually needed assistance in the bathroom repeatedly asked to be taken to the bathroom, but was ignored. With difficulty, she got out of her chair and to the bathroom on her own.

Example 12: Two clients chatted during lunch, "I like the company here" and the other client remarks, "And it passes the time."

Example 13: While a client slept in a chair, a worker pointed at the client and commented to another worker, "That one's in a catatonic state."

Example 14: Clients played dominoes showing no signs of dementia.

Example 15: A client remarked that she felt sick and had a fever. Her temperature was taken 2 hours later, and she was feverish.

## Case Study 2

The day care in Case Study 2 published a brochure that described the goals and services of the day care, intended primarily for family caregivers. It described a service by a non-profit advocacy group. Its goal was "to provide and to secure the provision of high

quality services for people with dementia...and for carers of people with dementia” and to provide people with dementia “the chance to socialise and enjoy activities and outings, and give carers a break.” It described a service population of “people with dementia and their families.”

All clients were picked-up at their home by a volunteer driver or by a day care worker and arrived at day care at 10 am sharp. Average attendance was five. Worker-client ratio averaged 1:1. However this varied slightly as volunteers did not arrive or worked only the busier parts of the day. As clients arrived, each was greeted and hugged by one or more workers. Morning tea was served as clients arrived. Each worker knew how each client took tea or coffee and prepared it in the kitchen before serving it in the sitting room where an activity was conducted concurrently. Morning activities included reading aloud excerpts from books, looking at magazines, listening to music, and conversation. Craft activities followed. The craft was either a continued effort on a project that wasn't yet complete or a new project. Craft time averaged an hour but was often extended depending on the interests of the clients. Workers brought magazines and craft materials from home to supplement the day care's provisions. All were encouraged to participate but those who didn't were offered another activity. Several workers participated in crafts along with the clients. Some clients felt that the crafts were childish and refused to participate. One male client usually refused to participate in the crafts stating, “I'm not a child.” Other clients stated, “I'd rather crochet” or “It's just not for me.” However, the majority of clients actively participated in the activities.

Lunch was purchased from a local elementary school, delivered by a volunteer driver, and served at noon. While some workers brought their own lunch, the clients and workers ate together. After lunch, clients relocated to the sitting room. While other clients helped workers clear the table, wash the dishes, and clean the kitchen and dining room table. At 1 pm the workers directed a 5-minute exercise session where clients stretched and rotated their arms,

neck, and legs. Another activity involved clients sitting in chairs in a circle and tossing a ball to one another. Some clients knitted, went for a walk with a worker, or laid down in the bedroom. Activities followed that often included dominos, listening to music, dancing, and looking at magazines. Smokers sat in the hallway near the open front door or went outside. Tea and biscuits were often served again round 3 pm. Clients were taken home by a volunteer driver or a care worker at 4 pm.

Throughout the activities of the day, there were threads of conversation among workers and clients. Workers instigated conversations with clients on topics such as current events, sometimes politics, whether lunch was good or not, clients' past, where clients and workers lived as children and how the town had changed, current affairs, and the day care workers' lives. For example, "I worked in the garden yesterday," "You wouldn't believe what happened at the grocer yesterday!" or "I lived in Tullibody as a child and nothing else was there and now look at it!" The workers talked more to the clients than to each other. Those clients who did not talk looked at the speaker and appeared to follow the exchange.

I have described the typical routine at day care. What follows are specific examples.

Example 1: Three clients arrived at day care with a worker who had picked them up at their homes. The other workers greeted the clients, "I'm so glad to see you today. Your cheeks are rosy from the cold!" Each client was hugged and helped to remove their coats.

Example 2: A client said, "I'm not doing that [crafts] today. I'm going to just sit over here." A worker asked, "Do you also want music?"

Example 3: A client was upset and continued to ask to go home. Workers, knowing that the caregiver was at work, talked with her and sat with her until her crisis had passed.

Example 4: "I really like these beets," said a worker. The worker asked each client at the dining table, "Do you like beets [client's name]?" One client described how her mother cooked beets. There was an verbal exchange of recipes among clients and workers.

Example 5: “My goal, really, is to just make them happy while they’re here. We really don’t know what happens when they go home,” said the manager.

Example 6: “I really do think of them as my friends,” said a volunteer worker.

Example 7: It was a client’s first time in day care. While sitting at the dining room table waiting to be served, another client told her, “I come for the food and company.”

Example 8: “Are those booties for your new grandbaby?” asked a worker.

Example 9: “Is everyone happy with lunch today? I know yesterday most of you didn’t like the peaches,” commented a worker as the clients ate.

Example 10: “She can be a bit pushy, but she’s a good worker and she’s available to us whenever we call her,” commented the manager as we watched a volunteer making the moves for clients playing a game of dominoes. The clients had been playing independent of assistance.

Example 11: A worker asked, “Did anyone watch the news report last night? Here is a recap...”

See Appendix G for physical descriptions of day cares

## **The Population**

### Client

Client demographics and measures. There were a total of 14 clients. No differences were found between sites among demographics or administered measures. There were no differences among gender scores or reports, with the exception of Satisfaction with Day Care Services, with males reporting lower satisfaction. Day care satisfaction averaged 4.5. The combined MMSE score averaged 14 and ranged from 6-18. The average age was 80. Females outnumbered males by just over 2 to 1 (71% and 29%). Clients attended on average two days a week. However, males attended on average 1 day a week more than females.

A total of six dyads were excluded. Two refused to attend and two were placed in residential care. Two other dyads were not included because their caregiver could not be contacted following prior consent allowing the researcher to make contact with them.

Client benefit. The majority of the clients reported that they had benefited from their attendance at day care and that they enjoyed attending day care. *Company* was the most frequently reported benefit, reported by 57% (8) of all clients. For example, these client reports included:

- “Sometimes at home is lonely...I like the company.”
- “It’s good company. It keeps me from sitting in the house for 4 hours.”
- “I enjoy myself. We talk.”
- “I come for the company, the talking.”
- “The people and everything else. We meet a lot of different people you can sit and talk to. I get on well with them all.”
- “It’s friendly. I get to meet people and talk to them. Being a Christian, I don’t like to hide my light. I like to spread it.”

Other clients reports of benefits included:

- “We get the best of everything. I look forward to coming here. There are days when I don’t feel like coming and I’d rather be at home, but I can’t say anything against it and the people are wonderful {staff}. We are very well-looked-after and the food is good. I’m in the house myself. It’s nice, real nice. I’m using my own language, who the hell can ask for more? I’ve nothing but praise for the place. Extremely nice people and it doesn’t cost us a cent. I can’t speak of it highly enough. Everybody gets the same treatment. Doesn’t cost us a farthing. Nice people, pleasant. It smells like home. It’s private. I enjoy my day here. Everybody

is like yourself—pleasant and easy to talk to. The only day I’ve not come is if I woke up with a headache. I’ve never missed a day.”

- “A lot of benefits, everyway. They treat you fine.”
- “It’s good company. It keeps me from sitting in the house for 4 hours. Everyone is friendly.”

Day care workers’ reports of client benefits were consistent with clients’ reports. The only reports of no benefit were reported by 36% (5) of Case 1 clients. However, two of which also reported liking “...the company. I get to know different people” and that they liked “the friendly people.” Examples of reports of no benefits included:

- “No. No benefits to me.” There is “...nothing in particular {that I like}.” “I’d set it on fire to burn it because it’s no use to me. It’s all rubbish.” “No. I don’t see anything great about this place.”
- “None. It gets me out of the wife’s way.”
- “No financial benefits. No {other benefits}.” Would you like to come here more often? “I don’t know.”

*Improved client energy* and *improved client mood* were the client benefits most frequently reported by the caregivers. Whereas the day care workers most frequently reported *company*, as the clients had reported. (See Table 1, *Clients’, Caregivers’, and Day Care Workers’ Perspectives of the Benefits of Day Care.*) Between cases, caregivers’ reports of benefits did not differ, nor did workers’ reports of benefits differ.

Client consent. The information and consent sheet was read aloud to 11 clients. The six consent questions were also read aloud. Five clients provided a yes or no response to the questions, while six clients provided answers intermittently or not at all. One client said that he could not answer the consent questions, stating, “I can’t remember what you just read.”

Three clients did not want me to read the consent form, so I asked if I could ask them some questions and they agreed.

### Caregivers

Caregiver demographics. There were a total of 14 caregivers and they were similar across sites. The average age was 71. All caregivers were family members. Husbands were more likely than wives to send their spouse to day care, wife caregivers placed husbands in day care more days per week than husband caregivers placed wives. The majority of caregivers were female (87%) and included wives, daughters, and sisters. However, the majority of spousal caregivers were husbands (62%). There were no brother or son caregivers.

Caregiver benefit. Most caregivers reported that they were very happy with the day care services and that they had benefited from their use. *Free time* and *getting a break* were the primary benefits for caregivers reported by both caregivers and day care workers. Caregiver reports of benefits did not differ between cases. Nearly all (92%) caregivers reported that they had more time to themselves since their relative began attending day care. Reduced stress was a reported benefit by over half (64%) the caregivers.

### Day Care Worker

Day care worker demographics and measures. A total of 20 workers were included. They were similar across sites on age (average was 43). Dementia Quiz scores differed with Case 1 workers scoring lower at 6.6, and Case 2 workers scoring 9. Most workers were female (85%), 14% were male. All male workers were in Case 1. Volunteers comprised 26% of the workers. All volunteers worked in Case 2, comprising 40% of their workforce. Worker:client ratio in Case 1 was 1:4, and in Case 2 was 1:1

Two workers were not included in the analysis because they were on vacation and could not be reached until after the study's end.



**Table 1****Clients,' Caregivers,' and Day Care Workers' Perspectives of The Benefits of Day Care**

	Caregiver reports of benefits	Client reports of benefits	Day care worker reports of benefits
Benefits for caregiver	Getting a break (7), Free time (6), Reduced stress (5), Freedom from watching over family member in the home (5), Don't worry about family member (3)	No benefits (10), Don't have to worry (1), Break (1), Free time (1), Separated from family member (1)	Getting a break (19), Free time (10), Know client is safe (10), Free not to worry (4), Reduce stress (3), Receive a meal (2), Don't have to watch family member (1), Recreation (1), Better interaction w/ family member (1),
Benefits for client	Improved energy (8), Improved mood (8), Different environment (4), With like people (4), Cognitive improvement (3)	Company (8), No benefits (5), Enjoy it (3), Get out of house (2), Don't know (1)	Company (19), Stimulation (13), Change of environment (12), Receive a meal (6), Maintain skills (6), Activities (5), With people own age (4), Personal care (3)

\*number of persons listing this benefit

## **Analysis**

At the onset of the study it was determined that I would collect data for 3 months. At the end of this period I was confident that I had acquired sufficient data to meet my research objectives. I had developed a deep understanding of the environments through continuous contact with the environments and participant surveys.

### **Case Narratives**

Narratives were developed from the observational data, the two environmental recording forms, and day care brochures. The narratives served as the framework for organizing the case study data. An explanation of the cases was built from these narratives (Yin, 1994). Examples were provided to illustrate the data.

### **Surveys**

Tables were created of the survey data to display, enhance data review, and aid comparison among informant responses.

Focus group and clustered data. The varied single-word and phrase responses gathered through surveys presented a challenge. Many responses were similarly worded or seemed identical in meaning. Without a logical way to group the responses, the strength of the data was reduced. For example, 10 reports of *break* means one thing; and 3 reports of *respite*, 4 reports of *rest*, and 2 reports of *time to relax* means something else, but it can't mean break without appropriate groups external to the study to decide that. This survey data was reviewed by age-relevant focus groups to judge where similarly worded responses should be considered identical in meaning. See Appendix H for more about the focus groups.

Each worker usually reported a number of benefits for the clients and family caregivers without specifying a most important benefit. The most frequently reported benefit was named as the primary benefit reported by the workers. For example when workers were asked to report on the main benefits for the family caregivers, of the 20 day care workers surveyed there were 19 reports of *break*, 10 reports of *freetime*, and 10 reports of *know family member is safe*. Break was reported as the primary benefit. The same process was used to evaluate workers' reports of benefits for the client, family caregivers' reports of benefits for the client, and clients' reports of benefits for themselves. Clients' reports were not as verbose and this process was not needed to determine the primary benefit because most clients reported only one benefit. All these benefits were tabulated and ranked.

Other responses. Yes/no and single-word responses were tabulated for their frequency.

### **Measures**

The Dementia Quiz. Analyzed according to measure directions.

MMSE. Analyzed according to measure directions.

MEAP and Environmental Recording Form. The data gathered using these measures was organized with relevant data, usually into the narratives or day care descriptions.

Satisfaction with Day Care Services. Analyzed according to measure directions.

## **Discussion**

### **Day Care Benefits**

Adult day care for people with dementia is primarily a social occasion for its

clients, the people with dementia. Clients enjoy companionship and interaction with other clients and workers. The environment may be more beneficial to females, who find it to be more comfortable than males find it. Females may respond more positively to the day care environment than males (Curran, 1996). This may be because activities or the environment in general, are more or are perceived to be more geared to females' interests and likes. Another factor that may inhibit males' comfort is their minority status at day care. Females are the dominant gender, both among clients and workers. It's no surprise that males are less satisfied at day care compared to females, yet males' weekly attendance is higher. The source of the gender discrepancy in day care attendance lies with the family caregiver.

The discrepancy between caregiver and worker reports of client benefits is related to the very different environments in which each population observed the clients. The day care workers' reports of company were based on observations of the clients' at day care. The family caregivers' reports of improved energy and mood were based on observations of the client at home and may have been a result of the clients' day care attendance and its effects, and possibly a result of the beneficial effects of company. Workers also were reporting on benefits for clients as a group. Whereas caregivers were reporting on benefits for their family member.

Family caregivers, the majority of whom are spouses, benefit from day care by getting a break and free time and by having more time to themselves. They also benefit by the reduced stress that results from the primary benefits of free time and break.

Some clients in Case Study 1 reported not benefiting from day care attendance. No clients in Case Study 2 reported not benefiting. Both cases reported the same type of benefits and an identical primary benefit. So the environments were

experienced in the same way, yet a few Case 1 clients reported not benefiting. How can this be? The environments differed. Observations found them to differ in obvious ways that are presumed to effect the clients' experience and amount of benefit. The observational data showed Case 2 clients appeared to enjoy themselves more than clients in Case 1. Case 2 clients laughed more, talked more and were talked to more, interacted more, and were touched more. These behaviors occurred primarily with workers or in response to workers. Clients receiving attentive care in a supportive environment where they are positively stimulated and experience companionship, benefit more than clients who are in an environment neutral or negative on these qualities. This type of environment is beneficial to people with dementia (Anderson, 1992; Morgan & Stewart, 1999). Better care is more beneficial than poorer care. As other studies have found, the type and frequency of interactions between Case 2 workers and their clients encouraged the maintenance of social skills (Alzheimer's Society, 2005), promoted attention, comment, participation in therapy (Pulsford, Rushforth, & Connor, 2000), and feelings of physical and emotional security (Lyman, 1989a). The Case 2 environment is more beneficial for the clients than the Case 1 environment.

It is not suggested that the Case 1 clients experienced no benefit. The majority did report benefiting, and just by being around people they experienced companionship (clients' number one reported benefit). Is it possible that the small amount of companionship Case 1 clients received was enough to benefit them (and is why most had reported benefiting)? Is the *passive companionship* (being in close proximity to people) in Case 1 as beneficial to people with dementia as the *active companionship* (positive frequent interaction) in Case 2? These two populations did not differ on any other variables. It is likely that Case 1 clients benefited from the

little companionship and little interaction they received but would have responded well to more of both.

### **Comparing Environmental Features of Case Study 1 and Case Study 2**

Several features distinguished the day care environments and may be related to the differences in benefit.

#### Worker:Client Ratio

Both sites offered good worker:client ratios. However, the Case 2 ratio was much lower than that of Case 1.

Environments with low worker:client ratios are usually thought to provide an environment that is more comfortable to people with dementia (Alzheimer's Society, 2005).

#### Day Care Size

Case 1 averaged 15 clients daily. Case 2 averaged 5 clients daily.

The size of day care may also be a factor in the impact the day care has on its clients. Larger special care units for people with dementia have been related to higher agitation, intellectual deterioration, and emotional disturbance (Annerstedt, 1994; Sloan et al., 1998). Conversely, smaller units for people with dementia have been related to less anxiety and depression, more mobility (Annerstedt, 1997; Skea & Lindsay, 1996), and increased supervision (McCracken & Fitzwater, 1989), social interaction and friendship among clients (McAlister & Silverman, 1999; Moore, 1999; Netten, 1993). There is no information in the literature on the optimal group size for maximum therapeutic benefit.

#### Suitability of the Physical Site

Although both sites were aesthetically pleasing, comfortable, and unobtrusively secure, the confusing layout in Case 1 of multiple-rooms on either side of a hall separated by heavy fire doors made it difficult or impossible for clients to navigate unassisted.

Whereas, the Case 2 environment was simple and its open layout was not confusing and was easily navigated by clients.

The design of the facility is an important consideration because a goal of day care is to maintain competence in people with dementia as long as possible (Lyman, 1989b). The clients need an environment that is easily understood and one that they can operate. If freedom of movement is restricted their functionality may be negatively effected (Regnier & Pynoos, 1992).

#### Worker-Client Interaction

Case 1 worker-client interactions were custodial in nature. Conversation between workers and clients occurred infrequently. Other types of interaction, such as touching or formal activities, also occurred infrequently. Little effort was made on the part of the workers to facilitate conversation or interaction. There were many instances where clients were ignored, even when the client made an appropriate comment or an appropriate request. Disparaging amusement was observed. Often, issues or requests that were real to the clients were not treated by the workers as real. Workers used the clients' impaired memory advantageously.

Conversation between Case 2 workers and clients was frequent and usually due to worker initiation. Workers were warm and friendly toward the clients and their interaction resembled friendships.

The frequency and quality of the care worker-client interactions may reflect the quality of their relationships (Pulsford, Rushforth, & Connor, 2000). Interaction

promotes the maintenance of social skills longer (Alzheimer's Society, 2005), attention, comment, and participation in therapy (Pulsford, Rushforth, & Connor, 2000).

### Activities

Case 1 offered little to no activities, fostering no sense of accomplishment or satisfaction.

The Case 2 workers actively prepared and participated in activities. Clients were offered choices, whether a formal activity (craft, exercise) or not (clearing the dishes), that encouraged independence and the chance to do something that made them feel competent (Lyman, 1989a).

Activity and stimulation are important needs of people with dementia. For them, the importance of the activity is in the enjoyment of the process. The outcome or product is immaterial. Offering activities that each client enjoys and efforts toward gaining participation should be considered part of the care worker's routine of care because of the potential for activity inclusion to enhance self-confidence, self-esteem, quality of life (Baker, Wuest & Stern, 1992), maintenance of current levels of functionality (Rabbitt 1988), and well-being (Pulsford, Rushforth, & Connor, 2000).

### Separation into Functional Groups

Case 1 workers separated the clients into functional groups. These groupings effected the type of activities and amount of interaction to which the clients were exposed. For the low-functioning group, the result was an environment almost silent with little activity.

Clients in Case 2 were not separated.

Separation of people with dementia into functional groups is not necessarily a negative. Each client needs an amount of stimulation that is appropriate to that



individual. Each individual needs exposure to and membership in an interacting group. An interactive group provides stimulation and an opportunity to interact at a level that is appropriate to ability (Sands & Suzuki, 1983). Most Case 1 members in the lower functioning group were not appropriately stimulated and some perhaps would have benefited through exposure to the higher-functioning clients. In environments where the size and layout of the day care dictate the separation of clients into groups (as may have occurred in Case 1), the isolation that may result may be overcome by worker interaction with clients, such as initiating conversation and activity.

The worker:client ratio, size, suitability of the site, quality of client-worker relationship, and quality of the activities offered are important components of a day care. There is literature on the relationship of each of these components to adult day care for people with dementia. The qualities of each of these components in the day care may be indicators of the day care managers' and workers' knowledge of and sensitivity to factors important to care provision for people with dementia. The qualities of each of these components may also exemplify the workers' and managers' level of commitment to serving this population. In relation to Case 1, the quality of these factors tells a story of workers who were primarily involved in accomplishing their care routine (e.g., feeding, toileting). That the site was not physically accommodating to clients may suggest that this feature was considered of low importance. The worker:client ratio and the size of the day care were not detractors. The infrequent interaction and the low level of client activity suggest that these factors were not considered by workers to be important or to be needs to people with dementia. Workers' ignoring of clients was especially disconcerting because it

was so common. When a clients' appropriate attempts to communicate with the workers are not effective, then the chances of this population being understood through a communication problem or disorientation are slim. Workers' behaviors suggests that they viewed their role as custodial. These behaviors may also suggest they did not think their clients were capable of experiencing or responding or benefiting from interaction.

The care managers, who worked in each day care, may have set the stage for the workers' treatment of the clients (Peterson, 1988). Case 2 managers were very involved in the care of the day care clients, working alongside the day care workers. Their care-giving behaviors served as an example to workers of what was expected from them. Case 1 managers were not actively involved in the care of the clients. If they did have a perspective of care-giving behavior like the Case 2 managers, it was never observed nor actively communicated to the workers. There was no opportunity for their behaviors to serve as a model and continued reinforcer of client treatment (Peterson, 1988). The managers are influential in setting group norms and values and are an important determinant in how the workers will then define and relate to their clients (Peterson, 1988). Care workers holding negative attitudes about people with dementia or low expectations of benefit from therapeutic or health promoting activities may not be motivated to invest time and effort into their clients. This may be the situation with the care workers in Case 1. It is also possible that they did not have the time or energy to invest (Campbell, 1984) into a more supportive, holistic care routine.

The stated aims of each day care may explain some of the differences in the care each provided. Although the aims of each don't initially appear to differ, something stands out when one considers that the primary difference between the day

cares is the amount and quality of interaction and stimulation. The aim of Case 1 did not include providing clients “the opportunity to socialize,” as the Case 2 aim had. Also, the aim of Case 2 used the word “enjoy” in reference to the clients’ experience at day care. Case 1 made no reference to the clients’ level of enjoyment.

### **What Factors are Responsible for the Benefit to the Clients?**

The factors, worker:client ratio, day care size, suitability of the site, client-worker relationship, and activities offered are important components of the day care environment. There were instances in the day care environments where these factors changed temporarily, yet did not effect the usual operation of the day care.

At times, the worker:client ratio in Case 1 was lower at 1:2, due to low attendance that day (day care size was smaller too). For example, when the day care was not at capacity but had the usual number of workers, or when the first bus trip returned with only three or four clients, then left to pick-up more clients. This resulted in few clients with one worker. The amount or quality of the interaction, conversation, or activity did not improve. In Case 2, there were instances throughout the day where the worker:client ratio was higher at 2:4, yet did not effect usual operations. For example when volunteers did not show-up, a number of whom worked short shifts and arrived for short periods throughout the day.

It may not be necessary that each of these features exist in their preferred form for the environment to be beneficial. Attentive workers providing a reassuring, safe, and stimulating environment may be enough to temper challenging environmental features.

## **Client Consent and Information**

### Client Consent

Clients' reactions to my attempts to gain consent were mostly positive. Most clients responded in an affirmative manner to the consent questions, providing yes answers. Their behaviors may have been an indication of understanding the study information and willingness to participate in the study, or they may have been providing affirmative responses to please me. Some clients certainly understood what I was asking of them and some understood the consent questions. But were the clients actually consenting? Were they able to remember what was read to them long enough to understand and make a valid choice to consent? Is remembering something just long enough to make a choice a valid choice if you don't remember shortly thereafter? No to all three. Even with the most competent and capable people with dementia, there will always be doubts about the validity of their responses and the credibility of their intent because by definition a person with dementia has compromised cognition. They need and should have assistance in any important matter and in requests for consent, should they encounter it. People with dementia cannot provide their consent. This does not mean that there aren't other areas in which they are capable.

### Client Provision of Information.

The clients were very good reporters. Most seemed to enjoy the attention and seemed to enjoy talking with me. They answered most questions with appropriate answers. They also reported benefits that were consistent with the care workers' reports of (client) benefits. Their reports of primary benefits were identical to workers' reports. These reports involved the clients' enjoyment of the company at day care and having people to talk to.

All the clients who had reported that they did not benefit from day care had attended the day care observed to be less beneficial, Case 1. Did these clients accurately report how the day care had effected them (without benefit)? After all, no clients at the Case 2 day care reported not benefiting. There is something to their reports: were the clients unable to perceive that they had benefited or were unable to perceive what that benefit would be?

Although Case 1 clients reported not benefiting, they *all* also reported that they liked coming to day care, as did *all* the Case 2 clients. Case 1 day care satisfaction scores also were not different from the clients who had reported benefiting from day care in Case 2. Case 1 clients may not recognize a benefit in attending day care, yet enjoy day care.

### Limitations

The sample provided no representation of minority groups.

### Researcher Comments

Although I intended this study to explore the adult day care from the perspective of the client, I realize that it did not. Although, I observed extensively and surveyed all populations involved, these surveys did not truly *explore* the day care from the perspective of the client. These surveys may have been my downfall. Although I did not read the survey questions verbatim, and used the questions to begin a dialogue on a topic, I accepted answers to questions whether they got at what I really wanted to know or not. While I had encouraged clients to elaborate, I did not probe because I tried to interact with the participants systematically to minimize my personal influence. This behavior was an artifact of my prior exposure to mostly

quantitative research. I should have explored and probed, allowing my curiosity and client responses to drive the questions. A more appropriate measure would have been the interview. The interview differs from the survey in that it is a guided conversation and open-ended, rather than a structured query. However, at this point it is unknown how much more information the clients would have provided in an interview where they received probing, because often they are not talkative.

Administering the Environmental Recording Form during every visit, as this study had planned, is too consuming for the return of mostly redundancies. It should be administered in its entirety once a month. A shortened version should be created that includes the Activities section with the Stressors, Interaction, Staff, and Safety Features sections listed concisely on one page to serve as reminders of points of interest.

### Implications, Ideas, and Points

This study provided data on some important factors in the day care environment that should be considered when designing a day care intervention or care program for people with dementia.

It is hoped that the need for personal interaction and physical stimulation in the day care was demonstrated and its application was exemplified by the Case 2 workers.

The day care workers need to be aware of their potential role in creating a therapeutic environment.

A warm and supporting care worker attitude is important in communicating to clients that their environment is safe.

Day care workers can meet clients need to be occupied primarily through positive personal interaction.

How do we get workers with these attitudes? Lead by example. Design the day care to have an accommodating environment and show workers how the job is done. Be warm and supportive and talkative and do interesting things with the clients.

People with dementia can provide information about what they like, so we should start asking them.

The clients like companionship. What ways can we expand upon this like? Can it be utilized into more formal activities?

The importance of stimulation and activity should be promoted more in the care worker's training.

Find ways to play with people with dementia.

A phenomenological investigation of the experiences of the day care clients should be conducted to learn how the clients experience the day care. A phenomenological study is focused on the essence or structure of an experience, where inner experiences are analyzed to develop an understanding of what is really happening and what the essence is of the phenomenon being studied.

I would like to see the clients in environments that provide care more suited to the varied stages of the disease and that provide more suitable activities.

We do not know how much activity the clients want. Do they always want a task to occupy them? We do not know.

I do not know if the interview method is the best method to find more information about client preferences in day care. Pilot environments that introduce novel activities and environments to clients may be an effective way to learn what the clients want, prefer, respond to, and enjoy in day care.

I should have found out what the clients really wanted out of day care: what activities, excursions, crafts, music, lessons, lectures, movies, etc. I would like to have conducted activity sessions, crafts sessions, taught them a class, and studied their responses in the effort to stimulate them, show them a good time, and entertain them. I think that is important.

The day care environment may be a good candidate for a real-time data analysis of positive and negative conversation and interaction between clients and workers.

## **Conclusions**

These cases exemplified the importance of the day care worker in creating a therapeutic environment. Workers who (1) communicated safety to the client through a relaxed, uncritical environment, and (2) facilitated client stimulation through activity and personal interaction, satisfied clients' basic needs to be safe and occupied. The resulting environment was less anxious and stressful for clients (Anderson, 1992) promoting participation in activity (Pulsford, Rushforth, & Connor, 2000) and improved self-image (Shoham & Neuschatz, 1985).

However, environments that pose challenging features related to worker:client ratio, size, suitability of the site, client-worker relationship, and activities offered that may detract from day care effectiveness may be overcome by attentive workers who provide a safe and stimulating environment.

People with dementia may be able to effectively comment on the environmental features in their environment, reporting likes and dislikes. There is the potential for the clients to be involved in improving the day care, making it more



comfortable, more interesting, more suitable to its population of clients. There is opportunity for more exploration into the clients' ability to be a reporter on their care environment and into the outcome once their recommendations are implemented into their care environment.

## CHAPTER V

## **An Exploration of Four Day Care Environments**

### **Introduction**

Workers who (1) communicated safety to the person with dementia through a relaxed, uncritical environment and (2) facilitated their stimulation through activity and personal interaction, fulfilled their basic needs to be safe and occupied. This type of environment is less anxious and stressful for clients and encourages the use of remaining skills (Anderson, 1992) and maintenance of social skills longer (Alzheimer's Society, 2005).

I wondered which of the two day care environments in Study 1 was more typical. Many of their features were situated at either ends of their continuums and not thought to be integral components in a quality day care. Instead, a safe and stimulating environment created by the workers was thought to be most important component in quality day care.

This study aimed to explore the typicality of the day cares in Study 1 through observation and to further explore the day care client's ability to provide useful information through interview.

Four day cares serving adults with dementia were explored. The day cares were located in Birmingham, Alabama in the southeast United States. These settings had been reviewed and found to offer environments with a large number of potential participants (66) with managers who supported the occurrence of the study in their day care. However, between two of the day cares, only six family caregivers provided consent for their family member to participate in the study. No consent was gained at the other two day cares (due to oversights on the part of the day care

managers). Without consent, the client could not be interviewed and observations specific to the client could not be recorded.

The day cares continued to be explored for their typicality in the field of adult day care for people with dementia. The depth of study was lessened. Also, no data could be gained on the second research topic exploring the clients' provision of useful information.

### **Research Questions**

The project aimed to address the following research questions:

1. What is a typical adult day care environment for people with dementia?
2. How responsive are the clients in an opened-ended interview?
3. What are the clients' preferences at day care for activities, environment, etc.
4. How does the client experience day care?

### **Methodology**

#### Review Board

The research proposal for this project was reviewed and approved by the University of Alabama at Birmingham Institutional Review Board. The board reviews and approves, requests modification, or disapproves all university-related research under the objective of ensuring the protection of research participants. The review board requires that their stamp, the date of approval, and the date of expiration (1 year from the start date) be on the front of any study material, such as interviews, handouts, etc.

#### Preparing for Data Collection

Investigator skills. This researcher has had 2 years of experience working as a research coordinator in an academic research institution with geriatric populations. She has also gathering data and counseled these populations. She has worked as a social worker, crisis counselor, and benefits counselor for indigent hospital patients. While a sociology undergraduate, she worked as a research assistant.

Study protocol.

I. Introduction to the case study and research questions

A. Introduction

- Areas were identified in the research literature where little information existed or did not exist at all. These areas regarded information on what is a typical day care, contribution of the person with dementia to the research process, queries of what they want at day care, and how they experience day care. It is hoped that this study will produce information to improve the quality of day care.

B. Case study topics (questions that need to be answered to address the research questions and how to get them answered)

- What is a typical day care?
  - a. Answer based on observations
- Are these day cares like those in Study 1?
  - a. Answer based on observations
- Describe the day care sites' physical environments?
  - a. Answer based on observations
- What activities are offered?
  - a. Answer based on observations

- What is the ratio of workers to clients?
  - a. Answer based on observations
- What size are the day cares?
  - a. Answer based on observations
- Describe the worker:client interactions?
  - a. Answer based on observations
- Describe how the workers communicate with the clients?
  - a. Answer based on observations
- What are the client populations?
  - a. Answer based on observations, MMSE, demographics
- How responsive are clients to open-ended questions?
  - a. Answer based on interviews
- What activities do the clients want in day care?
  - a. Answer based on interviews
- What do they enjoy most at day care?
  - a. Answer based on interviews
- How would they like to be spending their days?
  - a. Answer based on interviews
- How do the clients experience day care?
  - a. Answer based on interviews

## II. Data collection procedures

### A. Names of sites to be visited and contact persons

- All day care sites within a 45-mile radius of the researcher's university that included people with dementia or exclusively served those with dementia were asked to participate in the

study.

- Site 1: located in Downtown Birmingham, [name of contact person withheld]
- Site 2: located in Downtown Birmingham, [name of contact person withheld]
- Site 3: located in housing project, [name of contact person withheld]
- Site 4: located in purpose-built day care facility {name of contact person withheld}

C. B. Data collection plan

- Data collection for 3 months due to start April 2002, and due to end on or about end of July, 2002.
- Draft consent-to-be contacted (pre-consent) letters to caregivers
- Get letter from site managers supporting study to be sent with pre-consent letter
- Mail consent letter and support letter to caregivers with return envelope with postage
- Keep tab of who has been sent consent letters and who has returned them
- Take field notes while awaiting responses
- Gather day care brochures
- Complete the MEAP
- Complete the Environmental Recording Form monthly
- Meet with family caregivers when they drop-off or pick-up day care clients to obtain consent to contact their family member

- Log the data into tables to keep track of caregiver and client, consents, interviews, and measures completed. Separated by day care location
- Score measures, put score on right, top corner
- Type field notes
- Maintain the case study database well so that it is readily available for review

### III. Outline of case study report

A. Objects of studies' interest

B. Aim of study

C. Findings

### IV. Case study questions

A. Day care environments

- What is a typical adult day care environment for people with dementia?

B. Reporting and day care experience of the client

- How responsive are the clients in an opened-ended interview?
- What are the clients' preferences at day care for activities, environment, etc.
- How does the client experience day care?

Pilot case. A formal pilot case was not conducted. I did not need to nor was there room to refine my research procedures. The environment I knew well and I had visited each site prior to data collection while gaining the participation of each day care manager. The research focus also did not need revision, as I knew the procedures related to accessing the clients in this exploratory study.



## **Participants and Facilities**

Samples were drawn over a period of 3 months from four day care facilities in central Alabama, US. A method of convenience sampling was implemented and all facilities serving some or only clients within a 45-mile radius of the researcher's home were contacted for study participation. Eligible participants were 66 male and female, community-dwelling individuals attending adult day care at least once a week for at least 1 month with a physician's diagnosis of dementia. There were no unusual features in the study sample.

## **Consent**

Informed consent was sought from family caregivers. The consent procedure operated as follows: to maintain the confidentiality of clients and family caregivers, the day care facilities could not provide the researcher with a caregiver's contact information. The day care managers distributed pre-consent letters (written by the researchers) to the caregivers by mail or by hand (when family caregivers picked-up or dropped-off their family member at day care). The pre-consent letter briefly described the objective of the study, stated that the day care manager supported the study, and requested that the caregiver contact the researcher if he thought he might be interested in participation and in order to learn more about the study. Once caregivers telephoned the researcher, the study was described, questions were answered, and the caregiver stated whether they would consent for the client to participate. If the caregiver chose to consent for their family member the researcher and the caregiver made plans to meet at the day care (when the caregiver picked-up or dropped-off the client) so that informed consent forms could be signed and any other

questions answered in person. (It is a requirement of the UAB Institutional Review Board that participants' signatures be obtained in person by the researcher and that participants be provided the opportunity to ask the researcher questions in person.)

Once consent was obtained from the caregiver for the client's participation, the clients were asked if they would like to participate in the study. Clients were given an information sheet (see Appendix I) that they could read if they chose to. The information sheet was also read to them. This information sheet stated that they would be asked about *the club*, their likes and dislikes of the club in an effort to improve the club. If the client was in agreement, the client was interviewed.

To review the caregiver's consent forms, please see Appendix J.

### **Participant Observations**

Observations were performed continuously over a 3-month period 60 days of observation that were divided equally among each day care. The day cares of Case A, B, C, and D were each observed on 15 occasions. Each day care visit averaged 4 hours. The majority of the time in the day care was spent observing the clients and care workers. The observations were overt, as the care workers and clients had been informed of the purpose of my presence. I interacted with the participants only casually and nondirectively, so that I would not alter the course of events. In between observations, I gathered demographic data from the day care managers about the workers, gave the workers the Dementia Quiz to complete and return, and interviewed the few clients whose caregiver had provided their consent. Field notes were kept and formal measures to record information were completed. Each of these environments welcomed me and I experienced no difficulties as an unobtrusive part of the environments.

## **Interviews**

Client. The three participating client were interviewed in the day care during a face-to-face meeting with the researcher. Several measures were also completed. An aim of the study had been to explore the clients' response to open-ended questions and prompts. The completion time of the interview averaged 20 min. Completion time for the measures averaged 5 minutes.

## **List of Measures**

Dementia rating. A measure of physician diagnosed dementia severity was obtained from client medical records maintained by the day care facilities.

Demographic information. Client and worker demographics were obtained from the day care manager.

Environmental Recording Form. This exploratory measure created for this study and completed via observation, was designed to record pertinent information, such as client:worker interactions, activities, dining routine, client opportunity for choice, etc.

Interview. The open-ended interview was developed for this study to elicit information from the clients about their day care experiences and comments on the environment. The questions were designed to supply information that could be used to improve the day care experience for the clients. Clients were encouraged to qualify their responses with explanations or descriptions. Please see Appendix K to review.

The Mini-Mental State Examination (MMSE). The MMSE (Folstein, Folstein, & McHugh, 1975) was administered to clients to assess cognitive impairment. A

score was calculated from the total number of correct responses. The sum represents a measure of cognitive impairment. The highest possible score was 30.

Multitphasic Environmental Assessment Procedure (MEAP). The MEAP (Moos & Lemke, 1984) was used to gather descriptive data on the facility, such as safety features, social recreational aids, and prosthetic aids.

Participant observations. The observations were conducted to gather detailed, in depth information on each day care, its clients and workers, interactions, and on the environment in order to develop each case study.

Satisfaction with Day Care Services. This exploratory measure, developed for Study 1, was used to assess client satisfaction with the day care service. Each client was asked to rate how happy s/he had been with the day care service over the past 2 weeks by choosing descriptors ranging from *not happy at all* to *extremely happy* that had been assigned to a 7-point scale, with higher scores indicating greater satisfaction. The participant's response to this one question is the participant's score.

## **Results**

### **Four Day Care Environments. Four Day Care Interventions**

I have described the real-life context in which the day care intervention occurred and have described the intervention itself.

#### Site A

The service was described as government-funded, public, and non-profit day care for older individuals with dementia, but also accepted older individuals with other debilities. The daily cost to attend was \$12.50. Operating hours were Monday-Friday from 7am-6pm.

The day care was located in the Office of Senior Citizen's Affairs in the business district of a large city. No transportation was provided. A county-sponsored

bus toured several other county-sponsored facilities and passed by the day care, but very few rode the bus and most days no one rode it. Most clients were delivered to the facility by their family caregiver. Average attendance of clients with dementia was 25. At the time of this evaluation, 27 clients were enrolled in the day care, 22 of which had a dementing disease. Average age of the clients with dementia was 80, (range 72-96). The average age of the other clients was 84. Male:female ratio was 3:19. Racial composition was 77% black (17), 23% white (5). Worker:client ratio was 1:4. All workers were black.

Upon arrival, clients were served a full breakfast cooked on site by a day care worker. Almost half the clients wore body-covering plastic aprons during meals to prevent them from soiling their clothes. The day care included only two rooms but was very spacious. As clients finished breakfast, they went into the sitting room connected to the kitchen.

Activities included listening to music, conversation with other clients and workers, looking at magazines, or watching television. One worker always sat amongst the clients and chatted. When all clients had finished breakfast 1-1.5 hours later, two workers led the clients in craft activities for about 1 hour. Just over half usually participated.

Lunch was also cooked by the chef and served in the large kitchen. Workers and clients ate together at a very large table. There was usually little talking. After lunch, clients returned to the sitting room, remained in the kitchen to clean the tables, or helped the less stable clients walk outside to their ride home. A daily schedule that hung on the wall listed a second hour of crafts after lunch but this was never observed to occur. Workers led clients through the halls of the building for 5 minutes of exercise at least once a day. Clients were then encouraged to go to the toilet. A worker

remained in the bathroom to assist, as clients came and went. Monthly birthdays were celebrated on a single day each month. The parties were extravagant with music, cake, gifts, and often dancing, and loved by the clients.

Workers hugged clients when they came in the morning and when they left in the evening. Workers knew clients' histories and often asked them about their families, pets, and activities. Most conversation was directed at everyone, clients and workers. Clients who were talkative and could banter with the workers received more attention. Personal conversations with clients were short and common, and usually about a client's family or was a joke. Workers did not talk about themselves much.

I have described the typical routine at day care. What follows are specific examples.

Example 1: The day care was short by two workers all day. There were no attempts to find substitutes.

Example 2: A client asked a worker, "I'm still hungry. Are there any leftovers?" The worker gets her lunch leftovers from the kitchen.

Example 3: A worker told a client, "We're having your favorite for lunch today [name]."

Example 4: "Yes, [name] has pretty skin. Her Momma didn't let her get no sunshine when she was a kid! I used to get in trouble if I didn't stand in the shade," commented a worker about an especially youthful looking black client.

Example 5: As a client walked toward the door to meet her caregiver, a worker said, "Ain't I gonna get a hug [name]?"

Example 6: "Did you make it to your grandson's baseball game last weekend?" asked a worker.

Example 7: "Is your son coming to get you today or your daughter [name]?"

asked a worker.

Example 8: A worker called the clients to the tables for craft times, then left the room for 20 minutes without explanation. Other workers did not engage clients.

Example 9: Four female clients sat in a circle and talked about fashion for 45 minutes.

Example 10 A worker was always at a desk by the door in the sitting room doing paperwork. She commented and joked intermittently to clients throughout the day, and laughed along with others, usually without looking up. For example, “Where do you think you’re going [name]?” “I bet you think you’re going to get more shoes for your birthday!” “Has somebody fed the fish today?”

Consent. No client consents were obtained. There are no client interviews, MMSE scores, or Day Care Satisfaction scores.

The day care manager responsible for distributing the pre-consent forms to the caregivers forgot to do so. I became suspicious that something was amiss because I had not received any contacts from caregivers 2 weeks after I left the pre-consent forms with the manager. I contacted the manager and she profusely apologized for not distributing the forms. She described her disorganization after moving into another office just down the hall from her previous office and that, along with her other work, what she had promised to do for me had also been postponed. She said she would distribute them that day. After another 2 weeks of no contacts from caregivers, I again contacted the manager and she said that she still had not distributed the forms. At that point, I asked her not to distribute the forms because, with consideration given to my schedule, there was not enough time to gain consent from the caregivers and gather the data on the clients. The manager said that she “felt sick about this.” She also said that it was ironic that she had let this opportunity slip by. She said she was currently

distributing some of her administrative duties to other co-workers because she wanted to be more involved in research with the day care clients.

### Case Study B

The facility served adults with a variety of debilities, including Down syndrome, dementia, and other psychiatric problems. The service was described as government-funded, public, and non-profit. The daily cost to attend was \$8.00 if the family income was over \$1000 per month and incomes of less than \$1000 did not pay any fees. Operating hours were Monday-Friday from 7am-6pm.

The day care was located in a Projects development (government housing community for low-income people) in the suburbs of a large city. Attendance averaged 50 (range 45-55). There were 18 clients with dementia. Their average age was 72 (range 58-89). Worker:client ratio was 1:10. All workers and clients were black.

The facility had four county-supported vans that picked-up and returned clients home. Buses arrived between 8 and 10 am. Mornings were busy with large groups of clients arriving at different times. Clients with dementia were grouped with trained dementia care workers (state requirement in public facilities) but were also among non-dementia clients. All clients were assigned to a flexible client group, room, and worker, but could move about the large facility. Clients were given a snack and fruit juice upon arrival, and chatted, listened to music, or wandered around the very large facility until craft time at 10:30. Craft time lasted an hour. The activities were very creative, involving for example, sand, shells, and multiple coats of paint. They also sometimes involved steps that the workers did later for the clients, such as spray painting and laminating.



Lunches were prepared at a local school and retrieved by a facility worker. The clients would return to their assigned room to eat at its tables with their assigned worker. At non-meal times, the clients often sat at these tables to talk and stare and would often sit there all day. A schedule posted on a wall listed a second craft time after lunch, but this was never observed to occur. At 3:00 workers gave out snacks again.

There was a lot of activity all the time in this day care. For example, workers talked loudly to each other, delivery drivers came and went, the majority of other clients who did not have dementia were more mobile and communicative and were moving about, and some of the mobile clients with other conditions talked to the clients with dementia, patted them on the hand, and led them to their room for lunch. All doors in this many-roomed day care were always open, as were the two doors that opened onto a patio and lawn. Clients did not appear agitated by the activity. Instead, clients often watched people walking around, the delivery trucks come and go, and they watched people talking until they stopped.

The vans departed at 2:30 to take participants home and traveled the entirety of the large county that funded the facility. Other clients lived in the housing project or were picked-up by a caregiver and tended to stay at day care until closing at 6pm.

I have described the typical routine at day care. What follows are specific examples.

Example 1: Some clients spent most of the day outside sitting on the porch, while others wandered around, going outside from time to time.

Example 2: A client commented as she is helped out of the van by a worker, “I love the journey.”

Example 3: A worker calls to another worker in another room in sight, “Is

[client's name] down there. I thought so. Just making sure.”

Example 4: “It is too pretty for you to be sitting there. Let’s go outside [name], said a worker to a client sitting silently at a table.

Example 5: A worker commented to a client during crafts, “Don’t you be making a mess. Get that broom over there and sweep up that sand.”

Example 6: “Don’t worry. You’ve got time to eat and I’m going to sit right here with you,” stated a worker to a client who had not finished lunch and was the only one left at the table.

Consent. No client consents were obtained. There are no client interviews, MMSE scores, or Day Care Satisfaction scores.

It was presumed, the manager mistakenly thought she had distributed the forms. I became suspicious that something was amiss because I had not received any contacts from caregivers 2 weeks after I left the pre-consent forms with the manager. Initially, the manager said she had distributed the pre-consent forms along “with a stack of other papers” to the caregivers. It is presumed that the manager believed she had distributed the forms but mistakenly did not. (This manager operated at her desk amid a flurry of loose papers and folders.) I asked about the forms after 2 weeks and I was told that she had not distributed the forms and that she would now distribute them. After another 2 weeks of no caregiver responses, I asked again and she said that she had been too busy preparing for a site visit from the state regulators. At this point I asked her not to distribute the forms because I would not have time to complete the work. She apologized and said that she would do anything to make up for this. This loss of data was unfortunate. The facility was large, accommodating 12 clients and the caregiver response rate would likely have been very good considering the clout and respect the manager held with the caregivers.

### Site C

The facility served mostly elderly persons with dementia, but also served 2 mentally handicapped children twice a week after school, and occasionally served older persons suffering from depression. The day care was for-profit privately owned and operated. The daily cost to attend was \$37.00-\$47.50. Cost varied due to the services provided (e.g., showers, feeding tube, diabetic monitoring). Operating hours were Monday- Sunday from 6am to 6pm. The facility best accommodated those with mild to moderate dementia.

The day care was located in a purpose built, free-standing building in a residential area. Sixteen clients with dementia regularly attended. Average daily attendance was 12. Averaged age was 81. Most clients were white (94%), 1 was black. Over half (69%: 11) the clients were female, 5 (31%) were male. Worker:client ratio averaged 1:6. Seventy-five percent of workers were white (3), 1 was black.

Transportation was not provided. A county bus served the area and charged a low fee, but very few clients used it and instead were brought by a caregiver. Upon arrival clients ate scones and coffee, tea, or milk. Workers often read to clients during meals and at other times throughout the day. Clients and workers played bingo, dominoes, or cards every day, but never crafts.

A cook prepared lunches for the staff and clients, who ate together. Clients were free to wander about the large one-roomed day care. One client would sweep most of the day and talk about her days on the farm as a girl. After lunch, clients again played cards. Other clients sat at the table and watched the game. Conversation was common during meals and activities, and usually about the meal or activity. Workers again read to clients, stopping occasionally to ask clients questions, for example, their

opinion of the topic, how the event made them feel, or what they would have done in the situation. The readings were often religious.

I have described the typical routine at day care. What follows are specific examples.

Example 1: “I’ve got to go to work! I’ve got to go to work!” shouted a client as he pulled on the front door. The workers coaxed the client into sitting down three times in 15 minutes, as he continued to think that he needed to go to work.

Example 2: A worker walked each client, arm in arm, to their ride in the evenings, hugging some of them.

Example 3: “So, Bilbo Baggins now had to decide if he wanted to leave the comfort of this home or go away on an exciting and scary adventure,” said the worker after reading an excerpt from the Hobbit. “What would you have done [client’s name]?”

Example 4: A client remarked to a new client, “Remember. You can’t ask for something you haven’t got,” as he taught her to play Go Fish,“

#### Site D

The facility served those with dementia but occasionally served older persons suffering from depression. The service was described as church-based, non-religiously affiliated, and non-profit. The daily cost to attend was \$38.50 per day and \$22.00 for a half-day. Operating hours were Monday-Friday from 7:30 am to 5:30 pm.

The facility was located in a church in the business district of a large city. Average attendance was 10 (range 8-12) and average age was 78. Ninety percent of the clients were female (19), 3 (10%) were male. The majority of clients were white

(92%,  $n=9$ ), 8% ( $n=1$ ) were black. Reportedly, the facility best accommodated those with mild to moderate dementia. Worker:client averaged 1:3. Seventy-five percent (3) of workers were black, 1 was white.

No transportation was provided. All clients were brought to day care by a caregiver. Upon arrival clients had scones and tea, coffee, or milk. Clients and workers sat together and talked, stared, or sat on the patio of this very small one-room day care. Bingo, dominoes, and cards were played almost every day and occasionally clients and workers colored with markers and assembled floor puzzles. Each morning, the manager took the mobile clients on a long walk down the sidewalk of the city, up and down the elevator, and through the church.

Lunch was prepared in the church's kitchen and delivered to the day care downstairs. Workers were not involved in clean-up activities after lunch or at any time. Workers did not eat with clients, except when clients needed feeding. After lunch, clients watched a movie while the workers ate lunch. Craft activities were not offered.

Conversation was seldom, occurring mostly during the activities, such as games. The talk was usually related to the activity. During the manager's walks, he constantly talked about the weather, the buildings, the shops, the recent changes in town, etc.

I have described the typical routine at day care. What follows are specific examples.

Example 1: "First floor shoes, second floor ladies apparel, third floor unmentionables," said the manager as he and clients rode the elevator during the daily walk.

Example 2: Workers encouraged clients to sit if they were wandering

Example 3: A client's requests to be moved from her easy chair to her

wheelchair were usually ignored. Workers accommodated this request once a day.

Example 4: “How many cards are you going to play today, [name],” asked a worker as she setup a game of Bingo.

(For a description of each day cares’ physical environment, see Appendix L)

## **Analysis**

### **Case Narratives**

Narratives were developed from the observational data, the two environmental recording forms and day care brochures. The narratives served as the framework for organizing the case study data. An explanation of the cases was built from these narratives (Yin, 1994). Examples were provided to illustrate the data.

### **Measures**

MEAP and Environmental Recording Form. The data gathered using these measures was organized with relevant data, usually into the narratives or physical descriptions of each day care (see Appendix L).

### **Client Vignettes**

Vignettes were composed of the six clients whose caregiver had consented. To review see Appendix N.

## **Discussion**

### **Comparing Environmental Features of Day Cares A, B, C, and D**

The day cares were evaluated on the environmental factors that differentiated the day cares of Study 1: worker:client ratio, size, suitability of physical site, worker-client interaction, activities offered, and the separation of dementia clients. (See Appendix M for a tabular comparison of these features.)

### Worker:Client Ratio

The ratio was high for day cares A and B, and was low for day cares C and D.

A low ratio is generally expected to provide a more comfortable environment for people with dementia (Alzheimer's Society, 2005).

### Day Care Size

Day cares A and B were the largest, with an average attendance of 25 and 50, respectively. C and D were smaller with an average attendance of 12 and 10. Size was evaluated using each sites total population average, including adults without dementia because clients with dementia were not separated from the other clients and they experienced day care as a member of that larger group.

Larger care environments for people with dementia are related to higher agitation, intellectual deterioration, and emotional disturbance (Annerstedt, 1994; Sloan et al., 1998). Smaller environments are related to more mobility (Skea & Lindesay, 1996), increased supervision (McCracken & Fitzwater, 1989) and social interaction and friendship among clients (McAlister & Silverman, 1999; Moore, 1999; Netten, 1993).

### Suitability of the Physical Sites

All sites were aesthetically pleasing, comfortable, and unobtrusively secure.

Site A was comprised of two large rooms. One of which was a full kitchen that served clients breakfast and lunch daily. Atmosphere was non-confusing, basic, and non-institutional atmosphere.

The circular layout of B had the potential to confuse or disorient, but this was not observed. Clients may not have become lost because of the circular layout. Atmosphere was basic, cluttered, and non-institutional atmosphere.

C was one large, L-shaped room. Atmosphere was non-confusing and homey atmosphere.

D was so small that clients had little room to move about. This may be why workers directed clients who were walking about to go outside to the patio. If it had not had a patio, its size would have been unacceptable. Atmosphere was non-confusing and homey.

For years now the trend in adult day care and many other care settings has been away from institutional settings toward settings with the characteristics of home. The trend continues (Alzheimer's Society, 2005).

#### Worker-Client Interactions

Site A workers interacted frequently and jovially with light conversation and jovial comment about any topic or related to clients personally (e.g., family, interests). Workers knew client history, family, and personal interests well. Clients were often called by name. Workers and clients hugged at departures.

Day care B conversations were friendly but infrequent. Most worker-client touching occurred as clients were helped on and off the bus or when workers were guided to a room or to the bus. Workers were not knowledgeable about client history, family, or interests. Their demeanor was warm.

Day care C workers interacted with clients mostly during organized activities. Reading activities encouraged interactions that were often personal. The workers behaved warmly to clients.

Day care D workers interacted blandly with clients and only during formal activities. The workers gave very little of themselves (not expressive, little talk). This was not a very encouraging environment for clients.

Clients who experience greater interaction maintain social skills longer



(Alzheimer's Society, 2005) and may be more likely to participate in therapy (Pulsford, Rushforth, & Connor, 2000).

### Activities

Day care A clients were most frequently occupied by comment and conversation with workers. Workers actively participated in crafts and exercise activities, and allowed clients to do crafts as long as they liked. Clients also had the freedom to roam about. Confidence and independence may have been encouraged in those clients who assisted with cleaning after meals or helped clients to their cars. A full kitchen that served full meals may have been stimulating to clients. The workers themselves provided a great deal of entertainment and stimulation through conversation.

Day care B workers actively participated in the only formal activity offered, crafts. Clients had free range of the day care space including outside to the large yard. This may have encouraged confidence. The workers were not very involved in facilitating activities. However, the environment itself was very stimulating to clients because of the variety of activity that constantly occurred and the exposure to the outdoors.

Site C workers were actively involved in the games and reading activities. Clients were free to roam the site.

Day care D provided few games and a movie. The long walks outdoor may have encouraged client confidence. Clients could not walk around inside, but had to go to the patio.

Participation in activities improves self-confidence and self-esteem (Baker, Wuest & Stern, 1992) and encourages the maintenance of current levels of functionality (Rabbitt 1988).

### Separation of Clients

This feature is not relevant here, because clients were not separated. Although all site B clients were loosely grouped to a room and worker, they were not separated from the others because clients could leave their group and were always scattered throughout the very large facility. Clients returned to their room for lunch. These grouping existed to keep track of the clients.

### Race

Not a factor in Study 1.

Day care A was operated and populated by mostly blacks.

Day care B was operated and populated entirely by blacks.

C was operated and populated by mostly whites.

Site D was operated and populated by mostly whites.

A winner! Day care A and day care B offered the best social care, judged by A's frequency of positive interaction and worker's playful demeanor, and by B's stimulating environment and supportive workers. Both environments stimulated clients, but in different ways. The workers' demeanor was warm and supportive. These environments offered more freedom than most day cares, which is stimulating and encourages skill maintenance (Regnier & Pynoos, 1992). These factors fostered an environment that was comfortable and stimulating to clients.

These environments were notable in other ways:

Day care B had the highest worker:client ratio. Low worker:client ratio, usually thought to be an indicator of quality, did not predict better quality, and high worker:client ratio did not predict poorer quality.

Day cares A and B were the largest sites. There were no observation of agitation (Sloan et al., 1998) or emotional disturbance (Annerstedt, 1994), as has been associated with large day cares. Small care environments are usually related to more social interaction and friendship among clients (McAlister & Silverman, 1999; Moore, 1999; Netten, 1993), yet A and B, the largest day cares offered the most social interaction and were the most stimulating.

Their environments also defied the trend toward a homey atmosphere.

Although day care A did well interacting with clients, the workers were not actively trying to facilitate interaction among clients. They were trying to entertain them. Day care B did well stimulating clients, even though the workers were not stimulating clients. The environment itself was. Regardless of the method, these environments provided stimulation and supportive care.

#### Formal Activity Encouraged Interaction between Client and Worker

The inter-relationship between formal activities and worker:client interactions was exemplified in each day care. Formal activities promoted worker:client interaction. These activities stimulated clients and is a start in efforts to satisfy client needs to be occupied.

People with dementia value the process of the activity. Activity enhances self-confidence, self-esteem, quality of life (Baker, Wuest & Stern, 1992), maintenance of current levels of functionality (Rabbitt 1988), and well-being (Pulsford, Rushforth, & Connor, 2000).

Due to the consent problems, I was not able to further explore the day care client's ability to provide useful information through interview.

### **Researcher Comments**

Low response rate. Aside from the two day care managers' delay in sending out caregiver consent until it was too late, I believe the reason for the low caregiver response at the other two sites was caused by the method by which the caregivers were asked to respond to me (which was suggested by the university Institutional Review Board who reviews all research objectives, processes, and methods of consent). The IRB suggested that the caregivers telephone me, rather than have the caregiver provide consent for the day care manager to release their contact information to me. Then I would call them (as I had in Study 1).

The day care directors also suggested that the low response rate occurred because the caregivers were overburdened. One director stated that, "Even though your asking very little of them and even though they or their family member could potentially benefit, they just cannot imagine even doing one more thing. The families are simply just maxed-out."

Bad luck and bad timing. In addition to the poor choice of methodology used to contact and gain caregiver consent for the client, two facilities did not distribute the pre-consent forms to the caregivers. I sincerely believe that not distributing the forms was not of passive-aggressive intent. I am convinced that both managers were sincerely interested in participating in the study: their accommodating and interested behavior toward me, their interest in the study and effort put into talking about the day care with me, and their support of the study to their staff, making the staff approachable. Further, it was also each manager's choice to participate in the study,

not someone superior to either of them. I saw nothing to suggest that a manager, after choosing to participate in the study, changed her mind.

### **Limitations**

The sample was one of convenience, recruited from consenting facilities within a 45-mile radius of the researcher's home calling their facility a *day care service* and providing daytime care for four or more people with dementia.

### **Conclusions**

These day cares offered a peek at the variability in adult day care services for people with dementia. These were all typical environments because variability in day cares environments is the norm. Consistent among day care environments was the use of formal activities.

They are an important part of day care especially in environments with less dedicated and interactive workers, because these activities consistently encourage interaction.

## CHAPTER VI

## **Final Conclusions**

### **Tell Me That I'm Safe and Give Me Something to Do**

People with dementia need information. They need information about the environment they are in (their position in it, is it safe). They can't define the environment and their place in it as well as they used to. They need someone to get this information right to them, i.e., communicate that they are safe unequivocally. In the day care, that person is the worker. The worker can satisfy the client's need for feeling safe by interacting with the client in a supportive way.

People with dementia need occupation. They need something to do (activity, stimulation). They can't act independently (finding something to do) or motivate themselves (doing it) as well as they used to. They need someone to get something for them to do right to them, i.e., to put it in their hands. In the day care, that person is the worker. The worker can satisfy the client's need to be occupied by facilitating their involvement in interactions and activities.

Workers efforts to promote the involvement of their clients have the greatest influence on their response to treatment (Pulsford, Rushforth, & Connor). In the first evaluation, in Case Study 2, workers facilitated interaction and activity by:

1. Asking clients questions about their views, preferences, family: "Do you like these beets?" "Should we have tea again? Does everybody want tea?" "You're about to have a grandbaby, aren't you?" "I think I'd rather the rain just come at once than drizzle all day."
2. Asking clients questions about their past: "I don't remember it ever being this cold when I was a little girl. Do you?" "What was your town like as a child?"
3. Physical and verbal displays of affection: such as hugging when the clients

arrived and left, “I love you,” “Now, bundle up.”

4. Commenting on the clients’ present activity: “You crochet well. What are you making?” “Are those booties for your new grandbaby?” “You’re good at hitting the ball today! You’re on the ball!”
5. Participation in activities: crafts, memory games, dominoes, tea, lunching together, “Who was Ginger Rogers married to?” “I’m having a hard time getting the yarn to stick to the glue. Is anyone else?”
6. Providing a supportive, accommodating, non-critical environment: warm tone of voice and demeanor, and lack of criticism, “Come sit by me” “You’re doing a great job {knitting}. And you’re so fast!”

The workers’ efforts: promoted comment, promoted feelings of safety, required the making of choices, directed the clients’ attention and actions, recalled their attention to their current activity, oriented them to a future activity, promoted return-affection, promoted emotional responses, complimented clients, offered approval, reminded client of issues of personal relevance, stimulated clients, promoted the recall of general information, encouraged confidence, promote feelings of usefulness, heightened alertness, and elicited memories. They may also have encouraged group involvement and cohesion.

The workers efforts can make or break the success of a day care with regard to the clients, despite other positive environmental factors.



## **Adult Day Care Clients Are Good Reporters on Their Care Environment**

The people with dementia in the cases of this thesis were good reporters, answering most questions gladly and appropriately. On all accounts they provided useful information. They provided reports supported by my observations. They provided data that was triangulated with day care workers' data and found to be consistent. Conversely, clients reported that they did not benefit from day care, that they were moderately satisfied with it, and that they liked coming to day care. Without knowing how they defined benefits, one can't say whether these reports are inconsistent. My belief is that they were not considering *talking with others* or *making friends* a benefit. It appears that they validly reported what they liked most about day care.

So it is clear that clients like the company and talking at day care. What other sorts of data can they provide? They have provided perspectives of goals for their health care (Bogardus, Bradley, & Tinetti, 1998) and expressed interest in knowing more about their disease (Marzanski, 2000). A counseling program even exists for people with dementia focused on emotional support and helping them make sense of their experiences (Stokes & Goudie, 1990). There are informed people other than myself who are optimistic about the ability of the person with dementia to provide useful information with respect to the care environments they are a part of.

Clients provided useful information that contributed to this study of the day care environment. It is up to us to pose the right questions to them in order to get information with construct validity. This will require 'sit down' methods involving talking with the person and investigating meaning in the answers they provide.

If we can improve the means to reach the valid data inside people with dementia, there is real opportunity to improve their services, experiences, and life.



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## APPENDICES

Appendices A: Study 1 Client, Caregiver, and Worker Consent Forms

Pre Consent Form

**PLEASE sign  
and return by  
post today.**



**UNIVERSITY OF STIRLING**  
**Centre for Social Research on Dementia**  
Department of Applied Social Science  
Stirling FK9 4LA Scotland

Direct Telephone 01786 466303  
Facsimile: 01786 466306  
International Fax: +44 1786 466306  
e-mail: acm4@stir.ac.uk

Dear Carer,

I am a researcher from the University of Stirling and will be visiting the day care which your family member attends. I am interested in the activities provided by the day care and in any thoughts you and your family member have about day care in general.

In order for me to contact you to ask you these questions in the future, Alzheimer Scotland Action on Dementia must have your permission to give me your name and phone number. If you do agree to let me contact you, all information will be totally confidential and no names, phone numbers, or other personal details of yours or your family member's will be documented. However, if you do not agree to release this information, your family member's attendance at the day care will not be affected in any way.

Thank you very much,

Ann Monahan

---

Please tear off this portion, sign, and return by post in the enclosed self-addressed stamped envelope. Retain the above portion for your records.

I **give permission** for the day care to release my name and phone number to the researcher

I **do not give permission** for the day care to release my name and phone number to the researcher

Please sign \_\_\_\_\_ date \_\_\_\_\_

carer of: \_\_\_\_\_

## Family Consent

DATE:  
LOCATION ID#:  
ATTENDEE ID#:

### **The Benefits of Day Care From the User's Perspective**

#### **Information Sheet**

I am a PhD student from the University of Stirling conducting a study in day cares in the Central Scotland area. The purpose of the study is to describe the benefits of day care attendance, and to find out what you and your relative think the benefits of day care are. The study will start in March 1999 will be completed in June 1999.

I am asking your permission to include both you and your relative in this study. You are absolutely free to decide whether you or your relative take part in the study. You or your relative are also free to withdraw from the research at any time without it affecting your relative's care in the day care in any way. To help you make an informed decision I include the following information about what you and your relative's participation will involve:

I will be visiting the day care weekly and taking notes. I will interview your family member in day care. I will ask him/her questions about experiences s/he has had in day care, what s/he thinks are the benefits of day care, and I will give a short cognitive quiz; this all will take approximately 1 hour. I would also like to interview you. I will ask you about the ways both you and your relative have benefited by your relative's day care attendance. The interview with you will take approximately 1 hour. In order to ensure accurate information, the interview with you will be audiotaped. However, if you are uncomfortable with my audiotaping the interview, it can progress without it. I will also ask the day care manager about the benefits of day care for your relative.

All the information gathered from you and your relative will be assigned an identification number to assure anonymity. None of the information gathered will be linked to you, your relative, or the day care by name. All the information gathered will be kept in a locked filing cabinet at the University, which only my supervisor (Dr. Murna Downs) and I have access. If you would like to discuss this further or are unsure about anything, please contact Ann Monahan at the University on 01786 466300.

When you are sure you and your relative are willing to participate in the study, please complete the consent form.  
Please keep this for your records.



Family Consent  
DATE:  
LOCATION ID#:  
ATTENDEE ID#:

### The Benefits of Day Care From the User's Perspective Consent Form For Family

Name → Your Relative's Name: \_\_\_\_\_  
(please print clearly) Surname: \_\_\_\_\_

- Have you read the information sheet? Yes/No
- Have you been given a contact number should you have any questions about the study? Yes/No
- Do you understand what your participation will involve? Yes/No
- Do you understand that you can withdraw from the study at any time without giving any reason? Yes/No
- Do you understand that you can withdraw from the study at any time without your relative's care in the Day care being affected? Yes/No
- Do you agree that you will take part in this study? Yes/No

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

Print Name: \_\_\_\_\_

Relation to Day care Client: \_\_\_\_\_

## Client Consent

DATE:  
LOCATION ID#  
ATTENDEE ID#:

### **The User's Perspective**

#### **Information Sheet**

I am a PhD student from the University of Stirling working in the Central Scotland area. I would like you to describe any benefits you are experiencing here.

I will be asking your permission for you to be included in this study. You are absolutely free to decide whether or not to take part or to withdraw from the research at any time without it affecting you in any way.

To help you make an informed decision, I am giving you the following information about what your participation will involve:

I would like to interview you while at the day care. I would like to know what your experiences have been like here and if you think you have benefited from being here. I will ask you some other questions and to try to remember a few things. I will also ask your relative some questions about your day care. The meeting with you will take approximately 1 hour.

All the information gathered about you will be assigned a identification number to assure your anonymity. None of the information gathered will be linked to you by name. All the information gathered will be kept in a locked filing cabinet at the University, to which only my supervisor (Dr. Murna Downs) and I will have access.

If you would like to discuss this further or are unsure about anything, please contact Ann Monahan at the University on 01786 466300, or ask me questions at the day care.

When you are sure you are willing to participate in the study, please complete the consent form.

Client Consent  
DATE:  
LOCATION ID#  
ATTENDEE ID#:

## The User's Perspective

### Consent Form

Client's Name → First name: \_\_\_\_\_

(please print clearly) Surname: \_\_\_\_\_

- Have you read the information sheet? Yes/No
- Have you been given a contact number should you have any questions about the study? Yes/No
- Do you understand what your participation will involve? Yes/No
- Do you understand that you can withdraw from the study at any time without giving any reason? Yes/No
- Do you understand that you can withdraw from the study at any time without your care in the Day care being affected? Yes/No
- Do you agree to take part in this study? Yes/No

Signature of Client: \_\_\_\_\_ Date: \_\_\_\_\_

Print name: \_\_\_\_\_

Appendix B: Study 1 Client, Caregiver, and Worker Survey Data Organized into  
Tables

22CR		17CR	
Yes		Yes	
Yes		No	
yes		Yes	
Yes, quite a lot.		Yes	
Sometimes at home is lonely. I have a daughter and husband at home. I like the company.			<i>It passes the time. I just tag along with the rest. The company. I get to know different people.</i>
Not really, no. I rather enjoy it.			<i>I wouldn't say that. I enjoy the company..</i>
Yes, I'm sure I could.			<i>No, but I like the company.</i>
The company. I like the company very much.			<i>There is no benefit to come out of it, but I am with other people enjoying the company.</i>
I don't really think so. No.			<i>No. I have no family, I am on my own. I have a sister, I don't live with her. (does she benefit?) don't think so.</i>
We go out a lot.			<i>It passes the time of the day.</i>
No. I don't think so. I get on very well with them all.			<i>No.</i>
I have more company than before.			<i>No. I just join in on the company.</i>
No. I have a husband and a daughter at home.			<i>It's a wee bit far out, maybe, too far out to come too much.</i>
No. I like them all. All are very good. A lot of them I've known a long time.			<i>No.</i>
Oh, yes. I've made friends here.			<i>Maybe, I'm not thinking right. I'm good for a laugh if anything.</i>
No.			<i>No.</i>
No. all are very kind.			<i>No, they help out.</i>

No	15CR
No	
yes	
Yes.	
<i>Nothing in particular, I like you.</i>	
<i>No. I can't say I don't like anything.</i>	
<i>Don't think so. I don't know anybody here.</i>	
<i>No. No benefits to me.</i>	
No	
<i>Nothing all the time.</i>	
<i>I'd set it on fire. (why?) to burn it. (why) cause it's no use to me. It's all rubbish.</i>	
No	
No	
<i>Don't come back. Find a better job.</i>	
<i>No. I don't see anything great about this place.</i>	
<i>(Client did not remember being picked-up)</i>	
<i>No. They are nice people.</i>	

Yes	No
No	No
Yes. Interviewed client on 2 <sup>nd</sup> try.	yes
Yes.	Yes
Atmosphere is good. I get left to myself.	Not much to improve about it. We get the best of everything. I look forward to coming here. There are days when I don't feel like coming and I'd rather be at home, but I can't say anything against it and the people are wonderful [staff]. We are very well-looked-after and the food is good.
No	That would be unfair. The bus comes to our very door. It's first class. Everybody's pleasant.
No	Yes.
No financial benefits. (other benefits?) no.	I'm in the house myself. It's nice, real nice. I'm using my own language, who the hell can ask for more? I've nothing but praise for the place. Extremely nice people and it doesn't cost us a cent. I can't speak of it highly enough. Everybody gets the same treatment. Doesn't cost us a farthing. Nice people, pleasant. It smells like home. It's private. I enjoy my day here. Everybody is like yourself—pleasant and easy to talk to. The only day I've not come is if I woke up with a headache. I've never missed a day.
No	<b>I think so, because she's worried stiff. She'll not always have me. I'm 82.</b>
Tea and toast in the morning.	She must not expect to eat me out of the house. This is a typical day. Nice meal. Everybody is pleasant. I'm quite sure no one would miss it. I'm quite sure everyone feels the same or they wouldn't be here.
No	No. keep It as it is. Everything is great, everything is done for us.
No	I'm a wee bit more tolerant of myself, and my daughter, and other people.
I don't know.	No, because it wouldn't be good the same. Two days is fine. It gives me something to look forward to.
No	No, they don't need it. They have kind, gentle manners. It couldn't be improved upon. What more could anybody ask for. I've never heard one unpleasant word since I've been coming here, you can put that down.
It depends on the friends, but I could recommend it.	yes
No	Excellent, they come to my gate, take me back to my gate.
no	They take things in earnest.

Yes	Yes	3CR
Yes	Yes	
Yes	Yes	
Yes	Quite like coming here.	
<i>It's good company. It keeps me from sitting in the house for 4 hours. Everyone is friendly.</i>	<i>It passes the time. It's homey.</i>	
No	<i>Can't really say—I've not looked at it seriously enough.</i>	
<i>Yes. Can't confide in neighbors, you don't know what they would say.</i>	<i>Depends on what type of problem.</i>	
<i>A lot of benefits, everyway. (how?) they treat you fine.</i>	<i>None. It gets me out of the wife's way.</i>	
<i>Oh yes, they have their own job everyday and meals to make, so they don't have to worry with me.</i>	<i>I don't think so. No, unless she wants to get me out of her way.</i>	
<i>Some days we paint, other days we're looking through pictures. Coming here really and truly helps you.</i>	<i>Whatever they're doing, I follow on.</i>	
No	No	
No	<i>Don't know the answer to that.</i>	
<i>I'm alright now with the 3 days, the 3 days is quite sufficient, and it keeps my sons doing their job.</i>	<i>Wouldn't mind. Yes.</i>	
<i>No, because they've got their own advice.</i>	No	
<i>I don't have any friends. If had friends would tell them to come.</i>	Yes	
No	No	
<i>No, are alright, are nice.</i>	No	



11CR		1CR		2CR	
No	Yes	No	Yes	No	Yes
No		No			
No		No			
Yes		Yes			
Yes		<i>Oh eye, I could stay here all the time, it's lovely.</i>			
<i>I come for the company, the talking.</i>		<i>Everything that's here, the dancing.</i>		<i>It's friendly, I get to meet people and talk to them. Being a christian, I don't like to hide my light, I like to spread it.</i>	
No		<i>Not a thing.</i>		No	
No		No		No	
<i>Is always company.</i>		<i>I like it and it's nice. I like the place. I like the people</i>		<i>Meeting people, learning different ways. It can help if people need to be advised (PWD referring to religious guidance).</i>	
No		No		No, but it's good to be separated sometimes.	
<i>I like to see the company</i>		<i>(client points out the window to the mountains) see up at the very top. Like that It's great.</i>		<i>Knitting, keeps me busy. We do what we like.</i>	
<i>No, they've been too long with it.</i>		No, not a thing.		No	
no		No		No	
<i>No, the time I come is alright.</i>		No		No	
no		<i>I just say how's you doing that's all. I have nothing to do with it.</i>		No	
yes		<i>No. got nothing to do with me.</i>		Yes	
<i>Couldn't do without it</i>		No		No	
<i>I like them all</i>		No		No	

Yes	CR19	12CR could not include client-lives in housing facility	Yes
Yes			Yes
Yes			Yes
Yes, it's quite good.			Yes
The people and everything else. We meet a lot of different people you can sit and talk to. I enjoy coming. I get on well with them all.		Girls are very good, and acceptable, nothing is a bother to them. They will talk to you about anything and take you as you are. It is very good. I'm glad to come into this place. Are safe and everything else. Are well looked-after.	
No			No
Yes			Yes
I enjoy it. It gets me out of the house. There's nothing to do in Lennoxton.		Don't need to cook. No one comes to me to cook. All the people, we enjoy ourselves. The company.	
No		Yes, they know I'm safe.	
We play dominoes, sit and blether.		Is very good. Look at photographs of stars. Couldn't ask for any better people.	
No, don't think so.		No	
No. I'm still the same.		No	
No. This is enough.		Yes	
No. they're doing fine.		No	
Eye would, eye. I definitely would.		Yes	
No		<b>N/a client lives in housing facility.</b>	
They're good. Can't do enough for you.		Thoughtful, nothing is any bother to them. They really try to plan for good times.	

No	No	16CR
Yes	No	
Yes	Yes	
Most of the time.	Yes	
The friendly people.	The talking	
Can't say there is anything I don't like.	No	
No.	No	
There are no benefits	I enjoy myself. We talk.	
He gets some time to do what he wants when I'm here.	No	
We keep busy.	Chatting, tea in the morning	
Nothing.	No	
No.	No	
No.	No	
No.	I think so.	
Yes.	No. They pick us up everyday and that's not bad.	
No.	No. I like them/	
No.		

5CR	No		No	No, client did not understand. She is a normally talkative person too.	Could not get any information from her. She did not seem to understand what I wanted.	---	---	---	---	---	---	---	---	---	---	---	---	---
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<p><i>Why did you choose this particular day care? How learn of this dc? )</i></p>	<p><b>CG1</b></p>
<p><i>Did You Consider Using Other Day cares?</i></p>	<p><i>What Are The Benefits Of This Day care To You?</i></p>
<p><i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i></p>	<p><i>Do You Have More Time To Yourself?</i></p>
<p><i>How Do You Spend The Time When Your Relative Is In Day care?</i></p>	<p><i>Has Your Level Of Distress With Caregiving Increased, Decreased, Or Stayed About The Same, Since Your Relative Began Attending Day care</i></p>
<p><i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i></p>	<p><i>Are There Any Services That The Day care Does Not Provide That You Would Like Provided?</i></p>
<p><i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is? )</i></p>	<p><i>What effect does day care have on your relative?</i></p>
<p><i>If s/he does benefit, why do you think s/he benefits?</i></p>	<p><i>Unsol Check box if mentioned</i></p>
<p><i>Unsol Support</i></p>	<p><i>Unsol Caring related burden comments</i></p>
<p><i>Comments about staff?</i></p>	<p><i>Where do you get most information about dementia education? (Has the day care provided any?)</i></p>
<p><i>Comments about transportation?</i></p>	

Recommended. Social work services sent Lorraine and she still comes once a month..
No
To get a wee break.It is a relief having her out of house, takes pressure away, and stress away. I have to make sure she's not doing anything she shouldn't. .[See, I have to do everything for her; I lay out her clothes in the order she should wear them, and invariably, she puts things on in the wrong order. I went to buy a paper today, then heard the fire alarm and had to come home. She was standing in the doorway. The bread had failed to come up and was on fire and she couldn't do anything about it. All she had to do was switch it off.']
Walk daily, tend garden, play golf, go to Perth to have my accordion tuned,
'Oh eye. It is a bit of a relief. Don't know what I would do without it.'
Walk daily, tend garden, play golf, go to Perth to have accordion tuned. I have time to go out and do things.
'Decreased on days she goes to day care, but overall it is higher since she was diagnosed (last year).'
'I'd like a way to go on holiday. I need a holiday. Either respite or day care where I go so I could take her.'
'I don't know anything about it.'
It tires her out mentally and physically. She's always ready to go somewhere when she gets home.
She says she likes it , but doesn't say much about it. She says the people are nice.
Mood improvements
Are very helpful, are very good.
yes
Are on time.

**CG2**

<i>Why did you choose this particular day care? How learn of this dc.?</i>
<i>Did You Consider Using Other Day cares?</i>
<i>What Are The Benefits Of This Day care To You?</i>
<i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i>
<i>Do You Have More Time To Yourself?</i>
<i>How Do You Spend The Time When Your Relative Is In Day care?</i>
<i>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</i>
<i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i>
<i>Any Services That The Day care Does Not Provide That You Would Like Provided?</i>
<i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is?</i>
<i>What effect does day care have on your relative?</i>
<i>If s/he does benefit, why do you think s/he benefits?</i>
<i>Unsol Check box if mentioned</i>
<i>Unsol Support</i>
<i>Unsol Caring related burden comments</i>
<i>Comments about staff?</i>
<i>Where do you get most information about dementia education? (Has the day care provided any?)</i>
<i>Comments about transportation?</i>

It was chosen for me. It had just started.
No.
For those 5 hours while she is at day care, I choose what I want to do. It pleases me to see her enjoy herself. And it pleases her. The chat that arises from going to day care. Her attitude has changed and our relationship has improved, and my stress has been reduced. It has provided information about other services available and has been responsible for increasing my knowledge of dementia. Leslie and Edna have been a tremendous help. Their visits, contacts, and outings make me feel like I have a backup. It has made my job much easier.
Go out on my own: to Stirling, supermarket, look around shops, clothes shopping, visit my friends that she's not interested in.
yes
I am free to do whatever I feel like doing. Sometimes I stay in the house and enjoy just pottering around, reading, or go for a walk.
Decreased.
No. I feel that other people have more need. We can get out and about together.
No. I can't think of any.
They have tea and toast in the morning. Singing, some creative activities, games, knitting is always available and she likes that.
She is fuller of life when she comes home. Wanting to chat. It helps her tremendously. Improves her personality. She's happier and more relaxed about everything. It boosts her ego, she feels good about herself. Increases confidence.
It is a stimulating experience for her. The relationship with the helpers. They are so good to her, they chat, and are affectionate. It boosts her ego, she feels good about herself. Increases confidence. She has always been overanxious, bossy, she is the oldest child, and irritable and bad-tempered before attending day care, but after beginning day care, her personality has
Emotional improvements. Mood improvements. Happiness.improvements.
They have been a tremendous help. Their visits and contacts have been a comfort. And the 24 hour helpline is a comfort, just knowing it is there.
She's really no trouble. We do a lot together.
Leslie and the other girls are really nice people, so warm and supportive.
<i><u>problems she's having and I can cope better. Now I know that she can't help it and that we can't reason things out. I know that it is an organic illness. It has provided information about other services available and has</u></i>
They pick her up on time every day.



<p><i>Why did you choose this particular day care? How learn of this dc.?</i></p>	<p><b>CG3</b></p>
<p><i>Did You Consider Using Other Day cares?</i></p>	<p><i>What Are The Benefits Of This Day care To You?</i></p>
<p><i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i></p>	<p><i>Do You Have More Time To Yourself?</i></p>
<p><i>How Do You Spend The Time When Your Relative Is In Day care?</i></p>	<p><i>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</i></p>
<p><i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i></p>	<p><i>Any Services That The Day care Does Not Provide That You Would Like Provided?</i></p>
<p><i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is?</i></p>	<p><i>What effect does day care have on your relative?</i></p>
<p><i>If s/he does benefit, why do you think s/he benefits?</i></p>	<p><i>Unsol Check box if mentioned</i></p>
<p><i>Unsol Support</i></p>	<p><i>Unsol Caring related burden comments</i></p>
<p><i>Comments about staff?</i></p>	<p><i>Where do you get most information about dementia education? (Has the day care provided any?)</i></p>
<p><i>Comments about transportation?</i></p>	

The social worker asked if bill would like to go.
No.
It takes the pressure off, which is quite a lot. I must watch him a lot of the time, and bathe him. When he is gone I can get things done without having to worry about him.
I can run into Stirling. I can do anything between 10 and 3.
Yes.
Gardening, housework, shop. I can do anything between 10 and 3.
Stayed about the same.
I would have him at Alva rather than the other day care if I could because he likes it. Yes, and he would want to go also.
No.
He doesn't tell me much. He doesn't ever remember eating.
It makes him happy. He really enjoys it. Happy as a laurie
It keeps him busy. He exercises, plays quizzes. It keeps him awake. Gets his mind working and all this makes him happy. I don't know what he would do (without it). He thinks he's going to work and he's as happy as a laurie.
Increased happiness
Yes.
Caring for him is no problem.
The drivers are nice.
Day care.
They are always prompt to pick him up and if they're late, they call.

**CG7**

<i>Why did you choose this particular day care? How learn of this dc.?</i>
<i>Did You Consider Using Other Day cares?</i>
<i>What Are The Benefits Of This Day care To You?</i>
<i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i>
<i>Do You Have More Time To Yourself?</i>
<i>How Do You Spend The Time When Your Relative Is In Day care?</i>
<i>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</i>
<i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i>
<i>Any Services That The Day care Does Not Provide That You Would Like Provided?</i>
<i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is?</i>
<i>What effect does day care have on your relative?</i>
<i>If s/he does benefit, why do you think s/he benefits?</i>
<i>Unsol Check box if mentioned</i>
<i>Unsol Support</i>
<i>Unsol Caring related burden comments</i>
<i>Comments about staff?</i>
<i>Where do you get most information about dementia education? (Has the day care provided any?)</i>
<i>Comments about transportation?</i>

Rhona contacted me. To get a bit of a break
No
Freedom to do things. I have free time. I don't have to worry about whether she's all right in the house- I have to keep my eye on things when she's here. I am getting by at the moment and am quite pleased with the relief from day care.
Nothing. I always got things done. I could cook before. Now am doing more of it and now am also cleaning.
On the days she goes only.
I can go out because ceilia is not always interested in things I want to do. I have some handy work to do and I can get that done.
Stayed about the same.
No. At moment am coping well.
No.
Knitting. I don't know what she gets up to. Sing songs. They (the staff) help care for them.
I don't know but it must be a help to her.
Mixing with other women. It is different from what she has here. I hope she benefits. It must be a help to her. Although she is reluctant to go and says she'll never go again, it must be good for her. Rhona says she is fine and seems to enjoy herself.
Bathtime and getting her soiled clothes are the only problems.
The girls who pick her up are good and when they come in the house she is ready to go with them.
The library. No.

**CG8**

<i>Why did you choose this particular day care? How learn of this dc.?)</i>
<i>Did You Consider Using Other Day cares?</i>
<i>What Are The Benefits Of This Day care To You?</i>
<i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i>
<i>Do You Have More Time To Yourself?</i>
<i>How Do You Spend The Time When Your Relative Is In Day care?</i>
<i>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</i>
<i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i>
<i>Any Services That The Day care Does Not Provide That You Would Like Provided?</i>
<i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is.?)</i>
<i>What effect does day care have on your relative?</i>
<i>If s/he does benefit, why do you think s/he benefits?</i>
<i>Unsol Check box if mentioned</i>
<i>Unsol Support</i>
<i>Unsol Caring related burden comments</i>
<i>Comments about staff?</i>
<i>where do you get most information about dementia education? (Has the day care</i>
<i>Comments about transportation?</i>

To get a break. It was very hard to handle. social worker.
No. this was the only one offered.
I get a rest.
Can do nothing new.
Yes.
I visit with friends, go to the shops, meet my daughter for coffee and a chat.
Decreased.
If he wanted to and he probably would.
No.
I don't know. He says they talk.
He tells me all the gossip, I don't know if he makes it up or not. We blether. He is more with it. More sensitive and sensible.
He enjoys it. He is more talkative. He is with men his own age.
Amount and quality of conversation improved
My daughters. No.
They come between 10 and 11:30 and it doesn't bother me but he gets agitated when

**CG5**

<i>Why did you choose this particular day care? How learn of this dc?)</i>
<i>Did You Consider Using Other Day cares?</i>
<i>What Are The Benefits Of This Day care To You?</i>
<i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i>
<i>Do You Have More Time To Yourself?</i>
<i>How Do You Spend The Time When Your Relative Is In Day care?</i>
<i>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</i>
<i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i>
<i>Any Services That The Day care Does Not Provide That You Would Like Provided?</i>
<i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is?)</i>
<i>What effect does day care have on your relative?</i>
<i>If s/he does benefit, why do you think s/he benefits?</i>
<i>Unsol Check box if mentioned</i>
<i>Unsol Support</i>
<i>Unsol Caring related burden comments</i>
<i>Comments about staff?</i>
<i>Where do you get most information about dementia education? (Has the day care provided any?)</i>
<i>Comments about transportation?</i>

Sw suggested it. It gives me a bit of a break
No
It gives me a bit of a break. It is a great benefit. I can relax. The mornings are hectic till she leaves but once they pick her up I can relax. I don't have to worry about locking doors.
I wasn't able to have a break before.
Yes.
I can get out to the garden without having to wonder if she is in or out or what she's doing.
Stayed about the same. It has helped but she's getting worse.
No, 2 days is sufficient.
I thought they could find someone who could cut hair while at day care or suggest someone elsewhere who could. Mentioned to staff but not come to anything
They make flower arrangements, make things. I really don't know. Have dinner. She doesn't tell me much.
She knows the people who come for her. She says they are nice people. She comes away quite happy.
They kiss and hug her when they drop her off. She gets a new environment. She gets to be with other people and it is different from in this house.
Happiness improved
Margaret has a habit of turning on gas without lighting eyes, day care arranged for someone to install an alarm on the gas oven and install an alarm on the back door. (he did not refer to this as support)
Margaret is a problem, she wants to visit an aunt. I turn my back and she's out the door.
The people are lovely. Are nice people. Are brilliant, lovely. So understanding and helpful in everything they do. It's the way they talk to her and treat her, friendly and there is nothing regimental about it.
Don't have much.
It's good if you now exactly when they are coming. Tull comes sometime after 10. Alva comes at 9:45 always. They both always come around 10.



**CG6**

<i>Why did you choose this particular day care? How learn of this dc.?</i>
<i>Did You Consider Using Other Day cares?</i>
<i>What Are The Benefits Of This Day care To You?</i>
<i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i>
<i>Do You Have More Time To Yourself?</i>
<i>How Do You Spend The Time When Your Relative Is In Day care?</i>
<i>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</i>
<i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i>
<i>Any Services That The Day care Does Not Provide That You Would Like Provided?</i>
<i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is?</i>
<i>What effect does day care have on your relative?</i>
<i>If s/he does benefit, why do you think s/he benefits?</i>
<i>Unsol Check box if mentioned</i>
<i>Unsol Support</i>
<i>Unsol Caring related burden comments</i>
<i>Comments about staff?</i>
<i>Where do you get most information about dementia education? (Has the day care provided any? )</i>
<i>Comments about transportation?</i>

Sw dept mentioned it. We both (my husband and I) work so it is necessary.
No.
We were going mad because she was not seeing to herself, even basics like bathing. So we had to do it which was extra work for us and we had no time. it takes away the pressure.
I am able to have better and stimulating conversations with her.
Yes. Didn't effect work day but don't spend so much time there at night.
Mostly no differently, except that husband doesn't check on her throughout the day. But I know that she's being cared for.
Decreased markedly.
Yes. She needs something to do for the bulk of the day everyday.
No.
They do her hair, give her a shower, she eats, bakes, shops, sews, paints. Made Easter card.
She is always excited in the morning to go. She is happier. Better communication. More stimulating conversation. She says good morning. She'd forgotten the days but not anymore. She is more interested in herself. She drinks less sherry. It has made her so much happier, the change is amazing.
It must be the people, attention. They make her feel quite special. It makes her think. Maybe it's the small groups; mother said they are small.
Improvements in happiness, conversation, life interest

**CG 17**

<i>Why did you choose this particular day care? How learn of this dc?)</i>
<i>Did You Consider Using Other Day cares?</i>
<i>What Are The Benefits Of This Day care To You?</i>
<i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i>
<i>Do You Have More Time To Yourself?</i>
<i>Day care?</i>
<i>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</i>
<i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i>
<i>Any Services That The Day care Does Not Provide That You Would Like Provided?</i>
<i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is?)</i>
<i>What effect does day care have on your relative?</i>
<i>If s/he does benefit, why do you think s/he benefits?</i>
<i>Unsol Check box if mentioned</i>
<i>Unsol Support</i>
<i>Unsol Caring related burden comments</i>
<i>Comments about staff?</i>
<i>Where do you get most information about dementia education? (Has the day care provided any?)</i>
<i>Comments about transportation?</i>

Sw informed me of day care.
No.
I'm pleased. It takes a load off me. I know he is alright, getting looked after.
I don't worry about him and I can't leave my house.
Yes.
I don't worry about him and I can't leave my house
Decreased, because I know he's all right.
Yes, if he wanted to go.
No.
I don't know.
.He brightens up in company. He says it's (day care) his home now .
.It passes the time, takes him out of the house. He enjoys it. He loves to chat up the girls. Getting out and mixing with others is good. The girls that come for him are nice. He's as bright as a button when they arrive.
Our father died when he was 16 and as the oldest boy, he took over and was good to us. You don't forget these things. He's really no bother
They must have a love for their job.
Dr. gave me a book about it. No.
The girls that come for him are nice . He's as bright as a button when they arrive.

<p><i>Why did you choose this particular day care? How learn of this dc?)</i></p>	<p><b>CG22</b></p>
<p><i>Did You Consider Using Other Day cares?</i></p>	<p><i>What Are The Benefits Of This Day care To You?</i></p>
<p><i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i></p>	<p><i>Do You Have More Time To Yourself?</i></p>
<p><i>How Do You Spend The Time When Your Relative Is In Day care?</i></p>	<p><i>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</i></p>
<p><i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i></p>	<p><i>Any Services That The Day care Does Not Provide That You Would Like Provided?</i></p>
<p><i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is?)</i></p>	<p><i>What effect does day care have on your relative?</i></p>
<p><i>If s/he does benefit, why do you think s/he benefits?</i></p>	<p><i>Unsol Check box if mentioned</i></p>
<p><i>Unsol Support</i></p>	<p><i>Unsol Caring related burden comments</i></p>
<p><i>Comments about staff?</i></p>	<p><i>Where do you get most information about dementia education? (Has the day care provided any?)</i></p>
<p><i>Comments about transportation?</i></p>	

Sw	
No.	
She is in their care. I know she's under care of good people. Don't have to look over her shoulder., don't worry about her hurting herself or others. Can get work done, deskwork, reading.	
Don't have to look over her shoulder., don't worry about her hurting herself or others. Can get work done, deskwork, reading. I have become a house husband. I have learned new skills.	
No. never have.	
deskwork, reading	
Sayed about the same.	
No.	
No.	
Occupational therapy, crafts	
She looks forward to it. jogs memory. She talks about staff. She says she's happy. She used to be a nurse and sometimes thinks she works there.	
She is with people of her generation, relating to people.jogs memory.she knows and likes the staff.	
Increased happiness.	
I know she's under care of good people. They are not just interested in lifting and laying; they are interested in families interest.	
No.	
Erratic pick up and drop off times.3hrs on bus per day, wonder if this is good use of qualified staff.	

<p><i>Why did you choose this particular day care? How learn of this dc.?)</i></p>	<p><b>CG21</b></p>
<p><i>Did You Consider Using Other Day cares?</i></p>	<p><i>What Are The Benefits Of This Day care To You?</i></p>
<p><i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i></p>	<p><i>Do You Have More Time To Yourself?</i></p>
<p><i>How Do You Spend The Time When Your Relative Is In Day care?</i></p>	<p><i>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</i></p>
<p><i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i></p>	<p><i>Any Services That The Day care Does Not Provide That You Would Like Provided?</i></p>
<p><i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is?</i></p>	<p><i>What effect does day care have on your relative?</i></p>
<p><i>If s/he does benefit, why do you think s/he benefits?</i></p>	<p><i>Unsol Check box if mentioned</i></p>
<p><i>Unsol Support</i></p>	<p><i>Unsol Caring related burden comments</i></p>
<p><i>Comments about staff?</i></p>	<p><i>Where do you get most information about dementia education? (Has the day care provided any?)</i></p>
<p><i>Comments about transportation?</i></p>	

Social worker suggested she use it.
No.
I have time to myself. Before I found it hard to manage. I wasn't well myself.
Doing volunteer work. I'm trying to get a job and am finding it difficult so I am doing volunteer work until then. It was a godsend to me to get time to myself.
Yes.
Decreased.
No.
No.
They listen to music, sit and have a blether,, but apart from that I don't know what kind of place it is.
It brightens her up. Puts her in a happier frame of mind. She is not as stressed out. It makes her tired. She looks forward to going.
Change of company and change of environment. She is with other people like herself. The girls make a fuss over her when they bring her home.
Mood improvements, happiness improvements
The girls make a fuss over her when they bring her home. They are very nice.
No.
Happy with it.



<p>Getting out is very important to her. Being confined to the house is one of the worst things for her. Social worker.</p>	<p>Why did you choose this particular day care? How learn of this dc?)</p>
<p>No.</p>	<p>CG11</p>
<p>It is a relief to me to see her going out. It has been great, but the opportunities to use day care and respite should be extended.</p>	<p>Did You Consider Using Other Day cares?  What Are The Benefits Of This Day care To You?</p>
<p>I can get out and about, otherwise I would be stuck here.</p>	<p>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</p>
<p>Yes. It is respite for me.</p>	<p>Do You Have More Time To Yourself?</p>
<p>I have always been a bit of a countryman, going out walking. I like get out and meet my pals.</p>	<p>How Do You Spend The Time When Your Relative Is In Day care?</p>
<p>Decreased.</p>	<p>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</p>
<p>Yes.</p>	<p>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</p>
<p>No.</p>	<p>Any Services That The Day care Does Not Provide That You Would Like Provided?</p>
<p>They watch television, sometimes go on bus runs. Wee parties. Should be extended with more trained people (e.g. opportunities to use day care).</p>	<p>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is?</p>
<p>She's quite cheered up by going and quite perky when comes back. It takes her away from lookin at the wall and lookin at me. Talkative when she comes back.</p>	<p>What effect does day care have on your relative?</p>
<p>Different environment.</p>	<p>If s/he does benefit, why do you think s/he benefits?</p>
<p>Improved mood, improved amount conversation, improved happiness.</p>	<p>Unsol Check box if mentioned</p>
	<p>Unsol Support</p>
	<p>Unsol Caring related burden comments</p>
<p>Nice when they come for her. Their way of handling them is quite good. There should be nurses at day care.</p>	<p>Comments about staff?</p>
<p>Pamphlets from Fraser House. None from whitehill.</p>	<p>Where do you get most information about dementia education? (Has the day care provided any?)</p>
<p>Biggest prob is they say will come 9-11. I have to have her ready for 9. Wife often thinks they aren't coming.</p>	<p>Comments about transportation?</p>

<i>Why did you choose this particular day care? How learn of this dc.?</i>	<b>CG15</b>
<i>Did You Consider Using Other Day care You?</i>	
<i>What Are The Benefits Of This Day care You?</i>	
<i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i>	
<i>Do You Have More Time To Yourself?</i>	
<i>How Do You Spend The Time When Your Relative Is In Day care?</i>	
<i>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</i>	
<i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i>	
<i>Any Services That The Day care Does Not Provide That You Would Like Provided?</i>	
<i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is?</i>	
<i>What effect does day care have on your relative?</i>	
<i>If s/he does benefit, why do you think s/he benefits?</i>	
<i>Unsol Check box if mentioned</i>	
<i>Unsol Support</i>	
<i>Unsol Caring related burden comments</i>	
<i>Comments about staff?</i>	
<i>Where do you get most information about dementia education? (Has the day care provided any?)</i>	
<i>Comments about transportation?</i>	

Why did you choose this particular day care? How learn of this dc.?)	Daughter checked into it
Did You Consider Using Other D	No
What Are The Benefits Of This Day care To You?	It gives me some time to myself. He can be very tiring looking after. I know they are looking after him well. Gives me a break during the week. I benefit a great deal from his going. I can get rest.
What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?	Get around to doing things. Can get out for a while while he's away. Can catch up on crochet, macromet, tv, sleep. I can do as I like. Can potter in the garden. can do things I can't manage to do while he's around.
Do You Have More Time To Yourself?	Yes.
How Do You Spend The Time When Your Relative Is In Day care?	
You Level Of Distress W/Caring Increased, Decreased, Same, Since Day care	Decreased.
Would You Like Your Relative To Attend Day care More Than S/He Does Now?	Yes.
Any Services That The Day care Does Not Provide That You Would Like Provided?	No.
What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the	They have lunch, afternoon tea. tea dances. the place is big enough that they can get on their own.
What effect does day care have on your relative?	He seems to be quite fond of it. He gets up sharp on the mornings he's going. He gets up like a shot.
If s/he does benefit, why do you think s/he benefits?	It's good for him. He's glad to go, is very happy to go, anxious to go.
Unsol Check box if mentioned	
Unsol Support	
Unsol Caring related burden comments	
Comments about staff?	Very nice.
Where do you get most information about dementia education? (Has the day care provided any?)	Daughter. None from Whitehill.
Comments about transportation?	The bus is nice. Two ladies come and they take him by the hand.

Sw recommended
No
Can get away, get a break.
Relax a bit. Couldn't ever leave her alone.
No- just when she's gone to day care.
Bike. Go to the bank, run errands.
Decreased.
Only if she wanted to. Don't know if she'd want to go another day.
No
Bingo, trips, dominoes,
She comes home smiling and laughing. She likes it. She is more talkative when she comes home.
It's good for her to get out. She talks to people there and she gets on with them. She likes the people.
Mood, happiness improvements, amt conversation improvements.
Are good.
Sw gave me book. None from Whitehill.
No prob for me. Prob for her-she has to wait.

<p><i>Why did you choose this particular day care? How learn of this dc.?)</i></p>	<p><b>CG16</b></p>
<p><i>Did You Consider Using Other Day cares?</i></p> <p><i>What Are The Benefits Of This Day care To You?</i></p>	<p><i>What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?</i></p>
<p><i>Do You Have More Time To Yourself?</i></p>	<p><i>How Do You Spend The Time When Your Relative Is In Day care?</i></p>
<p><i>You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care</i></p>	<p><i>Would You Like Your Relative To Attend Day care More Than S/He Does Now?</i></p>
<p><i>Any Services That The Day care Does Not Provide That You Would Like Provided?</i></p>	<p><i>What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is.?)</i></p>
<p><i>What effect does day care have on your relative?</i></p>	<p><i>If s/he does benefit, why do you think s/he benefits?</i></p>
<p><i>Unsol Check box if mentioned</i></p>	<p><i>Unsol Support</i></p>
<p><i>Unsol Caring related burden comments</i></p>	<p><i>Comments about staff?</i></p>
<p><i>Where do you get most information about dementia education? (Has the day care provided any?)</i></p>	<p><i>Comments about transportation?</i></p>

She was sitting so much and doing nothing so I went to the sw.
No
I have peace of mind all day when she's at day care and I can do something else.
I can plan to do anything I want that day.
Yes, definitely.
I go to my church club. I do work for her (PWD) in her home like clothes washing and grocery shopping.
Increased, because she is getting worse.
Yes but more might be too much for her.
No.
Tea in the morning, games, bingo, puzzles, sandwiches, sometimes lunch, they take them out in the summer.
She says she enjoys it. There is a box of old-fashioned stuff, it takes her back. She says it's nice but small, and the girls are nice. She is more chatty when she arrives home from day care, and is quite bright. The days she doesn't go she is quite depressed, yet wouldn't be fit to go
Being with others like her, and she likes the people there and the girls who work there.
Mood and amt of conversation improved.
Chap who drives bus is helpful. Girls are nice. PWD likes the girls who work there. Have only talked to Rhona on phone but she was nice.
Daughter bought her book, no information from Whitehill.
Chap who drives bus is helpful.

Why did you choose this particular day care? How learn of this dc.?)	CG
Did You Consider Using Other Day cares?	
What Are The Benefits Of This Day care To Yo	
What Things Have You Been Able To Do Now That You Were Not Able To Do Before Your Relative Began Attending This Day care?	
Do You Have More Time To Yourself?	
How Do You Spend The Time When Your Relative Is In Day care?	
You Level Of Distress W/Cging Increased, Decreased, Same, Since Day care	
Would You Like Your Relative To Attend Day care More Than S/He Does Now?	
Any Services That The Day care Does Not Provide That You Would Like Provided?	
What Do You Think A Typical Day Is Like for your relative in day care? and what do you think the activities/schedule is?)	
What effect does day care have on your relative?	
If s/he does benefit, why do you think s/he benefits?	
Unsol Check box if mentioned	
Unsol Support	
Unsol Caring related burden comments	
Comments about staff?	
Where do you get most information about dementia education? (Has the day care provided any?)	
Comments about transportation?	

#### RELATIVE DEMOGRAPHICS

1. Age
2. Sex
3. Date relative began attending this day care: \_\_\_\_\_
4. Days per week attends this day care: \_\_\_\_\_
5. Address (check box if same as caregiver )

#### Check box if Caregiver mentions improvement or declines in the following:

6. Emotional improvements  or declines ?
7. Mood improvements  or declines ?
8. General level of interest in life improvements  or declines ?
9. Amount and quality of conversation improvements  or declines ?
10. Happiness improvements  or declines ?

S3	<p>Respite. Knowing their relative is in a safe environment while they get time to themselves.</p>	<p>Mental stimulation, socializing, meeting people if their own age. For those living on their own- the benefit is getting a hot meal. Some benefit from personal care, showers.</p>
S2	<p>break, reduces their stress level, by giving them time out. They know their relative is in a safe environment and getting taken care</p>	<p>Activities help their mind and body stay active. And reminescence, it helps them express their feelings.</p>
S1	<p>They get a break from everyday work with the PWD. It is a benefit to them that they can do what they want to for a wee while.</p>	<p>Company. Change of scenery.Help in understanding that they are sick and that they can't do whjat they used to do. Change of scenery.</p>
	<p>Main benefits of day care attendance for the family carer?</p>	<p>Main benefits of day care attendanc for the PWD?</p>



S6	<p>Respite. Allows them to do their job, time to pursue their own things whatever it may be, and to do anything they can't do while being a care. they know client is enjoying themselves.</p> <p>Socialization with people own age group. Stimulation is good for them. Involvement in activities.</p>	<p>Gives them a break. Time for themselves. The client has something to look forward to and this helps the carer, also the carer gets better conversation out of them.</p> <p>They are with other people and are trying to maintain skills they once had. Something to look forward to. It enables them to sort out personal problems. They can stay at home longer. (Why?) Because they are getting out of the home and for those who live alone, are able to retain some of their skills they might lose. They break the carer gets enables the client to keep them at home longer.</p>	S4	<p>Respite. A break. 2-3 hours away from the person they care for, shopping, get their hair done, meet with friends of to have a rest.</p> <p>Stimulation (activities, music, moving around, play games, reminescence, break form carers, different company, interesting activities. Stimulating them cognitively and their memory.</p>
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S10	<p>Family gets respite. Relieves stress in the home.</p> <p>Enables them to live on their own as long as possible, because if they are on their own too much and don't get stimulation they get confused. They also get a nice meal.</p>	
S9	<p>Respite. Freedom without worrying about family, knowing they are in a safe environment. Knowing that their relative is getting a bit of social interaction with people their own age.</p>	<p>Social interaction with other people. Hot meal/wholesome food. Company and different activities.</p>
S8	<p>Can get about their business and know that their relative is taken care of. This responsibility is somebody else's, they know they are safe.</p>	<p>The company, especially for those living alone. They use their minds and bodies here in the activities.</p>
S7	<p>To give them time to themselves. Respite time for themselves. Chance to do things. Chance to recollect their thoughts.</p>	<p>Different company. Enjoyment in being with company other than family. Taking part in activity they wouldn't be</p>

S14	<p>Time on their own. Respite. They know their relative is in a safe place and getting a good meal and attended to.</p> <p>Company of other clients. Social stimulation, able to maintain their independence. Maintenance of independence is main thing.</p>	<p>Gives them a break from the client, can do things they couldn't otherwise do. Otherwise they would be tied to a house. It must take the pressure off a bit, from watching someone like that all the time.</p> <p>Don't see it as a great benefit. Certain ones don't want to come. Some want to go home after dinner.</p>	<p>Gets them off their hands for a while.</p> <p>Getting out, trips.</p>	S11	<p>Gives them a bre3ak, time to do what they have to do.</p> <p>Can maybe offer them a bit more than family can because they are busy caring for them all the time. attention.</p>
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S15	<p><i>Gives them a wee break. Time to self.</i></p>	<p><i>Mixing with people own age, they all have a lot in common. It takes them out of the house, would probably be stuck in the house. Company.</i></p>
S16	<p><i>(No data, staff on vacation)</i></p>	<p><i>(No data, staff on vacation)</i></p>
S17	<p><i>Gets a break, respite. Caring for them brings so much strain, as much as they love their relative. It's important that they get a break.</i></p>	<p><i>There are varying degrees of benefits for the clients. But they get a different environment, enjoy blethering. It's a day out for them. It perks a lot of them up. The environment is stimulating. A lot of them wouldn't get stimulation otherwise.</i></p>
S18	<p><i>Carer gets piece of mind knowing that their family member is being cared for and is safe, respite, wee break.</i></p>	<p><i>Social contact, get a break from the family, activities and doing things they wouldn't do in their own home, meeting people they otherwise wouldn't meet, good meal, feel safe, personal care for those who need it.</i></p>

S19	<i>Respite, break.</i>	<i>Social stimulation, good company.</i>
S20	<i>They are getting a break and can relax. They know they are safe and are being cared for.</i>	<i>Contact and mixing with other folk of their same age group with same interests.</i>
S21	<i>Relief that they have time for themselves and know that the family member is well-taken care of. It is a benefit to the carer that the client benefits.</i>	<i>Stimulation, trying to help them keep memory, company, social interaction, they get love, care, and attention, and anything they may not get at home.</i>
S22	<i>Break, time to get thoughts together and to charge their batteries. They need time to rest from this hard work.</i>	<i>Stimulation, company, especially for those on their own, they chat.</i>
S23	<i>(No data, staff on vacation)</i>	<i>(No data, staff on vacation)</i>

S24	<p><i>Respite, assurance that person is well looked-after.</i></p>	<p><i>Getting out of home environment, stimulation helps them retain skills such as living skills. QOL is improved from the friendships and companionship.</i></p>
S25	<p><i>Free time, they don't have to worry about their relative while at day care because they know they are in capable hands and are getting meals, toileted, pads changed. They are looked-after. They are not sitting blank—they always have company around them.</i></p>	<p><i>They are encouraged to participate in activities, so they use their brain and eyes for bingo, singing songs, playing dominoes. They are not tied down to strict routines. They have company all day and the groups form bonds. They probably would never be in a car if they weren't coming here, and they enjoy the car run. They feel they're amongst friends and can talk away and won't be told-off.</i></p>

## Appendix C: Environmental Recording Form

Date  
Location ID

## Environmental Recording Form

**client**

### Activities

1. What activities do the clients engage in at day care?
2. Do the patients seem to enjoy the activities (examples)?
3. Do they foster a sense of accomplishment, satisfaction, mastery (provide examples)?
4. How much exercise do the patients get and is it routine?
5. Are the activities appropriate for impaired adults or are they childlike?
6. Are clients free to participate or not?
7. Are the individuals asked what they want to do?
8. How is individual choice encouraged or accommodated?
9. What efforts are made to encourage self-determination (e.g., choice to participate, including choice to not participate)?
10. How do workers inhibit independence?
  - a. Is it used as a form of control by workers?
11. When are the clients given the opportunity to do something that makes them feel competent; like they have achieved something worthy?
12. What efforts are made to preserve client self-identity?
13. Do the activities create a social group that is inclusive and enjoyable?
14. List formal activities/schedule:
  - a.
  - b.
  - c.
  - d.
  - e.
  - f.

### **DAY CARE WORKERS**

#### Conversation

15. Are patients routinely given the opportunity to talk about their feelings?
16. How much to the clients and workers talk?
17. How superficial are personal conversations?



18. How do workers facilitate conversations between workers and between other clients?
  - a. Does it work?
  - b. Do they get client attention, comment, participation?
19. What type of things do the patients and day care workers talk about?
20. How animated and emotional are the day care workers to the clients during these conversations?
21. How do the workers communicate with the client?
  - a. Treat clients as competent partner?
  - b. Treat clients respectfully?
  - c. Do they ever speak negatively?
  - d. Do they speak positively?

Interaction

22. How much touching occurs?
23. Are the day care workers enthusiastic and engaging?
24. Are workers passive in their care?
25. Do the day care workers create a social group that is inclusive and enjoyable?
26. Do the client-day care worker relationships resemble friendships?
27. Are there close relationships between the workers and clients?  
How to measure closeness?
28. Any disparaging amusement?
29. What sort of relationship do the day care workers and clients have (reciprocal exchange, maternal exchange, authoritarian)?
30. How do the day care workers refer to the patients?
  - a. Do the day care workers refer to client's by name?
  - b. How often do the day care workers refer to the clients as 'they' or 'these people'?
31. Record characteristics of day care workers.
  - a.
  - b.
  - c.
  - d.
  - e.
32. Do the day care workers take a stance of situational normalcy?
  - a. Degree of normalization?
  - b. What things are normalized?

33. How do day care workers define problems with clients?
  - a. Does she use a medical model?
  - b. How are they defined in the notes day care workers keep?
  - c. Do they classify the patients in 'stages' of the disease (mild, moderate, severe)?
  - d. Is there a systematic approach to dealing with clients' behavioral problems (sexual, aggression, etc.)?
34. What sort of overgeneralizations of client have the day care workers used?
35. How do day care workers expectations influence clients treatment and clients behavior?
36. How do the day care workers infantilize the clients?
37. How often do day care workers take over unnecessarily?
38. Are there patterns of paternalism?
39. Is there any exploitation of the clients' disabilities (impaired memory), used for example, to make caregiving easier (repeatedly pacifying patients with lies or deception).
40. Are issues the presents to the day care workers accepted as real and important (if it is important to the clients)?
41. Are clients feelings (ex., legitimate anger, confusion, discomfort, fear) dismissed as 'part of the disease'? (Patients experience lack of credibility and validation).
42. Are there situations in which a client has attempted to express needs to day care workers, the needs were unmet, and the result was frustration for the patient?

#### Other

43. Do the day care workers use a separate bathroom?
44. Do they take breaks in a separate room?
  - a. How often?
45. What facilities/spaces are assessable only to workers?

#### Safety/Accessibility Features

46. How safe is the environment?
  - a. Is it unobtrusively secure?
  - b. Are there call bells and alarm cords?
  - c. Are there grab bars in the toilets?
  - d. Are there raised toilet seats?
  - e. Wide doors?
  - f. Other safety features?
47. Are presthetic aids available?
  - a. What are they?

#### Environment

48. Describe facility design
49. Describe sights
50. Describe sounds
51. Describe smells

52. Describe touches
53. Is facility physically attractive?
54. What sort of environmental props set the stage for interactions
55. Are there orientation aids?
  - a. Describe them?
56. Does the environment support companion vs. privacy? Can the client make a choice as to his environment?
57. In what ways is the setting iatrogenic?
58. Are troubles with the patients in caregiving and care settings attributed to the disease (dementia typifications) of the care recipients (but are actually troubles with the environment design, etc)?
59. Is there room to walk around?
60. Is it a spacious facility?
61. Describe physical amenities.

Stressors

62. Are shepherding tasks notably stressful to clients?
63. Stressors in the environment for clients?
64. Other stressors?

Obtain copy of mission statement

## Appendix D: Case Study 1 Client, Caregiver, and Worker Survey

Client Questionnaire

DATE:

LOCATION ID#

ATTENDEE ID#:

1. *Why do you come (to day care) here?*
  
2. *Do you like coming here?*
  
3. *What do you like about it?*
  
4. *What do you not like about it?*
  
5. *If you have a problem, whom do you confide in?*
  
6. *What do you think are the benefits of coming her to you?*
  
7. *Do you think there are any benefits to your family (primary carer)?*
  
8. *What do you think are the benefits of coming her to your family (primary carer, e.g., husband, wife, mother...)?*
  
9. *What is a typical day like here?*
  
10. *If you could change anything about it, what would you change?*
  
11. *Is there anything that you are able to do now that you were not able to do before you began coming here?*

12. *Would you like to come here more often if you could?*

13. *Do you have any advice for the people who work here?*

14. *Would you recommend this place to a friend? If so, why?*

15. *Comments on Transportation?*

16. *Comments on Staff?*

**CHECKLIST OF ACTIVITIES**

(list all activities offered to clients on 1-10, then for each activity listed *Ask client if s/he participated and if s/he liked the activity?* Note their response after the activity.)

1.

2.

3.

4.

5.

6.

7.

Family Questionnaire

DATE:

LOCATION ID#:

ATTENDEE ID#:

### **CAREGIVER DEMOGRAPHICS**

1. Age
2. Sex
3. Relation to day care attendee
4. *Why do you use this day care service?*
5. *Why did you choose this particular day care? (How did you learn of this day care?)*
6. *Did you consider using other day cares?*
7. *What are the benefits of this day care to you?*
8. *What things have you been able to do that you were not able to do before your relative began attending this day care?*
9. *Do you have more time to yourself?*
10. *How do you spend the time when your relative is in day care?*
11. *Has your level of distress with caregiving increased, decreased, or stayed about the same, since your relative began attending day care?*
12. *Would you like your relative to attend day care more than s/he does now?*
13. *Are there any services that the day care does not provide that you would like provided?*

### **RELATIVE DEMOGRAPHICS**

14. Age
15. Sex
16. Date relative began attending this day care: \_\_\_\_\_
17. Days per week attends this day care: \_\_\_\_\_
18. Address (check if same as caregiver \_\_\_\_ )

19. *What do you think a typical day is like for your relative in day care? and what do you think the activities/schedules is?)*
20. *What effect does day care have on your relative? (what causes this effect?)*
21. *How do you think your relative benefits from attending day care? (what about the day care causes this benefit?)*

**Check if caregiver mentions improvement or declines in the following:**

22. *Emotional improvements\_\_\_ or declines\_\_\_?*
23. *Mood improvements\_\_\_ or declines\_\_\_?*
24. *General level of interest in life improvements\_\_\_ or declines\_\_\_?*
25. *Amount and quality of conversation improvements\_\_\_ or declines\_\_\_?*
26. *Happiness improvements\_\_\_ or declines\_\_\_?*
27. *Support from staff yes\_\_\_ or no\_\_\_?*



Staff Face-to-Face  
LOCATION ID#  
STAFF ID#:

DATE:

## **Staff member Questionnaire** (to be completed with researcher)

1. *What do you think are the main benefits of day care attendance for the family carer?*
  
2. *What do you think are the main benefits of day care attendance for the day care client?  
(what benefits them most?)*
  
3. *On a scale of 1-5, where 1 is 'not important at all' and 5 is 'very important,' rate the importance of each of the following potential benefits of day care:*
  - a) *interaction and socializing with others*            1    2    3    4    5
  - b) *attention from staff and others*                    1    2    3    4    5
  - c) *opportunity for physical exercise*                1    2    3    4    5
  - d) *opportunity for involvement in activities, such as meal preparation*                    1    2    3    4    5
  - e) *opportunity to use skills not used at home*        1    2    3    4    5
  - f) *well-balanced lunch*                                    1    2    3    4    5
  - g) *change of scenery/getting out of house*            1    2    3    4    5
  - h) *others \_\_\_\_\_*                                        1    2    3    4    5
  
4. *On a scale of 1-5, where 1 is 'not successful at all' and 5 is 'very successful,' rate how successful this day care is in providing attendees with the following:*
  - a) *opportunity to be involved in stimulating activities*    1    2    3    4    5
  - b) *opportunity for improving self-competency*        1    2    3    4    5
  - c) *opportunity to do things on one's own*                1    2    3    4    5

- |  |          |          |          |          |          |
|--|----------|----------|----------|----------|----------|
| <i>d) opportunity for interaction and socializing</i>  | <i>1</i> | <i>2</i> | <i>3</i> | <i>4</i> | <i>5</i> |
| <i>e) opportunity for physical exercise</i>            | <i>1</i> | <i>2</i> | <i>3</i> | <i>4</i> | <i>5</i> |
| <i>f) opportunity to not feel different or labeled</i> | <i>1</i> | <i>2</i> | <i>3</i> | <i>4</i> | <i>5</i> |
| <i>g) opportunity to feel safe</i>                     | <i>1</i> | <i>2</i> | <i>3</i> | <i>4</i> | <i>5</i> |

**5. What do you think are the 3 main drawbacks for the person attending day care?**

1)

2)

3)

**6. On a scale of 1-5, where 1 is 'not a drawback at all' and 5 is 'a very Big drawback,' rate how much of a potential drawback each of the following is:**

- |  |          |          |          |          |          |
|--|----------|----------|----------|----------|----------|
| <i>a) getting to day care</i>                | <i>1</i> | <i>2</i> | <i>3</i> | <i>4</i> | <i>5</i> |
| <i>b) being in an unfamiliar environment</i> | <i>1</i> | <i>2</i> | <i>3</i> | <i>4</i> | <i>5</i> |
| <i>c) costs to family</i>                    | <i>1</i> | <i>2</i> | <i>3</i> | <i>4</i> | <i>5</i> |
| <i>d) surrounded by strangers</i>            | <i>1</i> | <i>2</i> | <i>3</i> | <i>4</i> | <i>5</i> |
| <i>e) day care is not long enough</i>        | <i>1</i> | <i>2</i> | <i>3</i> | <i>4</i> | <i>5</i> |
| <i>f) other _____</i>                        | <i>1</i> | <i>2</i> | <i>3</i> | <i>4</i> | <i>5</i> |

## Appendix E: Day Care Satisfaction Form

Day Care Satisfaction  
LOCATION ID#  
ATTENDEE ID#:

**Please look at this scale and identify the word or number that describes how Happy you have been here over the last 2 weeks?**

0 - Not Happy At All

1 - Not Very Happy

2 - A Little Happy

3 - Happy

4 - Quite Happy

5 - Very Happy

6 - Extremely Happy

## Appendix F: Rationale for Choice of Measures

### Choice of Measures

Dementia Quiz (DQ). The DQ (Gilleard & Groom, 1994) is a 25-item questionnaire found to be a reliable measure of general dementia knowledge, and which correlates significantly with an established dementia knowledge test, Alzheimer's Disease Knowledge Test ([Diekmann, Zarit, Zarit, & Gatz, 1988]; Gilleard & Groom). The dementia quiz used here was shortened by the authors of the measure and includes 17-items of the original version. This shortened version is valid and reliable (Gilleard & Groom). This version was shortened by the measure's authors, is valid and reliable, and currently in use by several UK researchers, Dr. Bob Woods (Bangor) and Rebekah Proctor (Leeds).

Environmental Recording Form. This exploratory measure is based on Lyman's *Day in, Day out with Alzheimer's* (1993) and the factors found pertinent in the evaluation of an adult day care facility. The measure was designed for this study to serve as a reminder of features and other things to evaluate in the adult day care environment. It is completed via observation.

Survey. The questions included in this measure were designed to supply knowledge to fill the literature gap regarding the benefits of day care for clients. The survey was chosen for its focus on specified questions.

Mini-Mental State Examination (MMSE). The MMSE (Folstein, Folstein, & McHugh, 1975) is the most commonly used dementia screening test (Schmand et al., 1995). It is quickly administered and easily used, and has been proven valid and reliable at distinguishing between dementia, depression, and depression with cognitive impairment (Folstein, Folstein, & McHugh).

Multitphasic Environmental Assessment Procedure (MEAP). The MEAP (Moos & Lemke, 1984), completed via observation, was used to gather descriptive

data on the facility, such as safety features, social recreational aids, and prosthetic aids.

Satisfaction with Day Care Services. Developed for this study, this exploratory scale was used to assess satisfaction with day care services. Its design is that of a Likert scale of five degrees.

## Appendix G: Study 1 Physical Descriptions of Day Cares





## Environmental Observation

### Case Study 1.

Day care description. The day care was comprised of a suite of rooms in a privately owned, wardened facility (i.e., assisted-living facility). The local government-funded Social Work Board (i.e., social services agency) purchased the day care services from the private facility. Hours of operation were 9 am-4 pm, Monday–Friday. Average attendance was capacity at 15. Day care worker:client ratio averaged 1:4. Lunch, snacks, and transportation to and from the facility were provided. Total population included in the study was nine.

The facility's front door opened onto a hall with a sitting room located at either end of the hall, and in the middle of the hall was a bathroom. Each sitting room was furnished with a card table with four chairs, a couch, additional chairs, end tables, a bookshelf with several magazines and books, and a stereo. One sitting room had a karaoke machine, the other has a TV and VCR. There was a coat rack in the hall corner. A door in the middle of this hall opened onto a long, wide hall that was part of the assisted-living facility. Directly across this hall was the remainder of the day care: a hall with the third sitting room at one end and the dining room at the other end. The second bathroom was in the middle of this hall and the kitchen was off the dining room. The dining room was furnished with a china cabinet and three tables, each accommodating four chairs. There was a photo of a town chapel on the wall. The clients did not have access to the large kitchen. The third sitting room had a couch, a club chair, and end tables.

The environment was newly decorated in muted tones of green and peach. The facility was clean and tidy. In every room of the facility, there was a large window and wall decoration. There were grab bars and pull-cord alarms in the toilets.

Wheelchairs were available for use. Hallways were wide. Silverware was fat and easily grasped. The facility employed a cook to prepare the morning toast and the lunch meal. Clothes were kept on hand if a client needed to change clothes. Files were kept of each client's work history, medical history, and current medications. Notes were recorded following every client visit. Workers classified the clients by their disease stage (mild, moderate, severe) or perceived level of functioning (e.g., high-functioning, low-functioning) and labeled behaviors (e.g., wandering) in accordance with the medical model. A separate bathroom and lounge, where scheduled breaks and lunches were taken, was provided for the workers.

### Case Study 2.

Day care description. Case 2(a) was located in the activity hall of a church and operated 9 am–4 pm Tuesday and Thursday. The average attendance was capacity at five and client/day care worker ratio was usually 1:1. The front door opened onto a long, wide hall, off of which the bathroom and kitchen were located. At the end of the hall was a large room furnished with a large table surrounded by eight chairs, six wing chairs arranged in a circle around a coffee table in a corner, and a stereo. A large, free-standing bulletin board displaying clients' craftwork acted as a room divider that visually halved the room from the mostly empty other side where the clients smoked. Windows with a view of the mountains ran the length of one wall. The environment was neutrally colored and the furniture was oldish and mismatched. The facility was clean.

One of the bathroom stalls was handicap- equipped with grab bars, a raised toilet seat, a wide door, and a pull-cord alarm. The front doors of the facility were usually locked. Lunches were provided by a local school and were delivered by a

volunteer driver to the day care or were picked-up by a day care worker. Clothes were available if clients needed to change. Files were kept of each clients' work history, medical history, and current medications. Notes were recorded following every client visit. Workers were not heard labeling behaviors or classifying clients in disease stages. Clients were classified by disease stage (e.g., mild, moderate, severe) in the client notes. Workers did not talk about client medical problems in front of the clients.

Many magazines and books were provided. There was no television nor bed available. There were two toilet stalls in the bathroom.

Case 2(b) was located in a typical one-bedroom apartment, was government-owned, and operated from 9 am-4 pm Monday, Wednesday, and Friday. The average attendance was capacity at five and client:worker ratio was usually 1:1. Located on the first floor, the front door opened onto a short hall off of which was: a bathroom; an office/bedroom with a twin bed, club chair, small desk, and telephone (this room was rarely used); and, a sitting room/dining room. The kitchen was off the sitting room/dining room. The dining room had a large dining table with six chairs. The sitting room had several wing chairs and other comfortable chairs arranged in a circle around a coffee table. Clients who smoked sat in the entry hall with the front door opened. There were two bulletin boards with clients' craftwork. Each room had large windows and wall decoration. There was no television.

The environment was darkly colored and the furniture was oldish and mismatched. The facility was clean. In the bathroom, there was a pull-cord alarm, a raised toilet seat, grab bars, and a wide door. The front door was usually locked. The hallway was wide. Lunches were provided by a local school and were delivered by a volunteer driver or were picked-up by a day care worker. Clothes were available if

clients needed to change. Files were kept of each clients' work history, medical history, and current medications. Notes were recorded following every client visit. Workers were not heard labeling behaviors or classifying clients in stages of the disease. Clients were classified in these stages (e.g., mild, moderate, severe) in the client notes.

These two facilities were analyzed as one because both were operated and funded by the same non-profit organization, clients attended both, care workers, volunteers, and managers worked at both sites, the day care programs were identical, and the physical environments differed little. Additionally, client attendance and client:worker ratio was identical at both sites. These two facilities are referred to collectively as Case 2.

## Appendix H: More on the Focus Groups

## Information on the Focus Groups

The purpose of conducting a focus group was to sensibly address the challenge of survey data where individual respondents use different words to describe seemingly identical things. I could not make assumptions about what was meant or implied. They did not use the same words, they did not say the same thing. I had no basis for grouping the data without outsider input.

Two focus groups were organized. One group comprised males and females ages 60 and up, and represented the older caregivers in this study. The second group of male and female was between the ages of 40 and 59, and represented the children caregivers and day care workers.

Each group met for 30 minutes. Upon meeting, each member received a list of words randomly printed on a page. They were provided a pencil and asked to draw a line connecting the words you deem to be identical or very similar. They were told that a words on the page may be identical to several words on the page or to none. They did this three times with different topics of words. Some of the words were repeated on the sheets. They then transferred their groupings to a list. Each member read aloud their lists and decided for themselves if they had reached consensus about which words were identical or very similar. When consensus was reached, the members voted on which word from each of the lists of similar words was the best word to describe the concept.

## Appendix I : Study 2 Client Information Sheet



## Information Sheet

### The Environment at Facilities

I work at UAB and would like to ask you some questions about the club.

- I'd like to ask you why you come here, what you like about it, what you do not like about it, what you would like to do when you're here, and what do you like to do for fun.
- I'd also like to know how you feel when you come here, and what you think about the club.

I am asking these questions to try to find ways to improve the club.

To make it more enjoyable and fun for you.

You don't have to answer any questions.

Appendix J: Case Study 2 Caregiver/Proxy Informed Consent for Family Member

## **Exploring The Day Care Environment for People with Dementia**

### **Informed Consent**

**Investigator:** Ann C. Monahan  
**Faculty Advisor:** Richard Shewchuk

**Sponsor:**

### **Explanation of Procedures**

Your family member who attends adult day care is being asked to participate in a study of persons with dementia and adult day care workers. This study is being conducted by an investigator at UAB. The purpose of this study is to explore the day care environment and how the person with dementia experience day care, and their likes, dislikes, and preferences (e.g., meals, activities) at day care. If you decide to allow your family member to participate, s/he will be asked to complete a series of questions with the researcher about their likes, dislikes, and preferences for meals and activity in day care. S/he will also be asked to complete 2 questionnaires about how happy they are with the adult day care and about their quality of life. The questionnaires will take approximately 10-30 minutes.

### **Risks and Discomforts**

The risks and discomforts associated with participation in this project are no greater than the risks and discomforts of day-to-day living.

### **Benefits**

Your family member may derive no direct benefit from participation in this study. However, their participation will provide information that may be helpful in the providing a day care service that is more suitable to its service population.

### **Confidentiality**

The information gathered during this study will be kept confidential as permitted by law. However, the UAB Institutional Review Board (IRB) will be able to inspect your records and have access to confidential information which identifies you by name. The results of this study may be published for scientific purposes, however, your identity will not be revealed.

Please initial to show that you have read the above information\_\_\_\_\_

### **Withdrawal without Prejudice**

You or your family member are free to withdraw from this project at any time without prejudice of any kind.

### **New Findings**

Any significant new findings that may develop during the course of the study that may affect your willingness to continue in the research will be provided to you by Ann Monahan.

### **Costs to Participants**

There will be no cost to you or your family member for your participation in the research.

### **Payment for Research Participation**

Neither you nor your family member will receive monetary compensation for participation in this project.

### **Payment for Research-Related Injuries**

UAB has made no provision for monetary compensation in the event of injury resulting from the research and in the event of such injury, treatment is provided, but is not provided free of charge.

### **Questions**

If you have any questions about the project or research related-injuries, you may call the project investigator, Ann C. Monahan, who may be reached at (205) 934-3509. You may also call Richard Shewchuk, Faculty Advisor, at (205) 934-3509. If you have questions regarding your rights as a research participant, you may call Ms. Sheila Moore, Director of the UAB Institutional Review Board for Human Use at (205) 934-3789 or 1(800) 822-8816 (press option #1 and ask the operator for extension 4-3789) Monday through Friday from 8:00 a.m. to 5:00 p.m., CT.

### **Legal Rights**

You are not waiving any of your legal rights by signing this consent form.

**Signatures**

You have read or have had read to you all of the above. The study has been explained to you and all of your questions have been answered. Your signature below indicates that you agree to participate in this study. You will receive a copy of this consent form.

---

Signature of Family Member (You)

Date

---

Signature of Investigator

Date

---

Signature of Witness

Date

Appendix K: Study 2 Client Interview Form

## Client Interview Form

DATE:

LOCATION ID#

ATTENDEE ID#:

1. *Why do you come here?*
2. *Do you like coming here?*
3. *What do you like about it?*
4. *What do you not like about it?*
5. *Do you benefit being here?*
6. *What would you like to do while you're here?*
7. *What should you be doing with your time here?*
8. *What do you like to do with your time?*
9. *What are your favorite activities?*
10. *How would you define FUN?*
11. *How do you feel when you come here?*
12. *What do you think about the people here?*
13. *What do you think about during the day when you're here?*

14. *What does it feel like to be you?*

15. *If receive transportation to day care—Do you like the ride here?*



Appendix L: Study 2 Physical Descriptions of Day Care A, B, C, and D

## Environmental Observation

### Case Study A.

Day care description. The day care was located in the Office of Senior Citizen's Affairs in the business district of a large city. Average attendance was 25. At the time of this evaluation, 27 clients were enrolled in the day care, 22 of which had a dementing disease. Average age of the clients with dementia was 80, (range 72-96), average age of other clients was 84. Male:female ratio was 3:19. Racial composition was 77% black (17), 23% white (5). Worker:client ratio was 1:4. All workers were black.

The most direct entrance to the facility was from the client drop-off spot, and through a set of clear-glass, locked doors. These doors were unlocked by the push of a button on the wall in the hall just inside the door. The facility was comprised of two large, conjoined rooms. One room was furnished with four large tables and 16 chairs, and three tables with 12 chairs lined one of the walls. Large windows lined one wall of the room. The kitchen was located off this room. It was observed that this room was used exclusively for lunching. The manager reported that the room was also used for craft activities, but this was not observed. The conjoining room was furnished with six rectangle and circular tables, each with four chairs. Large windows lined one wall that looked onto a parking lot, where the clients were dropped-off by their rides, usually family caregivers but sometimes city transportation services. Beyond the parking lot was a busy street, groomed business lawns, trees, and a park. Six recliners, facing inward, lined these windows. There was a cabinet with a television and a radio, and a china cabinet housing a doll and a teapot. An aquarium sat beside a bookshelf with many, mostly current, magazines. A sink and coffee pot were located on a counter in the back of the room. No bed was available. A bathroom was located

directly across the hall where there were two toilet stalls. The facility had been recently renovated. It was bright, white, and the tables and chairs were new. A row of mismatched, brown recliners lined one wall. The facility was clean. One of the bathroom stalls was handicap-equipped with grab bars, a raised toilet seat, a wide door, and a pull-cord alarm. Workers were not heard labeling behaviors or classifying clients by stage of disease. The workers sometimes took breaks for short periods in the kitchen, but most workers did not take breaks at all. There was no separation of clients into groups.

### Case Study B

Day care description. The day care was located in a Projects development (government housing community for low-income people) in the suburbs of a large city. Attendance averaged 50 (range 45-55). There were 18 clients with dementia. Their average age was 72 (range 58-89). Worker:client ratio was 1:10. All workers and clients were black.

This facility was comprised of two large rooms and one small room, all linked together in a loop. The front door opened onto the largest room. It was furnished with four rectangle tables, each with 4-6 chairs, and a television. There were three bulletin boards that were decorated with colorful information about maintaining good hygiene and eating a healthy diet. The walls were also decorated with clients' crafts. There were four small windows across one wall. Off this room was a short rectangular hall with a chair and loveseat where clients and workers often smoked. A bulleting board was located over the love seat where the facility's health rating, daily schedule, calendar of events, and some of the clients' craft work was posted. At one end of the hall was a door to the outside, which was usually open in good weather or when

people were smoking, and the manager's tiny, square office. Her door was always open. At the other end of the hall was a small room with three tables, each with four chairs, and a loveseat. There was a window in the corner, file cabinets, and a refrigerator with dead plants on its top. Also at the end of the hall was a long hall leading to the other large room. It was furnished with five tables, each with 4-5 chairs. There were three bulletin boards decorated colorfully with information about teeth hygiene, the basic food groups, and reasons to be nice to people. Off this room is the kitchen and a hallway leading to the first large room already described. There was no bed available. There were two toilet stalls in the bathroom.

The environment was dimly lit and the furniture was oldish and mismatched. The facility was clean. One of the bathroom stalls was handicapped equipped with grab bars, a raised toilet seat, and a wide door. There was no pull-cord alarm. The two frequently used door (the front door and the door by the manager's office) were never locked during hours of operation. The doors were usually open with weather permitting, and if the doors were open there were always clients and workers sitting together outside.

Files were kept of each clients' work history, medical history, and current medications. The workers did not have their own lounge or bathroom. There were no volunteer workers.

### Site C

Day care description. The day care was located in a purpose built, free-standing building in a residential area. Sixteen clients with dementia regularly attended. Average daily attendance varied greatly, ranging from 6-12. It was common to have less than six clients and was common to have more than 12. Their age

averaged 81. Most clients were white (94%), 1 was black. Over half (69%: 11) the clients were female, 5 (31%) were male. Worker:client ratio averaged 1:6. Seventy-five percent of workers were white (3), 1 was black.

The population of clients ran the gamut from the quite talkative, polite, socially aware, but exceedingly forgetful, to the non-talkative who mostly stared and slept. This facility was comprised of one large L-shaped room and a large, fenced, and grassy back yard. Bathrooms were located at one end. The facility was clean. There were three tables where games were played and lunch was eaten, and three separate sitting areas of couches and chairs. There were many windows. The door onto the patio was often open when the weather permitted.

The environment was new and darkly colored. Although there were many windows, the facility was dimly lit. The facility was clean. One of the bathroom stalls was handicap-equipped with grab bars, a raised toilet seat, a wide door, and a pull-cord alarm. The front door of the facility was always locked.

Clothes were available if clients needed a change of clothes. Files were kept of each client's work history, medical history, and current medications.

The manager, whose office was down the hall, visited the day care throughout the day, stopping and chatting with clients and helping when needed. He also was an RN and performed nursing duties when the other RN was not available. Clients were never separated into smaller groups. The workers did not have their own lounge or bathroom, and were never observed taking breaks. There were no volunteer workers.

#### Site D

Day care description. The facility was located in a church in the business district of a large city. Average attendance was 10 (range 8-12) and average age was 78. Ninety percent of the clients were female (19), 3 (10%) were male. The majority

of clients were white (92%,  $n=9$ ), 8% ( $n=1$ ) were black. Worker:client averaged 1:3. Seventy-five percent (3) of workers were black, 1 was white.

The population of clients ran the gamut from the quite talkative, polite, socially aware, but exceedingly forgetful, to the non-talkative who mostly stared and slept. This facility was comprised of one large room, an exercise room, an enclosed patio, and a bathroom. There was a row of windows down one half of one wall. There were two tables with chairs and a row of recliners on either end of the room. There was a television, VCR, and radio on a trolley in the middle of the room. The exercise room was rarely used. The door onto the patio was often open when the weather permitted. The atmosphere was relaxed and comfortable. The facility provided no transportation.

The environment was newly renovated, brightly lit, and the furniture was new the facility was clean. The bathroom was large and handicapped equipped with grab bars, a raised toilet seat, and a pull-cord alarm. The two doors opening into the facility from the business offices of the church were always locked. Lunches were prepared by the church kitchen staff who prepared meals predominately for the church staff. Clothes were available if clients needed to change clothes. Files were kept of each client's work history, medical history, and current medications. Workers did not label clients' behaviors or classify clients by disease stage.

The manager, whose office was down the hall, visited the day care throughout the day, stopping and chatting with clients and helping when needed.

clients were never separated into smaller groups. Workers did not have their own bathroom or lounge, but did take breaks outside of the facility. Two volunteers visited the facility 1 day each week and had been for 2 and 3 years.

## Appendix M: Study 2 Tabular Comparison of Day Care Environmental Features

	Ratio	Size	Suitability of Physical Site	Worker-Client Interaction	Activities	Grouping
Site A	1:4	25 22*	The day care was aesthetically pleasing, comfortable, and unobtrusively secure. The surroundings of this 2-room day care were basic, not homey, but not confusing. Clients had access to all spaces.	Interactions were friendly and jovial. Conversation was light, and consisted of short, jovial comments about any topic or related to the clients' personally (e.g., family, interests). Workers knew clients' history, family, and personal interests well and commonly called clients by name. Workers initiated interaction through conversation. The workers were not actively trying to facilitate interaction among clients. Instead, the workers were trying to entertain them.	Workers actively participated in crafts and exercise activities, and allowed clients to do crafts as long as they liked. Clients also had the freedom to roam about. Confidence and independence may have been encouraged in those clients who assisted with cleaning after meals or helped clients to their rides. A full kitchen that served full meals may be stimulating to clients. The workers themselves provided a great deal of entertainment and stimulation through conversation.	No
Site B	1:10	50 18*	The day care was aesthetically pleasing, comfortable and unobtrusively secure. The circular configuration of large rooms may have been confusing to clients, although they were not observed to be confused. It did not have a homey atmosphere, but clients had full access to its spaces, and access to outdoors.	Conversations were friendly but infrequent. Most worker-client touching occurred as clients were helped on and off the bus or when workers were guiding them to a room or to the bus. Workers did not appear to be knowledgeable about clients' history, family, or interests, but their demeanor was warm clients.	Workers actively participated in crafts with clients. There was no other formal activity to occupy the clients. That clients had the freedom to go almost anywhere may have encouraged confidence. The workers were not very involved in facilitating activities. However, the environment itself was very stimulating to clients because of the variety of activity that constantly occurred and the exposure to the outdoors.	Loose groupings of clients to assist workers in keeping track of clients.
Site C	1:6	12	This L-shaped day care was aesthetically pleasing, comfortable unobtrusively secure, and homey. The environment was not confusing to clients. Clients were free to roam the day care.	The workers behaved warmly to clients. Workers interacted with them only during formal activity. Reading activities encouraged interactions that were more personal than those that resulted from other activity.	The games and readings stimulated interaction between clients and workers. The activities existed to occupy the clients.	No
Site D	1:3	10	This one-room small day care was aesthetically pleasing, comfortable, unobtrusively secure, and homey. Clients had little freedom and could only wander on the patio. It was too small to be confusing.	The workers were not very involved in facilitating interactions in the clients, as the interactions primarily occurred during a formal activity. The workers gave very little of themselves (not expressive, little talk). Their demeanor was bland.	The games and walks occupied clients and stimulated interaction between the clients and workers. The activities existed to occupy the clients, and to exercise them. This was not a very encouraging environment for clients. Confidence may have been increased in the clients who were mobile enough to go on the walks.	No
*Refers to the number of clients with dementia who attended a day care that served clients with other conditions.						





## Appendix N: Study 1 Vignettes

Client vignettes. A vignette was written for each of the six clients whose caregiver consented for their participation in the study. Each vignette begins with a brief description of the client's living situation, observed behaviors, and diagnosis. Their behavior in the day care is described and the information they were able to provide during the interview is described (such as reports on benefits, activities). Only the first three vignettes provide any interview or measure data.

Vignette 1 (V1): She was a 70 year woman who was a former school teacher. she had been diagnosed with moderate AD months earlier. She was a very thin, well-dressed woman who had only been attending the day care for 4 weeks at the date of the interview. She was very mobile and always participated in the group activities, which she said she liked. She also said she liked the people. She said she felt good in the day care because it was homey and friendly and reported that the benefits of the day care were its homeyness and the nice and friendly people. She said that she liked the hominess most about the day care. She reported that her daughter (family caregiver) did not receive any benefit by her attendance at day care, but that her daughter realized that she (V1) was benefiting. When V1 was asked to describe how happy she had been in the day care and was shown a scale ranging from *not happy at all* to *extremely happy*, she said, "Happy. If I say I'm happy, all these others aren't necessary" (she points to the other response options: *quite happy*, *very happy*, *extremely happy*). She initially showed little sign of dementia symptomology. As the interview continued, she told me that her parents were still living. I continued to refer to the day care as *here* or *the club*, she said "I don't even know what this place is. You could tell me that. What's it name?" I told her "Horizons." She said, "Well that answers the whole thing."

Why telling her the name of the facility satisfied her curiosity is unknown. She may have been satisfied with my answer because, she may have been uncomfortable with having asked the question in the first place. My answer of “Horizons” gave her the opportunity to say ‘oh well, I see’ and to act as though she was following me. I was relieved that she did not question me further about the function of the day care though. It is common for family members not to disclose to a person with dementia that they have the disease so I certainly did not want to enter into a question and answer session about why she was there. This polite, articulate woman often clarified her responses with, “It is difficult for me to say because I haven’t been here long” or “I’m not sure if I’m answering you correctly. Is that what you meant?” She is an example of the varied and puzzling effects of a dementia of the brain. She was an articulate and intelligent woman: her concern with whether she had answered the question that I had intended to ask, and her awareness that her short exposure to day care may render her responses uneducated. At the same time, she did not know where she was or what she was supposed to be doing there, nor did she know that her parents were not alive.

Vignette 2 (V2): She was a very mobile and verbal 83 year old woman who often used the pronoun *we* instead of *I* in conversation, referring to her husband who was her primary caregiver. She assigned everyone a name other than their accurate name, which she used to consistently refer to each person. With the exception of exercise, she always participated in the group activities even though she said she did not like them and preferred to be outside. She had been diagnosed with Alzheimer’s disease 3 years prior. She was a seemingly sweet, elderly woman with a big, white puff of a hairdo. However, she severely insulted several other day care clients repeatedly and daily. She told them how stupid, crazy, and ugly they were with a

severely acidic tongue and facial maneuvers to match. She targeted those who were sitting near her. Targets included one very confused client who talked often and in fragmentary speech of the seeming past, such as, an altercation with someone and what she had said to the person in her defense, things her mother used to say, and things she used to do on her job. The other target was a 12 year old mentally disabled girl. The day care workers were never observed to make any attempts to stop the clients verbal criticism or to prevent it from continuing, even though the insults to the girl frequently resulted in her crying.

The client (V2) said she benefited “very little” from the day care. She said that her husband (caregiver) benefited from her day care attendance, but she could not tell me how. She said what she liked most about the day care was being able to “come in and sit down and just hush.” The question receiving the most emphatic response from V2 was whether she liked the food. She brightened and said, “love, love, love the food.” This interview was not completed. Although she was looking at me and seemed interested in me and what I was saying, she would not respond to further questions or she would provide answers that were not relative to what had been asked. For example, I asked her if the workers were friendly. She responded, “I’ll be their friend.” When I asked if the workers hugged her, she responded, “ Sure, we can hug.” It is unclear if she was answering the question and meant that they did hug. Attempts to clarify her answer resulted in no response or her changing the subject. She may have not been interested in my questions or could not follow them and was covering-up by acting as though she didn’t hear them or by changing the subject by asking me a question.

Vignette 3 (V3): She was a 71 year old woman who looked much younger than her years. She was college educated and her occupational history was in retail

clothing sales. Her retired husband was her primary caregiver and she had a son and daughter who were both grown. She had a family history of Alzheimer's disease and had been diagnosed with Alzheimer's disease 5 years ago and participated in an early intervention group aimed at assisting persons cope with their diagnosis and the life changes it brings. She openly discussed her disease and her problems. Her lifestyle remained very active, and she liked to exercise, eat in restaurants, and vacation with her husband. She is a very stylishly dressed woman with a strong northern accent and an easy-going attitude. Upon first observation of V3, nothing appeared amiss. She gave yes/no responses at appropriate times. Only in conversation with her did it become apparent that she could not follow her train of thought and that she made comments that were not relevant to topic. She was very mobile and always participated in the group activities, which she said she liked. She also said she liked the people and that the benefit of day care was being able to see her friends, and that the change was good for her because she worked during the week. When asked if her husband (caregiver) benefited by her attendance at day care, she reported, "I have a nice place to be," but when prompted, did not elaborate on what this meant. She reported that having people to talk to was what she liked most about day care. When asked to describe how happy she had been in the day care by pointing to the seven options on the Day care Satisfaction scale which ranged from *not happy at all* to *extremely happy*, she rated her satisfaction as *very happy*.

Vignette 4 (V4): She was a 56 year old married woman with a 7 year old daughter. She did not have an occupational history outside the home, as she was a homemaker. Her husband, who worked full-time in maintenance at the local university, was her primary caregiver. She was diagnosed 3 years ago with early-onset Alzheimer's disease of an especially aggressive type. Her husband stated that she had

been having problems for 6 years. When she first arrived at the day care several months earlier she would talk. But she quite abruptly stopped talking. Language has even ceased with her husband. She did not participate in the activities. She usually sat at a table, arms crossed, staring, looking slightly angry. Throughout the duration of the study, she was never observed talking. She did shake her head yes or no and was occasionally observed slapping her palm on her leg when she was seemingly aggravated or agitated. When I approached her to participate in the study, I asked her if I could ask her some questions. She shook her head no (this was attempted on two occasions). No interview data was obtained.

Vignette 5 (V5): She was a 61 year old woman from a rural background with a 10<sup>th</sup>-grade education. Her occupational history was in a sewing factory and as a homemaker. She had three adult children. One of her daughters and her son-in-law were her primary caregivers, as her husband was deceased. She was diagnosed with Progressive Supranuclear Palsy, a neurodegenerative disorder like Alzheimer's and Parkinson's disease, 4 years ago and was considered to be moderately demented. She was constantly hunched over whether sitting or standing, and because she constantly drooled she always kept a napkin in her hand and wiped her mouth and chin when prompted. She was very quiet and sometimes spoke in a whisper. She appeared completely out of touch with her surroundings by these and other motor difficulties caused by the palsy, however, at times she was able to make appropriate comments regarding what she wanted (water, napkin, bathroom) and she could at times appropriately answer simple questions, yet speaking seemed to be an incredible effort for her. However, she did not participate in the activities and only sat, hunched over at the table, staring and sleeping. No interview or measures were collected.

Vignette 6 (V6): He was a 75 year old electrical engineer diagnosed with severe dementia and usually did not speak or participate in activities. When he did speak, it was unclear whether he was speaking to anyone present—at least he did not seem to expect or be interested in a response from anyone. He was totally unresponsive to any conversation directed toward him. He frequently commented about, “get things squared away.” He also frequently checked the door, trying to exit, and at times became quite aggressive at workers’ attempts to redirect his interests away from leaving. His wife prepared a lunch for him that he ate on his own and required about 45 minutes to eat. He was mostly unresponsive, usually showing no awareness that someone was talking to him or sitting beside him. No interview data was obtained.