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The purpose of the study was to learn more about the ways in which caregivers perceive the effects of adult day services. The goal was to help inform adult day providers about services family caregivers find useful. An ecological model was used as a framework. Data were collected from focus groups consisting of spouse and nonspouse family caregivers of past and current participants in two different program models of adult day services: adult day care and adult day health services.

There were few differences in the way caregivers of past and current participants perceived adult day services. One major difference was that some caregivers of past participants perceived that the programs had failed to provide support to them after their family member passed away. Although spouse and nonspouse caregivers used adult day services for different reasons, the main reason reported by both was to keep their family member active. The perceptions of caregivers using the adult day care model differed little from those of caregivers who used adult day health services. One difference was

that some caregivers saw the staff at the adult day care center as role models who taught them how to care for and accept dependent family members.

Talking to family caregivers about their experiences with adult day services can provide practitioners with valuable insights about the services and activities that family caregivers find useful and those they may need to assist them in their efforts to care for impaired family members. Adult day providers need to understand what effect services and activities have on caregivers and family members to enable them to create programs that benefit both.

Ecology of Adult Day Care for Family Caregivers

by

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Susan L. Patterson, Author

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I would like to thank the family caregivers who took time from their busy lives to share their perceptions of adult day services. It is obvious from your shared personal experiences that caregiving can be both rewarding and challenging. The care you provide for family members is admirable and an inspiration to others who struggling to care for dependent family members.

Thank you to my two dearest friends, Diana Haberland and Renee Windsor, for their patience and support in what has been a challenging but rewarding journey. My gratitude to Dr. Tom Embree, my confidante and mentor, for helping me get my life back and for always being there for me. Thank you to my sisters, Patricia Clegg and Deborah Cummings, for reviewing my work and sharing their candid but valuable opinions. I extend my gratitude to my brother and sister-in-law, David and Linda Dillon, who kept me laughing even in my darkest hour. Last but not least, my love and appreciation to my sons, Sean and Ryan Patterson, who gave me the strength and courage to embark on this journey.

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DEDICATION

I dedicate this dissertation to my Mother, Dorothy Dillon, who was my best friend, confidante, and greatest supporter. Without her encouragement I would never have attempted this challenging journey. We shared many wonderful adventures on the open road. I only wish she was here to share the culmination of this journey but I know that she is up there having the greatest adventure of all. Thank you Mom for your friendship, your love, and your support. Happy trails to you until we meet again!

Ecology of Adult Day Care for Family Caregivers

Chapter I

Introduction

By 2030, more than 20% of Americans, one in five, will be 65 or older (Quadagno, 1999). As the elderly population continues to grow, more and more services will be needed to provide care for those who become dependent as a result of acute and chronic illnesses associated with aging (Hooyman & Kiyak, 1999). Adult day care is a respite service frequently cited as beneficial for both family caregivers and dependent family members (Beisecker, Wright, Chrisman, & Ashworth, 1996).

Adult day services offer family caregivers needed time out from, and complement, the care they provide for impaired family members (Caserta, Lund, Wright, & Redburn, 1987; Conrad & Guttman, 1991; Zarit, Stephens, Townsend, & Greene, 1998). Although various service models of adult day care have been proposed, in general, adult day programs provide therapeutic activities, medical care, and socializing to help maintain, restore, or improve the mental and/or physical functioning of impaired adults (Conrad & Guttman, 1991; Zarit et al., 1998). In addition, adult day services have been promoted as preventing or delaying institutionalization of the participant (Guttman, 1991; Lawton, Brody, & Saperstein, 1989; Zimmerman, 1986).

We know what type of services adult day programs provide and we know that adult day services have beneficial effects on family caregivers and impaired family members. Overall, we know very little about the types of services provided by adult day care that family caregivers find useful. Specifically, we know very little about the ways in

which spouse and nonspouse caregivers experience the effects of adult day services and how these experiences may differ depending on the program model. Furthermore, there is little understanding of whether caregivers of past participants perceive adult day services differently than caregivers of current participants. This study examined the issues illustrated in the following case studies. The case studies were developed from focus groups of spouse and nonspouse caregivers of past and current participants in two models of adult day programs. The first study describes the experiences of a granddaughter of a past participant of an adult day care center based primarily on a social model. The second study describes the experiences of a husband whose wife currently attends an adult day health center based primarily on a medical/rehabilitation model.

Case Study One

Liz thought back to five years ago, when she enrolled her grandmother, Sophie, in adult day care. She remembered feeling very good about having Sophie in the program. Liz decided to enroll Sophie in an adult day program because she wanted her to do something beside sit in her chair and stare out the window while she was at work. She wanted to see Sophie involved physically, mentally, and socially. Despite her severe memory loss, Liz felt that her grandmother needed to be involved and stimulated.

Liz had to work but she did not want Sophie to be home alone. Along with her memory loss, Sophie had arthritis and was not able to get around anymore. Liz felt it was not safe for her grandmother to be at home without supervision. Because of Sophie's cognitive impairment, Liz was not able to ask her if she wanted to attend an adult day program. Nevertheless, Liz remembered that her grandmother was happy with Liz's

decision to enroll her because when Liz picked her up at the center Sophie always had a big smile on her face.

Before Liz enrolled her grandmother in adult day care, she worried about Sophie when she was at work. Sophie's attendance at adult day care allowed Liz to go to work knowing that Sophie was receiving good care. Sophie had arthritis in her hands and the clay therapy was wonderful for her. Liz recalled that the social activities and the games they played with balls got her moving more than she had moved in years. Liz explained that after a day at the center, Sophie was more sociable at home, which made life more enjoyable for both of them.

Liz reminisced that the staff at the adult day center was more like family. She was able to talk to a staff member when she dropped Sophie off in the morning and when she picked her up after work. They were emotionally supportive to both her and Sophie. She recalled that one of the strengths of the staff was the high level of knowledge about different community services that were available for older people. Liz admitted that she had never heard of these services before talking to the staff. She wanted to keep Sophie at home for as long as she was able to care for her. She firmly believed that Sophie's attendance at adult day care gave her grandmother three more years at home before she had to be placed in a nursing home two years ago.

Case Study Two

Jack often feels overwhelmed from caring for his wife, Nancy, who is in her fourth year of attendance at an adult day health center. He thinks that caregivers are not normal if they are not experiencing stress. According to Jack, Nancy's problems started when she fell in their backyard and fractured her leg. She needed ongoing rehabilitation

for which Medicare would not pay. Jack thought that adult day health services could provide the physical therapy she needed.

When Jack enrolled Nancy in the adult day health center he said he just eased her into the program. Nancy's memory had deteriorated to the point that she did not know what was happening. In fact, she thinks she is at work when she is at the center. Nancy's memory loss has accelerated in the last year. She used to remember some of the activities she liked at the adult day health center. Now, according to Jack, he has to remind her every morning that the senior van is coming to take her to the center.

Because of Nancy's memory impairment, Jack worries that when he forgets something, memory loss is happening to him, too. He is afraid that he may end up like his wife. He is also frustrated with Nancy because her memory loss has led to personality changes that he cannot understand. Jack feels that Nancy's behavior is like that of a child in her terrible twos. His wife can be nasty to him but she is an adult who cannot be spanked.

Jack says that the therapeutic activities Nancy is getting at the adult day health center are helping her mobility. He reports that recently Nancy walked into the kitchen, bent over at the waist, and tied her shoe. This is something she had not done since she broke her leg. Jack is still surprised over the event. He attributes her recovery to the activities at the center. Although Nancy's mobility is improving, her memory problems have not improved. Jack thinks that she is more dependent on him since he enrolled her in adult day health services. He does not talk to the staff about his feelings.

Jack thinks the staff is more interested in Nancy's mobility than her memory problems. He is not certain that adult day health services offer Nancy all the assistance

she needs. He never sees her at the center so he does not know if she is socializing and doing activities that might help her to be more alert and sociable at home. Although adult day health services allow Jack time to do some of the things he enjoys when not caring for Nancy, he is concerned about whether the services benefit Nancy.

These brief case studies highlight the importance of the proposed study on family caregivers' perceptions of adult day care use. From these two examples, we learn that Liz and Jack experienced adult day services very differently. Liz reported that she was content with her decision to enroll her grandmother in adult day care. The program seemed to meet her needs. Sophie attended an adult day care program that was based primarily on a social model. Liz wanted Sophie to be physically, socially, and mentally involved. The program emphasized socializing and activities that promoted increased physical and cognitive functioning. The activities helped Sophie to be more alert and increased her mobility. Sophie's improved mobility made it easier for Liz to care for her. As a result of her socializing at the center, Sophie became more sociable at home, which made both of their lives more pleasant.

Adult day care offered respite for Liz so that she could be at work without worrying. Knowing that Sophie was receiving good care in a safe environment decreased her anxiety. Liz's interactions with the staff were very positive. They gave Liz the emotional support she needed, which may have helped her to feel less distressed about caregiving. The staff provided Liz with information about resources in the community that also helped her provide better care for her grandmother. Attending an adult day care program may have also helped to delay Sophie's institutionalization.

In contrast, Jack is not as satisfied with adult day health services. The center Nancy is attending has a strong medical/rehabilitation component, which may not be meeting his needs. In spite of the eight hours a day of respite that Jack gets while Nancy is at the center, he is very distressed. Although Jack enrolled Nancy in an adult day health program that could provide the physical therapy she needed for her leg, he hoped that her involvement in the program would improve her memory. The therapeutic activities have allowed Nancy to be more mobile at home. Nancy's memory, however, has not improved. She is less alert and sociable at home, which causes Jack a great deal of anxiety.

Jack does not seem to be communicating with the staff. According to Jack, Nancy was placed in adult day care because she needed physical therapy for her leg. In reality, Nancy has had severe dementia for a long time. Nancy's personality has changed and he is unable to cope with her aggressive behavior. He needs to learn how to cope with Nancy's memory loss and subsequent personality changes. The staff may not be supportive of Jack's educational or emotional needs or he may be reluctant to talk with the staff about Nancy's memory impairment. The program may emphasize physical rehabilitation more than socializing and activities that might promote improvement or maintenance of Nancy's cognitive functioning.

Liz is more positive about adult day care than Jack is about his experiences with adult day health services. As a caregiver of a past participant, Liz is no longer involved in daily caregiving. Consequently, she may only remember her positive experiences with adult day care. Despite their close relationship, Liz is Sophie's granddaughter. Her relationship with Sophie is not as intimate as Jack's relationship with his wife. Liz may

not have felt the terrible sense of loss that Jack appears to be experiencing. Women tend to be more realistic about the losses inherent in aging (Hooyman & Kiyak, 1999). Furthermore, Liz may not have experienced caregiving as intensely as Jack. Because men often do not have as much experience providing care, caregiving may be more intense for men when they are faced with the responsibility (Dwyer & Seccombe, 1991).

Jack is experiencing a great deal of stress as a caregiver of a current participant of adult day health care. His distress may be causing him to feel negatively about his life experiences, including his experience with adult day health services. He and his wife had a traditional marital relationship. She always took care of him and their children while he was at work. He is now overwhelmed by the day-to-day concerns of caring for her. He expected his wife's memory to improve but it has worsened. He may be grieving over the loss of the relationship they had prior to Nancy's illness. Unlike Liz, Jack does not have a close relationship with the staff. He does not seem to be getting the information and support he needs. Liz talks to the staff when she takes her grandmother to adult day care. Nancy takes the van every day, thus Jack does not have the opportunity to communicate with the staff on a regular basis, nor does he seem make an effort to stop by the center to talk with them. Because some men may be reluctant to ask for emotional support, he may be too embarrassed or ashamed to admit he needs help (Zastrow & Kirst-Ashmann, 1990).

The purpose of this study was to learn more about how family caregivers perceive the direct and indirect effects of adult day services. In doing so, the goal was to help inform adult day care providers about services that family caregivers find useful and

helpful. In general, this study was interested in the kind of services provided by adult day care that family caregivers find helpful.

Specifically, this study asked the question: How might family caregivers' perceptions of the effects of adult day care assist people to provide adult day services that caregivers find helpful? To assist service providers, I looked for differences in (a) the way caregivers of past and present participants perceive the effects of adult day services, (b) the way caregiving spouses versus other family members perceive the effects of adult day services, and (c) caregivers' perceptions of adult day services derived from different models. An ecological perspective was used as a framework. Perceptions of experiences were obtained from focus groups consisting of family caregivers of past and current participants who attended two different program models of adult day services.

Chapter II

Literature Review

Adult day care evolved from the concept of the Russian psychiatric day hospital. In 1933, the chief physician of Moscow Psychiatric Hospital was confronted with a serious shortage of beds in the ward. Enlarging the existing ward was not feasible. The solution to the problem was to maximize the existing space by creating a new program, the day hospital. The plan specified that patients would be treated in the hospital during the day and return home in the evening (Wolf-Klein, Maar, & Foley, 1988).

Ten years later, the concept of adult day programs was utilized in Britain and Canada to provide medical care and psychosocial rehabilitation to soldiers returning from World War II (Cameron, 1967). In 1950, the British expanded the early model of adult day care to meet the needs of impaired older adults. The Older Americans Act of 1965 paved the way for adult day programs in the United States. The act encouraged the development of programs to provide socialization and recreation for older adults who were in jeopardy of premature nursing home placement (Wolf-Klein et al., 1988).

Under the Older Americans Act, Medicare was responsible for funding adult day programs. Medicare abandoned the project because the first evaluation reports concluded that adult day care was not a cost-effective replacement to institutionalization. Medicaid agreed to pay for low-income older adults but the practice varied from state to state (Wolf-Klein et al., 1988). Because of the lack of federal funding, adult day care became a grassroots response to local communities' need to care for frail older adults.

Although adult day care centers have a multiplicity of programs and are offered in a variety of settings, the primary purpose of adult day care is to maintain, restore, or

improve the physical and mental functioning of participants through a variety of medical and social services (Conrad & Guttman, 1991; Zarit et al., 1998). Adult day services commonly include individualized care plans; personal care; social, physical and educational activities; health monitoring; nutrition service; transportation; counseling; and emergency care (National Adult Day Services Association (NADSA), 1999). In addition, adult day care offers caregivers temporary respite and relief from the demands of caregiving. The aim of relieving the strain on caregivers is often coupled with the program goal of preventing or delaying the institutionalization of the care recipient (Brody, Saperstein, & Lawton, 1989).

Although adult day care was originally intended for older adults with a physical or cognitive impairment, a recent survey by NADSA (1999) reported that most adult day centers will provide services to adults with physical or cognitive disabilities who are 18 years and over. Furthermore, some adult day centers are expanding their target populations to include younger adults with developmental disabilities and chronic mental illness (Cox, 2000).

Adult day programs have become an important component in the continuum of long-term care for impaired adults (Bea van Beveren & Hetherington, 1995). Twenty-five years ago, only a few programs existed. Currently there are over 2,000 programs nationwide (NADSA, 1999). The number of adult day programs has increased because adult day care is a valuable service for family caregivers as well as participants (Caserta, Lund, Wright, & Redburn, 1987). Moreover, as services are relatively inexpensive when compared with nursing home care, programs are viewed as an attractive community long-term care alternative (Hall, 1989).

Ecological Theory

Although an ecological model is often used to describe and explain early childhood development, it also provides a valuable framework for understanding development across the life course. Ecological theory is interested in transitions from one setting to another as the developing person moves from stage to stage throughout the lifespan. In each stage of development, settings are added or replaced and the interactions between settings change accordingly. More importantly, ecological theory is concerned with how increasingly complex reciprocal interactions between changing settings affect outcomes of the developing person and the person's family (Bronfenbrenner, 1977). For example, in infancy, the home/family is the primary context for development (Bronfenbrenner, 1986). In childhood, school attendance leads to interactions between home and school settings. In adulthood, interactions between home and school are replaced with interactions between home and work settings. In later life, retirement leads to a move back to the primary setting of development, the home and family. Some older adults with physical or cognitive disabilities may also need the services provided in an adult day care setting. Of course, developing persons of any age typically have interactions in and across multiple settings; the portrayal of ecological contexts is purposely simplistic to illustrate changes across the life span.

From an ecological perspective, development takes place within the context of particular settings, of which the family/home is the most important (Bronfenbrenner, 1992). The ecological environment is conceptualized as a nested arrangement of structures, each embedded within the next (Bronfenbrenner, 1977). The microsystem is a complex network of activities, relationships, and interactions between the developing

person and environment in an immediate setting that contains the person, such as the home, work, or adult day care center (Bronfenbrenner, 1998). Each member of a microsystem influences every other participant in the setting (Bronfenbrenner, 1992). The mesosystem comprises the interactions between two or more major microsystems containing the developing person at a particular stage of life, such as home and work, or home and adult day care. An exosystem consists of two or more settings, one of which does not include the developing person directly but that affects the person indirectly. The macrosystem refers to the overarching cultural context and institutional patterns, such as political, economic, and social systems that provide a blueprint for society (Bronfenbrenner, 1977). For example, Social Security and Medicare provide medical and financial protection for older adults in retirement.

Ecological theory provides a meaningful model for understanding interactions between the home and the adult day center and how these interactions affect the participant and family caregiver. Sophie's home/family comprised a microsystem. In addition, Sophie participated in a second microsystem, adult day care. The interactions or communications between the two settings created a mesosystem. An exosystem of Sophie's was Liz's work. Sophie was not involved in Liz's work but Liz's work demands affected her ability to care for Sophie during the day. Therefore, Liz's work affected her grandmother indirectly as Sophie was enrolled in adult day care because Liz had to work. Figure 1 illustrates Sophie's developmental environment using this ecological model.

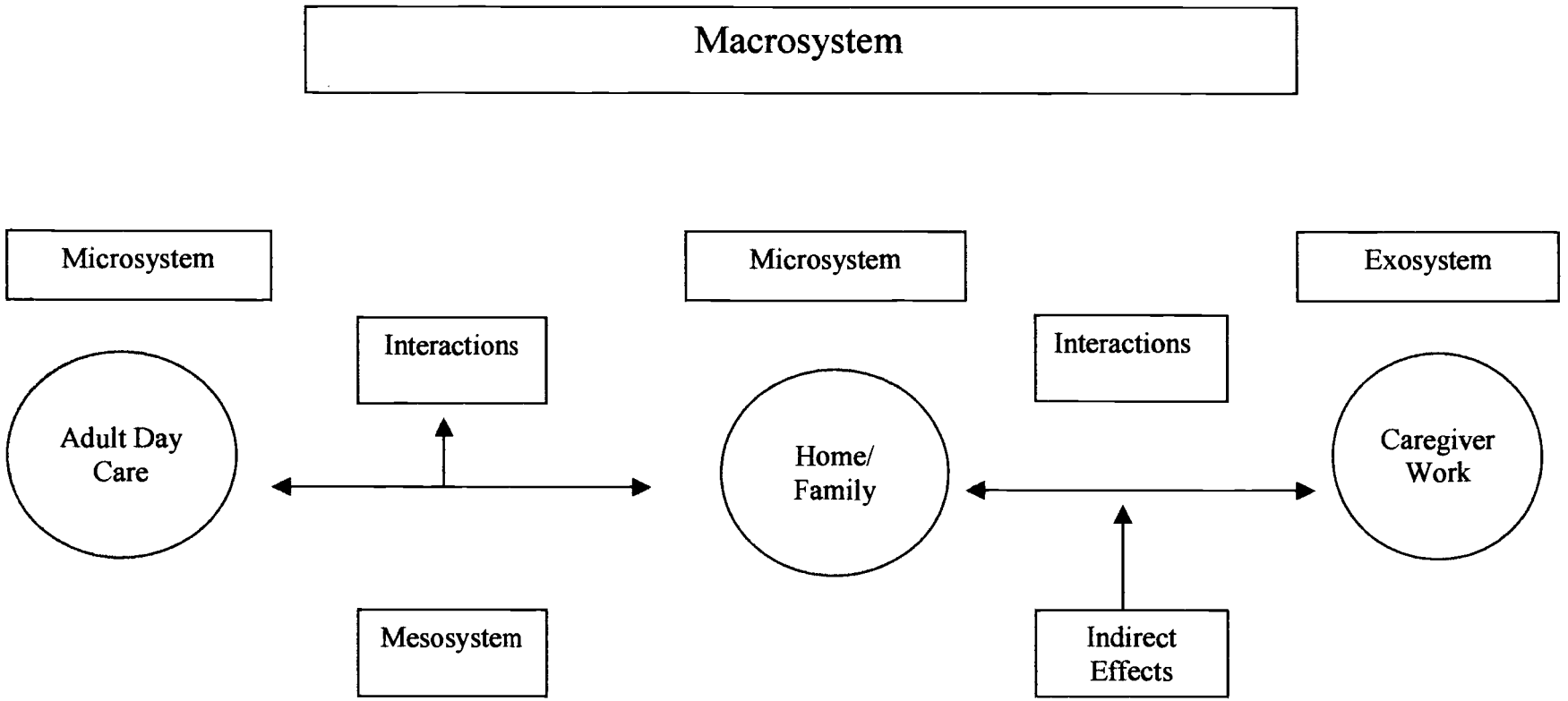

Figure 1. Ecological model of Sophie's developmental environment

From a caregiver's viewpoint, adult day care is an exosystem. The activities and interactions that take place in the adult day setting have indirect effects on the family caregiver. For example, Sophie's daily socializing at the adult day center made her more sociable at home, which improved her relationship with Liz. Figure 2 illustrates this ecological model but from a different viewpoint, that of the family caregiver. In this model, Liz is the developing person, and the adult day center is an exosystem rather than a microsystem setting

Both Liz and Jack experienced indirect effects from the exosystem of adult day care. Sophie's and Nancy's attendance at adult day care gave Liz and Jack respite time. Liz worked and Jack enjoyed time off from caregiving tasks. Knowing that Sophie was receiving good care in a safe environment may have reduced Liz's stress about caregiving. Sophie's activities at the adult day center helped her to improve her mobility and sociability. That made it easier for Liz to care for her at home. Liz's interactions with the staff provided the emotional support she needed. The staff at the adult day center gave Liz information about important resources in the community that helped her provide better care for her grandmother.

Jack also experiences indirect effects of adult day services. The physical therapy Nancy receives at the center has made her more mobile at home and reduced some of the personal care that Jack has to perform for her. He also has some adverse indirect affects from Nancy's participation at the center. Primary among these is his concern that his wife is not getting the activities and socializing at the center that she needs. According to Jack, her participation in adult day health services has not helped her to be more alert and

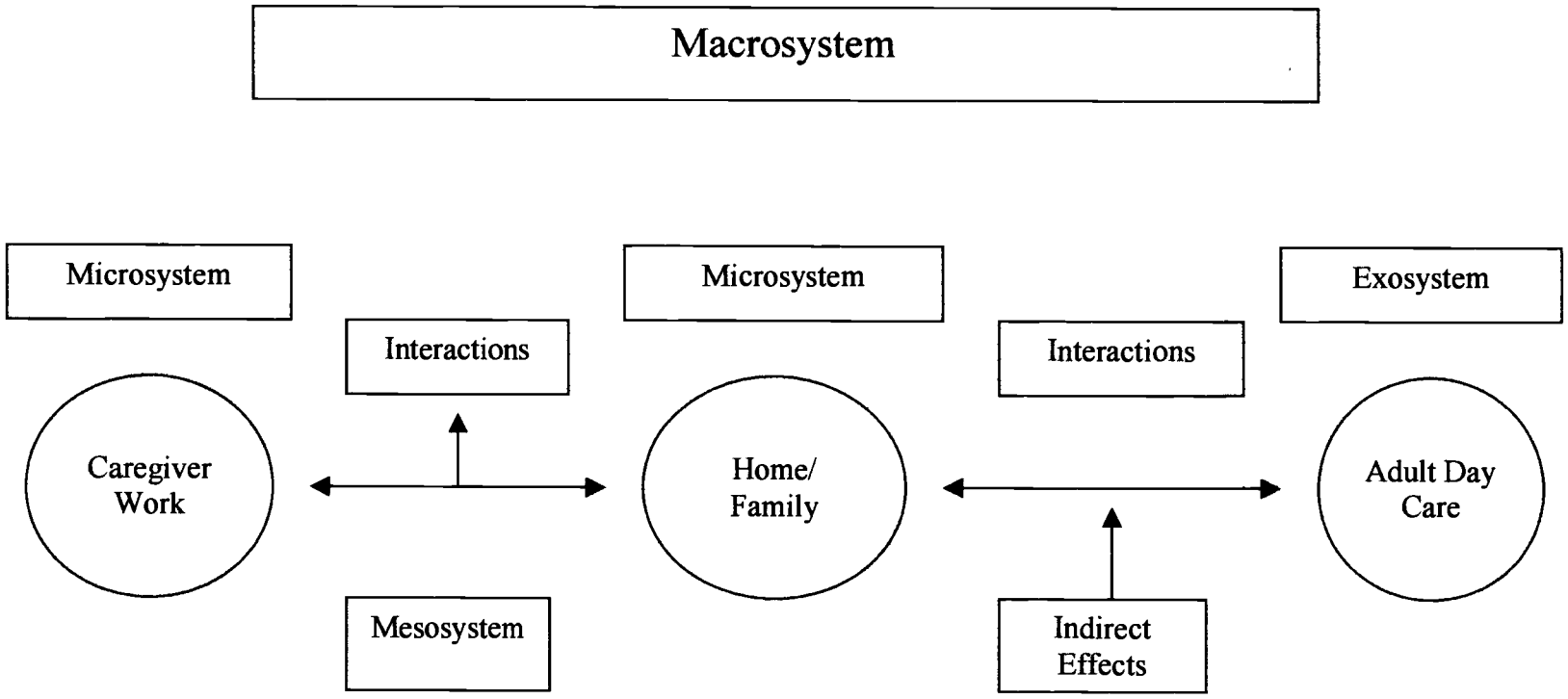

Figure 2. Ecological model of adult day care from the caregiver's perspective.

sociable at home. Furthermore, his wife's participation in adult day care has not increased Jack's support system.

The macrosystem has both positive and negative effects on developing individuals. It affected Sophie and Liz in different ways. On one hand, Medicare and Social Security policies, respectively, enabled Sophie to receive medical treatment and provided an income for retirement. On the other hand, Medicare does not pay for a care recipient to attend adult day care. Although Medicaid will pay for adult day care, the care recipient must meet stringent income requirements. These policies can place a financial strain on caregivers, like Liz, who want to keep their family member at home as long as possible, yet have to work. The scarcity of community resources could also have a negative affect on dependent family members like Sophie. Some communities may not be able to support adult day care centers or may support only one type of adult day care that may not be appropriate for the care recipient's needs.

From Liz's perspective, federal work policies, such as the Family and Medical Leave Act of 1993 (FMLA), enable a family caregiver to take needed time off to care for ailing family members. Workplace policies, however, may be counterproductive to federal policies. Although the FMLA mandated that businesses with 50 employees or more allow employees to have family leave, the act did not require businesses to provide leave with pay. Many caregivers who live on one income, like Liz, cannot afford to take time off from work without pay. In contrast, there are workplace policies that can have positive effects on caregivers. Some businesses allow employees flex time and job sharing arrangements, which permit caregivers to accommodate the responsibilities of work and caring for impaired family members.

The Effects of Adult Day Care

Research on adult day care has suggested both positive and negative effects on family caregivers. A major positive effect of adult day services for caregivers is respite from caregiving tasks that allows them time to rest or attend to other responsibilities (Brody et al., 1989; Zarit, Gaugler, & Jarrott, 1999). Respite has been defined as "any service or groups of services that provides temporary periods of relief or rest for caregivers away from the patient" (Lawton et al., 1989, p. 5). Respite provided by adult day care has been shown to affect caregivers' well-being by decreasing caregiver stress and burden, and improving caregivers' quality of life (Cox, 1997; Gottlieb & Johnson, 1995; Kosloski & Montgomery, 1993; Strain, Chappell, & Blandford, 1988; Zarit et al., 1998).

Numerous studies have cited respite as a positive effect of adult day services on family caregivers (Adler, Kuskowski, & Mortimer, 1995; Lawton, Brody, Saperstein, & Grimes, 1989; Zarit et al., 1999). Adult day services provide a practical way to diminish the constant care demands of family caregivers. The time out permitted by adult day care allows caregivers to resume the normal routines of work and the responsibilities of children and other family members (Feinberg & Kelly, 1995).

An important goal of adult day services is to decrease caregiver stress and burden. Adult day care has been found to decrease the burden of care by reducing the amount of time and energy spent in caregiving tasks (Kosloski & Montgomery, 1993; Montgomery & Borgatta, 1989). Research on caregiver stress and the use of adult day care, however, was inconsistent as to the positive effect on caregivers. Some studies have shown that adult day services have decreased caregiver stress (Gottlieb & Johnson, 1995; Guttman,

1995; Zarit et al., 1998). In contrast, Henry and Capitman (1995) reported that adult day use had no effect on caregiver stress.

Adult day services may help to improve the caregiver's life satisfaction (Strain et al., 1988). A care recipient's involvement in an adult day program may reduce the time family members spend with each other. Consequently, they may have fewer feelings of frustration, impatience, and irritability toward the care recipient (Hall, 1989). Caregiver/care recipient relationships can become strained from the day-to-day demands of dependent family members. Caregivers who used out-of-home services such as adult day care have reported less relationship strain between caregiver and care recipient (Beisecker et al., 1996).

Brody (1985) noted that families go to great lengths to prevent institutionalizing their loved ones. A primary goal of adult day care is to prevent or delay nursing home placement of dependent family members by providing caregivers with time away from the demands of caregiving. Some studies have found that adult day use has led to delayed institutionalization of participants (Kosloski & Montgomery, 1995; Lawton et al., 1989). In addition, Guttman (1991) found that adult day services reduced the desire to institutionalize. Gottlieb and Johnson (1995) found, however, that adult day care is sometimes only a stepping stone toward nursing home placement because it allows caregivers to see how well a family member would adjust to institutionalization.

Models of Adult Day Care

Ecological theory suggests that it is important to determine the characteristics of participants and activities in a setting to understand how the setting may affect a person's development (Bronfenbrenner, 1992). Recall that in the ecological model, adult day care

is a microsystem in which dependent family members are direct participants and an exosystem for family caregivers in that they are affected indirectly by what happens to the participant in the adult day setting. Consequently, the services, activities, and participants in the adult day setting may have indirect effects on caregivers.

Adult day care centers vary as to services, clients, and activities. A consequence of this diversity in programs is that researchers have been unable to agree on specific models that characterize participants and the types of activities that take place in these settings (Bea van Beveren & Hetherington, 1995). This controversy over typologies of adult day care may have resulted in part from the many titles that have been used to describe similar service models. Adult day care has often been referred to as adult day care, adult day health care, and adult day hospitals (Bea van Beveren & Hetherington, 1998). The titles, however, may indicate very different programs and services. The confusion may have resulted from one or more service models existing at a given adult day care center, no matter what the site was called (Szekais, 1985).

Although researchers have proposed a variety of typologies, a number of these share the distinguishing characteristics of two broad-based models that resulted from an early attempt to categorize adult day centers (Conrad, Hanrahan, & Hughes, 1990; NADSA, 1999; Weissert et al., 1989). Weissert (1976) defined Model I, the day hospital, as a medical model of physical rehabilitation in which staff administered rehabilitative physical, occupational, and speech therapy. Participants had multiple chronic physical conditions and were often wheelchair-bound. Model II, adult day care, referred to a social model, which included socializing, recreational activities, some health care services, and

nutrition. The participants in a social model program were a more heterogeneous group with various physical, mental, or social impairments.

Lyman (1993) suggested that the medical and social models identified by Weissert (1976) characterized current adult day services. She found that adult day dementia health centers following a medical model focused on rehabilitation. These programs had full-time nursing staff and physical, occupational, and speech therapists. The nursing staff was licensed to administer medications for managing the symptoms of dementia, such as depression, agitation, and aggressive or combative behavior (Cefalu, Ettinger, & Espeland, 1996). Medical terminology was used in diagnostic assessments and client records. Clients were referred to as patients rather than participants and patients were labeled by their medical diagnosis. The centers tended to have structured programs, which were designed by the staff and closely adhered to by patients (Lyman, 1993).

Adult day programs based on a social model provided socializing, activities, and some medical care (Zarit et al., 1998). Health service delivery was not emphasized. They usually did not have full-time nursing staff. Nurses worked on contract, visiting at least once a week to monitor blood pressure and assess any changes in the care recipient's cognitive or physical status. Generally, at least one member of the staff was a certified nursing assistant (CNA) who is able to administer medications. The focus was on social activities in a safe, comfortable setting (Kirwin, 1986). Group activities such as singing, dancing, and cooking were encouraged. Program schedules in social adult day centers tended to be flexible and responsive to the immediate needs of the clients (Monahan, 1993).

Medical and social models may have different effects on caregivers. According to Lyman (1993), staff in adult day dementia health centers tended to distance themselves from patients in order to avoid the distress of being personally involved with an older adult with dementia. As a consequence, patients appeared to be passive, withdrawn, and unsociable with each other. Because the patients had dementia, they were often treated like children. Staff/patient interactions were based on the idea that the staff knew what the patient needed. Staff was apt to be controlling and often assisted patients unnecessarily, which may have resulted in increased dependency. This increased dependency, in turn, may have necessitated more care on the part of staff, which may have led to increased staff stress (Lyman, 1993). Furthermore, if the care recipient becomes increasingly dependent as result of attendance at adult day health services, the result may be increased caregiver burden and more stress for the family caregiver.

People with dementia and their families are often socially isolated. Monahan (1993) suggested that the social component of care may be as effective as the medical component for the well-being of the participant. Creating an environment with increased opportunities for socialization may help participants compensate for sensory losses from cognitive impairments. The care recipient's socializing at the center has been shown to have a positive indirect effect on the caregiver. The participant's increased sociability at adult day care may make the care recipient more sociable at home, which can improve the relationship with the caregiver (Zimmerman, 1986).

Social adult day programs tended to have flexible schedules that may allow participants some personal freedom. This flexibility may encourage independence and self-esteem. When care recipients have increased independence, they may need less care,

and staff may experience less caregiver stress (Lyman, 1993). The care recipient's increased independence may mean that the family caregiver would have to perform fewer caregiving tasks, which could reduce caregiver burden and stress.

Although Lyman (1993) and Monahan (1993) have argued that social adult day programs are as valuable as medically based programs for maintaining the physical and cognitive functioning of participants, the current trend in the adult day service field is toward adult day health centers. Most new adult day centers are adult day health centers and some existing social model adult day centers are converting to adult day health centers (Cox, 2000). Adult day health centers tend to have more resources than social adult day centers, such as nurses; physical, occupational, speech therapists; personal care services; subacute care; and transportation. These additional services are in response to the need to expand funding sources to meet the demands of an aging population that is increasingly more frail and cognitively impaired. A recent study (Cefalu et al., 1996) suggested that adult day health care may be appropriate for participants with greater degrees of functional and cognitive decline as a means of assisting and supporting caregivers to maintain dependent family members who need a high level of care in the community.

Caregivers of Past and Current Participants

Researchers interested in adult day services have consistently collected data from caregivers of current clients. The negative effects of caregiving, however, may distort caregivers' perceptions of adult day services. Caregivers of current participants who experience depression or stress may have negative appraisals of self and their experiences with caregiving. Therefore, they may evaluate adult day services in a negative way,

reporting dissatisfaction with treatment from staff for the caregiver and the participant (Jarrott et al., 1999). Caregivers who consider adult day use in retrospect have had time to process their experiences away from the stresses associated with caregiving. Because an event's meaning is not always fully understood at the time, caregivers of past participants may have different perceptions of the effects of adult day care use from caregivers currently using adult day services because they have had time to consider their experiences (Robinson, 1996).

In contrast, Collins, King, and Kokinakis (1994) suggested that surveying caregivers retrospectively was a limitation. They maintained that the experience of institutionalization may have caused the subjects to over-report or under-report the role that services played in the decision. Families often consider nursing home placement as the last option for providing care for an impaired family member. There is a strong desire to keep an ailing family member at home as long as possible, therefore, institutionalizing a family member is a very distressing event for most caregivers (Zarit & Whitlatch, 1993). Alternatively, research on retrospective reporting suggested that an event that is very traumatic or upsetting may actually produce superior memory for information with which it was associated (Banaji & Hardin, 1994).

Other studies have suggested that when people recall the past they tend to revise their memories in ways that make them more consistent with the present. Whether people perceive change as a result of an event is due in large part to the theory they invoke to reconstruct their past (Conway & Ross, 1984; Howard, 1962). Therefore, if people invoke a theory of change, they may recognize a change and overestimate the degree to which they have been transformed (Conway & Ross, 1984). For example, Liz may have

been distressed about leaving her grandmother home alone while she was at work. In retrospect, she may have believed that placing her grandmother in the adult day care program adult day alleviated all of her stress, even though, at the time, it may have only reduced some of her stress. Liz's account of her experience with adult day care may have been an interpretation grounded in her theory of change. Liz believed that adult day care use could help her, she anticipated a change from placing Sophie in the program, and she adopted the theory of change resulting from Sophie's attendance in the program.

Spouse and Nonspouse Caregivers

Families are the primary basis of security across the life course, particularly in later life (Shanas, 1979). Family members care for and protect elderly, dependent, family members, going to great lengths to keep them at home for as long as possible (Brody, 1981). Wives and daughters are responsible for the majority of care for dependent family members, though husbands and sons also provide care for impaired spouses and mothers (National Alliance for Caregiving & AARP, 1997).

Spouses are the primary providers of care for an impaired husband or wife. In the absence of a spouse, an adult daughter usually assumes responsibility for caregiving (Brody, 1981; Cantor, 1983; Stoller, 1983). Sons act as caregivers but usually only when no daughter is available. Furthermore, sons are more likely than daughters to have a spouse who provides additional support (Horowitz, 1985). In the absence of a daughter in the family, daughters-in-law often provide as much care for parent-in-laws as for their own parents (Ingersoll-Dayton, Starrels, & Dowler, 1996).

Types of care provided to family members are related to the closeness of the kinship bond and the gender of the caregiver and care recipient (Cantor, 1983; Dwyer &

Seccombe, 1991). Daughters are more likely to assist with instrumental hands-on services, such as bathing, meals, and laundry, while sons tend to help with finances and errands (Dwyer & Seccombe, 1991; Horowitz, 1985). Daughters may provide more personal care because the majority of care recipients are mothers or mother-in-laws who are comfortable with a daughter providing intimate care (National Alliance for Caregiving & AARP, 1997). Moreover, personal care provided by daughters may reflect the societal expectation that the home is a woman's domain and caregiving a natural female behavior (Hooyman & Gonyea, 1995).

Daughters provide more care than sons, even when they are employed (Brody & Schoonover, 1986). Although more women have entered the workforce, employed women contribute as many hours of time caregiving as women who are not employed (Brody & Schoonover, 1986). Caregiving demands, however, can have a disruptive effect on work and family, which may lead to caregiver stress and strain (Scharlach, Sobel, & Roberts, 1991).

Research suggested that adult children preferred adult day care to other respite services (Cotrell, 1996). Adult children caregivers tended to use adult day services to enable them to remain in the workforce (Beisecker, Wright, Chrisman, & Ashworth, 1996). The other advantages of adult day care were that it was affordable, the caregiver was able to work, and family member had an opportunity to socialize outside of the home.

Stoller (1990) suggested that men caregivers tend to use more services, including adult day care, than women caregivers. Force (1993) found, however, that spouse caregivers, especially husbands, providing care to a spouse with Alzheimer's Disease

were reluctant to use adult day services, especially if they were using in-home services. Spouse caregivers worried that the care recipient might feel abandoned or rejected. They often felt guilty about leaving their spouse with strangers, especially if the care recipient had a cognitive impairment (Cotrell, 1996). Spouse caregivers were also found to be reluctant to turn care over to a formal service provider, such as adult day care, because of feelings of affection for and/or obligation to the loved one (Zarit, Stephens, Townsend, Greene, & Leitsch, 1999).

Conclusion

Adult day care is a valuable resource for caregivers who take advantage of the services. Of those caregivers who do, adult children tend to use adult day services more than spouses because it is affordable, it allows the caregiver to work, and it gives the care recipient an opportunity to socialize outside of the home. Although men are more apt to use adult day care than women, it appears that husbands who provide care for wives with Alzheimer's Disease may be reluctant to use adult day care because they are concerned that the care recipient may feel abandoned or rejected. We know that wives and daughters provide the majority of elder care but wives may use adult day services less than daughters or husbands. We need to know more about the ways spouses and nonspouses perceive the effects of adult day services to help adult day programs provide services that meet the needs of both.

An applied research approach was used to assist adult day care providers in understanding how they might better meet the needs of spouse and nonspouse caregivers. The purpose of applied research is to help practitioners solve practical problems, which is congruent with the goal of this study: to inform people who provide adult day care about

services that caregivers find helpful (Hedrick, Bickman, & Rog, 1993). Research in the field affords an opportunity to gain valuable insights into the expected and unexpected ways caregivers perceive the effects of adult day services.

This review suggests that caregivers of current participants in adult day care who are experiencing stress or depression may have negative appraisals of their caregiving experiences. Consequently, they may also perceive adult day services negatively. In contrast, family caregivers of past participants may invoke a theory of change, which may influence them to overestimate or underestimate the effects of their adult day care experience. We know that caregivers of past and current participants may perceive the effects of adult day services differently. What we do not know is the ways in which caregivers of past participants may perceive the effects differently than caregivers of current participants.

Two broad-based models of adult day care have been used to characterize the participants, activities, and services in the adult day setting. Adult day health centers are based primarily on a medical model and adult day care centers are based primarily on a social model. Both models offer some type of social and recreational activities. Adult day health services emphasize health services and rehabilitative therapies but social adult day care offer some health services. These models may have different effects on caregivers, but it is not clear how caregivers who use adult day care and caregivers who use adult day health services perceive the effects of these models. This research will contribute to our understanding of these issues.

Chapter III

Method

Research Questions

This study focused on the services provided by adult day care that family caregivers find helpful. Specifically, this study asked the question: How might family caregivers' perceptions of the effects of adult day care assist people to provide adult day services that caregivers find helpful? As a way to identify information that might be helpful, the following questions were posed:

1. In what ways do caregivers of past participants perceive adult day services differently than caregivers of current participants?
2. In what ways do caregiving spouses perceive adult day services differently than nonspouse caregivers?
3. In what ways do different models affect caregiver's perceptions of adult day services?

Design

This study employed qualitative methodology using focus groups. A major advantage of using focus groups is that the interactions among the participants replace the interactions with the interviewer, which leads to greater emphasis on the participants' point of view (Morgan, 1988). Focus groups allow the researcher to observe how participants may have discussed issues among themselves (Berg, 1998). Unlike personal interviews, focus groups permit the participants time to reflect and recall experiences. Moreover, experiences of one participant may stimulate memories and opinions of other members of the group (Lofland & Lofland, 1995). The dynamics inherent in focus groups

can provide a catalyst for open discussion that can facilitate the collection of data on a wide range of services and outcomes.

Focus groups are homogeneous in that group members have a shared interest in the subject under study because they are currently using a service or product or have used it in the past (Krueger, 1988). The focus groups used for this study consisted of family caregivers whose dependent family member attended adult day services. Because focus groups are homogeneous, Morgan (1995) suggested that a more powerful study would vary group composition so as to facilitate comparison. He noted that segmenting, or sorting different categories of participants into separate groups, can facilitate analysis of groups that may represent potentially different perspectives. Therefore, two focus groups each were recruited from two adult day centers: one consisted of family caregivers of past participants and one consisted of family caregivers of current participants. These caregivers were recruited from two adult day centers that used different models of adult day services: an adult day care center based primarily on a social model and an adult day health center based primarily on a medical model.

Adult Day Settings

Adult Day Care

The adult day care facility is located in but not affiliated with a church in a small city in Oregon. The facility is open five days a week, Monday through Friday, from 7:45AM to 5:30PM. The staff consists of an administrator who is a registered nurse (RN), an assistant administrator, a care manager who is a social worker, an activity director, one part-time and two full-time program assistants who are certified nursing assistants

(CNAs), and one to two community volunteers who donate a few hours each day. The CNAs provide assistance to participants and oversee meals and activities. They are also responsible for dispensing medications to participants. The average daily attendance is 12 participants.

The adult day care provides daily activities and meals for participants as seen in Table 1. The participants also have field trips on a monthly basis. Special events include animal therapy, art therapy, and music therapy. In addition, participants' vital signs are monitored on a weekly basis for any changes in health status.

Adult Day Health Services

The adult day health services program is located in a senior center in a midsized city in Nevada. The facility is open six days a week, Monday through Saturday. The hours are 7:30AM to 5:30PM, Monday through Friday, and 8:00AM to 4:30PM on Saturday. The staff consists of two RNs, one of whom is the program supervisor and one of whom is the program coordinator; one licensed practical nurse (LPN); seven program aides who are CNAs; and one to two community volunteers who donate a few hours per day. The CNAs are responsible for overseeing the participants' activities and meals. The LPN dispenses participants' medications. The average daily attendance is 30 participants. As seen in Table 1, the adult day health center provides daily activities and meals for participants. According to the director of the adult day health center, the participants also have outings at least once a month. They attend concerts, rodeos, horse shows, and the State Fair. They also participate in special events such as ballroom dancing, pet therapy, and music therapy. Participants' vital signs are monitored on a weekly basis.

Table 1

Typical Daily Activities

Time	Adult Day Care	Adult Day Health Services
07:30 – 09:30AM	Coffee and cocoa/Free time	Breakfast
		Current events
		Socialization activities
09:30 – 10:30AM	Crafts or cooking	Crafts
		Exercise for motor skills
10:30 – 11:45AM	Exercise or walk	Crafts
		Reminisce-word games
12:00 – 01:00PM	Lunch	Lunch
01:00 – 02:00PM	Ceramics or word games	Basketball/horseshoes/soccer
		Dice bingo game
02:00 – 03:00PM	Ceramics or word games	Games
		Exercise
		Snacks
		Stuff envelopes/shred paper
03:00 – 04:00PM	Movie/music/quiet time	Movie/sing-a-long
		Exercise
04:00 – 05:00PM	Movie/music/quiet time	Bingo
		Free time for visiting

Note. Derived from weekly schedules distributed to participants at the adult day care and adult day health services.

Some participants of the adult day health center have weekly physical, occupational, or speech therapy. The adult day health center has a contract with the Veteran's Administration (VA), which provides for six older adults with disabilities to attend the adult day health center and receive therapy through the VA. As a result of this contract, therapists from the VA will evaluate any participant of the adult day health center who may need therapy and make suggestions about treatment to the participant's caregiver.

Comparison of Ecological Settings

Ecological theory suggests that diverse settings may have different effects on a person's development (Bronfenbrenner, 1992). There are both differences and similarities between the adult day care and the adult health day center, which may have different direct and indirect effects on participants and caregivers. As seen in Table 1, both centers provide meals and scheduled activities. Note, however, that the activity schedule of the adult day health center is more structured than that of the adult day care center. Observations at both centers revealed the activity schedule at the adult day care center to be more flexible. For example, participants at the adult day care center may sit anywhere in the main room. A number of round tables are provided for participant seating. These tables are used for activities and meals. If participants do not feel like joining in the activities, there is an adjoining room with couches and a television set where they may go for quiet time.

The adult day health center is a smaller facility than the adult day care center. There is one large room and one small room. Round tables are pushed to the side in the large room. Because the setting is smaller and there is a large number of participants, the

participants are seated in a circle for most of the day with the exception of times for meals, crafts, and some games when the tables are pushed into the middle of the room. There is a small quiet room for resting that accommodates one to two persons. There is a television set, which is usually not available to the participants except during group movie time. According to the program supervisor, participants, especially men, are sometimes allowed to watch sports, such as baseball, golf, or tennis, when they are not interested in a particular activity or game.

As noted, the adult day care used in this study had a more flexible schedule than the adult day health center. Lyman (1993) also found that adult day care centers tend to have more flexible schedules than adult day health centers. She suggested that this flexibility may encourage independence and self-esteem. The care recipient's increased independence may have an indirect effect on the family caregiver in that the caregiver would have to perform fewer caregiving tasks. The need to perform fewer tasks for a dependent family member may help to reduce caregiver stress and burden.

Most of the current participants in both adult day centers are older adults who have physical and/or cognitive impairments. Both centers provide care for persons with special needs who are 18 years or older. Both centers monitor participants' vital signs on a weekly basis for any changes in health status. Medicaid reimburses both centers for low-income participants who would otherwise be unable to afford to attend. Unlike the adult day care, however, the adult day health center has some participants who receive physical, occupational, or speech therapy and whose fees are paid through a contract with the VA. The VA contract also provides for therapists to evaluate any participant who may need treatment.

The adult day care center has fewer participants and a lower client/staff ratio than the adult day health center. A lower staff/client ratio may lead to increased opportunities for interactions between staff and participants. In addition, a smaller group of care recipients afford more opportunities for interactions among participants, in that there are fewer people to with whom to interact, which may result in increased socializing. The care recipient's socializing at the center has been shown to have a positive effect on the caregiver. The participant's increased sociability may make the participant more sociable at home, which can improve the relationship between the caregiver and dependent family member (Zimmerman, 1986).

There are also differences in the type of staff employed by the centers. The adult day health center employs a LPN and a program coordinator. The adult day care center employs an assistant administrator, an activity coordinator, and a case manager who is a social worker. Although the adult day health center does not employ a social worker, family caregivers may use the services of social workers employed by the senior center, which houses the adult day health center.

Although the participants at the adult day care center have access to public transportation from Dial-a-Bus, it is not a service that is offered as an integral component of the program. A flyer providing information on how to access Dial-a-Bus is included in every application package but the staff is not involved in arranging transportation services. Access to affordable public transportation, however, is structured in the adult day health program. Over 20 care recipients of the adult day health center are provided with daily public transportation designed for older adults with disabilities, known as Citilift. According to the program supervisor, participants' tickets for Citilift are held by

the adult day health center so that they will not be lost. The adult day health center also provides participants with tickets if needed. In addition, the program supervisor trains new Citilift drivers on how to assist people with memory impairment.

Sample

For the purpose of this study, the primary caregiver was defined as the person in the family who provided the most instrumental aid to the care recipient. Data describing past and current family caregivers and past and current participants are presented together in the tables. All caregivers in Sample A and B were White. To my knowledge, no gay or lesbian caregivers participated in this study.

Sample A

Sample A consisted of family caregivers of past and current participants recruited from an adult day care center.

Subsample A1. Subsample A1 consisted of randomly selected family caregivers of past participants of the adult day care center. The adult day center compiled a list of clients for each year from 1995 to 1999. The list was limited to that time frame for several reasons. First, as time passes, caregivers' memories of their experience with adult day services may change and/or diminish. Second, aging caregivers may become physically and/or cognitively disabled, which may impair their memories and/or their ability to attend. Lastly, this time frame was used as a way to maximize the number of caregivers of past participants who were still living in the area. The five lists included 209 past and current participants.

To draw a sample, systematic sampling with a random start was employed (Rubin & Babbie, 1997). Every 10^{th} name per list was drawn. Because a list represented the participants attending the adult day center in a particular year, some clients who participated for several years appeared on more than one list. Furthermore, more recent lists contained both past and present participants. If the name selected was a duplicate or was a current participant, the name was skipped and the name immediately following was used. A list of 22 caregivers of past participants was drawn in this way.

Caregivers were contacted by a letter sent from the director of the adult day care center. The letter briefly described the study and requested their participation. A similar letter, as shown in Appendix A and B, was used to recruit all focus group participants. Letters were sent to 22 caregivers only 6 of whom were able to attend. I made follow-up telephone calls two weeks prior to the date of the focus group session to request participation and to answer any questions about the study. I was able to contact 20 of the caregivers. One caregiver had moved out of the area and her telephone had been disconnected. One caregiver was deceased. Of the 20 contacted, 5 caregivers stated that they may come but did not attend. Three caregivers were unable to attend because of health problems and four caregivers were unable to attend because of work. Two caregivers gave no reason for being unable to attend.

As noted, there were six family caregivers of past participants in Subsample A1. Table 2 reports the characteristics of the caregivers of the past participants. One caregiver identified her father, who was the spouse of the past participant, as the primary caregiver; the other participants reported that they were the primary caregiver for their care

Table 2

Characteristics of Family Caregivers by Subsample

	Adult Day Care		Adult Day Health	
	A1 Past n = 6	A2 Present[a] n = 7	B1 Past n = 6	B2 Present n = 10
Relationship				
Spouse	2	2	2	4
Nonspouse	4	3	4	6
Primary caregiver	5	3	6	8
Marital status				
Married	6	3	4	7
Divorced	0	0	1	2
Widowed	0	2	1	1
Gender				
Female	5	4	5	8
Male	1	1	1	2
Median age	53.5	61	67.5	67.5
Employment				
Full-time	1	0	1	5
Part-time	3	1	0	2
Unemployed	0	4	0	0
Retired	2	0	5	3

[a]One participant did not complete the demographic survey.

recipient. Two caregivers were spouses, two were daughters, one a daughter-in-law, and one a granddaughter. Only one caregiver reported having children at home during the time that she was providing care. At the time the care recipient attended adult day care, four caregivers used in-home respite or bathing assistance in addition to adult day services to provide care for the family member. The characteristics of past care recipients at the time they participated are reported in Table 3. At the time of the focus groups, four participants lived in a nursing home and one participant was deceased.

Subsample A2. Subsample A2 consisted of randomly selected family caregivers of current participants of the adult day care center. There were 26 participants attending the adult day care at the time of the focus groups. At the same time letters were sent to caregivers of past participants, 14 caregivers of current participants were contacted, of whom 7 were able to attend the discussion group. As this study was interested in family caregivers, 12 clients who lived in adult foster homes were excluded from the sample. Their caregivers did not receive a letter.

I made follow-up telephone calls two weeks prior to the date of the focus group session. I was able to contact all 14 caregivers. One caregiver was unable to come because she was moving. One caregiver was unable to attend because of illness. Three caregivers were unable to attend because of work. Two caregivers agreed to attend but did not come.

As noted, there were seven family caregivers of current participants in Subsample A2. The characteristics of caregivers are reported in Table 2. To allow additional time to complete the survey, caregivers were requested to return demographic surveys at the end of the demographic surveys at the end of the discussion session.

Table 3

Characteristics of Care Recipients at Time of Participation by Subsample

	Adult Day Care		Adult Day Health	
	A1 Past	A2 Present	B1 Past	B2 Present
	n = 6	n = 6	n = 6	n = 10
Marital status				
Married	4	3	2	4
Divorced	1	0	0	1
Widowed	1	1	4	5
Never married	0	1	0	0
Gender				
Female	4	4	4	6
Male	1	1	2	4
Median age	75	81	86[a]	81
Mean years of attendance	3.7	.25	2.1	1.3
Mean number of days per week	3.5	3.5	3.5	4.5
Living arrangements				
Lives alone	0	1	0	0
With spouse	3	2	2	3
With spouse and children	1	1	0	1
With children	1	0	3	5
Other	1	1	1	1

[a]Age information is missing for one care recipient .

Five of seven were returned. Three of the caregivers were spouses, one was a stepdaughter, one a daughter, and one a sister. One caregiver did not complete the survey. A nonrelative (professional) caregiver was present at this focus group, but her responses have been eliminated for this analysis. She explained that she received the letter requesting participation sent to the family and assumed that, as she provided care full-time for the participant, she should attend the focus group. Only one caregiver reported having a child at home and one caregiver used additional services such as in-home respite or bathing assistance. The characteristics of current care recipients are reported in Table 3.

Sample B

Sample B consisted of family caregivers of past and current participants recruited from an adult day health care center.

Subsample B1. Subsample B1 consisted of randomly selected family caregivers drawn by the director from a list of past participants of the adult day health center. The director compiled a list of clients from 1998 and 1999. The list was limited to that time frame because the director stated that she wanted to contact caregivers still living in the area. Caregivers of past participants were then screened by the director because some of the caregivers had recently lost their family members and were in the process of grieving. The director felt that it would be inappropriate to request their attendance. Letters were sent to caregivers of past participants selected by the director at the same time that letters were sent to caregivers of current participants. No follow-up phone call was made to the caregivers.

There were six family caregivers of past participants in Subsample B1. The characteristics of caregivers of past participants are presented in Table 2. Two were daughters, one was a son, two were spouses, and one was a nonrelative who self-identified as a long-time friend. At the time the care recipient attended adult day health services, two caregivers used additional services such as in-home respite or bathing assistance in addition to adult day health services to provide care for the family member. The characteristics of past care recipients are reported in Table 3. Currently, one past participant lived in a group home and five were deceased. One caregiver did not answer the question concerning the number of years the participant attended.

Subsample B2. Subsample B2 consisted of randomly selected family caregivers of current participants of the adult day health center. There were 32 participants attending the adult day health center at the time of the focus groups. As this study was interested in family caregivers, three clients who lived in group homes were excluded. Letters were sent to 29 caregivers from the director of the adult day health center, which were mailed in a monthly billing statement. Of the 29 caregivers of current participants invited, 10 were able to attend the meeting. No follow-up phone call was made to the caregivers.

There were 10 family caregivers of current participants in Subsample B2. The characteristics of caregivers of current participants are reported in Table 2. As seen in Table 2, eight of the caregivers self-identified as primary caregivers, one caregiver identified his wife as the primary caregiver, and one caregiver reported that she shared the responsibility with someone else. Four caregivers were spouses, four were daughters, one a son-in-law, and one a sister. None of the caregivers reported having children at home. Currently, four caregivers used additional services such as in-home respite or

bathing assistance, along with adult day health services, to provide care for the care recipient. The characteristics of the current participants are reported in Table 3. One caregiver did not answer the question concerning the number of years the participant attended.

Demographic Survey

A survey was used to collect descriptive demographic data, as recommended by Rubin and Babbie (1997). Separate surveys, which appear in Appendix C and D, were designed for caregivers of past and current participants. The instruments were paper-and-pencil questionnaires produced in large print for ease of reading for older adults. The questionnaire was designed to obtain the following data: demographic data on the caregiver and the dependent family member, family caregiver's relationship to the care recipient, utilization of additional services while participant attended adult day care, and changes in living arrangements during participant's attendance. In addition, the survey designed for caregivers of past participants asked where the past participant's current living arrangements were and whether the past participant was deceased.

Focus Group Questions

Krueger (1988) suggested that questions for focus groups require both reflection and feedback from participants. The questions for this study were designed to encourage caregivers to share their experiences and perceptions of adult day services. A semistructured format was used. The questions provided a guideline for group interactions but also allowed the facilitator to generate new questions stimulated by responses of the group members.

The 20 questions used for this study are presented in Appendices E and F. The first few questions allowed group members to introduce themselves and get acquainted with each other. They were designed to provide a background about the caregiver's relationship to the participant, the circumstances that led to the participant's enrollment, and the length of time the participant attended adult day care. These questions were directed to individuals in the group. Ideally, they gave all members of the group an opportunity to share some of their experiences. Question 5 provided a transition to more general questions focused on caregiver perceptions.

The next set of questions addressed the effects of adult day care reported in the literature. There were specific questions about respite, caregiver stress, staff support, and the delay or prevention of nursing home placement. Questions 14 through 19 attempted to generate responses that uncovered new insights into ways that adult day care may affect caregivers. Finally, the last question gave caregivers the opportunity to express any opinions or additional comments not yet addressed.

Focus Group Procedure

Although a different facilitator was used for Subsamples A1 and A2 than Subsamples B1 and B2, a uniform procedure was used for all of the focus groups. An experienced professional, not associated with the adult day centers, facilitated the group discussions. The facilitator used a list of open-ended questions as a guide allowing for additional input as appropriate. The focus groups lasted approximately 90 minutes each. At the beginning of each focus group, the facilitator explained the study and emphasized the respondents' right to refuse to answer any question or to leave at any time. Confidentiality was also explained.

The sessions were audiotaped and a note taker was present during the sessions of Subsamples A1 and A2. The purpose of the notetaker was to ensure that participants were accurately identified on the audiotapes. A notetaker was not present during the sessions of Subsamples B1 and B2, however, I had no difficulty identifying the participants. The audiotape from Subsample A1 was transcribed by the administrative assistant of the adult day care center. The audiotape from Subsample A2 was transcribed by an office specialist. A professional secretarial service transcribed audiotapes from Subsamples B1 and B2. I listened to the audiotapes while reading the transcripts to verify the participants' identification. Although anonymity was not possible in this study, participants were guaranteed confidentiality. Each participant was assigned a pseudonym in the report of the findings. Notes and audiotapes were compiled and the results described so that neither names nor identifying information was included.

At the end of each group, the facilitator thanked the focus group members for participating. As indicated earlier, focus group participants completed a short, demographic questionnaire at the end of the group sessions. Completion of the questionnaire and/or participation in the focus group indicated consent. The discussion groups for Samples A1 and A2 met in a large room at the church where the adult day service was located. The discussion groups for Samples B1 and B2 met in a large conference room at the senior center where the adult day service is located. The location of the focus groups facilitated the participation of current caregivers who were able to leave their family members at the adult day health services center while they participated in the group discussion. The focus groups were informal and relaxed, and refreshments were served.

Data Analysis

The object of a focus group is to collect rich data in a social context in which people can consider their own views in relation to the perspective of others (Patton, 1987). This is consistent with the ecological theory used in this study. Bronfenbrenner (1977) suggested that to understand human nature requires examination of the interactions among more than two people in a natural environment. A focus group presents a natural environment where participants are influencing and influenced by others as they are in real life (Krueger, 1988).

Data collected from focus groups can be difficult to analyze because they are group data (Berg, 1998). Therefore, group discussions must be interpreted within the context of the group. It is necessary to avoid taking comments out of context and sequence or coming to premature conclusions because participants sometimes modify or reverse their positions during the course of the focus group (Krueger, 1988).

A thematic content analysis of interviews was performed on the data from this study (Berg, 1998). Content analysis provides a way to identify and organize data. Data collected from each focus group were read repeatedly in search of emerging themes and patterns. The data were sorted by the themes (Berg, 1998). As ecological theory provided the theoretical perspective for analysis, particular attention was paid to the indirect effects of adult day use for family caregivers. Although this study used a deductive approach, Berg (1998) suggested that an inductive approach should also be used "in order to present the perceptions of others in the most forthright manner" (p. 230). Therefore this study used both aspects of inquiry: deductive and inductive.

As suggested by Patton (1987), a coding scheme, as seen in Appendix G, derived from the theory, analytic insights, and interpretations that emerged during the content analysis was applied to the data. Color-coding was used to highlight themes and patterns pertinent to the study. Notes referring to key themes or categories were made in the margins. In addition, WinMax, a qualitative analysis computer program, was used to organize the data, facilitating a systematic and thorough analysis (Strauss & Corbin, 1998). Data reduction took place in the course of data coding.

A constant comparison method was used (Huberman and Miles, 1994). While coding an incident for a category, a comparison was made with previous incidents within the same focus group and among participants of the other focus groups (Glaser & Strauss, 1967).

The constant comparison method was used to verify major themes and subthemes identified by all caregivers within the focus groups. Huberman and Miles (1994) suggested a re-analysis of data as part of the analysis process. Therefore, a second uncoded transcript from each focus group was analyzed, coded, and compared with the first set of coded data. For each research question, the data were compared by (a) past and current caregivers; (b) spouse and nonspouse caregivers; and (c) two different models of adult day services. Once the three questions were addressed, the entire analysis process was repeated with a clean set of data. This re-analysis helped ensure that no important themes or patterns were missed in the initial analysis and that coding was consistent (Huberman & Miles, 1994).

Having valid and reliable codes is important in data analysis. The definition and meaning of themes can change during the coding process. If agreement is achieved in

regard to themes and patterns between the two sets of coded data, then reliability may be assumed. If disagreement exists between the themes and patterns of the two sets of coded data then it may be necessary to reconsider the theoretical conceptualization of the study (Rubin & Babbie, 1997).

As suggested by Berg (1998), after coding and re-analysis were completed, the data were set aside for a brief period of time. This allowed for time to step back from the data and perhaps see them from a different perspective. The data are reported here using the research questions as a means of organizing the results and discussion. Key themes and patterns are highlighted and selected comments from caregivers are used as examples.

Chapter IV

Results and Discussion

The purpose of this study was to learn more about the ways in which family caregivers perceive the direct and indirect effects of adult day services. In doing so, the goal was to inform adult day providers about services that family caregivers find helpful and useful. The results are organized according to the research questions. The coding scheme appears in Appendix G.

Specifically, this study addressed the question: How might family caregivers' perceptions of the effects of adult day care assist people to provide adult day services that caregivers find helpful? To assist service providers, I looked for differences in (a) the way caregivers of past and present participants perceive the effects of adult day services, (b) the way caregiving spouses versus other family members perceive the effects of adult day services, and (c) caregivers' perceptions of adult day services derived from different models. Within the context of focus groups, family caregivers shared valuable insights about the ways in which adult day services affected their lives and the lives of family members for whom they provide care.

Caregivers of Past Versus Current Participants

Studies on adult day services are often limited by collecting data from caregivers who currently use services or those who have used services in the past but not both (Collins, King, & Kokinakis, 1994; Jarrott, et al., 1999). In this study, focus groups consisting of caregivers of current and past participants were compared to determine the

ways in which caregivers who used adult day services in the past may perceive services differently from caregivers who were presently using services.

Overall, there were few differences in the ways caregivers of past and current participants experienced adult day services. Both groups of caregivers were satisfied with the services they received. The consensus among caregivers was that, "It was a lifesaver. I couldn't have made it without it!" These results are consistent with other studies on caregiver satisfaction with adult day services (Henry & Capitman, 1995; Rothman, Hedrick, Bulcroft, Erdly, & Nickovich, 1993).

Caregiver Satisfaction

According to Jarrott and her colleagues (1999), the negative effects of caregiving may distort caregivers' perceptions of adult day services. Caregivers of current participants who experience stress or depression may have negative appraisals of their experiences with caregiving. Consequently, they may report dissatisfaction with adult day services.

In contrast to Jarrott et al.'s (1999) findings, many of the caregivers of current participants in this study acknowledged that they experienced caregiver stress but they were still satisfied with adult day services. Moreover, they implied that respite provided by adult day services helped ease their stress. For example, Larry, a caregiver whose wife has Alzheimer's Disease, stated that

> She follows me around like a dog. She is by my side waiting for me to do this, and do that, and that becomes so irritating to me that I had some hard problems. It was so stressful. I didn't want to admit that she and I needed the help that adult day services could provide. But I finally came to it (adult day care) and it's wonderful.

Cora, a caregiver of a developmentally disabled sister reported:

> So for our situation, it (adult day care) has been a good thing. It kept my sister positive when she first moved here. Oh, she was meaner than a junkyard dog. We didn't know, when she first moved here, if she was going to kill my husband and I off, or we were going to kill her.

Caregivers of past participants also recalled experiencing reduced caregiver stress or depression at the time their family attended adult day services. Bob, a caregiver whose wife had Alzheimer's Disease, described his unhappiness at having to enroll his wife in adult day care:

> Well, when she started here I was very depressed. It was a major transition. I went through a major depression. Not wanting it to happen, but adult day services was really something she needed and it did her a lot of good.

Frances, who cared for a family friend, shared her stress when she stated:

> Oh, it's (adult day services) the only way. On a holiday, she would drive you up the wall with what can I do now. I said this is a free day, you know. We're going to do whatever we want to do but she still wants to know what she can do now.

People tend to revise their memories as a result of using intervention programs, such as adult day services. Consequently, people may attribute greater gains than seems warranted by adopting a theory of change as they go through the program (Conway & Ross, 1984; Howard, 1962). Bob and Frances felt that the use of adult day services was valuable for their family member. The candid retrospective reports of the stress and depression they experienced and similar reports by caregivers of current participants, however, suggested that caregivers who used adult day services and found them to be satisfactory may have realistic memories about how much the program was able to change their lives.

indirectly affected by it. Family members' attendance in adult day care affords caregivers time away from caregiving responsibilities. As an indirect effect of adult day care, respite relieves caregivers from the constant demands of care, which may help to reduce caregiver stress and increase caregiver satisfaction. This is consistent with other studies that have shown that adult day services reduced caregiver stress by providing respite for family caregivers (Gottlieb & Johnson, 1995; Zarit et al., 1998).

Nursing Home Placement

Delaying institutionalization of the family member is a major goal of adult day services. Caregivers of current participants did not discuss delayed nursing home placement. Caregivers of past participants, however, reported that adult day services had helped to delay institutionalization of their family member for two to three years. Carolyn, for example, said, "It made it possible for my mother to stay home a lot longer than she would have been able to. We were very pleased with the program." Liz agreed: "I think it gave my grandmother a couple more years before she had to go to a nursing home." These results were consistent with other studies on the effect of adult day services on nursing home placement (Kosloski & Montgomery, 1995; Lawton, Brody, & Saperstein, 1989).

The ecological model explains how the activities, services, and interactions between participants within the microsystem of the adult day care setting may influence the development of care recipients. A goal of adult day care is to provide activities and services that help to improve or maintain the participant's physical and/or mental functioning. Thus, from the ecological perspective, family members' participation in the

adult day care setting may lead to delayed nursing home placement by improving or maintaining care recipients' functioning.

Lack of Support Groups

Although caregivers of past and current participants perceived similar satisfactory experiences with adult day services, one group of caregivers of past participants, whose family members were deceased, shared their disappointment about one aspect of adult day programs. Mabel, a caregiver who was grieving for her mother who had passed away six months prior to the focus group meeting, explained that she felt abandoned by the adult day center after her mother died:

> Well, for me with my mom gone, I didn't know how to handle my grief. What happens to the caregiver? The caregiver is so terribly important and then after somebody is gone . . . I did call one support group but I felt better that day and I didn't go. So what I was saying is they were wonderful with my mother, they were wonderful with me. Well, when it's over it's over . . . Is there something that can kind of get you through the next stage of your life, picking up the pieces, or something to go through the grief?

Mabel expressed the feelings of other caregivers in the group who were uncomfortable about attending support groups with strangers but felt they may have benefited from sharing their grief with other caregivers whose family members had attended the same adult day services.

The discussions of caregivers of past participants whose family members passed away while attending adult day services suggested that these caregivers need support and encouragement after their family member has died. According to the ecological theory, shared supportive links between mesosystems and exosystems can enrich human development. When the exosystem of adult day care is removed from caregivers'

environment, a transition occurs that may have repercussions throughout their network of linked systems, which can negatively affect development (Bronfenbrenner, 1977).

Most adult day programs do not offer support groups for family caregivers after their relative passes away. In general, support groups assist family caregivers to learn and understand more about specific problems associated with caregiving and they provide encouragement and support to caregivers. The success of these programs is based on the concept that caregivers whose family members are attending adult day services have shared experiences that help them to form a common bond among them (Dilworth-Anderson, 1987). Because family caregivers play a central role in providing care for older impaired family members, they need assistance and support to fulfill their roles.

Crafts as Family Heirlooms

Caregivers of past participants also talked about the way they cherished the crafts made by family members in the adult day setting. The crafts may become family heirlooms that provide a link between the generations. For instance, Dorothy explained that

> Their ceramic things have been distributed to grandchildren and great grandchildren, so they each have something. Grandpa did some trees that went over big. He just did a great job. The family really loved them. And some of the little things like the spoon rest and stuff like that. It's just fun cause now we have the great grandchildren who didn't really know them, but we have their pictures on the refrigerator and so they know who great grandma and grandpa are, so we can tell them the major things they did and they made. And they have that connection.

Sherrie, whose husband was deceased, stated that "He enjoyed the music and the different games, and the little crafts they made. I still have those. Sometimes he didn't want to join but he was so proud of them."

Cherished possessions, such as family heirlooms, are objects that give meaning and continuity to one's life across generations. Symbolic objects are possessions that represent events, relationships, thoughts, and feelings (Prentice, 1987). Family heirlooms are symbolic objects that can have multiple meanings for a person. Sherman (1991) pointed out that family heirlooms are often cherished for their ability to evoke recollections about the past, such as pleasant events, which may assist people to cope with loss. Caregivers of present participants and those of past participants who were still living did not mention crafts made by participants. Most of the caregivers of past participants in this study had experienced a loss through the death or institutionalization of a family member. These caregivers used the crafts made by family members as a means of coping with their loss and giving meaning and continuity to both their lives and those of other generations in their families.

Summary

Both groups of caregivers were satisfied with adult day services. Caregivers of past and current participants maintained that services helped to relieve stress and depression. In other ways, however, caregivers of past participants differed from those of current participants. Only caregivers of past participants indicated that adult day services had helped to delay nursing home placement. One group of caregivers of past participants, whose family members passed away while attending adult day services, was unhappy with one aspect of the programs. These caregivers felt abandoned by the adult day centers because the programs did not provide support groups for grieving caregivers. Furthermore, only caregivers of past participants who were deceased or institutionalized perceived crafts made by family members as heirlooms, which helped caregivers to cope

with their loss and give meaning and continuity to their lives and those of younger generations.

Spouse Versus Nonspouse Caregivers

Spouse and nonspouse caregivers' responses were compared on their reasons for and feelings about using adult day services.

Reasons for Using Adult Day Services

Not surprisingly, spouse and nonspouse caregivers perceived that adult day services afforded them time off from caregiving responsibilities, which allowed them to work, pursue leisure activities, or attend to other family responsibilities. The experience of respite by both spouse and nonspouse caregivers was consistent with other studies that have found that respite has a positive effect on family caregivers (Brody et al., 1989; Feinberger & Kelly, 1995; Zarit, Gaugler, & Jarrott, 1999).

Inactivity of care recipients. The primary reason both spouse and nonspouse caregivers used adult day services was the inactivity of the care recipients when they were at home. Respite to work, to enjoy leisure activities, and to attend to other family responsibilities were actually secondary reasons. Both groups were interested in the direct effect of adult day services on care recipients as is typical of caregivers (Beisecker, Wright, Chrisman, & Ashworth, 1996).

Bronfenbrenner (1998) noted in his ecological theory that most human beings, especially parents, have the capacity and motivation to respond to the physical and psychological needs of their children. To acquire new knowledge and skills, however, parents must have access to resources outside the home and family that can provide the

needed experiences. The reports of family caregivers in this study suggested that caregivers of older adults share some of the same concerns and motivations as parents. They were able to provide new experiences for their family members through the use of adult day services.

Both groups talked about the difficulties they had in keeping family members occupied and stimulated during the day. They maintained that relatives sat and watched television or slept most of the day if they were not engaged in meaningful activities. Sherrie, wife of a participant with Alzheimer's Disease, complained that, "I couldn't keep him busy. Otherwise he went to sleep." Liz, a granddaughter of a former care recipient, maintained:

> I put my grandmother in adult day services because I wanted to see her do something besides sit in the chair and stare out the window. I wanted to see her physically and mentally and socially stimulated.

Carolyn, whose mother had Alzheimer's Disease, summed up what other caregivers felt when she said,

> One of the major changes in my mother with Alzheimer's Disease was the loss of initiative or interest in hobbies. And that was one of the major things about getting her into adult day services was that I wanted to see her doing something. At home I couldn't get her interested in anything. I'd try to get her to do puzzles with me but in a group setting she would do stuff, at home she wouldn't.

Spouse and Nonspouse caregivers believed that adult day services provided the stimulation that their family members needed. Dorothy, a daughter-in-law, stated:

> Well it really worked for mom. She sometimes would sit around and not feel like doing stuff but most of the time she would be stimulated throughout the day. Things to do, she loved the crafts and she loved the music and just the social interaction was really good for her.

Larry, whose spouse has Alzheimer's Disease, concurred that adult day services is more stimulating than home for care recipients. He added,

> She finds the adult day center an attractive place, and in my view, a stimulating place. So she looks forward to coming. She now attends three days a week: Tuesday, Wednesday, and Thursday though I find that I am pressed to find ways of doing things with her that will keep her active when she is at home with me. Otherwise, she sits and goes to sleep.

People need increasingly complex interactions between multiple settings to enhance their development (Bronfenbrenner, 1998). Older adults often lack the opportunity to interact in multiple settings when they become physically and/or cognitively impaired. The adult day setting has the potential to stimulate clients, particularly those with dementia, through activities that offer variety and fun, promote friendship, and are meaningful to the participants (Hasselkus, 1992).

The results of this analysis suggested that both spouse and nonspouse caregivers are concerned about their family members staying active and stimulated but lack knowledge about appropriate activities for older dependent adults, especially those with dementia.

Leisure. The majority of spouse caregivers, especially husbands, were retired and perceived adult day services as a way to enjoy leisure activities away from the responsibilities of caregiving. For instance, Larry, whose wife has Alzheimer's Disease, stated that, "I have my own life to live and things that I want to do. Family genealogy on the computer, gardening, and this that and the other thing," Jack enjoyed having some free time to relax and watch television. Dick stated that he liked having time to relax or run errands without worrying about his wife who had dementia. Nonspouse caregivers did not mention leisure time activities.

Time for other family members. Most of the caregivers in this study were related to the care recipient. One long-time friend, however, was the primary caregiver of a participant who was a single woman with no family. Unlike those spouse and nonspouse caregivers who used the services for leisure or work, Frances used adult day services so that she could have more time to devote to her own husband and family. Although kin, principally adult children, are the preferred choice over friends and neighbors of care receivers, some older adults have no children or other family members. Consequently, friends and neighbors may take on the responsibility of primary care (Cantor, 1979).

Paid work. Nonspouse caregivers, particularly daughters, maintained that adult day services allowed them to engage in paid work. The work setting of the family caregiver is an exosystem for the care recipient. The family member is not directly involved in the caregiver's work, however, the caregiver's work indirectly affects an impaired family member. Care recipients may be enrolled in adult day care when the caregiver is unable to provide care during the day because of work obligations. Other studies have also found that employed daughters tend to use adult day services in order to remain in the workforce (Beisecker, Wright, Chrisman, & Ashworth, 1996; Cotrell, 1996).

Typically, for daughters trying to balance paid work, the needs of their children, and those of an ailing parent, respite is not respite but an opportunity to meet other obligations (Deimling & Looman, 1990). Daughters who were employed were concerned about their impaired relative being home alone while they were at work. Katie, a daughter whose mother had dementia, explained that

> My mother lived with me for two years and because I work full-time and she could not be alone, she went to daycare for those two years. She had to go full-time, the whole day . . .

Alice, whose mother had multiple health problems, agreed with Katie, saying that, "We can work and she's here and we don't have to worry about her being home alone."

Some of the employed nonspouse caregivers stated they would not have been able to work without adult day services. For example, a sister maintained that, "If it wasn't for this, I don't know what would have happened. I couldn't take care of her myself and stay home." One caregiver, however, stated that she had to quit work to care for her mother who had Alzheimer's Disease. According to Mabel, her brothers had wives and families to support. As the only daughter, and because she had limited other family obligations as she was divorced with no children, she quit her job to provide care for her mother. It is not unusual for daughters to quit work to care for ailing parents (Scharlach, Sobel, & Roberts, 1991), reflecting the societal expectation that home is women's domain and caregiving a natural female characteristic (Hooyman & Gonyea, 1995).

Not surprisingly, because wives tend to live longer than their husbands, several wives were also employed and caring for ailing husbands. Belinda, for example, talked about her husband's complex medical condition and her reasons for using adult day services. She said:

> He needs 24-hour care, so he couldn't stay home because he is considered legally blind. He's had strokes and heart attacks since last June, just one after another, and in and out of the hospital and in a nursing home, in the VA nursing home twice, and then another one, and he hated it. But he kept bugging them until they let me take him home. So, I'm here because I work.

The circumstances of several of these women suggested that some working wives may be employed out of necessity and they perceive adult day services as a way to stay in

the workforce to earn additional income. Moreover, as women live longer than men, the raising costs of health care, medications, and long-term care may force older women to stay in the workforce long after retirement to enable them to keep their ailing spouse at home as long as possible. In some cases, then, paid work is necessary for caregivers.

Feelings About Using Adult Day Services

In the focus groups, caregivers shared their feelings about using adult day services. Most of the nonspouse caregivers had very positive feelings. For example, Liz stated:

> Actually I felt really good about having my grandmother come here. It was a positive thing for her. She really enjoyed it. She had arthritic hands and the clay therapy they did was wonderful for her. She did social and also some of the mental things that they did with people.

Katie, a daughter whose mother had dementia, felt relieved when her mother went to adult day services:

> I could go to work and not have to worry about if she's calling the police or the fire department, or just knowing that she was at least getting something a little constructive and not just sitting in her chair . . .

One daughter, Mabel, however, had negative feelings about enrolling her mother in adult day services: "I felt guilty even though I was exhausted. There was terrible guilt because I couldn't take care of her myself."

Some of the spouse caregivers were not as positive about using adult day services. Three caregiving husbands were reluctant users, although they were using home care services to aid with the personal care of their wives. Larry said that he could not admit that he needed any help. He felt that he could care for his wife by himself. Jack said that he brought his wife to adult day services because she fell and the doctor told him that she

needed to be more active. Dick did not want his wife away from home. He stated: "I was against it. I didn't see any reason why she should leave home two days a week and come down somewhere for finger painting and cut out words."

Several wives wanted their spouses to go to adult day services but felt some guilt about forcing them if they were reluctant to attend. Janet said: "It was kind of hard because he didn't want to leave me. We've been married 56 years. He followed me around like a puppy." Angela wanted her husband to attend adult day services but she decided not to push him. When he refused to go, however, she changed her mind because she needed respite. She admitted:

> I picked him up and he said 'I'm never going back there again.' I said, 'Well, ok.' We let it go at that but as he's declining, going down, and I needed time. I just said, 'You're going to have to try this once more.' He didn't make any objection. When I told him yesterday, 'Now we are going to go to adult day services,' no comment. Got slowly motivated in the morning but anyway he got over here and he does enjoy it now.

Force (1993) also found that husbands of wives with Alzheimer's Disease, were reluctant to use adult day services, particularly if they were using other outside services. Spouse caregivers may be hesitant to turn care over to formal services, such as adult day services, because of feelings of love and obligation to a family member (Zarit, Stephens, Townsend, & Leitsch, 1999). Furthermore, spouse caregivers, especially those who care for relatives with dementia, tend to worry that their family member may feel abandoned or rejected if they are left with a stranger (Cotrell, 1996). Older adults with dementia, such as Alzheimer's Disease, may become confused or distressed with people they do not know or in settings that are unfamiliar to them (Hasselkus, 1991).

Other wives wanted their spouses to attend adult day services. One wife insisted that her husband attend because she needed some time away from the responsibilities of

caregiving and felt that he could not be home alone. Carol stated that, "I did discuss with him about coming to adult day services. He said no, he didn't want to go but I insisted." Belinda, an employed caregiver, said:

> Well, I wanted him to go. But he didn't want to. He wanted to sit in the car, I said, you can't sit in the car eight hours a day. See, he has to wear a foley (catheter) the rest of his life. He can't be operated on for the prostate. So, it's really bad because I have no help at home. We have two children but one lives in Mississippi and on lives in Indiana. So, I'm here.

These wives needed the services and were realistic about using them. Their perceptions suggested that within group differences may be as important as between group differences. This is consistent with other research on adult day services that suggested that wives appeared to be more accepting and realistic than husbands about their perceptions of adult day service utilization (Force, 1993).

Summary

Responses of some spouses, caregiving husbands in particular, suggested that they used adult day care for leisure time to relax, pursue hobbies, or run errands. Nonspouse caregivers, especially daughters, used adult day services as a means to stay in the work force, as did several employed wives. The primary reason both spouse and nonspouse caregivers used the services was that adult day programs provided stimulating activities that dependent family members needed but were unable to get at home.

Models of Adult Day Care

Two models of adult day services were compared in this study: adult day care based primarily on a social model and adult day health services based primarily on a medical model. Ecological theory suggests that it is important to determine the

characteristics of participants and activities in a setting to understand how the setting may affect a person's development (Bronfenbrenner, 1992). In the ecological model, adult day services is a microsystem for care recipients in which they are direct participants, and an exosystem for family caregivers who are indirectly affected by the activities, services, and experiences of participants in the adult day setting. To compare the ways in which the different models may affect caregivers' perceptions of adult day services, caregivers were asked specific questions about activities and services of the program in which their family member was enrolled.

Activities

A basic tenet of ecological theory is that for development to occur people must participate in an activity (Bronfenbrenner, 1998). The activity should include reciprocal interactions although not all interactions are interpersonal. They can involve objects and symbols in the immediate setting, however the objects and symbols must invite attention, exploration, and imagination (Bronfenbrennner, 1998). Caregivers whose family members attended the adult day care program suggested that activities could facilitate development because they were both mentally and physically therapeutic for care recipients. Liz found that the clay therapy and games helped her grandmother's manual dexterity and mobility. She also felt that the exercise program helped keep her grandmother out of a wheelchair until she was placed in a nursing home.

> I think the exercise program was really good for my grandmother. She did nothing, basically refused to hardly move and during the course of being here she had to have knee surgery, a knee replacement. The adult day care is the only place that really got her moving a little bit more. I think it kept her out of a wheelchair for as long as possible. She did not actually go into a wheelchair until she moved into a nursing home last year . . . So, they somehow worked magic.

Cora recalled the inactivity of the residents of the nursing home in which her father was placed, comparing it with the activities in the adult day care. She felt that the adult day care program was successful in keeping people mentally alert and physically active. Consequently, care recipients in an adult day care center would not decline as fast as those in a nursing home.

Care recipients are encouraged but not forced to participate in activities at the adult day care center. Dorothy asked the staff, however, to engage her mother-in-law in the activities:

> As time went along with mom, I just asked them if they would be a little more forceful with her to get her to become more involved rather than sitting. She can sit at home. That's what I told her, you're not there to just sit, the whole object is to participate. You can sit with your head back and eyes closed and your foot up on the footstool at home. That's not what this is all about. So, I just asked them if they would be more forceful with her and they were and she responded most of the time. Sometimes no but that's okay too.

Women care recipients in the adult day program appeared to like the crafts more than men participants. Sally pointed out that her husband and the men in his group enjoyed the music, games, and the sports on television.

> That's one of the things that my husband found annoying to him were the crafts. All of the men in the group kept complaining about the crafts. As long as there was music, they all seemed to be happy about it, you know, if they could sing and the piano being played. And they liked the sports. And if there were any games on the television, that seemed to quiet the ones down that were interested.

Caregivers whose family members attended adult day health services, like those using adult day care, were interested in keeping their family members active. These caregivers, however, seemed to be more interested in the social than the therapeutic activities. They talked about field trips, dancing, games, entertainment, and birthday

parties. For example, Janelle said that, "My mom loves the field trips. I mean they went to the college for that concert . . ." Angela's husband did not like the crafts but she noted that he also enjoyed the field trips:

> He didn't much care for the crafts but they danced, they played games, and they took them on field trips, they did so many things with them. It helped keep his mind going. It's a wonderful thing to have.

Fred pointed out that the adult day health program had a monthly birthday party for care recipients who were born during that month: "They put up the schedule for each day and then one day a month they have a birthday day. They usually have the names listed." Janelle stated that children from local grammar schools came to entertain the participants during the Christmas season.

In general, the goal of adult day services is to help maintain, restore, or improve the mental and/or physical functioning of impaired older adults. The adult day health service model tends to emphasize rehabilitation of the care recipient through therapeutic activities whereas the social model of adult day care emphasizes social rehabilitation, alleviation of social isolation, recreation, and maintenance (Conrad & Guttman, 1991; Weissert, 1976). Paradoxically, caregivers who used the adult day health services model highlighted the social aspects of the program that kept family members active through recreational activities that were entertaining and enjoyable to participants. Caregivers using the adult day care model, however, emphasized the therapeutic activities of the program that helped family members maintain or improve their level of functioning.

Alertness and mobility. Caregivers in both models agreed that program activities helped their family members to be more alert and mobile at the end of the day. Jack felt that adult day health services helped his wife to be more mobile after she had hip surgery:

> I don't know if they pick up physical attributes at times but she is a little heavy set. She's not been into the physical stuff, never has been really and she doesn't now. She doesn't even like to walk but a week or two ago, I was getting breakfast and I turned around and there she was standing in the dining room, full stand-up, ending over at the waist, tying her shoe. I just sat there and looked and I didn't believe but she was standing there tying her shoe.

Larry believed that his wife was more alert as a result of the activities provided by the adult day care program. Larry maintained:

> I have discovered that now when I meet her at the end of the day, she seems more joyful to me. That's something. There is an emotional expression, which I wasn't getting at home. Under Alzheimer's Disease there is just no, not much of that, and I found it great to come and meet her under those conditions, so it renewed a spark of life for us at the end of the day.

Care recipients' increased functional mobility and alertness may have affected family caregivers by making care recipients more independent in performing ADLS, which would make it easier for caregivers to provide care. According to the ecological model, to be developmentally effective, activities must take place on a fairly regular basis over an extended period of time. Adult day services offer care recipients the opportunity to participate daily in activities and exercise programs that help increase their functional mobility and improve their cognitive skills, which may lead to increased independence in the home setting.

Socializing

The emphasis of the adult day care model is primarily on socializing to prevent care recipients from becoming isolated as a result of their impairments (Monahan, 1993). Only two caregivers, however, responded to questions about socializing at the adult day care center. Cora stated that her sister who was developmentally disabled had learned about friendship:

> She has never been allowed to have friends since she has been out of high school and you can imagine that was back in 1957. She lived with my parents in a very isolated environment. I mean, and to see her come here and have wonderful people that she is actually surprised that these are really cool people here. These are wonderful people. She had no concept of what friendship was and about people caring about other people, and so on.

Another caregiver noted that her mother-in-law was able to make a close friend despite her increasing confusion due to dementia. Research on social interaction at adult day care centers has suggested that the setting provides opportunities for participants to express their individual identities in a social atmosphere that has often been denied them: interacting with their peers. It also allows them to engage in reciprocal relationships in which they are not only the receiver but also the giver (Williams & Roberts, 1995).

Responses of caregivers who used adult day health services suggested they perceived that the program emphasized socializing. When asked about socializing, Fred responded immediately: "Everything they did in there was on a social effort and they all joined in." Sarah felt that her sister, who was always an introvert, learned to be more outgoing:

> I know they're doing a good job because my sister all her life has been an introvert. She has never had any close girlfriends and she doesn't like parties. She's always been an introvert and for her to want to come every day, five days a week she wants to come over here. I know that they're

> making her feel good because I dress her in the morning and she tells me what she wants to wear. She picks out what she wants to wear. You know, it's good for her.

Caregivers who used adult day health services also felt that family members who socialized with others at the center were more interesting and sociable at home. Katie said that, "I know my mom always told me what they did during the day. She had something to talk about." Alice had the same experience with her mother.

> I cook the meal, we sit down, and we do her mail, and we talk about what's going on at the center. It's interesting even though it's pretty much the same activities, it comes out as if she's really delighted with it. There are variations on the theme and so she has a good time with it.

Caregivers who used the adult day health services model were particularly interested in the social aspects of the program. They noted that family members were more sociable and interesting at home. Their reports suggested an improved relationship between caregivers and their family members. Socializing at the adult day center may have the effect of improving relationships between caregivers and family members. The socializing of care recipients away from home allows caregivers time for themselves and frees them from being the family members' only friend, which can place a strain on relationships (Zimmerman, 1986).

Program Scheduling

As noted in Table 1, the activity schedule at the adult day health center appeared to be more structured and less flexible than the one at the adult day care program. Caregivers from both models of adult day services, however, perceived the structure of the programs similarly. The organization of activities at both was likened to the regimentation found in school, work, or a club. In fact, both caregivers and care

recipients often referred to it as school or work. Ethel, a caregiver whose family member attended adult day health services, explained: " Well, it's structured like a classroom except it's only for adults with just physical or mental problems."

Several caregivers stated that their family members thought they were going to work when in reality they were going to the adult day center. One caregiver said that her husband referred to the adult day care center as the club because there was a small group of men who talked and socialized together similar to a men's club to which he once belonged. Caregivers appeared to promote these misconceptions. Shelley stated that when her stepmother was reluctant to attend adult day care, she reminded her that she had to go to school: "That's what we call it, that this is your day at school and explain to her that this is important for her and then we don't give her any choices."

A caregiver at the adult day care center described the activities as somewhat regimented though care recipients are not forced to participate. Furthermore, the activities are designed to meet individualized goals of the care plans:

> Well, they have a schedule of activities so that there's one activity at a time; there's no choice. They don't make anyone do anything they don't want to do. I think that each participant has a care plan and I think it's individualized according to what the personality of the person is and what they think the needs are. Maybe for some people they might encourage cause they think that person needs it and it's good. They also have a schedule of daily activities so you could choose the days.

The ecological model suggests that for an environment to be developmentally effective the setting needs structure and stability (Bronfenbrenner, 1998). Only in a structured and stable environment can people develop competence, whereas in an unstable and unstructured environment people can become dysfunctional or unable to cope in a variety of situations. Bronfenbrenner (1998) hypothesized that interactions

between participants in a stable and structured setting have a significant impact on developmental outcomes. Both adult day centers had stable and structured environments, which may have contributed to caregivers' perceptions that family members had increased cognitive and functional abilities.

Health Services

Caregivers had similar positive experiences with the health services provided by both adult day programs. Both programs have health care conferences on a quarterly basis in which caregivers are given ample time to discuss their concerns. Caregivers valued the care conferences as a way to keep track of any changes in family members' medical condition. The directors at both centers also encouraged caregivers to call or drop in if they had any urgent concerns. Staff called family caregivers if they had a problem or concern about the care recipient.

Some caregivers noted that the staff at both centers monitored care recipients' medications. Caregivers felt that they did not have to worry about their family members receiving their medications while at the centers. Other caregivers were concerned about drug interactions and the effects of polypharmacy on the care recipient. Staff members at both centers provided valuable feedback about the way drugs were affecting family members.

Staff at both adult day centers acted as a liaison between the physician and the caregiver. At times there is little communication between caregiver and physician about treatment (Hasselkus, 1988). Caregivers sometimes feel confused and frustrated after a visit to the doctor. Physicians often spend little time with caregivers, giving orders about diet and medications or explanations about certain aspects of the care recipient's medical

condition that caregivers do not understand (Hasselkus, 1988). Caregivers felt that adult day staff at both centers allowed caregivers time to express their concerns, to learn about conditions and medications, and to understand physician's recommendations, which caregivers found helpful.

Staff Support

Caregivers in both models perceived the staff as being very compassionate and supportive. Caregivers could go to staff as if to friends who would listen to and assist with their problems. Ethel stated: "They are always ready to chat and sit down with you when you are having a problem." Staff members also were supportive to care recipients. Caregivers felt that the staff showed they cared for participants by hugging and touching them. This physical contact was important to family caregivers.

In his ecological theory, Bronfenbrenner (1977) hypothesized that the developmental potential of a setting is enhanced when there are many supportive links, such as shared goals and mutual trust between settings. Therefore, the positive interactions between the staff and the care recipient and the staff and the family caregiver may have important direct and indirect effects on the successful development of both.

Unlike caregivers who used adult day health services, however, caregivers whose family members attended adult day care also reported that they perceived the staff as role models. Caregivers who provide care to family members with dementia often struggle with accepting the changes in their loved one (MacRae, 1990). The staff at the adult day care provided a model of acceptance that was an inspiration to caregivers. Larry stated:

> Their acceptance of these individuals that come to the center as they are. This is my greatest problem. I find it difficult to accept my wife where she is because I had other years of living with her in quite a different role.

> They're an inspiration to me, and I am finding it difficult but moving towards acceptance of the condition as it is.

Other caregivers who used adult day care admired and were inspired by the staff's cheerfulness when dealing with people who were physically and cognitively impaired. Sally pointed out:

> You know, all of these people we are talking about are ill in some respect, mentally and physically. To me, that would be depressing to be around for however many hours a day but these girls are always smiling and always laughing and joking with them.

Younger caregivers used the staff as role models because they did not have friends or family members in whom to confide who might know about their concerns. Carrie explained:

> Our parents had children when they were older, so we're young to be going through this and not too many of our age-mates are. We did not have a lot of role models, especially among people we felt comfortable talking to before we started using adult day care. They're a godsend. They just say, "Yeah, it's okay. We understand, it's all right" . . ."

Caregivers used staff as role models by observing their behavior and modeling it. Social learning theory suggests that human behavior is learned by observation through modeling. By observing others, human beings form rules for behavior. On future occasions, this coded information serves as a guide for action (Bandura, 1986). For example, Larry, observed the interactions between his wife and the staff. Later, he thought about the staff's behavior toward his wife and learned to behave the same way toward her. He said:

> If they will be with her accepting, supportive, happy, loving, and relating to her, then I ought to be able to do it. So, I find them being inspirations. I go home thinking about some of them and the way they did something with my wife that particular day . . .

The capacity to learn by observation enables people to expand their knowledge and skills on the basis of information exhibited by others (Bandura, 1986). Although Larry and Carrie did not have people in their lives to teach them how to care for family members with dementia, by observing the staff at the day care center, they were able to learn more about accepting and caring for them.

Referrals

There were no differences in the way caregivers from both models perceived referral services. The social worker at the adult day care provided caregivers with referrals to foster care and nursing homes when care recipients were no longer appropriate for adult day care. The social worker also assisted caregivers in placing family members in a nursing home.

The adult day health center did not have a social worker on staff. A social services office in the senior center, however, provided referrals for caregivers. The program supervisor also provided caregivers with referrals when necessary.

Summary

Two models of adult day services, adult day care and adult day health services, were compared to understand the ways in which different models may affect caregivers' perceptions of adult day services. Caregivers using the adult day care model emphasized the therapeutic aspects of the program for care recipients whereas caregivers who used the adult day health services model highlighted the social and recreational aspects. Both groups of caregivers reported that the programs helped family members to be more alert and mobile at the end of the day.

Caregivers and care recipients in both groups noted that program schedules at the centers were regimented, similar to school or work. Family members' memories of school or work may be triggered by the organization of adult day programs. This enabled caregivers to remind care recipients that they would not want to miss school or work when they were reluctant to attend adult day services.

Both groups of caregivers reported positive experiences with the health services and referrals offered at the centers. Caregivers found that the periodic care conferences, medication monitoring, and nursing home referrals were helpful. Staff members were very supportive and were described as family and friends by both groups of caregivers. Unlike the caregivers using adult day health services, however, caregivers who utilized the adult day care model perceived the staff as role models. Some caregivers did not have people in their lives to teach them how to care for dependent family members. By observing staff behavior and modeling it, caregivers learned how to accept and care for family members with physical and mental impairments.

Chapter Summary

There were few differences in the way caregivers of past and current participants perceived adult day services. Both groups reported satisfaction with the services. One major difference was that a group of past participants perceived that the programs had failed to provide support to them after their family member had passed away.

Spouse and nonspouse caregivers used adult day services for different reasons. Husbands reported that they used the services for leisure time activities. Daughters and some wives used the services as a way to stay in the workforce. The main reason both groups used the services, however, was to keep their family member active. Spouse and

nonspouse caregivers also had diverse feelings about utilizing adult day services. Husbands and some wives were reluctant to use them because they felt guilty. Daughters reported that they felt good about using the services because they could work knowing that their family member was staying active in a safe environment.

The perceptions of caregivers using the adult day care model differed little from those of caregivers who used adult day health services. One difference was the way in which caregivers who used adult day care emphasized the therapeutic value of the program whereas caregivers who used adult day health services highlighted the social aspects of the program. Another difference was that some caregivers saw the staff at the adult day care center as role models who taught them how to care for and accept dependent family members.

Chapter V

Conclusions

The goal of this study was to help inform adult day care providers about services that family caregivers find useful. An applied research approach was used to assist adult day providers in understanding how they might better meet the needs of family caregivers who utilize adult day services. Focus groups were used as a means of collecting data in a social context in which family caregivers could consider their own views in relation to the perspective of other caregivers, which was consistent with the ecological model used as a framework for this study. Three types of comparisons were made to facilitate analysis of the perceptions of caregivers who may have different perspectives: caregivers of past participants versus those of current participants, spouse versus nonspouse caregivers, and caregivers using adult day care versus caregivers using adult day health services.

In general, this study was interested in the kinds of services that family caregivers find helpful. Specifically, this study asked the question: How might family caregiver's perceptions of the effects of adult day care assist professionals to provide services that caregivers find helpful?

Informing adult day providers about caregivers' perceptions of activities and services can provide practitioners with valuable insights about the ways in which caregivers experience adult day services. It can offer practitioners an opportunity to learn about the strengths and weaknesses of services and activities provided by their programs. Furthermore, it can enable adult day providers to design programs that benefit both caregivers and impaired family members.

Caregivers' perceptions of adult day services obtained in this study can inform practice about services and activities that caregivers find useful and those they may need. Useful recommendations derived from caregivers' perceptions in this study include the following:

- Adult day providers should consider providing support groups for caregivers whose family members pass away while attending the program. Because at any one time the number of bereaved caregivers might be small, providers might consider a transition support group involving caregivers of former participants who are deceased and those who have moved to a nursing home.
- The activity director or other staff member who design crafts should strive to create craft projects that highlight the creativity and personality of the family member. Caregivers and other family members cherish crafts made by care recipients, which can provide a link between generations and give meaning and continuity to the lives of participants and their family members.
- Service providers should consider educating caregivers about how to keep family members active and stimulated on the days that they do not attend the program.
- A social worker or other designated person should be available to assist family caregivers in placing family members when necessary.
- Adult day providers might need to use marketing strategies or educational programs to target spouse caregivers, especially husbands, who are sometimes reluctant to use services.
- Adult day staff should be aware of the need to model appropriate caregiving behaviors, such as kindness, patience, and acceptance of impaired older adults.

- Staff should be friendly and supportive with caregivers, taking time daily to talk to them about their concerns.
- Adult day providers may consider having care conferences on a quarterly basis, which provide enough time for caregivers to ask questions and express their concerns.
- The director or a staff member might consider acting as a liaison between physician and family caregiver when the caregiver is confused about the physician's orders or recommendations.

These recommendations are meant to assist practitioners in providing family caregivers with the activities and services that they find useful. Although most adult day programs undoubtedly are already providing at least some of the services and activities suggested in these recommendations, other practitioners may find them beneficial in designing new program components.

Limitations

Although this study met the goal of providing implications for practitioners, it did suffer from a number of limitations. The sample for this study was too small to presume that it is generalizable to the larger population of caregivers who use adult day services (Morgan, 1988). The goal of this research, however, was not to test hypotheses but to learn more about caregivers' experiences of and perspectives on adult day services. Small focus groups were appropriate for this study because the experiences of caregivers can be very intense. Having fewer participants in a group provided more opportunities for caregivers to both relate and compare their experiences (Morgan, 1995).

Sample bias is often an issue in qualitative studies using focus groups (Morgan, 1988). In this study, the subsample of caregivers of past participants in Sample A was randomly selected but the subsample of caregivers of past participants in Sample B was selected by the director of the adult day health center. As the caregivers in this subsample were chosen by the director, they may not be representative of caregivers of other past participants who utilized the services of the center.

The fact that the director of the adult day health center selected the sample of caregivers of past participants illustrates one of the challenges facing field researchers. To gain access to the target research setting, field researchers sometimes have to make bargains with gatekeepers before the actual research project can begin (Berg, 1998). Although administrators may want to support sound research and are sympathetic to specialized research requirements, they are sometimes unable or unwilling to comply with these needs (Hedrick, Bickman, & Rog, 1993). Program administrators are often bound by an agency's policies and procedures. As a result, to gain entry into the research setting, field researchers may have to forego certain procedures to meet the needs and the wishes of program administrators (Hedrick, Bickman, & Rog).

Although field research is especially effective for understanding how caregivers may perceive the effects of adult day services, there are some problems inherent in this methodological approach. Generalizability is a problem for field research for several reasons. First, field research may be subjective because the observations and measurements made by one researcher may produce results that would not necessarily be replicated by another researcher. If an observation depends in part on the particular observer, than it becomes more valuable as a source of insight than as proof or truth

(Rubin & Babbie, 1997). Second, because field researchers get an in-depth view of their subject, they can reach an unusually comprehensive understanding. Nevertheless, by its very comprehensiveness, this understanding is less generalizable than one based on rigorous sampling and standardized measurements (Rubin & Babbie). For example, the perceptions of adult day care use by family caregivers whose family members attend one adult day center may not be shared by family caregivers whose family members attend other adult day centers.

Even though this study may not be generalizable to the larger population of family caregivers who use adult day services, it is necessary to go beyond surveys and experimental studies, which can be distorted by participant misinformation and evasiveness, to understand how family caregivers actually experience and understand adult day services (Singleton, Straits, & Straits, 1993). I talked with family caregivers who use adult day services to learn how family caregivers themselves perceive the effects of these services.

The participants in both Sample A and B were White. These samples were not representative of perceptions and experiences of racial and ethnic minority groups who may use adult day services. Like most adult day centers, however, the centers used for this study were representative of the racial and ethnic background of the communities in which they are located. Another limitation of this study was that there were no known gay or lesbian caregivers or care recipients. In fact, demographic questions were not framed in a way that would allow gay or lesbian caregivers or care recipients to be acknowledged. The approach of this study is typical of research on adult day care.

Ultimately, it will be necessary for researchers and services providers to acknowledge and include gay and lesbian family caregivers and participants in their work.

Conclusions

Few, if any, studies have compared the ways in which spouse and nonpouse caregivers of past and current participants in different models of adult day care perceive the effects of the services and activities provided by adult day programs. This study suggested that there was little difference between the way in which caregivers of past and current participants perceived adult day services. Although spouse and nonspouse caregivers used adult day services for different reasons, both groups were very positive about the services and activities offered by the programs.

Model type appeared to have little effect on the way caregivers perceived the services. Caregivers may only have access to one type of model in their area, therefore, they may not be aware that other service models exist. Caregivers' perceptions of the programs may have been influenced by their needs and expectations no matter what the emphasis of the program. Furthermore, caregivers' perceptions of the services and activities at the adult day care may have resulted from more than one service model existing at that center. Szekais (1985) hypothesized that adult day programs have been referred to as adult day care, adult day health care, and adult day hospitals but these titles may actually indicate very different programs than the titles suggest. The confusion may have resulted from one or more service models existing at a given adult day center, no matter what the site was called.

Providing a setting for family caregivers to talk with each other about their experiences using adult day services can provide staff at adult day centers with valuable

input for program improvement. Focus group interviewing developed from the concept that many consumer decisions are made in a social context, often growing out of discussions with others. Market researchers began using focus groups as a way of simulating the decision-making process to gather more accurate information about consumer product preferences (Patton, 1987). In the same way, informal focus groups can provide adult day providers with caregivers' perceptions of services and activities they find useful or those they may need.

The ecological model was especially useful in analyzing the data and drawing implications for practitioners. For example, the fact that service providers model behavior for family caregivers reflects an interaction between the exosystem of the adult day center and the microsystem of the home and family. Such interactions can have indirect effects on family caregivers, helping them to develop increased acceptance of and patience with the care recipient.

This study has shown that the perceptions of family caregivers who utilize adult day services can provide practitioners with valuable insights, offer opportunities to learn about the strengths and weaknesses of their programs, and provide suggestions for services and activities that caregivers find useful. Recommendations for practitioners included providing support groups for caregivers of past participants who pass away while attending the program, educating caregivers about ways to keep care recipients active on nonattendance days, assisting family caregivers in placing family members, and acting as a liaison between the family caregiver and physician. Adult day providers need to understand what effect services and activities have on caregivers and family members to enable them to create programs that benefit both.

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APPENDICES

Appendix A

Dear Mr. Smith,

Grace Center for Adult Day Services needs your help. The National Adult Day Services Association has established standards for all adult day care centers in the United States. Beginning July 1, 1999, organizations like Grace Center can be accredited. Accreditation would demonstrate to all potential Grace Center participants and their families that we meet these standards. Grace Center for Adult Day Services is interested in accreditation. To qualify, we must first conduct an evaluation of our program.

As a caregiver of a family member who participated in our program, we would like to talk with you about the quality of our services. We invite you to attend a focus group discussion with other family members like yourself on July 20, 1999, at 4:00 PM, in Room 8 of the Grace Lutheran Church, to share your experiences with and opinions of our program. The meeting will last approximately ninety minutes and refreshments will be served.

A community member who is not associated with Grace Center will help lead the group discussion. Any information you provide in this focus group will be kept confidential. Notes will be taken and the discussion will be audiotaped. These notes and the transcripts from the audiotape will be summarized in a report to Grace Center. No names or identifying information will be included in the report, and once the summary statement is prepared, the audiotape will be destroyed.

We hope you will volunteer to help us. Should you choose to attend, you will not be obligated to answer any questions raised during the discussion, but you may speak freely if and when you wish.

Please consider our invitation seriously. We are very interested in your views of our program. Susan Patterson, an OSU doctoral student, who is helping us with this project, will contact you in a few days to see if you are interested in participating.

Thank you for your willingness to aid Grace Center for Adult Day Services. If you have any questions, please contact me at 754-8417.

Sincerely,

Cherie Babb, RN, MN
Administrator

Appendix B

March 1, 2000

Dear

Daybreak Adult Health Services needs your help. Susan Patterson, a doctoral student from Oregon State University, is conducting research on the intended and unintended consequences of adult day care utilization for family caregivers. Since helping caregivers cope with the responsibilities of caregiving is an important outcome of our program, the information she collects will help us evaluate the success of our program in meeting your needs.

As a caregiver of a family member who is currently participating in our program, we would like to talk with you about the quality of our services. We invite you to attend a focus group discussion with other family members like yourself on Saturday, March 18, 2000, at 1:30PM, at Daybreak, 1155 Ninth St., (the actual meeting will be in a conference room in the Senior Center) to share your experiences with and opinions of our program. The meeting will last approximately ninety minutes and refreshments will be served. We will provide complementary care for the duration of the meeting for participants who do not typically attend on that day.

Susan Patterson will help lead the group discussion. Any information you provide in this focus group will be kept confidential. Notes will be taken and the discussion will be audiotaped. These notes and the transcripts from the audiotape will be summarized in a report to Daybreak. No names or identifying information will be included in the report, and once the summary statement is prepared, the audiotape will be destroyed.

We hope you will volunteer to help us. Should you choose to attend, you will not be obligated to answer any questions raised during the discussion, but you may speak freely if and when you wish.

Please consider our invitation seriously. We are very interested in your views of our program. Someone from Daybreak will contact you to see if you are interested in participating.

Thank you for your willingness to aid Daybreak Adult Health Services. If you have any questions, please contact me at 328-2591.

Sincerely,

Dottie Piekarz, CHN III
Daybreak Supervisor

Appendix C

Questionnaire for Caregivers of Past Participants

Questions about You

1. What is your relationship to the participant?
   - ☐ Wife
   - ☐ Husband
   - ☐ Daughter
   - ☐ Son
   - ☐ Daughter-in-law
   - ☐ Son-in-law
   - ☐ Other relative
   - ☐ Other nonrelative (Explain) _____

2. Do you consider yourself to be the primary caregiver for your family member?
   - ☐ Yes
   - ☐ No

   If No, who is the primary caregiver and what is their relationship to the participant? _____

3. What is your marital status?
   - ☐ Married
   - ☐ Divorced
   - ☐ Widowed
   - ☐ Never married

4. Are you female or male?
   - ☐ Female
   - ☐ Male

5. When were you born?
   Month _____ Day _____ Year _____

6. What is your ethnic/racial identity?
   - ☐ White
   - ☐ African American
   - ☐ Hispanic
   - ☐ Other

7. How many children do you have?

   Number of children _____

8. At the time your family member was attending Grace Center, how many of your children lived at home who were under 18 years of age?

   Number of children _____

9. Were you employed at the time your family member attended Grace Center?
   - ☐ Yes ☐ Full time ☐ Part time
   - ☐ No

10. Grace Center provided care for your family member outside the home.

    Did you use any in-home care services, such as respite care or bathing assistance, when your family member attended Grace Center?
    - ☐ No
    - ☐ Yes If yes, what type? _____
      How many days per month? _____

Questions about Your Family Member

11. When did your family member enroll at Grace Center?
    Month _____ Day _____ Year _____

12. When was your family member discharged from Grace Center?
    Month _____ Day _____ Year _____

13. How often did the participant attend Grace Center for Adult Day Services?
    Visits per week _____ or Visits per month _____

14. When was your family member born?
    Month _____ Day _____ Year _____

15. Is your family member female or male?
    - ☐ Female
    - ☐ Male

16. What was your family member's marital status at the time she or he attended Grace Center?
    - ☐ Married
    - ☐ Widowed
    - ☐ Divorced
    - ☐ Never married

17. What was your family member's living arrangement when they attended Grace Center?
    - ☐ Lived alone
    - ☐ Lived with spouse
    - ☐ Lived with spouse and child(ren)
    - ☐ Lived with child(ren)
    - ☐ Lived with friends, housemate(s)
    - ☐ Other (Explain) _____

18. What is your family member's present living arrangement?
    - ☐ Lives alone
    - ☐ Lives with spouse
    - ☐ Lives with spouse and child(ren)
    - ☐ Lives with child(ren)
    - ☐ Lives with friends, housemate(s)
    - ☐ Lives in foster care
    - ☐ Lives in nursing home

☐ Other (Explain) _____

19. Did you and the participant live in the same household while she or he was attending Grace Center?
    ☐ Yes
    ☐ No

20. Did the participant make any changes in his or her living arrangement while participating at Grace Center?
    ☐ No
    ☐ Yes If yes, describe these changes _____

_____

_____

_____

21. Is your family member still living?
    ☐ Yes
    ☐ No If no, what is the length of time between discharge from Grace Center and the time he or she passed away?
    Months _____ or Years _____

Appendix D

Questionnaire for Caregivers of Current Participants

Questions about You

1. What is your relationship to the participant?
   - ☐ Wife
   - ☐ Husband
   - ☐ Daughter
   - ☐ Son
   - ☐ Daughter-in-law
   - ☐ Son-in-law
   - ☐ Other relative
   - ☐ Other nonrelative (Explain) _____

2. Do you consider yourself to be the primary caregiver for your family member?
   - ☐ Yes
   - ☐ No

   If no, who is the primary caregiver and what is their relationship to the participant? _____

3. What is your marital status?
   - ☐ Married
   - ☐ Divorced
   - ☐ Widowed
   - ☐ Never married

4. Are you female or male?
   - ☐ Female
   - ☐ Male

5. When were you born?

   Month _____ Day _____ Year _____

6. What is your ethnic/racial identity?
   - ☐ White
   - ☐ African American
   - ☐ Hispanic
   - ☐ Other

7. How many children do you have, if any?

   Number of children _____

8. How many of your children live at home who are under 18 years of age?

   Number of children _____

9. Are you employed?
   - ☐ Yes ☐ Full time ☐ Part time
   - ☐ No

10. Daybreak provides care for your family member outside the home.

    Do you use any in-home care services, such as respite care or bathing services, for your family member?
    - ☐ No
    - ☐ Yes If yes, what type? _____
      How many days per month? _____

Questions about Your Family Member

11. When did your family member enroll at Daybreak?
    Month _____ Day _____ Year _____

12. How often does the participant attend Daybreak Adult Health Services?
    Visits per week _____ or Visits per month _____

13. When was your family member born?
    Month _____ Day _____ Year _____

14. Is your family member female or male?
    - ☐ Female
    - ☐ Male

15. What is your family member's current marital status?
    - ☐ Married
    - ☐ Widowed
    - ☐ Divorced
    - ☐ Never married

16. What is your family member's living arrangement?
    - ☐ Lives alone
    - ☐ Lives with spouse
    - ☐ Lives with spouse and child(ren)
    - ☐ Lives with child(ren)
    - ☐ Lives with friends, housemate(s)
    - ☐ Other (Explain) _____

17. Do you and the participant live in the same household?
    - ☐ Yes
    - ☐ No

18. Has the participant made any changes in her or his living arrangements while participating at Daybreak Adult Health Services?
    - ☐ No
    - ☐ Yes If yes, describe these changes _____

_____

_____

_____

19. Has your family member been hospitalized while attending Daybreak Adult Health Services?

☐ No

☐ Yes If yes, describe these hospitalizations (how many, for what reasons, for how long, and so on) _____

_____

_____

_____

Appendix E

Questions for Focus Groups of Caregivers of Past Participants

1. Introduction of family members.
2. What is your relationship to the past participant?
3. How long did your family member attend Daybreak Adult Day Health Services?
4. What circumstances led to your family member's enrollment in Daybreak?
5. Before enrolling your family member did you discuss the adult day services program with him/her? What was the response?
6. How did you feel about having to enroll your family member in Daybreak?
7. What type of tasks, if any, do you currently perform for your family member, such as personal care, finances, or errands?
8. What role did Daybreak play in caregiving for your family member? Did you feel that you were able to relinquish your role as caregiver when your family member was at Daybreak? What role did you play and what role did Daybreak?
9. What type of relationship did you feel you had with the staff at the Daybreak program?
10. Caregiving can take time away from work, family, and leisure activities. How did your family member's participation at Daybreak help to provide you with the time you needed for your personal activities?
11. Caregivers sometimes experience stress because of the many tasks associated with caregiving. In what ways, if any, did you find caregiving to be stressful for you?
12. In what ways did your family member's participation in Daybreak program help to alleviate any stress from caregiving?

13. Did you feel that the staff provided the type of support you may have needed as a
14. caregiver? In what ways, if any, did the nursing consultations about such health concerns as urinary incontinence and medication management help you and your family member?
15. Sometimes caregivers would tell the staff that participants were more alert after spending a day at Daybreak. Did you find that to be true of your family member? In what ways, if any, were they more alert?
16. In what ways, if any, do you think the exercise activities at Daybreak helped your family member with mobility?
17. How did the staff help you to plan for care when the participant was no longer able to attend the program at Daybreak and needed another level of care?
18. Do you think that your family member's attendance at adult day services has helped to prevent or delay nursing home placement.
19. Now I would like to ask you to think about the program's strengths and weaknesses. First, what do you consider the strengths of the program?
20. What about the weaknesses?
21. What changes, if any, would you recommend to improve the program?
22. Is there anything else you would like to add about Daybreak, or about caregiving?

Appendix F

Questions for Focus Groups of Caregivers of Current Participants

1. Introduction of family members.
2. What is your relationship to the participant?
3. How long has the participant been attending Daybreak?
4. What circumstances led to your family member's enrollment in Daybreak Adult Health Services?
5. Before enrolling your family member did you discuss the adult day services program with him/her? What was the response?
6. How did you feel about having to enroll your family member in Daybreak Center?
7. What type of tasks, if any, do you currently perform for your family member, such as personal care, finances, or errands?
8. What role does Daybreak play in caregiving for your family member? Do you feel that you are able to relinquish your role as caregiver when your family member is at Daybreak? What role do you play and what role does Daybreak play?
9. What type of relationship do you feel you have with the staff at the Daybreak Adult Health Services?
10. Caregiving can take time away from work, family, and leisure activities. How has your family member's participation at Daybreak helped to provide you with the time you need for your personal activities?
11. Caregivers sometimes experience stress because of the many tasks associated with caregiving. In what ways, if any, have you found caregiving to be stressful for you?

12. In what ways has your family member's participation in Daybreak's program helped to alleviate any stress from caregiving?
13. Do you feel that the staff provides the type of support you may need as a caregiver?
14. In what ways, if any, have the nursing consultations about such health concerns as urinary incontinence and medication management helped you and your family member?
15. Sometimes caregivers tell the staff that participants are more alert after spending a day at Daybreak. Have you found that to be true of your family member? In what ways, if any, are they more alert?
16. In what ways, if any, do you think the exercise activities have helped your family member with mobility?
17. Now I would like to ask you to think about the program's strengths and weaknesses. First, what do you consider the strengths of the program?
18. What about the weaknesses?
19. What changes, if any, would you recommend to improve the program?
20. Is there anything else you would like to add about Daybreak Adult Health Services, or about caregiving?

Appendix G

Coding Scheme

Themes and Subthemes

- Caregiver Satisfaction
- Nursing Home Placement
- Lack of Support Groups
- Crafts as Family Heirlooms
- Reasons for Using Adult Day Services
    - Inactivity of care recipient
    - Leisure
    - Time for other family members
    - Paid work
- Feelings about Using Adult Services
- Activities
- Alertness and Mobility
- Socializing
- Program Scheduling
- Health Services
- Staff Support
- Referrals