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## A Study of the Impact of Adult Day Care Centers on the Caregivers of Clients with Dementia

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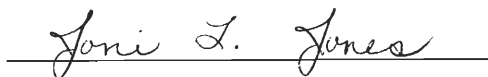
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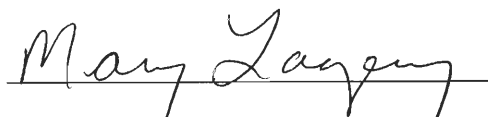
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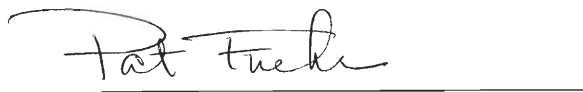
"A Study of the Impact of Adult Day Care Centers on the Caregivers of Clients with Dementia"



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Running Head: THE IMPACT OF ADULT DAY CARE CENTERS ON CAREGIVERS OF  
CLIENTS WITH DEMENTIA

A Study of the Impact of Adult Day Care Centers  
on the Caregivers of Clients with Dementia

Abby Olsen

Lee Honors College – Thesis

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### Abstract

The purpose of this descriptive study was to evaluate the impact of adult day care centers (ADC) on the perceived stress of the caregivers of loved ones with dementia and on their perceptions of their loved one's level of functioning or quality of life. Five caregivers whom had a loved one attending the same ADC were interviewed to obtain qualitative data concerning their perceptions about ADC utilization. Two assessment tools, the *Caregiver Strain Index* and the *QA Study Assessment Tool* were also used to determine quantitatively the impact of adult day care attendance on caregiver stress.

The results suggested that ADC attendance lessened the overall amount of perceived caregiver stress, but that a significant level of stress remained. Additionally, the caregivers' perception regarding the quality of the life and functioning of their loved one decreased over time, most likely related to the progressive nature of dementia.

## Introduction

Caring for a loved one who is suffering from a life limiting or degenerative illness can be very stressful and difficult for families. As a result of providing total care for a loved one, caregiver stress and burnout can occur. Caregiver stress is interpreted and defined differently by a variety of authors. Dictionary definitions of stress are “constraining force or influence,” and “a physical, chemical, or emotional factor that causes bodily or mental tension and may be a factor in disease causation” (Merriam-Webster, 2007). Therefore, caregiver stress can be interpreted as a mental and physical tension that results from caring for another person. Nolan and colleagues (1990) defined caregiver stress as “the result of a cognitive imbalance between the perceived nature of the demand and the perceived capabilities of the person” (Hunt, 2003, p. 28). Cohen and colleagues have defined perceived caregiver stress as, “The degree to which situations in one’s life are appraised as stressful” (Cohen, Kamarck, & Mermelstein, 1983, p. 387). Lazarus and Folkman (1984) defined stress as, “A particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being” (as cited in Hunt, 2003, p. 29). This environmental perspective argues that perceived stress of the caregiver should be the focus, rather than the actual stressor.

Overall, authors agree that caregiver stress is the result of perceived stress and imbalance that exists related to the caregivers’ desires and abilities. In order to help caregivers cope with the perceived stress caused by the physical and emotional demands inherent in providing care for their dependent loved ones, health care professionals, along with caregivers, must explore alternative methods of care that aim to alleviate some of this burden.

One approach to help families cope with caring for their loved one is through the utilization of adult day care centers. Adult day care centers (ADC) employ a social-medical-nursing model and provide day care and respite services for clients with various health problems including dementia, Parkinson's disease, closed head injuries, and social isolation. A multidisciplinary approach is used in some ADCs.

In 1960, the first ADC started as a day program at a geriatric hospital in Greensboro, North Carolina (O'Keeffe & Siebenaler, 2006). This program later developed into a community resource and became an ADC providing respite for local caregivers (O'Keeffe & Siebenaler, 2006). Currently, there are over 3,500 ADCs nationwide that provide care for 150,000 people every day (National Adult Day Services Association, 2007).

By utilizing ADC services, caregivers are able to spend time away from their loved one in order to continue their normal routine. Adult Day Care services may be used so the caregiver can maintain their own employment or deal with their own illness. It may also be used for the sole purpose of providing respite from the physical and emotional burden of being the primary care provider for their loved one who is ill. Adult day care centers provide care and stimulation for people with various cognitive impairments, especially those living with dementia (Zarit, Stephens, Townsend, & Greene, 1998).

The premise behind adult day care centers can be tied to the theory of mutuality. Mutuality is a conceptual framework that is rooted in evidence-based practice and involves positive interactions between caregivers and health care providers (Jeon, 2004). This framework is based on the concept that empathy, collaboration, equality, and interdependency must be present in an interaction in order for a helping relationship to develop (Jeon, 2004). According to Hagerty et al. (1993), mutuality is defined as "the



experience of real symbolic shared commonalities of visions, goals, sentiments, or characteristics, including shared acceptance of difference that validates the person's worldview" (cited in Jeon, 2004, p. 128). As applied to caregiver stress, the practice of mutuality can be employed to help decrease stress associated with the caregiver role (Kneeshaw, Considine & Jennings, 1999). However, in order for mutuality to occur, nurses must educate the caregiver on what to expect with the progression of the disease and resources available to help deal with the stressors of caregiving. This education and provision of available resources may have the effects of alleviating some of the caregiver's burden and improving coping with the inherent strain of this role.

The purpose of this thesis is to evaluate the impact of adult day care centers on the perceived stress of the primary caregivers of relatives with dementia. Specifically, the research questions are as follows:

1. *Does the utilization of adult day care services for a loved one with dementia, lessen the perceived stress of the primary caregiver of this individual?*
2. *Does the primary caregiver's perception of their loved one's quality of life change with the utilization of an adult day care service?*
3. *How does the utilization of ADC services impact the challenges associated with providing care for a loved one?*

#### *Mutuality as a Conceptual Framework*

Mutuality involves positive interactions between caregivers and health care providers. The theory of mutuality is also known as the nurse-patient relationship (NPR), which is an "interpersonal process that develops over time between patients and nurses" (Hagerty & Patusky, 2003, p. 145). Jeon (2004) found that the success of the nurse-caregiver depends on

the interactions between them and the context in which the experience is shared. In order to obtain complete mutuality, the nurse and caregiver must complete a process, which consists of the following phases: 1) lack of mutuality; 2) partial mutuality; and 3) constructive mutuality (Jeon, 2004). The first phase, lack of mutuality, includes mutual misunderstanding, passiveness, limited interactions, and negative feelings. The second phase, partial mutuality, includes limited understanding between the nurse and caregiver. With the final phase, constructive mutuality, both nurses and caregivers are able to understand the other's perspective and the relationship becomes "collaborative and helpful, based on mutual trust, respect, and understanding, which can simultaneously and/or consequently bring about therapeutic outcomes for the patient" (Jeon, 2004, p. 131).

Mutuality can be applied to the ADC setting in the sense that a trusting relationship develops over time between the primary caregiver and the nurses and staff of the ADC. These centers use a multidisciplinary approach to ensure that both the client and caregiver are the focus of care. By working with the caregiver and identifying concerns about their loved one, care can be genuinely individualized. The continuous feedback between the caregivers and multidisciplinary team, and the relationship that develops, enables the ADC staff to provide the best care possible and help to relieve some of the caregivers' stress. The relationship between the caregiver and the staff at adult day care centers may go through the three phases of mutuality. In the beginning, the caregiver may be uncertain or weary about the adult day care center and the services they provide. As trust grows between the caregiver and the staff, the relationship is able to reach constructive mutuality. As with all relationships, time is needed to develop a deep connection and mutual trust. After

constructive mutuality is reached, both parties consistently work together for the benefit of the client.

### Literature Review

The focus of the literature review regarding adult day care centers is presented in two primary areas: (1) client quality of life, and (2) benefits to caregivers.

#### *Clientele Quality of Life*

Ritchie (2003) studied the effects of ADC on patients and caregivers. She conducted her study in British Columbia and collected data from 32 participants, which included 21 seniors, 7 caregivers, and 4 nurses (Ritchie, 2003). Interviews and focus groups were used to develop a framework of the benefits, problems, and issues related to ADC. Concerning the patients' quality of life, Ritchie found many of the participants, including senior citizens, caregivers, and nurses, emphasized the effects of socialization rather than social isolation (2003). Caregivers explained that the companionship derived from the participation in ADC helped with their loved one's emotional health and prevented the onset of depression.

Zank and Schacke (2002) studied the effects of ADC utilization on patients and their caregivers. A quasi-experimental, longitudinal control group design was used for this study. Upon admission to the ADC, every caregiver who was planning on using the ADC for their loved one at least twice a week for three months was contacted to participate in the study (n = 43). A control group consisted of a matched sample that did not use day care (n = 40), but did utilize home-health services. All clients in the study had been diagnosed with a psychiatric disease, including dementia and/or depression. A positive correlation was found between participation in ADC and quality of life for the client. The results showed that the

group using ADC improved or stabilized in measurements of life satisfaction, overall well-being, and dementia symptoms. The control group patients worsened on these measures. The results of this study and those of Ritchie (2003) suggest that participation in adult day care programs may benefit clients by improving their overall quality of life.

### *Benefits to Caregivers*

Zank and Schacke (2002) based their study on a similar study done by Zarit, Stephens, Townsend, and Greene (1998). This study evaluated the psychological benefits of ADC for caregivers of a relative with dementia. Zarit and colleagues (1998) compared a group using ADC and a similar group not using ADC on feelings of overload, strain, depression, and anger among caregivers. To qualify for the experimental group, ADC services had to be used at least 2 days each week for 3 months. The results of this study showed that caregivers of those who attended ADC experienced “lower levels of caregiver-related stress and better psychological well-being than a control group not using this service” (Zarit et al., 1998, S275). Improvements in all areas including overload, strain, depression, and anger were evident for those participating in ADC.

Not all studies indicate a positive relationship between ADC and benefits for the caregiver. Although Zank and Schacke (2002) based their study on Zarit’s study (1998), they concluded that the use of ADC does not necessarily help with caregiver burnout and stress. Zank & Schacke did not find any negative effects associated with day care mentioned by caregivers. The only problem they found was that many of the caregivers had wished for longer hours of daytime operation of the day care. Zank and Schacke could not demonstrate positive effects of ADC on caregivers. Although experimental and control groups were used,

methodological errors may be responsible for the absence of positive correlation. Baseline interviews concerning the caregiver's state were given 10 days into the experiment, after their loved one had started ADC. It is possible that the initial stress level measurements may not have been accurate since evaluations were not done before the start of the experiment. In addition to errors in the methodology, this study lacked in the number of caregivers since 43% of the clients did not have relatives as primary caregivers. Other studies, however, tend to support the idea that ADC does benefit caregivers by reducing emotional strain and stress. During her focus groups with elderly persons, caregivers, and nurses, Ritchie (2003) found that the relief of caregiver stress dominated the discussions concerning benefits to caregivers. Participants felt ADC programs provided a needed respite from the stress created by worrying about their loved one. Many participants had to take early retirement or stop working in order to care for their relative. This could be prevented or delayed with the use of adult day care programs. Ritchie argued that ADC greatly benefits caregivers as well as the clients themselves.

### Methodology

The Marian E. Burch Adult Day Care Center in Battle Creek, Michigan was used as the site for this study. The mission of the Center is "To keep your loved ones in their own home environment for as long as possible with the highest quality of life for the loved one and you as the caregiver" (Marian E. Burch Adult Day Care Center Brochure, 2003). The Center opened in 1992 and provides "medical rehabilitation, overnight respite services, and social activities to Calhoun County residents 18 years and older with physical or mental disabilities" (Marian E. Burch Adult Day Care Center Brochure, 2003). In addition, nursing

services are available to care for the specialized needs of the clients. Clients participate in a variety of activities throughout the day to promote socialization, cognition, and stimulation of the senses.

HSIRB approval was obtained before the research for this study was conducted (see Appendix A). This descriptive study employed both qualitative and quantitative methods. The caregivers of six clients with mild to moderate dementia who attended the Marian E. Burch Adult Day Care Center for at least 3 months were selected with the assistance of the director of the center. The director made initial contact with the caregivers and provided a basic explanation of the study, determining the caregivers' willingness to be contacted by the investigators of the study. With approval obtained by the director from the caregiver, each participant was then contacted individually and the study was explained in full. The caregivers were given the option to: 1) participate in the study and set up an interview time; and 2) to decline participation in the study. During this process, it was made clear to each potential participant that their decision to participate or not to participate would in no way affect the care of their loved one at the ADC. In the end, five out of the six caregivers contacted agreed to participate in the study. Although this was a small sample size, the information gained from the interviews provided rich information about the impact that day care attendance has on the lives of the caregivers and their loved ones.

Informed consent was obtained at the beginning of each interview and the participants were told that they could choose to stop the interview and end their participation in the study at any time. After informed consent was obtained (see Appendix B), each caregiver was interviewed concerning his/her perceptions of their role as a caregiver (see Appendix C). Following the interview, each caregiver was asked to complete the *Caregiver Strain Index*

(Robinson, 1983), which quantitatively measured their current level of perceived stress using a dichotomous “Yes/No” scale (see Appendix D). In addition, each caregiver was asked to complete the *QA Assessment Tool*, which measured not only their perceived level of stress, but also perceptions about their loved one’s cognitive, social, and physical functioning, using a Likert scale (see Appendix E). These elements constitute, at least in part, their perceptions concerning their loved one’s quality of life. The scores from the *QA Assessment Tool* were compared to the scores that had been obtained on admission to the ADC to determine perceived changes in each caregiver’s stress level and changes in their perception of their loved ones’ functioning since admission. The caregivers’ perceived level of stress and perception of their loved ones functioning level was assessed by the director of the ADC when they began utilizing the services. The *QA Assessment Tool* was used because it was a tool the ADC already had in place for quantitative evaluation.

With the permission from the participants, the semi-structured interviews were audio recorded. After the semi-structured interviews, a hired transcriptionist transcribed the audiotapes. From the transcripts, relevant text was extracted from the interviews based on the research questions. The transcripts were read through completely for each participant first and then by question, comparing the responses of each participant. Relevant text was highlighted for analysis. Multiple readings of the transcripts took place in order to develop appropriate themes among the interviews. Highlighted portions of the transcripts for analysis included mostly responses to questions one and three from the semi-structured interview questions (Appendix C).

### *Semi-structured Interviews*

Semi-structured interviews were conducted at the caregivers' convenience and were held at either the ADC or the caregiver's home. A semi-structured interview format was used because there were specific questions (Appendix C) to be asked to all caregivers, for the purpose of comparison. The specific questions were chosen based on the conceptual framework for this study – mutuality. The questions allowed for the caregivers to relate ADC attendance to their overall quality of life and illuminated the connectedness between the caregivers and the staff at the ADC. In addition, the semi-structured format allowed for open communication and other questions and topics that arose. This format allowed for the opportunity of exploring more areas of interest and brought out themes among the caregivers.

The interviews varied in length, averaging approximately one hour. The interviews were audio-recorded and transcribed in order to identify themes between the participants. During the interview, topics discussed included: (a) the client's current health status; (b) length of attendance at adult day care; (c) challenges of caregiving; (d) changes in clients' physical and behavioral health since day care admission; and (e) advantages and disadvantages of adult day care attendance.

In addition to the qualitative information gained from the interview process, quantitative data was acquired, following the interview, through the use of the *Caregiver Strain Index (CSI)* and a *Quantitative Analysis (QA) Assessment Tool*.

### *Caregiver Strain Index (CSI)*

The *Caregiver Strain Index* is a tool used to screen for the identification of strain as a risk area for the caregiver (Robinson, 1983). The CSI consists of 13 items and measures the



amount of strain the caregiver is under. The 13 yes/no questions are scored one point for a “yes” answer and 0 points for a “no” response. A total score of seven or greater indicates that the caregiver is under a high level of stress (Robinson, 1983). At the end of the interview, caregivers were instructed to complete the *Caregiver Strain Index* to determine, quantitatively, their current level of caregiver stress. Although an initial score was not obtained at the beginning of ADC use, this tool is still considered useful to the current study because it numerically defines the caregiver’s current level of stress.

#### *QA Study Assessment Tool*

This tool was created and used by the ADC and is routinely completed at admission to the ADC by the caregiver. The *QA Study Assessment Tool* consists of two components: caregiver stress and client level of functioning. The first three statements in this tool are related to the perceived stress level of the caregiver and the remaining items are related to the caregiver’s perceptions about their loved one’s quality of life. The *QA Study Assessment Tool* was administered during this study and the results were compared to the initial results obtained by the ADC at the time of admission. Approval to access the initial *QA Study* results was obtained from the caregiver before the interview. By using the two separate results for this assessment tool, any change in the perceived stress level of the caregiver over time could be determined. In addition to caregiver stress level, the *QA Study Assessment Tool* also addressed the caregivers’ perceived changes in the physical and cognitive functioning of the loved one attending day care. As with the caregiver stress level, comparing past and present results from the tool assess the impact of adult day care attendance on the client’s functioning level.

## Results

*Demographics*

The participants in this study were all primary caregivers for relatives who had been diagnosed with dementia. The stage of dementia and the rate of progression varied. Table 1 provides additional demographic information about the participants. Overall, the clients all exhibited some signs of moderate to severe dementia including Sundowners' syndrome, fear, anxiety, wandering, and memory loss. The length of attendance at ADC varied from nine months to five years, with the average length of attendance being two years.

Table 1

*Demographics of the Caregivers*

Caregiver	Age	# Hours Work/Week (Outside home)	Relationship to Client	Lives with Caregiver
1	75	0	Daughter	Yes
2	56	30	Son	No
3	75	10	Husband	Yes
4	53	50	Daughter	Yes
5	67	40	Wife	Yes

In order to view the results more accurately, an annotated comparison between the caregivers follows. The perceived level of caregiver stress may be increased or decreased by a variety of additional factors in the caregiver's life.

*Caregiver One.* The first caregiver is providing care for her mother. She is retired and does not work outside of the home. Her mother was diagnosed with dementia in 2000

and has been attending ADC for over five years. Her ADC attendance is financed through grants and private pay. The caregiver stated that her personal health contributes to her level of caregiver stress.

*Caregiver Two.* This caregiver is providing care for his mother. He is self-employed and works approximately 30 hours a week outside of the home. His mother was diagnosed with dementia in 2001 and has been attending ADC for two years. Her ADC attendance is financed through Medicaid waiver and private pay. Additional factors that contribute to his level of caregiver stress include family problems, financial issues, role reversal, and grief. His mother does not live with him.

*Caregiver Three.* This caregiver provides care for his wife and works part-time, approximately 10 hours per week outside of the home. His wife was diagnosed with dementia in 2003 and has been attending ADC for one and a half years. Her ADC attendance is funded entirely through grants.

*Caregiver Four.* This caregiver works full-time, approximately 50 hours a week outside of the home, and is the primary caregiver for her mother. Her mother was diagnosed with dementia in 2002 and has been attending ADC for nine months. Additional stressors in her life include finances, family support, and balancing caregiver and work roles. Her ADC attendance is funded through grants.

*Caregiver Five.* The last caregiver is a is caring for her husband. She works full-time, approximately 40 hours per week outside of the home. Her husband was diagnosed in 2002 and has been attending ADC for two years. His ADC attendance is funded through grants and Medicaid waiver. Additional stressors in the caregiver's life include financial problems.

*Interview Themes*

From the semi-structured interviews, rich qualitative data emerged. This data was analyzed using pattern coding to identify themes among the caregivers. Pattern coding is a type of qualitative analysis, which groups summaries into smaller themes or constructs (Miles & Huberman, 1994). Using pattern coding, the transcriptions from the semi-structured interviews were analyzed and themes among the caregivers were identified.

The themes that emerged from the caregiver interviews revolved around the challenges associated with providing care for loved ones who are progressively more dependent and how the caregivers cope with these challenges. These included: (a) dealing with the loved one's mood swings and behavior; (b) maintaining a positive attitude; (c) making decisions to benefit both the loved one and the caregiver; (d) coping with the fact that their loved one will never be the person they were before the disease; (e) feelings of guilt; and (f) lessening of the burden of caregiving.

Although mood swings and behavioral problems are part of the disease, many caregivers have a difficult time dealing with this problem. One caregiver stated:

“Trying to cope with her mood swings [is difficult]. I could talk to her and it is normal and the next thing I talk to her and she doesn't recognize me.”

Another caregiver stated regarding their loved one's behavior:

“I have seen bursts of anger, but I wouldn't say that her personality is anger. I think now and then I would say she has fits like a toddler.”

The strain of caregiving can affect caregivers' attitudes and coping with their loved one's behavior can be difficult. One caregiver stated:

"I get disgusted with her once in a while. She won't do what I say and I have to repeat it, repeat it, and repeat it. After a while you get to where you let it go, it doesn't matter."

An additional concept related to the challenges of caregiving is making decisions for the loved one because they are incapable of making their own. One daughter stated:

"I think the greatest challenge is just always making sure that the decisions that you make are really in their best interests. I truly believe that life is a great circle and that she [mother] deserves the best care, the best situation.

Caregivers experience complex emotions as a result of caregiving. Regarding feelings of guilt, one caregiver emphasized:

"I can't do enough to relieve that sense of guilt that I have for not doing more. I think the most difficult thing that I face is keeping a [positive] attitude, to be caring and to be responsible."

Although the caregivers were utilizing ADC services and providing the best care they could, feelings of guilt still ensued. In order to cope better with their loved one's illness, counseling or caregiver support groups may be helpful.

When asked about the changes in their loved one's health, since day care admission, the answers were varied due to the clients' progression of dementia. One caregiver stated that initially after admission her mother would interact with other clients and participate, but

now is unable to interact much with her surroundings. In this case, this is likely more related to the progressive nature of dementia than by an actual negative impact of the adult day care program itself. On the other hand, another caregiver stated that she saw a vast improvement in her husband's behavior after starting at the ADC. She stated:

“He wasn't doing anything before he went out there, but sleeping. He looks forward to going – he has improved socially.”

In regard to the theme that ADC services lessened the burden of caregiving, several caregivers stated that adult day care attendance has contributed to an improved quality of life for their loved ones and helped them share the responsibility of providing care. Most of the caregivers had witnessed what they viewed as significant changes in their loved one's behavior, which they attributed to the benefits of socialization with staff and other clients.

Together the themes illustrate the conceptual framework of mutuality. Participants conveyed that they have a sense of trust and gratitude for the ADC services and believe that they are viewed by the director and staff as integral to the planning and implementation of individualized care for their loved one. The caregiver and staff of the ADC are able to work together to establish therapeutic outcomes for the client. A feeling of trust is the core component of mutuality and is accomplished as the relationship between the caregiver and staff established (Jeon, 2004).

### *Perceived Advantages*

From the themes, overall concepts of perceived advantages and disadvantages emerged. ADC utilization was believed to provide many benefits for both the caregivers and

clients. Perceived advantages associated with ADC attendance include improved socialization for the client and freedom for the caregivers. The caregivers unanimously stated that the greatest benefit to ADC utilization was the freedom it provided them to work or run errands, and to have respite from the constant strain of caregiving. One caregiver stated:

“It [adult day care] gives me freedom – I don’t have to worry about her. I know where she is.”

Besides providing the caregivers with a much-deserved break, additional benefits to adult day care utilization included socialization and feelings of purpose for their loved ones. One caregiver stated about her mother:

“Every morning she gets up and whether she says she is going to school or work or wherever, she gets excited that she is going. She has her different favorite people and she feels that she really makes a difference. By going there [to the ADC], she comes home and she feels very good about what she has accomplished.”

Overall, ADC attendance helped to improve the quality of life for each the client and the caregiver. ADC provided a much-needed respite for the caregivers and promoted socialization for the clients.

### *Perceived Disadvantages*

The only disadvantage of ADC revealed in the semi-structured interviews concerned the issue of transportation. Transportation is provided in the morning and afternoon for those

caregivers who wish to partake in that service. However, the buses must cover the entire county and the bus route changes daily depending on client attendance. Two of the five caregivers expressed concerns regarding transportation.

One caregiver expressed that the pick-up time varies every morning and could be anytime between 8:00-9:00 a.m. She stated:

“I know that they do the best that they can, but I don’t always know what time they are going to pick her up. But, the people there have been wonderful to us.”

Transportation issues were the only negative aspect of ADC attendance discussed in the interviews, and all other responses regarding attendance praised the care provided and the dedication of the staff.

### *Caregiver Strain Index*

The *Caregiver Strain Index* (Robinson, 1983) was given to quantitatively score the perceived level of stress of the caregivers. Table 2 presents the scores of each of the participants. The maximum score for the *Caregiver Strain Index* was 13.0. A score greater than 7.0 indicates a high level of stress. The mean score on the *Caregiver Strain Index* for this group of participants was 8.6 (n=5). Only one score was less than 7.0; four out of the five caregivers had a high level of stress. Interestingly, the participant with the lowest score was the only caregiver who did not live with the relative attending the ADC. An explanation for this lower score may be that this caregiver shared the responsibility of caregiving with his five siblings and they rotated who stayed over at nighttime during the week.



Table 2

*Caregiver Strain Index Results*

Caregiver	Score (Out of 13.0)	Represents a High Level of Stress (Yes/No)
1	8.0	Yes
2	6.0	No
3	9.0	Yes
4	10.0	Yes
5	10.0	Yes

*QA Study Assessment Tool*

The *QA Study Assessment Tool* was initially given at client admission to the Center and this tool was completed a second time to determine the change in perceived caregiver stress and the change in the perceived quality of life of their loved one over time. The first three statements on this tool refer specifically to the caregivers' stress level. The remaining statements on this tool refer to the caregivers' perception of their loved ones' functioning level – or quality of life. With this tool, a Likert scale was used to quantify the caregivers' responses. The caregivers were asked to respond to the statements with the following options: (a) 1= strongly agree; (b) 2= agree; (c) 3= neutral; (d) disagree; and (e) strongly disagree. The statements referred to the high level of stress and feelings of guilt. For the first part of the *QA Assessment Tool*, a score close to 1.0 indicates that the caregiver feels that they are under a great amount of stress. A score of 5.0 indicates that their stress level is low. For the second part of the *QA Assessment Tool*, a score close to 1.0 indicates that the caregiver believes their loved one's functioning is low. A score of 5.0 indicates that the caregiver believes their loved one's functioning is high.

In regard to the caregivers' perceived stress level, the mean score at admission was 1.5, and the mean score after ADC utilization was 2.38. Table 3 presents this data for each of the interviewees. This suggests that there may be a relationship between ADC attendance and a reduction in caregivers' level of perceived stress. Interestingly however, participants #1 and #2 had no perceived change in their individual stress levels on this measure. It is possible that since one of these interviewees had used ADC services for their loved one for 24 months and the other for 60 months the initial net change in perceived stress may have been missed. It is quite possible that had each of these interviewees' perceived stress levels been measured at 12 months, a net decrease may have been found.

Table 3

*QA Study Assessment Tool – Perceived Caregiver Stress*

Caregiver	Initial Score	Score After ADC Utilization	Length of ADC Attendance (months)	Net Change in Perceived Stress
1	1.0	1.0	60	0
2	1.6	1.6	24	0
3	2.3	4.3	18	+2.0
4	1.6	2.0	9	+0.4
5	1.0	3.0	24	+2.0
	Mean= 1.5	Mean=2.38	Mean= 27	Mean=+0.88

The second part of the *QA Assessment Tool* examined the caregivers' perception of their loved ones' functioning ability or quality of life. The mean score at admission was 2.75, and the mean score after ADC utilization was 2.62. Three of the five participants

believed that their loved one's functioning ability had declined since beginning ADC attendance. This is likely due to the progression of their loved ones' dementia, rather than on the quality of services provided by the ADC to enhance the quality of their lives and functioning abilities.

Table 4

*QA Study Assessment Tool – Perception of Client Functioning*

Caregiver	Initial Score	Score After ADC Utilization	Length of ADC Attendance (months)	Net Change
1	2.63	1.28	60	-1.35
2	3.13	4.25	24	+1.12
3	3.25	2.75	18	-0.50
4	3.75	2.43	9	-1.32
5	1.0	2.38	24	+1.38
Mean=	2.75	Mean= 2.62	Mean= 27	Mean= -0.67

## Discussion

The conceptual framework of mutuality was identified throughout the qualitative analysis. Qualitative analysis allowed for themes to emerge from the interviews and the themes related to concepts identified in the literature. As previously stated, the themes from the qualitative analysis included: (a) dealing with the loved one's mood swings and behavior; (b) maintaining a positive attitude; (c) making decisions to benefit both the loved one and the caregiver; (d) coping with the fact that their loved one will never be the person they were

before the disease; (e) feelings of guilt; and (f) lessening of the burden of caregiving.

Collectively, the themes illustrate the trusting and interpersonal relationship of mutuality. By building trusting relationships, the caregivers and the staff at the ADC are able to effectively communicate and focus on the status of the client. Care conferences between the multidisciplinary team at the ADC and the caregivers for each client are held every three months to personalize each client's plan of care. The conceptual framework of mutuality is an integral aspect for a high level of patient care.

The semi-structured interview, *Caregiver Strain Index*, and the *QA Study Assessment Tool* provided insight into the impact of ADC attendance on the perceived caregiver stress levels and the perceived quality of life of the clients attending ADC.

The average score on the *Caregiver Strain Index* was 8.6, which indicated that the caregivers were currently under a high amount of stress. Although this could indicate that adult day care attendance did not help alleviate stress, the qualitative data contradicts this assumption and indicates that attendance has indeed helped the caregivers deal with the demands of taking care of a dependent individual. In order to examine the impact of ADC attendance since admission, a comparison of current stress levels to admission stress levels on the *Caregiver Strain Index* would be necessary.

Analysis of the results for the *QA Study Assessment Tool* was done to describe the changes over time in the perceived stress of caregivers and the perceived client functioning from admission to the day of the interview.

As previously stated, the mean score for perceived caregiver stress on admission was 1.5 out of 5.0, and the mean score after adult day care attendance was 2.38 out of 5.0. This suggests that in the beginning the caregivers felt very stressed as a result of caring for another

person. Although the caregivers' perceived stress decreased over the time that their loved one was enrolled in ADC, the result indicates that the caregivers still suffer from a moderate level of stress. Outside stressors, in addition to the demands of caregiving, must be examined when analyzing caregiver stress. Additional stressors included financial problems, personal health, family disintegration, and personal careers. When viewing the overall concept, it would be unreasonable to believe that adult day care attendance would cause a caregiver's level of stress change from extremely high to extremely low because caregiving is only one role out of several the caregiver fulfills.

In addition to the length of time for attendance, the progressive nature of dementia must be addressed when viewing the results. Since dementia is a progressive disease, it is not appropriate to argue that ADC attendance would eliminate all perceived caregiver stress. As the disease inevitably progresses and the clients' functioning declines, a significant amount of perceived caregiver stress would be expected to remain and quite likely to increase. Although ADC attendance in this study did help decrease the overall perceived amount of caregiver stress, a certain amount of stress would still exist due to the nature of the disease and other stressors in caregivers' lives.

As previously stated, the mean score regarding the caregivers' perception of their loved ones' functioning or quality of life, at admission was 2.75 out of 5.0. The mean score after ADC utilization was 2.62 out of 5.0. Although this illustrates that overall the clients' functioning levels declined over time, the progressive nature of dementia is likely to be a confounding variable here. With the utilization of ADC, the clients were able to remain near their functioning level at admission. It would be inappropriate to interpret these results as negative toward utilization of ADC. Without the utilization of ADC, the perceived

functioning level of loved ones may have decreased substantially more. However, the clients utilizing ADC in this study remained close to their previous level of functioning.

### Limitations

There were limitations with this research study. The most significant limitation was the use of a convenience sample and the size. The results of this study cannot be generalized and are not statistically significant due to the small convenience sample. If the sample had been larger, with random selection of caregivers, the answers to the interview questions may have been more varied and additional themes may have emerged.

Another limitation to this study was that it focused only on one adult day care center. If a greater number of adult day care centers were used, the responses may have been different.

Subjectivity in the qualitative analysis of the data is another limitation to this study. The transcripts were read through a subjective lens and the themes identified may have been impacted by themes found in the literature. The interpretation of the themes was subjective, and multiple readings of the transcripts were completed to decrease subjectivity.

Additionally, there was variance in the stages of dementia and severity of manifestations of the loved ones who were the focus of the caregiver interviews and questionnaires. It is possible and likely that the perceived stress of caregiving increases as the dementia progresses to later stages, thus minimizing the demonstrable impact of adult day care services on caregivers. Recommendations for future research studies in this field include having a larger sample size, utilizing several ADC sites, and having the caregivers fill out the *Caregiver Strain Index* upon admission.

The findings from this study are similar to the findings found in the review of literature. Richie (2003) found that ADC attendance greatly impacted the lives of caregivers, as well as clients, and was a significant factor in reducing the amount of caregiver stress. Similarly, Zarit and colleagues (1998) found that caregivers who utilized ADC services experienced less caregiver-related stress and displayed improved psychological well-being. Overall, the results from our study parallel those the results found in the review of literature.

### Conclusion

The utilization of ADC services for a loved one with dementia correlated with the decrease in perceived stress of the primary caregivers in this small study. Additionally, the primary caregiver's perception of their loved one's quality of life remained fairly constant with the utilization of these services. Experimental studies are needed to fully examine the impact of adult day care utilization and the client's change in functioning level. The ADC provided a respite from caregiving for the caregivers involved in this study and promoted stimulation and socialization for their loved ones. There appears to be a benefit and need for this type of model of care, especially considering our society's growing elderly population. The continuation of research regarding the impact of ADC and alternative models of care for the elderly is an issue that must be looked at as a priority in health care.

In order to serve more caregivers and their loved ones, great effort is needed to change current legislation to allow Medicare coverage for ADC attendance so that individuals of all socioeconomic levels may benefit from these services. Communities and health care providers should be educated about the services that these facilities provide.

Caring for another human being requires great self-sacrifice and can increase a person's level of perceived stress. Adult day care centers are an excellent means of providing respite for caregivers and providing stimulation and socialization for their loved ones. Mutuality can be achieved through this model of care, which is of benefit to the client with dementia, the primary caregiver, and the staff of the ADC.



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## Appendices



Date: June 6, 2006

To: Joni Jones, Principal Investigator  
Abby Olsen, Student Investigator for honors thesis

From: Amy Naugle, Ph.D., Chair 

Re: HSIRB Project Number: 06-05-14

This letter will serve as confirmation that your research project entitled "A Study of the Impact of Adult Day Care Centers on the Caregivers of Clients with Dementia" has been **approved** under the **expedited** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: June 6, 2007

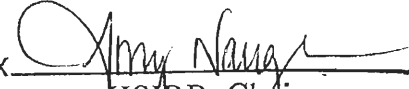
## Appendix B – Informed Consent Document

WESTERN MICHIGAN UNIVERSITY

H. S. I. R. B.

Approved for use for one year from this date:

JUN 06 2006

x   
HSIRB Chair

Western Michigan University  
 Department of Nursing  
 Principal Investigator: Joni Jones, PhD, RN  
 Student Investigator: Abby Olsen

As the legal guardian of a client enrolled in the Marian E. Burch Adult Day Care Center (MEBADCC), you are invited to participate in a research project entitled, "A Study of the Impact of Adult Day Care Centers on the Caregivers of Clients with Dementia." This study will investigate the perceived stress and feelings of caregivers regarding their responsibility in providing care for a loved one with dementia and their perception of the impact of Adult Day Care Center Programs both on their quality of life and that of their loved one participating in the program.

Your consent for participation in this study means that you, as a primary caregiver, will be asked to fill out two forms, "The Caregiver Strain Index" and "QA Study Long-term Outcomes" one time and to participate in one 30-minute interview conducted by the Student Investigator. This interview will be about your perceptions of your loved one's mental, physical and social functioning since he/she has been enrolled in the Adult Day Care Center Program. The interview will also focus on your perceived stress level related to caring for your loved one. The interview will be scheduled at your convenience and should last approximately 30 minutes. The interview will be audiotape recorded for later transcription. Immediately following the transcription, the audiotape will be destroyed.

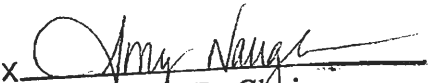
You may discontinue your participation in this study at any time, even after the interview has begun. Your decision to decline participation or to terminate participation in the study will have no effect on the services and care your loved one receives at MEBADCC. Although there are no likely immediate benefits to you for participating in this study, this research and similar studies may eventually be of benefit in determining the types of services and care that Adult Day Care Centers should provide that may alleviate the stress of caregivers.

Your name, the name of your loved one and any other identifiers will not be used on any of the data collection forms. The researchers will use a code number instead, thus all collected information will remain confidential. The researchers will keep a list of names and code numbers in a locked file in the principal investigator's office. The master list of names and code numbers will be destroyed once the researchers have collected and analyzed the data. All other data collection forms will be retained for at least three years. Any subsequent publication or public presentation of the findings of this study will not include the names of the participants or any other identifying information.

If you have any questions or concerns about this study, you may contact either Abby Olsen at (269) 660-2923 or Joni Jones at (269) 387-8158. You may also contact the Chair, Human

H. S. I. R. B.  
Approved for use for one year from this date:

JUN 06 2006

x   
HSIRB Chair

Subjects Institutional Review Board at (269) 387-8293 or the W.M.U. Vice President for Research at (269)387-8298 if any questions or concerns arise during the course of this study.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board, as indicated by the stamped date and signature of the board chair in the upper right corner. You should not participate if the stamped date is more than one year old.

Your signature below indicates that you agree:

- To allow your loved one's chart at MEBADCC to be reviewed by the Student Investigator for the purpose of accessing admission scores on the "QA Study - Long-term Outcomes". No other information from the chart will be accessed or recorded.
- To be interviewed for approximately 30 minutes by the Student Investigator concerning your perceived level of stress related to providing care for your loved one and your perceived assessment of the functioning of your loved one since being enrolled at MEBADCC. (This interview will be audiotape recorded. The audiotape will be destroyed after transcription is completed.)
- To complete "The Caregiver Strain Index", and "QA Study- Long-term Outcomes" one time, during the scheduled meeting, following the interview.
- For these results, to be used in the thesis report by the Student Investigator.
- For the final report of this study to be shared with the MEBADCC Director and Staff, for purposes of internal evaluation of programs and activities. (No identifying information of participants will be included.)

\_\_\_\_\_  
Print name here  
(Caregiver)

\_\_\_\_\_  
Sign name here  
(Caregiver)

\_\_\_\_\_  
Today's Date

(Name of Client -- \_\_\_\_\_)

Appendix C - *Semi-Structured Interview Questions*

- 1.) What are some of the greatest difficulties and challenges you face in providing care for your loved one?
  
- 2.) How long has your loved one been attending ADC? Have you seen differences in his/her functioning (behavior, emotions, communications, ability to perform activities of daily living) since they have been coming to ADC?
  
- 3.) How has having care provided by the ADC staff during the day affected your life? What is the best thing about ADC for you and your loved one? What is the worst thing about ADC for you and your loved one?
  
- 4.) Overall, would you say that the quality of your life has improved, gotten worse, or stayed about the same since enrolling your loved one in ADC? In what ways?
  
- 5.) Overall, would you say that the quality of your loved one's life has improved, gotten worse, or stayed the same since coming to ADC?

## Appendix D - Caregiver Strain Index

	Yes=1	No=0
Sleep is disturbed (e.g. because _____ is in and out of bed or wanders around at night)		
It is inconvenient (e.g. because helping takes so much time or it's a long drive over to help)		
It is a physical strain (e.g. because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g. helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g. had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g. from other family members)		
There have been emotional adjustments (e.g. because of severe arguments)		
Some behavior is upsetting (e.g. because of incontinence, _____ has trouble remembering things; or _____ accuses people of taking things)		
It is upsetting to find _____ has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be)		
There have been work adjustments (e.g. because of having to take time off)		
It is a financial strain		
Feeling completely overwhelmed (e.g. because of worry about _____; concerns about how you will manage)		
<b>TOTAL SCORE:</b> (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

Robinson, B. (1983). Validation of a caregiver strain index. *Journal of Gerontology*, 38(3), 344-348.



## Appendix E - QA Study Assessment Tool

(1 = Strongly Agree; 2 = Agree; 3 = Neutral; 4 = Disagree; 5 = Strongly Disagree)

<b>INITIAL ASSESSMENT</b>	<b>DATE:</b>				
I feel very stressed by the physical demands of providing care for my loved ones.	1	2	3	4	5
I feel very stressed by the emotional demands of providing care for my loved ones.	1	2	3	4	5
I often feel guilty about the frustration that I sometimes experience in trying to provide adequate care for my loved one in addition to meeting my other responsibilities.	1	2	3	4	5
My loved one's sleep pattern most nights is poor. (Frequent waking and restlessness)	1	2	3	4	5
My loved one's level of functioning seems to be rapidly declining.	1	2	3	4	5
My loved one's appetite is poor.	1	2	3	4	5
My loved one experiences frequent behavioral problems such as angry outbursts, wandering, crying, etc.	1	2	3	4	5
My loved one seems unable to remain focused on recreational activities and projects.	1	2	3	4	5
My loved one seems unhappy much of the time.	1	2	3	4	5
My loved one seems confused much of the time.	1	2	3	4	5
My loved one seems disengaged from the rest of the world much of the time.	1	2	3	4	5
Comments and initial observation:					

(1 = Strongly Agree; 2 = Agree; 3 = Neutral; 4 = Disagree; 5 = Strongly Disagree)

<b>CURRENT ASSESSMENT</b>	<b>DATE:</b>				
I feel very stressed by the physical demands of providing care for my loved ones.	1	2	3	4	5
I feel very stressed by the emotional demands of providing care for my loved ones.	1	2	3	4	5
I often feel guilty about the frustration that I sometimes experience in trying to provide adequate care for my loved one in addition to meeting my other responsibilities.	1	2	3	4	5
My loved one's sleep pattern most nights is poor. (Frequent waking and restlessness)	1	2	3	4	5
My loved one's level of functioning seems to be rapidly declining.	1	2	3	4	5
My loved one's appetite is poor.	1	2	3	4	5
My loved one experiences frequent behavioral problems such as angry outbursts, wandering, crying, etc.	1	2	3	4	5
My loved one seems unable to remain focused on recreational activities and projects.	1	2	3	4	5
My loved one seems unhappy much of the time.	1	2	3	4	5
My loved one seems confused much of the time.	1	2	3	4	5
My loved one seems disengaged from the rest of the world much of the time.	1	2	3	4	5
Comments and initial observation:					