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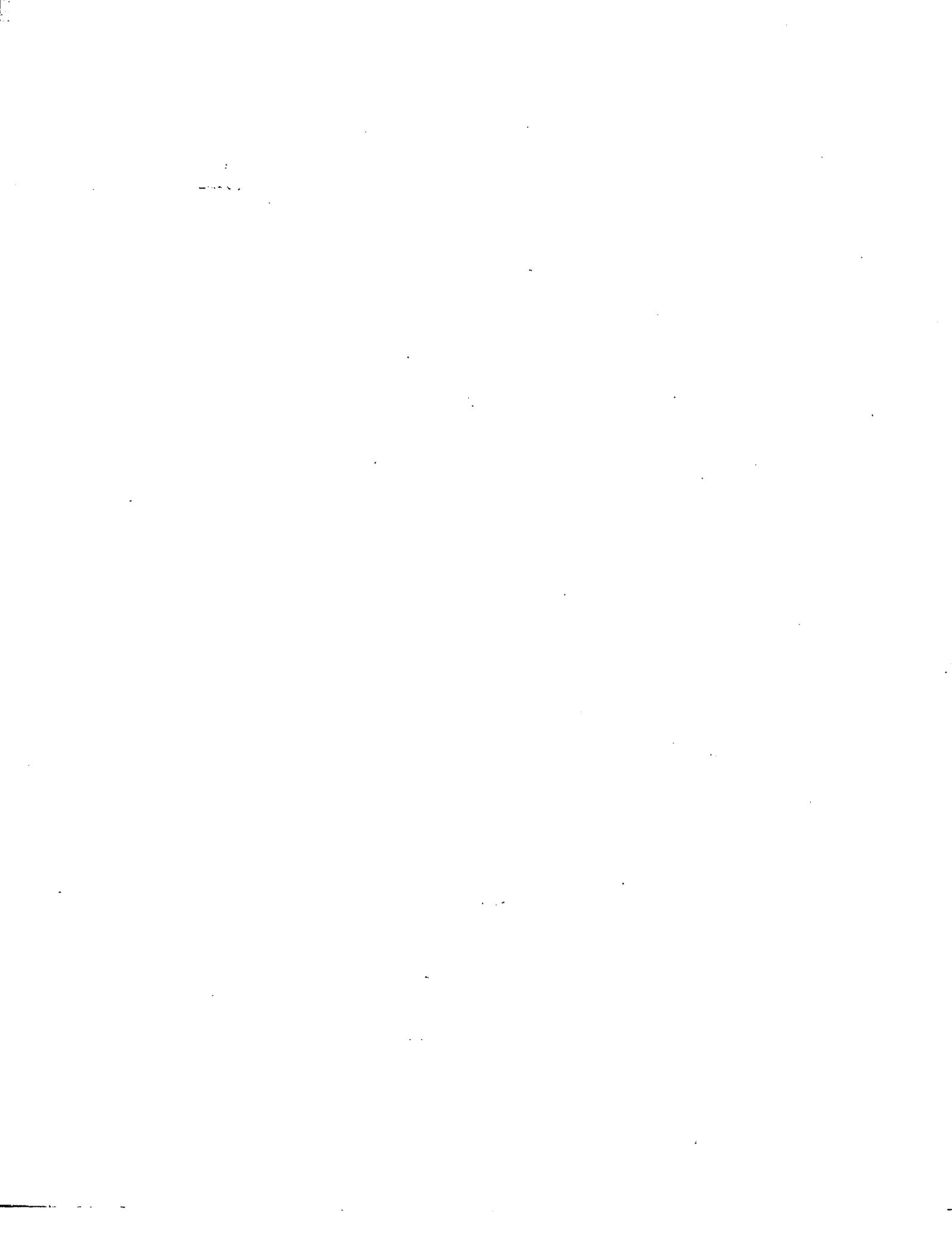
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**Satisfaction, functionality, and the impact of caregiving among
spousal and parental caregivers**

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The University of Arizona, 1990

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**SATISFACTION, FUNCTIONALITY, AND
THE IMPACT OF CAREGIVING AMONG
SPOUSAL AND PARENTAL CAREGIVERS**

by

Leif Thomas Swanson

**A Thesis Submitted to the Faculty of the
SCHOOL OF FAMILY AND CONSUMER RESOURCES**

**In Partial Fulfillment of the Requirements
For the Degree of**

**MASTER OF SCIENCE
With a Major in Family and Consumer Resources
In the Graduate College
THE UNIVERSITY OF ARIZONA**

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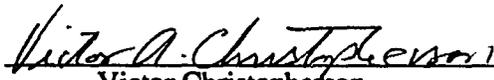
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ABSTRACT

A total of 85 adults in the Phoenix, Arizona, metropolitan area who were providing care to an elderly relative or spouse in their households, completed a questionnaire which assessed satisfaction with life and family, functionality, demographic variables, and the impact of caregiving on their lives. Various statistical analyses showed nonsignificant differences between those subjects who cared for an elderly relative and those who cared for a spouse across variables of caregiving, life satisfaction, family satisfaction, and overall functionality. However, significant differences between spousal and parental caregivers were found when assessing the probability of institutionalization of the care-receiver. Compared to national sample norms, caregivers reported significantly lower family satisfaction scores and were significantly more dysfunctional in terms of cohesion, adaptability, and overall functionality. Life satisfaction was significantly related to functionality of the family, but family satisfaction was not significantly related to functionality. Implications from this study are discussed.

CHAPTER I

1. INTRODUCTION

Just when their children are leaving the household, when a new career is beginning, or when retirement is approaching, many middle-aged adults find themselves faced with caring for a parent or elderly relative; these adults are known as parental caregivers. At the same time, elderly persons find themselves providing care to their disabled spouses; they are known as spousal caregivers. This study will present how the introduction of a care-receiver, one who requires assistance from another person, impacts the lives of those who are providing the care. Previous research seems to point toward a negative impact of caregiving, but there may be more complex issues and dynamics involved in this situation. This paper will investigate the impact of caregiving and other behaviors related to caregiving, evidence of caregiver burden, issues of family functionality, life satisfaction, family satisfaction, and whether spousal and parental caregiver groups have specific and unique issues and concerns related to caregiving.

The proportion of elderly persons living with their children or other relatives has declined over the past 35 years. According to Crystal (1982), the proportion of the elderly living with their children or other relatives dropped from three-fifths of all elderly persons in 1960 to one-third in 1980. In 1940, approximately fifteen percent of elderly males resided with adult children versus four percent in 1975. In 1950, 45 percent of the single elderly women were living with family as compared to 25 percent in 1977 (Mindel, 1979; DeLaski-Smith, 1984). In spite of the decrease, approximately 2.25 million persons 65 years and older in the United States were single, living in families, and not heading their own household in the 1970s (Neugarten, 1975; Mindel, 1979).

Elrod (1980) believes the number of elderly living with their children or other relatives decreased in the past several decades due to several factors. The preference of elderly persons to live independently, smaller family networks (many were childless or had small families), and changes in family composition (e.g., single parent, "reconstituted,"

childless, divorced, extended). Furthermore, research has shown that the majority of the elderly are strongly opposed to living with their children, preferring to live alone or with their spouse rather than to be thought of as burdens to their children (Silverstone & Hyman, 1982). In spite of a previous decline, the number of two- and three-generational households is forecasted to increase for several reasons: the increase in the elderly population, the increased length of time elderly persons are living with disabilities, and low national health funding for institutional care or for home health care (Glasse & Leonard, 1988; Horne, 1985).

A major factor that determines whether an elderly person does live with a child or other relative is physical or mental disability. One out of five elderly over age 65 has at least a mild degree of physical disability, and one in seven has at least a mild form of cognitive impairment (Manton & Liu, 1984). Moreover, the chance of being disabled increases with age (U.S. Senate Special Committee on Aging, 1986). A large proportion of those elderly who are disabled are cared for by spouses, but where that is not possible, living with a child or other relative is an option. The actual number of elderly persons who were not living with a spouse but were living with children, siblings, or other relatives has been estimated to be between eight and fourteen percent of that population (Barrow, 1986; Kivett & Learner, 1982; The American Association for Retired Persons, 1987). Still, a greater percent of disabled elderly persons are living with and being cared for by their families than are institutionalized (Brody, Poulshock, & Masciocchi, 1978).

As the "baby boom" generation ages, and as major achievements in disease prevention and medical care extend average life expectancy, significant changes in American population statistics will occur well into the next century. The percentage of persons 55 years and older (22 percent) should remain stable through the year 2000, but by 2010, the "baby boom" generation will have aged, with one in four Americans expected to be age 55 and above, and with one in seven at least 65 years old; by 2050 that number will increase to one in three persons, and one in five will be 65 years or older (Spencer, 1984). If the current percentage of disabled elderly living with their children or other relatives remains relatively constant and the elderly population increases as projected by government figures, there could be as many as five million elderly living in two- or three-generational

households in the next thirty years.

With the increase in the elderly population, the American public will find itself having to deal with caregiving situations more often. Horne (1985) proposes that coresidency of an elderly parent and an adult child can be beneficial and provide positive elements, such as a sense of family connectedness and history, companionship for both the caregiver and the parent, combined incomes, shared expenses and work loads (assuming the care-receiver is well-functioning). Nevertheless, caregiving can potentially create problems such as caregiver strain, interference with the caregiver's life, role conflict, family and marital issues, and decreased family functionality.

Confusion and conflict with roles of the caregiver can surface in the household where the adult child is providing care. The choice between roles is often demanding and stressful. Brody (1981) wrote of female caregivers in particular whose roles "as caregiving daughters and daughters-in-law to dependent older women have been added to their traditional roles as wives, homemakers, mothers, and grandmothers" (p. 472). Moreover, when the parent moves in with the adult child and her/his family, the caregiver may feel like she/he is in the role as the child again and must act appropriately to the parent. On the other hand, when elderly parents, who have always seemed self-sufficient and independent, are seen as dependent, demanding, and advice- and guidance-seeking, the adult child may become confused by the apparent reversal in roles between parent and child (Horne, 1985).

Marriage partners of victims of mental and physical disabilities such as Alzheimer's disease, stroke, Parkinson's disease, head trauma, and other dementias often experience a different form of role confusion than parental caregivers. The disabled spouse's role as husband/wife may be lost because the spouse and victim may no longer function as a marital couple. The spouse, for example, must sometimes act more like a mother/father than a wife/husband to the victim, helping him/her dress, go to the bathroom, or prepare meals, for example. Furthermore, the spouse may have to take on new roles involving such tasks as finances and decision-making.

There is often a lack of emotional and physical reciprocity in the marital relationship due to the nature of the disability; for instance, Alzheimer's disease victims may be unable to recognize faces, stroke patients may not be able to communicate, and dementia patients

may be emotionally withdrawn from the spouse. In addition, if the emotional response of the victim is negative (e.g., depression, irritability, anger) or if there is a lack of cognizance, the loss of the emotional support may have a greater negative impact on the spouse.

In these cases, the "normal" spouse not only assumes the caregiving duties and new roles, but she/he must also deal with complex grief/loss issues emerging in this situation from the "death" of the victim's personality and ability to think. The partner must proceed with the grieving process of the victim's original personality/self, yet cannot complete the grieving process as long as the physical presence of the victim remains. What occasionally results is confusion as to whom the "normal" spouse is married. For example, is the spouse married to the physical person, the personality, or the disabled body and original/new personality?

The parental caregiving arrangement creates a situation in which the parental caregiver must frequently divide her/his time between family members, the care-receiver, and her/himself (Brody, 1981; Horowitz, 1978; Treas, 1977). The demands by other family members and the care-receiver for the caregiver's time can be stressful to the caregiver. Treas (1977) noted that "growing numbers of middle-aged women were asked to choose between nursing frail parents or working to support themselves, their families, their own children" (p. 490).

When a choice is made to provide care to an elderly relative, family relations may be affected. In spite of extensive research on caregiver strain, little attention has been given to how the caregiving family functions in the midst of strain. The manner in which families handle crises may be predictive of the impact of caregiving on the family unit. Silliman and Sternberg (1988) propose that "family dynamics and aspects of the caregiver-care-receiver relationship may contribute to the perceptions of burden" (p. 377). Some caregiving households may be more able to handle stressors such as caregiving duties than others. Families that have high functionality may be better prepared to handle change and chaos, even if the parent is severely disabled. Constantine (1983) suggested that the outcome of a family crisis, e.g., the onset of a caregiving household, may depend upon the relationship between the demands of the problem and the family's coping resources. For example, the

family's ability to cope positively in a crisis may be predictive of how a solution is produced and carried out successfully.

The study of caregivers and the impact caregiving has on their lives is necessary if solutions to problems are to be effectively generated. Counselors, public policy makers, family members, and the general population need to understand the problems, conflicts, and concerns of caregivers; mental health counselors and caregiver-support counselors need to know who their clients are and the situations and dynamics involved with caregiving. Various questions arise concerning this topic. Is there a need for counseling or support groups for caregivers? Are caregivers negatively affected? Will caregiving affect the caregiver's family, employment status, or personal health? Will different counseling interventions be required for individual caregivers or types of caregivers such as those caring for a parent or spouse? While both spousal and parental caregiver groups may experience different situations and conflicts, are the two groups different? Does each group react to the demands of caregiving differently? Should separate counseling techniques/interventions be utilized and specific issues addressed, such as family issues with parental caregivers and marital issues with spousal caregivers?

CHAPTER II

2. LITERATURE REVIEW

2.1 Impact of Caregiving

The burden and strain associated with caregiving has been researched extensively (Shanas & Streib, 1965; Cath, 1970; Robinson & Thurnher, 1979; Kinney & Stephens, 1989; Quayhagen & Quayhagen, 1988; Mindel & Wright, 1982; Horne, 1985; Christianson & Stephens, 1986; Archbold, 1983). Common characteristics of caregiver burden can be found from a review of the literature. The burden and strain from caregiving is real and often intensive, reactions to the caregiving situation by the care provider and families are highly individualistic, and other variables such as the degree of disability of the care-receiver, family dynamics, interference with personal life, and the length of time of caregiving all are thought to influence life and family satisfaction and the amount of burden experienced by caregivers.

In a large number of caregiving households, the introduction of caregiving has a negative impact on the caregiver and the family unit. For example, the inability to maintain previous lifestyle was a negative effect of caregiving. Robinson and Thurnher (1979) reported that the restrictions on the caregiver's personal freedom were more burdensome than the actual activities of providing care. A survey of caregivers by the American Association of Retired Persons and the Travelers Companies Foundation (1988) strengthens Robinson and Thurnher's (1979) finding as it reported the following lifestyle changes as a result of caregiving: seventy-two percent of the sample had made lifestyle changes since becoming a caregiver, 34 percent spent less time with their own immediate family, 33 percent paid less attention to their own health, and 28 percent took fewer vacations. In fact, some families had not received prolonged respite care for several years as a result of constant caregiving demands (Robinson & Thurnher, 1979).

If the elderly person is disabled, the advantages of this type of living arrangement may be reduced. The presence of the elderly parent in the home of an adult child, and

especially if health care is required, can lead to increased family stress and strain. Reece, Walz, and Hageboeck (1983) found in their comparison of caregivers, that those experiencing the heaviest burden from caregiving were those involved in joint living with the older person. The overall level of caregiving activities was not as significant as was the relationship between coresidency and the degree of negative impact on the caregiver. Caregivers who care for a disabled parent may also experience a loss of personal privacy, an increase in family chores, limited leisure time and social activities, and consequent physical inconveniences within the household (Mindel & Wright, 1982).

Primary caregivers, in a study by Christianson and Stephens (1986), generally reported high levels of emotional strain. More than one-half reported the highest levels of emotional strain on a self-report scale. They also reported more emotional strain than physical or financial strain due to caregiving. Somewhat fewer, but still almost forty percent, reported levels of physical strain at the highest points on the scale. Almost sixty percent of the primary caregivers in their study experienced little or no financial strain associated with caregiving. Other research has supported these findings. Approximately eighty percent of caregivers in a study by Scharlach and Boyd (1989) reported some degree of emotional strain associated with caregiving responsibilities. Physical strain was reported by sixty percent of the sample, and financial strain by 54 percent. Emotional strain was also ranked first, and financial strain was last in another study of caregiver strain (Cantor, 1983). In this study, spousal caregivers are predicted to report higher levels of caregiver strain, including emotional, financial, and physical strain. Spousal caregivers are generally older, providing caregiving duties by her/himself, and more prone to health problems due to age than parental caregivers.

The demands of caregiving have the potential to negatively affect the employment status of the adult child caregiver, especially if the adult child is a woman. In recent years, more than half of all working-age women were actually in the work force (U.S. Social Security Administration, 1980). The resulting limitations on the middle-aged woman's employment status can be significant. According to Christianson and Stephens (1986), restricted working hours were experienced by almost one-third of both currently and recently employed caregivers. In addition, over 35 percent of recently employed caregivers

had left their jobs in order to provide care, over 21 percent had turned down a job offer, and over 28 percent had been unable to look for work due to caregiving responsibilities. Some women in the study reported they were unable to seek or retain suitable employment or to take advantage of advancement opportunities. As a result, the financial status of female caregivers and their families may be restricted due to caregiving demands.

Financial stress resulting from providing care to dependent parents has received conflicting comments from researchers. Horowitz and Dobrof (1982) place less importance on financial stress than emotional stress when associated with caregiving. Robinson and Thurnher (1979) also reported that financial assistance to elderly parents was not a potential source of stress. This was found for the majority of parental caregivers, regardless of the living arrangement of the care-receiver. On the other hand, Newman, Morgan, Moras, and Postalan (1976) reported that adult children caring for parents in their homes were twice as likely as children with parents in nursing homes to report financial difficulties. Another study found caregiver financial stress to be significantly correlated with the caregiver's own financial resources, more specifically, caregivers whose total gross household income was less than \$1,000 per month, and those who contributed more than twenty percent of their own income toward caregiving expenses reported higher levels of financial stress than other caregivers (Christianson & Stephens, 1986).

2.2 Differences Between Caregiver Groups

Although the research on caregivers as a whole has been extensive, few studies have been conducted to examine differences and similarities between caregiver groups. This study examined two different groups of caregivers: caregivers of spouses and caregivers of a parent in the caregiver's household (adult child and parent). Although each of these groups provide near-identical caregiving services (e.g., transportation, preparation of meals, administration of medicine, or personal hygiene assistance), their composition alone makes them unique. Spousal caregivers are providing care to their husbands/wives while at the same time maintaining a marital relationship with the care-receiver (Barusch, 1988). Parental caregivers have responsibility toward themselves, their spouses, the care-receiver, and their children (Soldo & Myllyluoma, 1983; Shanas & Streib, 1965; Mindel,

1979; Mindel & Wright, 1982; DeLaski-Smith, 1984).

Research findings support the belief that individuals experience caregiving differently according to their relationship with the care-receiver (Toseland & Rossiter, 1989; Young & Kahana, 1989). In Cantor's (1983) study of caregiver strain, the group at greatest risk of caregiver strain was spousal caregivers, who reported the greatest degree of physical and financial strain. However, parental caregivers were also negatively impacted, especially when feelings of responsibility toward other family members were strong. In another study, parental caregivers were found to have higher role strain, role conflict, and burden than spousal caregivers (Young & Kahana, 1989).

Constant caregiving may place a higher toll on the spousal caregiver's health, especially if emotional, financial, and other strain add to the physical strain of caregiving. Spousal caregivers in Cantor's (1983) study tended to have lower income, to be older, to be less likely to be employed, and to report poorer health than their counterparts. This finding was supported in another study in which spousal caregivers also reported poorer physical health and general well-being along with more stress symptoms than the parental caregivers (George & Gwynter, 1986). Parental caregivers are younger and generally healthier than spousal caregivers. Furthermore, parental caregivers have other family members to assist with caregiving duties, which provides the caregiver with respite opportunities.

Providing sufficient care to the care-receiver, such as administering medicine, bathing/grooming, managing finances, or preparing special meals, for example, may be a special concern of spousal caregivers, who may feel inadequate to provide care whether it is due to lack of knowledge and skills or to their own poor health. Because the spousal caregiving household usually includes only the caregiver and the care-receiver, a family network is not readily available to the spousal caregiver for assistance or advice. Also, spousal caregivers generally have lower incomes and tighter budgets than parental caregivers and may not be able to afford special equipment, supplies, transportation, or occasional home-health assistance.

Although they may be more worried about providing sufficient care, spousal caregivers are predicted to be more satisfied with current care arrangements. Spousal

caregivers will probably have lived alone together for a longer period of time than other caregivers. The elderly couple may rely on each other and may accept the arrangement as part of the conditions of marriage or as a stage of life. Parental caregivers are predicted to be less satisfied due to interference with the family unit; they, as adult children, would not anticipate providing care to a parent and may in fact become resentful of the situation.

Spousal caregivers may be more likely to assess their relationship to the care-receiver as poorer than parental caregivers. Caregivers of mentally and physically disabled spouses are often seen as "second victims." The "normal" spouse may suffer as much, if not more, than the disabled victim. Silliman's (1986) study of stroke patients found that "dependent patient functional status and additional life stress were both associated with caregiver's diminished social activity and emotional ill health. Insufficient social activity and help from families added to the risk of emotional ill health" (p. 644). The quality of the marital relationship in this situation will likely be disrupted. The caregiver, who has been married to the care-receiver for over forty years, for example, may not be able to easily adjust to a physical and emotional change in her/his spouse. Parental caregivers may report a lower quality of the relationship to the care-receiver as well due to family interference, resentment, and strain.

As proposed in this study, caregiving may negatively impact parental caregivers more than spousal caregivers regarding variables such as family time, privacy, social life, constant attention demands, and with other relationships. Parental caregivers may also report more interference with caregiving and with social, work, time with spouse, time with children, and quiet time. With family, the care-receiver, children, and work, the parental caregiver will have little time for her/himself and other family members and friends.

Montgomery and Borgatta (1989) found that after educational services were provided to caregivers, spousal caregivers were more encouraged to institutionalize the care-receiver than the adult children caregivers. Lund, Pett, and Caserta (1985) found that the spouse was the caregiver most likely to anticipate institutionalizing the Alzheimer's patient. Spousal caregivers may be emotionally and physically exhausted from caregiving. Supporting earlier research, spousal caregivers in this study may be more likely than

parental caregivers to institutionalize the care-receiver. Parental caregivers may deny the reality and severity of the situation (ie., that home care may be inadequate due to poor health of the care-receiver) and try to keep the parent as long as possible in the home. Feelings of guilt and obligation may prevent the parental caregiver from considering institutionalizing her/his parent.

The relationship of the caregiver to the care-receiver, however, does not guarantee that caregiving will be experienced differently among caregivers of different relations to care-receivers. Gallagher, Rose, Rivera, Lovett, and Thompson (1989) did not find significant differences in rates of depression among spousal and parental caregivers. Young and Kahana (1989) found no differences in mental health or physical health after-effects of caregiving among types of caregivers. Furthermore, Culfond, Olsen, and Block (1979) found that sixty percent of their sample of caregivers in multigenerational households reported no adverse effects of this arrangement on family functioning, and that ninety percent were satisfied with the family's living arrangement.

2.3 Life and Family Satisfaction

Life satisfaction is commonly associated with psychological and/or subjective well-being, although the exact definition is unclear among social scientists. Neugarten, Havighurst, and Tobin (1961) propose that an individual's life satisfaction is measured according to

"the extent that he (a) takes pleasure from whatever the round of activities that constitutes his everyday life; (b) regards his life as meaningful and accepts resolutely that which life has been; (c) feels he has succeeded in achieving his major goals; (d) holds a positive image of self; and (e) maintains happy and optimistic attitudes and mood" (p. 137).

Liang (1984) notes another definition of life satisfaction, offered by George (1981) and Lawton (1977; 1983): "Life satisfaction refers to a cognitive assessment of how satisfying one's life is in general. Specifically, it is the congruence between the attained and desired goals" (p. 621). Family satisfaction refers to the individual's subjective assessment of the interactions, dynamics, communication, and activities within the family unit. This

assessment will be negatively affected if a discrepancy exists between how the individual perceives the current family unit to be and how the individual idealizes how the family unit should be.

A study by Mindel and Wright (1982) examining caregiver satisfaction in multigenerational caregiving households, reported that two characteristics of caregivers of parents or older relatives, marital status and ethnicity of the caregiver, had direct effects on caregiver satisfaction. Socioeconomic status and consanguinity of the relationship were not found to directly affect caregiver satisfaction. Mindel and Wright (1982) also found that greater dependency of the elderly relative (according to age, impairment, activity, and role behavior) resulted in lower family satisfaction. The researchers reported that the primary caregiver's satisfaction decreased as the age and the level of impairment of the care-receiver increased, as the number of roles performed by the care-receiver decreased, and as the caregiver's perceived level of inconvenience increased. Furthermore, the data revealed that intergenerational housing satisfaction decreased when the new addition to the residential family inconvenienced family members, seemed to change existing relationships, or created physical moves for other family members.

In this study, parental caregivers may report lower life satisfaction ratings than spousal caregivers. Spousal caregivers may be more satisfied with their lives upon reflection while parental caregivers may be more depressed about how their lives and expectations have changed; they may be more pessimistic about their future and the current situation. However, spousal caregivers may report lower family satisfaction ratings than parental caregivers. The marital relationship has probably been disrupted by the disability which can result in an unbalanced relationship. Low family satisfaction of spousal caregivers may also be exacerbated if family support is not available, although recent trends of decreased family size, resulting in smaller networks of family support, may also affect family satisfaction ratings of parental caregivers (Katz, 1980; Brody, 1981; Silverstone, 1979).

2.4 Functionality

Various family functional types (or groups) were proposed by Olson, Sprenkle,

and Russell (1979) in which each family type has a characteristic style of problem solving and a characteristic mode of coping with crisis and with stress, e.g., caregiver burden. The Circumplex Model, a model of marital and family systems, was utilized by these researchers to assess family functioning on the basis of the degree of cohesion and adaptability within the family system (Olson, et al., 1979). Using a 4x4 matrix form, the researchers identified sixteen types of family systems according to a range from high to low on each of the two dimensions: cohesion and adaptability. The Circumplex model theorizes that families with balanced cohesion and adaptability generally will function more adequately in a problem situation, that solutions to problems will be generated, and that the family will maintain structure in times of a crisis (Olson, et al., 1979).

The definition of family cohesion used in the Circumplex Model consists of two parts: "the emotional bonding members have with one another and the degree of individual autonomy a person experiences in the family system (Olson, et al., 1979, p. 5)." There are four degrees of cohesion. At the extreme of high family cohesion, "enmeshment," overidentification with the family results in extreme bonding and limited individual autonomy. At the other extreme, "disengagement" is characterized by low bonding and high autonomy from the family. The middle two degrees, "separated" and "connected," are considered balanced and healthy. Specific variables used to assess the degree of family cohesion are emotional bonding, family boundaries, time, friends, decision making, and interests and recreation. Olson, et al., (1979) hypothesized that when the levels of cohesion are balanced, the family will deal more effectively with situational stress and developmental change.

The second factor, adaptability, was defined as "the ability of a marital/family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress" (Olson, et al., 1979, p. 12). Extreme degrees of the adaptability factor are believed to be dysfunctional to families, with functional families maintaining a balance between adapting to changes and maintaining the status quo. For instance, in times of stress, families may require greater adaptability while still maintaining some degree of stability. Variables of adaptability include leadership and control, discipline, negotiation, role relationships, and relationship rules.

Previous research has shown significant differences between problem families and "normal" families on levels of functionality. As hypothesized by the Circumplex Model, significantly more problem families (e.g., those with alcohol/drug abuse, adolescent juvenile delinquency, schizophrenia, other mental problems, runaway children, sexual abuse) were extreme while significantly more "normal" families (i.e., no-therapy matched control groups) were functional (Clarke, 1984; Garbarino, Sebes, & Schellenbach, 1985; Olson & Killorin, 1985; Killorin & Olson, 1984; Carnes, 1985; Rodick, Henggeler, & Hanson, 1985).

In a parental caregiving household, the family may remain more functional because caregivers have other family members to rely on for feedback and support. The presence of the care-receiver in the household may impact the family in some aspects as found in the research, but may not change the way the family functions. On the other hand, the advent of caregiving in the spousal caregiving household may have more negative effects on functionality since the network of support will be more limited. The presence of a disabled spouse in the household will likely upset the balance of the marriage relationship.

As an original research question, functionality levels of caregiver groups in this study were examined and compared to the general population using a national norm sample (Olson, Russell, & Sprenkle, 1983). This is not to suggest that caregiving households are related in form and function to households where alcoholism, delinquency, sexual abuse, or mental illness is present. Rather, caregiving and problem families may be related according to the presence of emotional stressors in the household. The majority of caregiving households, as well as problem households, experience high levels of emotional strain and stress. The potential exists that the manner in which the caregiving family reacts to the strain due to caregiving will be related to the level of functionality in the household. Caregivers are predicted to be different from the general population according to functionality, cohesion, and adaptability. More specifically, it is hypothesized that caregivers will be less likely to be classified as having balanced functionality, balanced cohesion, and balanced adaptability than families from a national sample due to the chronic nature of the caregiving situation. Furthermore, parental caregivers are predicted to be more balanced functionally than spousal caregivers, and they are predicted to be more likely

to have balanced adaptability and cohesion. Finally, functionality level is predicted to be related to life and family satisfaction ratings; dysfunctional families are predicted to report lower satisfaction with life and family.

2.5 Hypotheses

Hypothesis 1: Spousal caregivers will differ significantly from parental caregivers according to ratings of caregiver variables, life and family satisfaction means, and functionality classification.

Hypothesis 2: Caregiver subjects will report significantly different levels of family satisfaction and be more dysfunctional than adults in a national norm sample.

Hypothesis 3: Differences in the means of life satisfaction and family satisfaction among levels of functionality will be found.

2.6 Summary

This study examines spousal and parental caregivers and the differences between these groups in terms of the impact of caregiving, functionality, life satisfaction, and family satisfaction. It is predicted that parental and spousal caregivers will report negative effects of caregiving and will be more dysfunctional and have lower satisfaction ratings than the general population. Differences are predicted between caregiver groups in terms of caregiving variables; parental caregivers are also predicted to be more functional than spousal caregivers and report lower life satisfaction ratings, and spousal caregivers are predicted to report lower family satisfaction ratings.

CHAPTER III

3. METHODOLOGY

3.1 Explanation of Data and Terms

The term "parental caregiver" as used in this study denotes caregivers who are providing care in their household for a relative who is at least one generation before them. In this study all but one of the 41 "parental" caregivers were providing care to a parent or parent-in-law. The spousal caregiving group (N = 44) consisted of those persons who were providing care to their spouses in their household. Findings of this study for spousal caregivers, parental caregivers, and the total sample of caregivers will be presented.

3.2 Instrumentation

In the current study, a questionnaire of demographic variables and assessment of the impact of caregiving was developed from a variety of other research surveys: Mindel and Wright's (1982) survey of caregivers, Christianson's (1986) "Channeling Effects on Informal Care" survey, and the National Survey of Caregivers (The American Association of Retired Persons and the Travelers Companies Foundation, 1988). Items were selected based on reliability and validity and on relevance to this study.

Scores from related questions were summed to create a strain index, an impact index, and an interference index. The strain index was achieved by summing the ratings on a five-point scale of emotional, financial, and physical strain from caregiving. Cronbach's alpha for the strain index was 0.64 for this sample.

Subjects were asked five questions related to the impact of caregiving on their personal lives: personal limitations with family time, restricted privacy, limitations on personal social life, caregiving requires constant attention, and the impact on other relationships. Cronbach's alpha for the impact index was 0.78 for this sample. Scores were summed based on responses to the five questions (ie., 1-serious problem, 3-not a problem).

An interference index consisted of summed scores from five questions: how often caregiving responsibilities interfered with the caregiver's social activities, work or job, time with spouse, time with children, and personal quiet time or rest. Responses to the questions ranged from 1 (most of the time) to 5 (never). Cronbach's alpha for the interference index was 0.40 for this sample.

The Life Satisfaction Index A (Liang, 1984) was included in the questionnaire. Liang (1984) updated a revised version of the Life Satisfaction Index A (LSIA) by Adams (1969), originally developed by Neugarten, Havighurst, and Tobin (1961). A national sample in 1974 of 2,797 persons aged 65 and over was used to analyze the items in the original version of the index. Those items from the original which were lacking face validity or had large amounts of measurement error were excluded, and new items were included by Liang. Liang's version used a two-point scale in which respondents either agreed or disagreed with eleven statements (see Appendix A). A composite score ranging from zero to eleven points was established by the number of matched responses to the scale's norms. Zero points indicate no matches and thus low satisfaction; eleven points indicate a perfect match on all items and thus high satisfaction. Goodness-of-Fit indexes, developed by Joreskog and Sorbom (1981), varied from 0.97 to 0.98, indicating high reliability. Yet Horley (1984) criticizes the LSIA for the narrowness of its agree-disagree items; for a more accurate assessment of subjective well-being such as life satisfaction, he prefers open-ended discussions or clinical observations.

Olson and Wilson's (1982) Family Satisfaction scale is a fourteen-item questionnaire for assessing satisfaction with one's family (see Appendix A). Subjects responded to each item using a five-point scale (1-dissatisfied, 5-extremely satisfied). Responses to all fourteen items were totalled. Of a range from 14 to 70, higher scores indicate higher family satisfaction. A national sample of 2,056 individuals was used to develop norms for the scale. Cronbach's alpha for the authors' scale formed by summing the fourteen items is 0.92. Test-retest Pearson correlation coefficient for their scale is 0.75. The FACES III, acronym for Family Adaptability and Cohesion Evaluation Scales, is an assessment tool designed specifically to assess dimensions of functionality: family cohesion and family adaptability (Olson, et al., 1983). The FACES III, a twenty-item self-

report scale, was developed to overcome the limitations of the original 111-item FACES and thirty-item FACES II. A national sample of 2,453 individuals from "non-problem" families (from young parents with no children to retired persons) was used to develop norms for the scale (Olson, et al., 1983). High levels of reliability (internal consistency and test retest) and validity (content and construct) were found for the FACES III. Cronbach's alpha was 0.68.

There were ten questions each on cohesion and adaptability using a five-point scale for a total of twenty questions. Subjects were asked to rate on a scale from one ("almost never") to five ("almost always") how frequent each of the twenty behaviors occurred in her/his family. Scores from the ten questions on cohesion were summed as were the scores from the adaptability questions.

The use of the cohesion and adaptability sub-scales to assess the two dimensions of functionality was found to be valid for this sample. The correlation between adaptability and cohesion subscales from this study was 0.02, confirming previous findings that the two dimensions (cohesion and adaptability) are independent measures (Olson, et al., 1979). The correlation between adaptability and cohesion subscales from the national sample was 0.03.

Due to the curvilinear relationship of the cohesion and adaptability dimensions, scores from the low and high ends of the possible score range compose the "extreme" classification, while scores from the middle of the score range signify "balanced" classification. Cut-off scores for the cohesion dimension, based on a national sample of 2453 adults (Olson, et al., 1983), are 10-34 and 46-50 for extreme cohesion and 35-45 for balanced cohesion. Similarly, cut-off scores for the adaptability dimension are 10-19 and 29-50 for extreme adaptability and 20-28 for balanced adaptability.

The Circumplex Model allows for families to be placed into one of sixteen groups or one of three more general groups. In this study, caregiving families were classified using the three general groups of extreme, mid-range, and balanced functionality. Extreme functionality signifies dysfunctionality; balanced functionality signifies high functionality. Placement into the three general groups of functionality (e.g., extreme, mid-range, and balanced) is based on the classification of subjects in both the cohesion and adaptability

dimensions. Families scoring as "extreme" on both cohesion and adaptability are classified as having extreme functionality. Families with either extreme cohesion and balanced adaptability or balanced cohesion and extreme adaptability are placed in the "mid-range functionality" category. Balanced functionality placement requires scores from the "balanced" range on both cohesion and adaptability.

3.3 Sampling

The sample consisted of 85 caregivers in the Phoenix metropolitan area (estimated 1985 SMSA population 1.85 million) in which either an elderly parent had moved in with an adult child or with an adult child and his/her children or in which a spouse was providing care for a spouse. The sample was gathered by obtaining names of caregivers from a Phoenix-area non-profit volunteer organization providing free services to the homebound elderly. Participation was on a volunteer basis. Subjects were predominantly white, well-educated, and middle-class. See Table 1 for a summary of demographic characteristics of this sample.

3.4 Descriptive Variables

The subjects in this study participated on a volunteer basis. The selection of subjects was non-random. All but approximately five percent of the caregivers were white. Parental caregivers had an average age of 50.9 years which is similar to parental caregivers in the American Association of Retired Persons and the Travelers Companies Foundation's (1988) study who average 49 years of age; spousal caregivers averaged 67.1 years of age. Seventy-five percent of spousal caregivers were over sixty years old; only seventeen percent of parental caregivers were over sixty years of age. Almost all of the parental caregivers were female (nearly 98 percent) whereas 84 percent of spousal caregivers were female. Over fifty percent of the parental caregivers were married; all of the spousal caregivers were married. Caregivers in this study had higher education levels than other caregivers and elderly persons in the general U.S. population. Spousal caregivers spent an average of 13.1 years in school; the median level of education for all elderly persons was 11.8 years (The American Association of Retired Persons & the Travelers Companies

Foundation, 1988). Parental caregivers had an average education level of 14.2 years compared to parental caregivers in Mindel and Wright's (1982) study who had an average education level of 13.2 years. Over 63 percent of parental caregivers, compared to 42 percent of spousal caregivers, had at least some college or more.

Eighty percent of spousal caregivers were retired or not currently employed, whereas fewer than fifty percent of the parental caregivers reported non-employment. Parental caregivers were seven times more likely to be caring for a female care-receiver; ninety percent of parental caregivers provided care for an elderly female, as compared to only sixteen percent of spousal caregivers. Fifty-seven percent of the care-receivers were severely disabled. Fifty-seven percent of the caregivers had been providing care to the care-receiver for over three years.

An average age of 79.1 years was found for care-receivers of parental caregivers in this study; similar care-receivers in the American Association of Retired Persons and the Travelers Companies Foundation's (1988) study averaged 75 years of age. The average age of spousal care-receivers was 72.0 years of age. Fifty-four percent of parental care-

Table 1. Demographic Characteristics of Caregivers

Demographic characteristics	Spousal (n = 44)	Parental (n = 41)	F-values (ANOVA)	Significance
Sex of caregiver:				
Female (%)	84.1	97.6	$F = 4.66 (1,83)$	$p = 0.05$
Male (%)	15.9	2.4		
Ethnicity:				
White (%)	95.5	97.6	$F = 0.27 (1,83)$	
Other (%)	4.5	2.4		
Marital status:				
Married (%)	100.0	56.1	$F = 33.62 (1,83)$	$p = 0.001$
Not married (%)	0.0	43.9		
Employment:				
Employed (%)	19.5a	53.7	$F = 11.50 (1,80)$	$p = 0.01$
Not employed (%)	80.5	46.3		
Age of caregiver (mean)	67.1	50.9	$F = 56.50 (1,83)$	$p = 0.001$
Years of education (mean)	13.1b	14.2	$F = 4.38 (1,82)$	$p = 0.05$
Sex of care-receiver:				
Female (%)	15.9	87.8	$F = 88.60 (1,83)$	$p = 0.001$
Male (%)	84.1	12.2		

a: n = 41

b: n = 43

receivers were eighty years old or older; only twelve percent of spousal care-receivers were eighty years old or older.

Parental caregivers reported higher income levels than spousal caregivers. Over 47 percent of parental caregivers had a reported annual income level of \$25,000 and above; thirty-two percent of spousal caregivers were receiving similar income levels. Detailed demographic and caregiver variables are included in Appendix B, Table A.

3.5 Procedure

Names and addresses of persons who were currently providing care to an elderly relative or spouse in their households were obtained from a Phoenix, Arizona, metropolitan area volunteer organization. A letter was mailed to all sample caregivers explaining the research purpose and requesting participation. A follow-up phone call was placed to confirm the delivery of the letter and to receive verbal permission to send the questionnaire to their household. If the sample caregiver consented to participate, she/he was told that the questionnaire would be mailed to her/his household.

The questionnaire was mailed within two days of the phone call. A letter, enclosed with the questionnaire explaining the procedures, provided an estimate of testing time, instructed the subjects to answer each question as honestly as possible, assured the subjects' anonymity, and allowed the subjects the right to terminate the survey at any time.

The subjects were given approximately one week to complete the mailed, self-response questionnaires. The primary caregiver in the household filled out the questionnaire. Identification was not required of the subjects; however, a private identification number was placed on the questionnaires for statistical purposes. The questionnaire was mailed back to the researcher upon completion.

3.6 Statistical Analysis Procedure

Results from the questionnaires were analyzed to answer the research questions. The following statistical analyses were utilized for this purposes: averages, Pearson product-moment correlation coefficient, *t*-test, one-factor analysis of variance, and chi-square.

CHAPTER IV

4. RESULTS

4.1 Participation Rate

Of those persons who were contacted by phone, seventy-nine percent agreed to participate (68 of 86 caregivers); sixty-eight percent of those agreeing to participate returned the survey (N = 46). Those who were not contacted by phone were sent an explanatory letter and the questionnaire; the return rate was 55 percent for this group (21 of 38 caregivers). The total percent of questionnaires returned of those mailed to caregivers was 63 percent (67 of 106 caregivers).

An additional eighteen surveys were returned from members of a caregivers' support group to bring the total number of returned questionnaires to 97. Twelve questionnaires were rejected due to incompleteness, leaving a total of 85.

4.2 Hypothesis 1

Hypothesis 1: Spousal caregivers will differ significantly from parental caregivers according to ratings of caregiver variables, life and family satisfaction means, and functionality classification.

Caregiving Variables: Using *t*-test analysis, significant differences between caregiver groups were not found among variables assessing the impact of caregiving, but differences did appear nonetheless (see Appendix B, Table I). Spousal caregivers were slightly less satisfied with the quality of their relationship with the care-receiver, they reported marginally more worry about providing adequate care, and their assessed personal health was nominally poorer than parental caregivers. Parental caregivers were somewhat less satisfied with the current care arrangements. Care-receivers of parental caregivers were slightly more disabled than care-receivers of spousal caregivers.

The probability of placing the care-receiver in a nursing home was found to be

significantly different between caregiver groups. Spousal caregivers were more likely to institutionalize their care-receiver than parental caregivers were ($t(79) = -2.42, p < 0.01$). However, almost 75 percent of all caregivers responded that they would probably not institutionalize the care-receiver within the next year.

Using t -test analysis, non-significant differences between parental and spousal caregiver groups were found for the strain, impact, and interference indexes and for the individual questions comprising each index used in this study (see Appendix B, Table I). On the strain index, caregivers overall reported higher levels of emotional strain than physical strain; financial strain was present but at lower levels than emotional or physical strain. Spousal caregivers reported slightly more emotional, physical, and financial strain and overall strain than parental caregivers.

According to the impact index, caregiving had more of a negative impact on the lives of parental caregivers than spousal caregivers, although the differences between the two groups were not significant. Parental caregivers reported nominally more problems with limits on privacy, time with family, and with other relationships due to caregiving. Spousal caregivers were slightly more likely to report problems with the amount of attention demanded by caregiving and with limits on their social life. Overall, "limits on social life" was ranked first on the impact index as having the most negative effect on the caregiver sample, followed in order by "requirements for constant attention" and "effect on other relationships," "limits on time with family," and "restricted privacy due to caregiving."

Significant differences between the caregiver groups were not found with the interference index. Parental caregivers did, however, report marginally greater amounts of interference than spousal caregivers on four of the five interference index questions as well as the overall interference index score; parental caregivers reported more interference with work or job, time with spouse, time with children, and quiet time or rest than spousal caregivers. Spousal caregivers reported greater interference with social activities than parental caregivers. Overall, "interference with social activities" due to caregiving was ranked first on the interference index as having the most interference on the caregivers, followed in order by "interference with quiet time or rest," "interference with time with

spouse," "interference with time with children," and "interference with work or job."

Life and Family Satisfaction: Although not significantly different from parental caregivers according to *t*-test analysis, spousal caregivers reported lower life satisfaction scores. On a scale from 0 to 11 with higher scores indicating higher satisfaction, the sample had an average life satisfaction score from the Life Satisfaction Index A (Liang, 1984) of slightly more than four (see Appendix B, Table I).

Family satisfaction scores for parental caregivers were lower than for spousal caregivers on the average, however, they were not found to be significantly different, according to *t*-test analysis. The family satisfaction scale (Olson & Wilson, 1982) had a possible range of 14-70 with higher scores indicating higher satisfaction. An average score of less than 38 was found for the sample (see Appendix B, Table I).

Functionality: Comparing spousal and parental caregiver groups, significant differences in terms of functionality ($\chi^2 = 1.76$) and the adaptability dimension ($\chi^2 = 0.40$) were not found. Both spousal and parental caregiver groups were statistically identical on the cohesion dimension, based on a significant chi-square finding of 0.00 ($df = 1, p < 0.05$). Nevertheless, a greater percentage of spousal caregivers than parental caregivers were classified as of balanced or high functionality; a greater percentage of parental caregivers than spousal caregivers were classified as dysfunctional (See Table 2). Forty percent of spousal caregivers were classified as high functionality compared to 25 percent of parental caregivers. However, parental caregivers were more likely to be classified as mid-range functionality; fifty-three percent of parental caregivers and 42 percent of spousal caregivers were of mid-range functionality. Although non-significant, parental caregivers were more likely to be in the balanced adaptability classification than spousal caregivers. Overall, caregivers were almost evenly split between having extreme adaptability or balanced adaptability, yet a greater percentage of spousal caregivers in this study were classified as having extreme adaptability (fifty-five percent compared to 47 percent of the parental caregivers). In terms of the cohesion dimension, sixty percent of caregivers overall were classified as having extreme cohesion levels; forty percent had balanced

cohesion levels.

Table 2. Functionality of Caregiver Groups

Functionality (percentage)				
Type of caregiver	n	Bal.	Mid.	Ext.
Spousal	31	38.7	41.9	19.4
Parental	34	23.5	52.9	23.5
Sample total	65	30.8	47.7	21.5

(note: Bal.=balanced, Mid=mid-range, Ext.=extreme)

4.3 Hypothesis 2

Hypothesis 2: Caregiver subjects will report significantly different levels of family satisfaction and be more dysfunctional than adults in a national norm sample.

Family satisfaction ratings by the sample were significantly lower than those of a national norm (Olson & Wilson, 1982). Significant differences were found between Olson and Wilson's sample of 2,056 individuals and the caregiver sample ($t(66) = -5.94$, $p < 0.001$), spousal caregivers ($t(32) = -3.59$, $p < 0.01$), and parental caregivers ($t(34) = -4.87$, $p < 0.001$) (see Appendix B, Table B). The sample's mean percentile was only seven as compared to Olson and Wilson's norm sample mean percentile of fifty. Seventy percent of the sample had family satisfaction scores of 46 and below (scale range: 0 to 70), which is below the fiftieth percentile of Olson's norm. In fact, almost fifty percent of the sample placed at the first percentile of Olson's norm, with scores of 36 and below.

When comparing caregivers in the sample to a national sample (Olson, et al., 1983), significantly more caregivers were dysfunctional than families in the national sample ($\chi^2 = 10.54$ (df = 2), $p < 0.01$). Twenty-one percent of the caregivers were classified as extreme functionality (dysfunctionality) compared to only eleven percent of the national sample (N = 2,453). Thirty-one percent of the caregivers in this study were of balanced functionality; close to fifty percent of the national sample were of balanced functionality. This finding supports the hypothesis that caregiving families are more likely to be dysfunctional than families from a national norm. Parental caregivers as a group were also significantly different from the national norm ($\chi^2 = 11.48$ (df = 2), $p < 0.01$); however,

spousal caregivers were not significantly more likely to be dysfunctional than the national sample (see Appendix B, Table E).

Examining levels of cohesion, the hypothesis that caregiving families in the sample would be significantly more likely to be classified as of extreme cohesion than families in a national sample ($\chi^2 = 6.06$ (df = 1), $p < 0.02$) was supported (see Appendix B, Table F). Fifty percent of caregiving families in the sample were of balanced cohesion; seventy percent of the national sample families were of balanced cohesion. Significant differences were also found for the adaptability dimension between caregiving families and families from the national sample ($\chi^2 = 23.15$ (df = 1), $p < 0.01$); caregiving families in this study were more likely to be classified as of extreme adaptability (see Appendix B, Table G). Only 39 percent of the caregiving families were of balanced adaptability compared to 67 percent of the families from the national sample.

4.4 Hypothesis 3

Hypothesis 3: Differences in the means of life satisfaction and family satisfaction among levels of functionality will be found.

Analysis of variance statistics revealed a significant relationship between functionality level and life satisfaction ($F = 3.60$, $p < 0.05$), but not between functionality and family satisfaction ($F = 2.87$) (see Appendix B, Table H). Supportive of the hypothesis, balanced functionality caregivers were more likely to report higher life satisfaction than low functional or mid-range functional caregivers; dysfunctional caregivers reported the lowest life satisfaction scores. Nevertheless, caregivers of mid-range functionality had the highest ratings of life satisfaction followed by balanced functional caregivers. Despite non-significant differences, balanced functional caregivers were more likely to report higher family satisfaction than low functional or mid-range caregivers; dysfunctional caregivers had the lowest ratings of family satisfaction.

4.5 Summary

1. Spousal and parental caregivers in this study were not statistically different in

terms of ratings of caregiver variables, life and family satisfaction means, and functionality. "Probability of nursing home placement" of the care-receiver was the only question in which a significant difference was found between both groups; spousal caregivers were more likely to institutionalize the care-receiver.

2. The caregiver sample means for family satisfaction and functionality classifications differed significantly from a national norm. Caregivers in the study reported lower levels of family satisfaction and were more dysfunctional than the national norm sample.

3. Life satisfaction means of the caregiver sample were significantly related to functionality classification; dysfunctionally classified caregivers reported lower life satisfaction scores than more functional caregivers. Family satisfaction means of the caregiver sample were not significantly related to functionality classification.

CHAPTER V

5. DISCUSSION

Discussion of the hypotheses, implications, methodological limitations, recommendations for future research, and conclusions will be presented.

5.1 Hypothesis 1

Hypothesis 1: Spousal caregivers will differ significantly from parental caregivers according to ratings of caregiver variables, life and family satisfaction means, and functionality classification.

Spousal and parental caregivers in this study were not significantly different in terms of ratings of caregiver variables, life and family satisfaction means, and functionality. "Probability of nursing home placement" of the care-receiver was the only question in which a significant difference was found between both groups; spousal caregivers were more likely to institutionalize the care-receiver, which supports earlier findings from researchers Lund and associates (1985) and Montgomery and Borgatta (1989). Parental caregivers may have denied the need to institutionalize their parent or older relative possibly due to feelings of guilt, obligation and duty to parents, or overconfidence in continuing to provide adequate care.

Spousal and parental caregivers were nearly identical in their assessments of personal health, with the spousal caregivers reporting marginally poorer health ratings. Due to non-significance, this finding does not entirely agree with the prediction nor can it be supported by previous research in which spousal caregivers had lower health ratings (Cantor, 1983; George & Gwynter, 1986). While the 38 percent of spousal caregivers in this study who assessed their personal health as fair or poor is comparable to the thirty percent of the elderly population in 1986 (The American Association of Retired Persons, 1987), it is worth noting that parental caregivers (average age: 50.9 years) reported a larger

percentage of similar ratings than persons under age 65 in a national survey (39 percent versus seven percent, respectively) (The American Association of Retired Persons, 1987). Constant caregiving demands, personal time constraints, and role conflict may have placed a toll on the personal health of parental caregivers and spousal caregivers as well.

Significant differences in terms of ratings of the quality of the caregiver's relationship to the care-receiver were not found. Only slightly more spousal caregivers than parental caregivers reported lower ratings for the quality of the relationship, which moderately supports research by Silliman (1986). This finding may have been due to the length of the marital relationship and a comparison of the current relationship to previous years by spousal caregivers. As a result of pressure from caregiving demands and near-constant contact with the care-receiver, past relationship deficits with their parents may have resurfaced with parental caregivers, who then responded to the question accordingly.

Parental caregivers were somewhat less satisfied with the current care arrangements, and spousal caregivers were slightly more worried about providing adequate care than parental caregivers, both as predicted, although both findings were not significant. The approximately 57 percent of parental caregivers who responded "somewhat satisfied" to "very satisfied" with current care arrangements does not support a study by Culfond and associates (1979) in which ninety percent of parental caregivers were satisfied with the living arrangement. Regarding providing adequate care, spousal caregivers may have been concerned about the cost of providing care and their own physical limitations. Nevertheless, to suggest that one group of caregivers would not have equal amounts of concern about the quality of the care they were providing is unfounded. Having doubts and worries about providing adequate care and having some dissatisfaction with the care arrangement would seem to be a commonality of caregiving for all caregivers.

Non-significant results from the strain, impact, and interference indexes suggest that both spousal and parental caregiver groups are almost equally affected negatively by the caregiving situation. General findings from the strain index in this study agree with other research in which emotional strain was rated as highest followed by physical and then financial strain (Christianson & Stephens, 1986; Cantor, 1983; Scharlach & Boyd, 1989). It should be noted that the reliability of the interference index in this study was relatively

low (Cronbach's alpha was 0.40) due to the low percentage of subjects completing the five interference index questions; only 10 of 44 spousal caregivers and 20 of 41 parental caregivers completed each question.

Low ratings for interference with privacy or with social life, for example, may reflect other underlying concerns for the caregiver. Fengler and Goodrich (1979) suggest in their study that when caregiving couples could not continue social activities due to caregiving demands, they experienced feelings of isolation and low morale. The caregiving situation may also create feelings of obligations to remain in the household with the disabled spouse and fear of leaving the disabled spouse alone in the household.

Spousal caregivers had lower life satisfaction scores than parental caregivers, and parental caregivers had lower family satisfaction scores than spousal caregivers. Both findings were in contrast to the prediction and were not statistically significant. Spousal caregivers may have been less satisfied due to the changes in their lifestyles, especially if plans for a relaxed retirement were altered, or perhaps they were more honest in their reflection upon their lives. Also reporting relatively low life satisfaction ratings, parental caregivers may not have been satisfied with the current situation and the interference it created in their lives and families. Evidently, caregiving demands negatively affected life satisfaction scores of both caregiver groups, as an average score of four from a scale of zero to eleven for all caregivers was found. Unfortunately, national norms for Liang's (1984) revised LSIA were not available for comparison nor were life satisfaction scores of caregivers in this study before the onset of caregiving.

Contrary to the prediction that spousal caregivers would report the lowest levels of family satisfaction, parental caregivers had non-significantly lower family satisfaction ratings. Parental caregivers, who were also less satisfied with the current care arrangement than spousal caregivers, may have been less satisfied with how caregiving has affected their lives, resulting in low levels of family satisfaction. Caregivers may have sensed a lack of support from family members and perceived their families as being poorer in quality than the caregivers' "ideal" for their families. Once again, low family satisfaction ratings from both caregiver groups suggest caregiver strain may have been involved.

Although non-significantly different from parental caregivers, spousal caregivers

were generally more balanced functionally, in contrast to the prediction. Parental caregivers were classified as more balanced on the two dimensions, cohesion and adaptability, as predicted, but when the two dimensions were combined in order to classify overall functionality, they had lower functionality levels than spousal caregivers. In other words, parental caregivers were more likely to have one balanced dimension and one extreme dimension, which in turn created a larger mid-range grouping. A significant finding for the cohesion dimension was found ($\chi^2 = 0.00$ (df = 1), $p < 0.05$); there were statistically no differences between spousal and parental caregivers in terms of cohesion level. Overall, spousal and parental caregivers were generally evenly distributed across the three levels of functionality.

In summation, the fact that both caregiver groups responded only marginally differently from each other on caregiver variables, life and family satisfaction, and functionality suggests that perhaps caregivers are somewhat equally impacted by caregiving and may share common concerns, which will be addressed later in this paper.

5.2 Hypothesis 2

Hypothesis 2: Caregiver subjects will report significantly different levels of family satisfaction and be more dysfunctional than adults in a national norm sample.

The caregiver sample means for family satisfaction and functionality classifications differed significantly from national norms. Caregivers in the study reported lower levels of family satisfaction and were more dysfunctional than national norm samples.

The low family satisfaction ratings of the caregivers in this study as compared to a national sample (overall sample mean placed at the seventh percentile of a national norm) (Olson & Wilson, 1982) suggest that caregiving has a strong potential for lowering satisfaction scores. Family satisfaction scores by spousal caregivers were considerably low, although marriage research has shown that in the later years of marriage satisfaction tends to return to its initial level of the early marriage years or becomes greater (Gilford & Bengston, 1979; George, 1980). Furthermore, when a spouse becomes disabled and the other spouse assumes caregiving responsibilities, the reciprocity of the marital relationship

may be disrupted, resulting in decreased satisfaction. Florsheim and Herr (1990) suggest that in a spousal caregiving situation,

"the balance in the marital relationship may be upset by alterations in the affected individual's capacities for self-care and for providing physical and emotional support to his or her spouse. This imbalance in turn may result in the couple having difficulty adjusting to present conditions or may lead to an exacerbation of long-standing dysfunctional behavior patterns within the marital relationship" (p. 40).

The finding that balanced functional caregivers were just as likely to report low life and family satisfaction scores as their counterparts also suggests that the negative impact from caregiving may negate even positive factors such as balanced functionality, satisfaction with care arrangements, and quality of the relationship with the care-receiver.

When the caregiving situation is seen as more of a cost than a benefit, lower satisfaction ratings may result. Mindel and Wright (1982) wrote that

"to the extent that family members are able to maximize rewarding activities and minimize costly ones, the multigenerational household will be felt to be a satisfactory arrangement. If, however, circumstances are mostly punishing (cost producing) and of little reward, then it should be expected that the level of satisfaction in the shared household will be low" (p. 483).

Cantor (1983) suggests that caregiver strain

"is a very emotionally laden factor that appears to transcend the amount of direct involvement in the care of the person. However, the more time and effort the caregiver spends in giving assistance, the more likely a resultant disruption and negative impact on personal life are to occur" (pp. 602-603).

In addition, Hess and Markson (1980) propose that the high levels of care required for the disabled person create psychological costs that lead to a decrease in the level of satisfaction by the caregiver.

Caregiving families in this study were also significantly more dysfunctional than families in a national sample (Olson, et al., 1983). Olson and Wilson (1982) have hypothesized that "if the normative expectations of a couple or family support behaviors on one or both extremes of the circumplex dimensions, they will function well as long as all family members accept these expectations" (p. 43). However, in this study, one member

of the family was interviewed, the primary caregiver. The burden of one person providing the majority of caregiving duties may overcome that person's expectations of how her/his family system should operate, resulting in dissatisfaction with the situation. Other family members may be satisfied with the arrangement only because they have limited responsibilities or are emotionally distanced from the situation.

Interestingly, when separately comparing caregiver groups to the national sample, parental caregivers were significantly more dysfunctional, but spousal caregivers were not significantly more dysfunctional than the national sample. As mentioned previously, parental caregiving families may be more prone to external and internal pressures, such as childrearing and careers, and thus function less efficiently and effectively. When a crisis situation such as caregiving to a parent arises, problems with coping skills by the family unit may be exacerbated. Unfortunately, it is unknown whether functional status changes after the introduction of the caregiving situation into the household.

5.3 Hypothesis 3

Hypothesis 3: Differences in the means of life satisfaction and family satisfaction among levels of functionality will be found.

Life satisfaction means of the caregiver sample were significantly related to functionality classification; dysfunctionally classified caregivers reported lower life satisfaction scores than more functional caregivers. Family satisfaction means of the caregiver sample were not significantly related to functionality classification.

Functionality is a means of describing how the family unit adequately responds to and copes with crises. Dysfunctional households may already be at a disadvantage when the caregiving element is introduced. The responsibilities of caregiving and subsequent strain place increasing demands on the family unit. Therefore, satisfaction ratings would be expected to be low if the family unit has difficulties in handling the caregiving element. A dysfunctional caregiver, for example, may be overwhelmed by caregiving demands and thus report lower life satisfaction scores. On the other hand, family satisfaction, which involves comparing perceived conditions with "ideal" conditions, appears to transcend

functional status. A caregiver of balanced functionality may not be satisfied with the family unit, perhaps due to the impact of the caregiving situation. Likewise, a dysfunctional caregiver may be comfortable with crisis situations and satisfied with her/his family.

5.4 Methodological Limitations

Due to the nature of the research, limited resources, and difficulty in locating subjects, the utilization of random sampling was not feasible, which in turn reduced external validity. A modest percentage of subjects fully completed the questionnaire, which could affect internal validity. Differences between caregiver groups with respect to demographic variables should be viewed with caution as the sample was not representative of the general population. Subjects were predominantly white and well-educated. The presence of a disabled spouse in a spousal caregiver household: will probably affect the marital relationship negatively. The potential for non-reciprocity in this situation may affect family satisfaction and functionality. The question of whether the couple be functional if only one partner is contributing may arise. Interestingly, spousal caregivers were slightly more balanced functionally than parental caregivers.

FACES III was designed to assess family functionality for all family members. Olson (1985) warned that differences frequently appear across family members when using self-report scales, and he suggested that all family members complete the FACES III survey to more accurately assess functionality. In this study only one member, the caregiver, filled out the questionnaire which may have resulted in questionable validity.

5.5 Implications

While this study found few significant differences between caregiver groups, it should be noted that the sample was non-representative of the general population. Being predominantly white and well-educated, the sample may be significantly different from ethnic groups and lower socioeconomic classes, which tend to have strong kin ties and family traditions and encourage multigenerational living. Mindel and Wright (1982) believe that ethnic households in which an elderly relative is a coresident would not be as problematic as in white middle-class households. Unfortunately this hypothesis has not be

investigated.

Due to the small sample size ($N = 13$), data from parental caregivers with children were not analyzed statistically for significance in this study. Some differences did appear, however, when comparing parental caregivers in multigenerational households to other parental caregivers and to spousal caregivers. Parental caregivers in multigenerational households were younger than the other groups; their average age was 47.0 years of age compared to 52.6 years for other parental caregivers. Of all caregiver groups, parental caregivers in multigenerational households were more likely to be employed, less likely to institutionalize the care-receiver, and reported lower financial strain, lower physical strain, less interference with quiet time or rest, and lower interference with social activities. They also reported more interference with time with children, more interference with family time, more problems with the demands of attention, more interference with other relationships, and lower family satisfaction. Implications of these findings could be considered for future research.

As the number of caregiving households increases in the next forty years according to government predictions, the need for counseling services will likely increase. Specific issues such as stress reduction, coping skills, education, time management, guilt issues, grief/loss, unresolved family issues, management of multiple roles, and role conflict are likely to become more important (Ganote, 1990). Other issues concerning caregiving decisions may also appear, such as

"feelings of guilt, grief connected with the loss of the elder family member's health, disparate investments and interests in the caregiving arrangements of elders, scarce resources for elder caregiving that demand commitment and substantial sacrifice from family members, limited experience with joint decision making, and the rejuvenation of old conflictual family dynamics"

(Parsons & Cox, 1989, p. 122). Through counseling, the implications and problems involved with caring for a disabled spouse and symptoms such as anxiety, psychosomatic illnesses, depression, and physical ailments may be alleviated (Chodorkoff, 1990; Ganote, 1990). Grief counseling and therapy, respite care, family support, support groups, and other counseling techniques help to minimize the emotional cost to the caregiver. The

ability to handle the stress of caregiving will depend upon the caregiver's perception of the situation, her/his ability to be in control, and her/his awareness of the problem. Counselors may also recommend and encourage outside interests and social activities to act as healthy distractors to caregiving.

Support groups and individual counseling can provide additional emotional and informational support to caregivers (Crossman, London, & Barry, 1981). Through group and individual counseling, the caregiver can receive advice, encouragement, emotional support, permission to express feelings, a listening and understanding ear, and a sense of not being alone. Studies have shown that support groups have a positive effect in reducing caregiver burden and depression (Kahah, 1985). Toseland and Rossiter (1989) recommend support groups for specific types of caregivers. Researchers Toseland, Rossiter, Peak, and Smith (1990) compared the effectiveness of group and individual counseling to parental caregivers and concluded that

"both individual and group interventions help caregivers improve their ability to cope with the stresses of caregiving. The data also suggest that the type of intervention that is most appropriate for a particular caregiver might be determined by the types of problems and issues that the caregiver needs to address. Individual interventions appear to be more appropriate when psychological issues are most prominent. Group interventions are more appropriate when issues of social support are most prominent" (p. 216).

Although no major differences were found among caregiver groups in this study, the dynamic differences between these groups may support the need for specific types of counseling interventions.

Several themes tend to appear in caregiver support groups as mentioned by several research articles: caregiver pride (e.g., pride in doing the best possible job with a difficult situation), the need for validation, the need for information, social network issues (e.g., family acceptance of the situation, family support), concern with physical care, family organization (e.g., responsibilities and expectations), support networks beyond family support, feelings, learning new activities such as developing new strategies for coping with the patient's behavior, and making decisions and new adaptations (Davies, Priddy, & Tinklenberg, 1986; Aronson, Levin, & Lipkowitz, 1984).

Respite care has been shown to reduce caregiver burden mostly by allowing the caregiver to spend some time by her/himself without the obligation of caregiving, if only for a brief period of time (Miller, Gulle, & McCue, 1986). Florsheim and Herr (1990) write that a "lack of respite can in turn result in middle-aged children feeling exhausted and resentful about the limitations their caregiver status has placed on their lives" (p. 41). Researchers Caserta, Lund, and Wright (1987) noted in their study of 597 family caregivers to non-institutionalized dementia patients that respite-oriented services were perceived as most needed and utilized the most by caregivers.

Finally, an understanding of the caregiving situation by public policy makers and legislators is necessary. Is caregiving in the household a preventative measure against institutionalization? Should caregivers be given tax credit for caring? Social security reform with credits for caregiving is currently being proposed by national legislators (Glasse & Leonard, 1988). Should places of employment provide elder care services or time off from work? Parental caregivers want to keep the parents in the home; they do not want them to reside in nursing homes, which can create severe financial restrictions.

5.6 Recommendations for Future Research

Counseling intervention programs for specific caregiving groups, such as spousal caregivers and parental caregivers might be approached in future research. Counselors could address issues specific to caregivers of each group, such as marital relationship change in spousal caregiver households. Stroke patients and their spouses could be questioned before and after the disability. How does the spousal caregiver feel about the marriage in the current situation as compared to earlier years of marriage, for example? Was the marriage adversely affected by caregiving and the situation? Finally, is reciprocity in the marital relationship absent or unbalanced?

Family dynamics in the multigenerational household are likely to be complex. Scott's (1986) study of families of Alzheimer's disease victims found that the coping effectiveness of the caregiver was related to family support and that caregivers who did not receive enough support from families were most burdened. Therefore, the opinions of all family members in the multigenerational household should be sought by researchers. Low

family satisfaction may be reported by children and spouses of the parental caregivers, especially if they (i.e., the caregiver's child or the caregiver's spouse) are experiencing difficulties with lack of privacy, lack of attention from the caregiver, or inconveniences in the living arrangement. Research questions to investigate would be: how caregiving has affected their lives and relationships with other family members; are the family members resentful of the time constraints on the caregiver; and do the family members understand the situation and are they supportive?

5.7 Conclusions

The spousal and parental caregivers in this study were not statistically different for numerous variables. However, both parental and spousal caregivers appear to be negatively affected by the caregiving situation. A comparison of this study's results to other research findings would be inconclusive as both similarities and differences between caregiver groups has been previously reported (Cantor, 1983; George & Gwynter, 1986; Young & Kahana, 1989; Montgomery & Borgatta, 1989).

The significant differences of the sample to the national population in regards to family satisfaction and functionality is disturbing; the mean family satisfaction score of caregivers placed them at the seventh percentile of a national sample, and the caregivers were markedly more dysfunctional than a national sample of adults. These findings should be a cause for concern to counselors, social workers, public policy makers, and the general population. Social services such as counseling, support groups, and respite care may be the best solutions to alleviate the burden of caregiving.

APPENDIX A**PARENTAL CAREGIVER QUESTIONNAIRE**

Dear Caregiver:

Thank you for agreeing to participate in the following survey. The Caregiver Survey was designed to assist families who are concerned about or caring for an older relative.

As a first step in identifying how social agencies can help reduce the stress related to caregiving, I am asking that you complete the attached anonymous, confidential survey. The survey should be completed at your convenience and returned in the enclosed envelope by _____.

Once again, your participation is voluntary and your responses will remain confidential and anonymous.

Your cooperation in this survey is greatly appreciated. With your help, I hope to provide other caregivers like yourself with helpful information about caregiving.

Sincerely,

Leif Swanson
Graduate Student
Family Studies Department
School of Family and Consumer Resources
University of Arizona

CAREGIVER SURVEY

To be completed by the primary caregiver in the household.

The questions in this survey ask about your caregiving responsibilities -- that is, any activities you do in order to take care or provide care for an older relative. In addition, there are questions about how caregiving has affected your life and family. Your answers will be kept in the *strictest confidence* and will be used for *statistical purposes only*. So please be honest and candid with your responses.

You may withdraw from this study at any time. However, if the questionnaire is completed and returned it will be assumed that consent has been given.

Please mark the appropriate response to each question.

The survey should require approximately thirty minutes of your time.

1. First, what age group do you fall into?

- (1) 40 years or younger
- (2) 41- 50 years
- (3) 51- 60 years
- (4) more than 60 years

2. What is your marital status?

- (1) Single
- (2) Married
- (3) Widowed
- (4) Divorced/Separated

3. And are you...

- (1) Female
- (2) Male

4. What is your ethnic background?

- (1) White
- (2) Black
- (3) Hispanic
- (4) Other

5. Education completed:

- (1) No formal education
- (2) Elementary education
- (3) Some high school
- (4) High school
- (5) Some post-high school
- (6) College
- (7) Post-college

- 6. What is your family's annual income level?**
- (1) Less than \$15,000 a year
 (2) \$15,000-\$24,999 a year
 (3) \$25,000-\$34,999 a year
 (4) More than \$35,000 a year
- 7. How many children do you have living at home who are... (Please circle the appropriate number or numbers)**
- (1) Number of children under age 10..... 1 2 3 4+
 (2) Number of children 10-18 years old..... 1 2 3 4+
 (3) Number of children 19 or older.....1 2 3 4+
- 8. If others, besides children, live with you, please indicate below which people live with you. (Check *all that apply*)**
- (1) Spouse (5) Mother-in-law
 (2) Father (6) Aunt or uncle
 (3) Mother (7) Another relative
 (4) Father-in-law (8) Other
- 9. How many persons *aged 50 or older* do you have caregiving responsibilities for?**
- (1) One (2) Two (3) Three or more
- 10. During the *past 6 months* , have you suffered from any of the following? (Please *check all that apply*)**
- (1) Frequent headaches (5) Unusual drowsiness
 (2) Weight gain or loss (6) Inability to sleep
 (3) Skin disorders (7) Other (specify)
 (4) Nervousness _____
- 11. Overall, how would you assess your own health?**
- (1) Excellent
 (2) Good
 (3) Fair
 (4) Poor
- 12. Please indicate your employment status:**
- (1) Currently employed
 (2) Employed within past year, but not currently employed
 (3) Not currently employed
 (4) Not employed within past year

13. If you are currently employed or were employed within the past year, how many days (if any) have you lost from work during the past 6 months for the following reasons. (Enter the number of days for each reason)

- (1) Illness(es) _____ days
 (2) Family emergencies _____ days
 (3) Crisis/emergency with person _____ days
 (4) Lack of sleep _____ days
 (5) On-the-job accident _____ days
 (6) Other (specify) _____ days
 (7) _____ Check if *no* days lost in past 6 months

14. When were you *last* able to take a vacation that allowed you some time away from your caregiving responsibilities ? (Please check only one)

- (1) Less than 6 months ago
 (2) Between 6-12 months ago
 (3) Between 13 months and 2 years ago
 (4) More than 2 years ago

If you care for more than one person, please report on the *one person* for whom you provide the *most* care in answering the remaining questions in this survey.

15. Person's sex:

- (1) Female (2) Male

16. Person's age:

- (1) Less than 60 years
 (2) 60-70 years
 (3) 71-75 years
 (4) 76-80 years
 (5) More than 80 years

17. Relation to you:

- (1) Mother (4) Father-in-law
 (2) Father (5) Aunt or Uncle
 (3) Mother-in-law (6) Other

18. How long have you been caring for the person?

- (1) 0-6 months (3) 1-3 years
 (2) 6 months-one year (4) more than 3 years

19. Did any of the following events happen to the person to cause the need for you to provide care for him or her? (Check *all that apply*)

- (1) Major illness/injury
- (2) Progressive health deterioration
- (3) Hospitalization
- (4) Death of spouse
- (5) Financial restrictions
- (6) Retirement
- (7) Other (specify) _____

20. Currently, how many medical problems are experienced by the person you are caring for? (For example, stroke, glaucoma, high blood pressure, heart problems, cancer, diabetes, memory loss, sleep disorders, Alzheimer's disease, arthritis, incontinence, blindness, depression, etc.)

Behavior of the person you are caring for:

21. Person's behavior is embarrassing

- (1) Frequently embarrassing
- (2) Sometimes embarrassing
- (3) Behavior not embarrassing

22. Person gets angry or is uncooperative

- (1) Frequently becomes upset and yells or refuses to cooperate
- (2) Sometimes becomes upset and yells or refuses to cooperate
- (3) Not angry or uncooperative

23. Person is forgetful or confused

- (1) Frequently forgets things or gets confused -- a serious problem
- (2) Sometimes forgets things or gets confused -- not a serious problem
- (3) Not forgetful or confused

24. Frequency of sleep interruptions to give care

- (1) More than 7 times a week
- (2) 2 to 6 times a week
- (3) Less than twice a week
- (4) None at all

25. How many hours per week do the following people spend in providing care for the person you are caring for?

- (1) You..... _____ hrs
- (2) Others living within your household... _____ hrs
- (3) Others living outside your household... _____ hrs
- (4) Paid outside help..... _____ hrs

26. For *each of the categories of activities below* , please indicate how often your caregiving responsibilities interfere with these activities:

	Most of the time	Often	Some- times	Seldom	Never
	(1)	(2)	(3)	(4)	(5)
(1) Social activities outside the home	_____	_____	_____	_____	_____
(2) Work or job	_____	_____	_____	_____	_____
(3) Time with spouse	_____	_____	_____	_____	_____
(4) Time with children	_____	_____	_____	_____	_____
(5) Quiet time or rest	_____	_____	_____	_____	_____

27. Other than help provided by you or another family member, does the person receive help from an *outside source* ?

- (1) Yes (2) No (If 'No,' go to question 29)

28. If 'Yes' above, which of the following kinds of help does the person receive? (Check *all that apply*)

Outside help used for:

- (1) Personal care
 (2) Companion services
 (3) Nursing services/therapy
 (4) Counseling
 (5) Adult day care
 (6) Transportation
 (7) Telephone monitoring or reassurance
 (8) Other (specify) _____

29. Are you satisfied with the current care arrangements?

- (1) Very satisfied
 (2) Somewhat satisfied
 (3) Not too satisfied

30. Do you or do you not need *additional assistance* in order to continue providing care to the person? (Please *check only one*)

- (1) I do *not* need assistance, I can continue to provide care
 (2) I need *some assistance* , but generally I can do it myself
 (3) I need *considerable* assistance in order to continue
 (4) Even *with* assistance, I may not be able to continue

31. Do you worry about providing sufficient help for the person?

- (1) Quite a lot
 (2) Sometimes
 (3) Rarely
 (4) Not at all

32. How would you rate your relationship with the person?

- (1) We get along very well
 (2) We get along fairly well
 (3) We do not get along well

Personal limitations imposed by caregiving:**33. Limits on time with family**

- (1) Serious problem
 (2) A problem, but not serious
 (3) Not a problem

34. Restricted privacy due to caregiving

- (1) Serious problem
 (2) A problem, but not serious
 (3) Not a problem

35. Limits on social life due to caregiving

- (1) Serious problem
 (2) A problem, but not serious
 (3) Not a problem

36. Caregiving requires constant attention

- (1) Serious problem
 (2) A problem, but not serious
 (3) Not a problem

37. Caregiving hard on other relationships

- (1) Serious problem
 (2) A problem, but not serious
 (3) Not a problem

38. What is the probability of placing the person in a nursing home within the next year?

- (1) Certainly will be placed in nursing home
 (2) Probably will
 (3) Even chance
 (4) Probably will not
 (5) Certainly will not

39. How would you assess your strain from caregiving?

Little or none <-----> A great deal

- | | 1 | 2 | 3 | 4 | 5 |
|----------------------|-------|-------|-------|-------|-------|
| (1) Emotional strain | _____ | _____ | _____ | _____ | _____ |
| (2) Financial strain | _____ | _____ | _____ | _____ | _____ |
| (3) Physical strain | _____ | _____ | _____ | _____ | _____ |

Please assess the person's level of functioning and impairment in the following activities of daily living. (Please answer *all* items)

RESPONSE SCALE				
1	2	3	4	5
NONE	MILD	MODERATELY SEVERE	VERY SEVERE	EXTREMELY SEVERE

PERSON NEEDS HELP/ASSISTANCE WITH:

40. Eating, excluding cutting meat or buttering bread
 41. Getting out of bed or a chair
 42. Dressing or changing clothes
 43. Bathing in a tub or shower, at a sink or basin, or in bed, including getting in and out of the tub or shower
 44. Getting to or using the toilet, including helping with a bedside commode, catheter, colostomy bag, or diapers
 45. Cleaning up after bladder or bowel accidents
 46. Taking medications or giving injections
 47. Fixing meals or preparing special meals
 48. Doing laundry or day-to-day housework
 49. Shopping for food, clothing, medications, or other items
 50. Managing the person's finances, by writing checks or paying bills, but not including providing direct financial support
 51. Using the telephone
 52. Travelling, including leaving the house

53. Does the person have any cognitive or behavioral difficulties, such as forgetfulness, that affect his/her ability to perform any of the activities mentioned above in questions 40-52?

- (1) Yes, frequently
 (2) Yes, occasionally
 (3) No

54. What other kinds of help do you provide to the person? (Check *all* that apply)

- (1) Direct financial support
 (2) Assist with physical, occupational, or speech therapy, including supervision of exercises
 (3) Help with other medical treatments such as giving oxygen or changing bandages
 (3) Supervise for personal safety to prevent falls and injuries
 (4) Provide companionship
 (5) Arrange/coordinate outside help for person
 (6) Other (specify) _____

Please be open and candid in responding to the following statements:

55. I am just as happy as when I was younger
(1) Agree
(2) Disagree
56. My life could be happier than it is now
(1) Agree
(2) Disagree
57. These are the best years of my life
(1) Agree
(2) Disagree
58. I expect some interesting and pleasant things to happen to me in the future
(1) Agree
(2) Disagree
59. The things I do are as interesting to me as they ever were
(1) Agree
(2) Disagree
60. I feel old and sometimes tired
(1) Agree
(2) Disagree
61. Most of the things I do are boring or monotonous
(1) Agree
(2) Disagree
62. As I look on my life, I am fairly well satisfied
(1) Agree
(2) Disagree
63. I would not change my past life even if I could
(1) Agree
(2) Disagree
64. I have gotten pretty much what I expected out of life
(1) Agree
(2) Disagree
65. I have gotten more of the breaks in life than most of the people I know
(1) Agree
(2) Disagree

RESPONSE SCALE

1	2	3	4	5
ALMOST NEVER	ONCE IN AWHILE	SOMETIMES	FREQUENTLY	ALMOST ALWAYS

DESCRIBE YOUR FAMILY NOW:

- _____ 66. Family members ask each other for help.
- _____ 67. In solving problems, the other family members' suggestions are followed.
- _____ 68. We approve of each other's friends.
- _____ 69. Children have a say in their discipline.
- _____ 70. We like to do things with just our immediate family.
- _____ 71. Different persons act as leaders in our family.
- _____ 72. Family members feel closer to other family members than to people outside the family.
- _____ 73. Our family changes its way of handling tasks.
- _____ 74. Family members like to spend free time with each other.
- _____ 75. Parent(s) and children discuss punishment together.
- _____ 76. Family members feel very close to each other.
- _____ 77. The children make the decisions in our family.
- _____ 78. When our family gets together for activities, everybody is present.
- _____ 79. Rules change in our family.
- _____ 80. We can easily think of things to do together as a family.
- _____ 81. We shift household responsibilities from person to person.
- _____ 82. Family members consult other family members on their decisions.
- _____ 83. It is hard to identify the leader(s) in our family.
- _____ 84. Family togetherness is very important.
- _____ 85. It is hard to tell who does which household chores.

RESPONSE SCALE

1	2	3	4	5
DISSATISFIED	SOMEWHAT DISSATISFIED	GENERALLY SATISFIED	VERY SATISFIED	EXTREMELY SATISFIED

HOW SATISFIED ARE YOU:

- _____ 86. With how close you feel to the rest of your family?
 - _____ 87. With your ability to say what you want in your family?
 - _____ 88. With your family's ability to try new things?
 - _____ 89. With how often other family members make decisions in your family?
 - _____ 90. With how much other family members argue with each other?
 - _____ 91. With how fair the criticism is in your family?
 - _____ 92. With the amount of time you spend with your family?
 - _____ 93. With the way you talk together to solve family problems?
 - _____ 94. With your freedom to be alone when you want to?
 - _____ 95. With how strictly you stay with who does what chores in your family?
 - _____ 96. With your family's acceptance of your friends?
 - _____ 97. With how clear it is what your family expects of you?
 - _____ 98. With how often you make decisions as a family, rather than individually?
 - _____ 99. With the number of fun things your family does together?
-

SPOUSAL CAREGIVER QUESTIONNAIRE

Dear Caregiver:

Thank you for agreeing to participate in the following survey. The Caregiver Survey was designed to assist families who are concerned about or caring for a spouse.

As a first step in identifying how social agencies can help reduce the stress related to caregiving, I am asking that you complete the attached anonymous, confidential survey. The survey should be completed at your convenience and returned in the enclosed envelope by _____.

Once again, your participation is voluntary and your responses will remain confidential and anonymous.

Your cooperation in this survey is greatly appreciated. With your help, I hope to provide other caregivers like yourself with helpful information about caregiving.

Sincerely,

Leif Swanson
Graduate Student
Family Studies Department
School of Family and Consumer Resources
University of Arizona

CAREGIVER SURVEY

To be completed by the primary caregiver in the household.

The questions in this survey ask about your caregiving responsibilities -- that is, any activities you do in order to take care or provide care for a spouse. In addition, there are questions about how caregiving has affected your life and family. Your answers will be kept in the *strictest confidence* and will be used for *statistical purposes only*. So please be honest and candid with your responses.

You may withdraw from this study at any time. However, if the questionnaire is completed and returned it will be assumed that consent has been given.

Please mark the appropriate response to each question.

The survey should require approximately thirty minutes of your time.

1. First, what age group do you fall into?
 - (1) 40 years or younger
 - (2) 41- 50 years
 - (3) 51- 60 years
 - (4) 61-70 years
 - (5) more than 70 years

2. What is your marital status?
 - (1) Single
 - (2) Married
 - (3) Widowed
 - (4) Divorced/Separated

3. And are you...
 - (1) Female
 - (2) Male

4. What is your ethnic background?
 - (1) White
 - (2) Black
 - (3) Hispanic
 - (4) Other

5. Education completed:
 - (1) No formal education
 - (2) Elementary education
 - (3) Some high school
 - (4) High school
 - (5) Some post-high school
 - (6) College
 - (7) Post-college

6. What is your family's annual income level?
 - (1) Less than \$15,000 a year
 - (2) \$15,000-\$24,999 a year
 - (3) \$25,000-\$34,999 a year
 - (4) More than \$35,000 a year

7. How many children do you have living at home who are... (Please circle the appropriate number or numbers)
 - (1) Number of children under age 10.... 0 1 2 3+
 - (2) Number of children 10-18 years old. 0 1 2 3+
 - (3) Number of children 19 or older..... 0 1 2 3+

8. If others, besides children, live with you, please indicate below which people live with you. (Check *all that apply*)

- | | |
|--|---|
| (1) <input type="checkbox"/> Spouse | (5) <input type="checkbox"/> Mother-in-law |
| (2) <input type="checkbox"/> Father | (6) <input type="checkbox"/> Aunt or uncle |
| (3) <input type="checkbox"/> Mother | (7) <input type="checkbox"/> Another relative |
| (4) <input type="checkbox"/> Father-in-law | (8) <input type="checkbox"/> Other |

9. How many persons aged 50 or older do you have caregiving responsibilities for?

- (1) One (2) Two (3) Three or more

10. During the *past 6 months* , have you suffered from any of the following? (Please *check all that apply*)

- | | |
|--|---|
| (1) <input type="checkbox"/> Frequent headaches | (5) <input type="checkbox"/> Unusual drowsiness |
| (2) <input type="checkbox"/> Weight gain or loss | (6) <input type="checkbox"/> Inability to sleep |
| (3) <input type="checkbox"/> Skin disorders | (7) <input type="checkbox"/> Other (specify) |
| (4) <input type="checkbox"/> Nervousness | _____ |

11. Overall, how would you assess your own health?

- (1) Excellent
 (2) Good
 (3) Fair
 (4) Poor

12. Please indicate your employment status:

- (1) Currently employed
 (2) Employed within past year, but not currently employed
 (3) Not currently employed
 (4) Not employed within past year

13. If you are currently employed or were employed within the past year, how many days (if any) have you lost from work *during the past 6 months* for the following reasons. (Enter the *number of days for each reason*)

- (1) Illness(es) _____ days
 (2) Family emergencies _____ days
 (3) Crisis/emergency with person _____ days
 (4) Lack of sleep _____ days
 (5) On-the-job accident _____ days
 (6) Other (specify) _____ days
 (7) _____ Check if *no* days lost in past 6 months

14. When were you *last* able to take a vacation that allowed you some time away from your caregiving responsibilities ? (Please *check only one*)

- (1) Less than 6 months ago
 (2) Between 6-12 months ago
 (3) Between 13 months and 2 years ago
 (4) More than 2 years ago

If you care for more than one person, please report on the *one person* for whom you provide the *most* care in answering the remaining questions in this survey.

15. Person's sex:

- (1) Female (2) Male

16. Person's age:

- (1) Less than 60 years
 (2) 60-70 years
 (3) 71-75 years
 (4) 76-80 years
 (5) More than 80 years

17. Relation to you:

- (1) Husband (2) Wife

18. How long have you been caring for the person?

- (1) 0-6 months (3) 1-3 years
 (2) 6 months-one year (4) more than 3 years

19. Did any of the following events happen to the person to cause the need for you to provide care for him or her? (Check *all that apply*)

- (1) Major illness/injury
 (2) Progressive health deterioration
 (3) Hospitalization
 (4) Death of spouse
 (5) Financial restrictions
 (6) Retirement
 (7) Other (specify) _____

20. Currently, how many medical problems are experienced by the person you are caring for? (For example, stroke, glaucoma, high blood pressure, heart problems, cancer, diabetes, memory loss, sleep disorders, Alzheimer's disease, arthritis, incontinence, blindness, depression, etc.)

Behavior of the person you are caring for:

21. Person's behavior is embarrassing

- (1) Frequently embarrassing
 (2) Sometimes embarrassing
 (3) Behavior not embarrassing

22. Person gets angry or is uncooperative

- (1) Frequently becomes upset and yells or refuses to cooperate
 (2) Sometimes becomes upset and yells or refuses to cooperate
 (3) Not angry or uncooperative

23. Person is forgetful or confused

- (1) Frequently forgets things or gets confused -- a serious problem
 (2) Sometimes forgets things or gets confused -- not a serious problem
 (3) Not forgetful or confused

24. Frequency of sleep interruptions to give care

- (1) More than 7 times a week
 (2) 2 to 6 times a week
 (3) Less than twice a week
 (4) None at all

25. How many hours per week do the following people spend in providing care for the person you are caring for?

- (1) You _____ hrs
 (2) Others living within your household _____ hrs
 (3) Others living outside your household _____ hrs
 (4) Paid outside help _____ hrs

26. For each of the categories of activities below, please indicate how often your caregiving responsibilities interfere with these activities:

- | | Most of
the time
(1) | Often
(2) | Some-
times
(3) | Seldom
(4) | Never
(5) |
|---|----------------------------|--------------|-----------------------|---------------|--------------|
| (1) Social activities
outside the home | _____ | _____ | _____ | _____ | _____ |
| (2) Work or job | _____ | _____ | _____ | _____ | _____ |
| (3) Time with spouse | _____ | _____ | _____ | _____ | _____ |
| (4) Time with children | _____ | _____ | _____ | _____ | _____ |
| (5) Quiet time or rest | _____ | _____ | _____ | _____ | _____ |

27. Other than help provided by you or another family member, does the person receive help from an outside source?

- (1) Yes (2) No (If 'No,' go to question 29)

28. If 'Yes' above, which of the following kinds of help does the person receive? (Check all that apply)

Outside help used for:

- (1) Personal care
 (2) Companion services
 (3) Nursing services/therapy
 (4) Counseling
 (5) Adult day care
 (6) Transportation
 (7) Telephone monitoring or reassurance
 (8) Other (specify) _____

29. Are you satisfied with the current care arrangements?
 (1) Very satisfied
 (2) Somewhat satisfied
 (3) Not too satisfied
30. Do you or do you not need *additional assistance* in order to continue providing care to the person? (Please *check only one*)
 (1) I do *not* need assistance, I can continue to provide care
 (2) I need *some assistance* , but generally I can do it myself
 (3) I need *considerable* assistance in order to continue
 (4) Even *with* assistance, I may not be able to continue
31. Do you worry about providing sufficient help for the person?
 (1) Quite a lot
 (2) Sometimes
 (3) Rarely
 (4) Not at all
32. How would you rate your relationship with the person?
 (1) We get along very well
 (2) We get along fairly well
 (3) We do not get along well

Personal limitations imposed by caregiving:

33. Limits on time with family
 (1) Serious problem
 (2) A problem, but not serious
 (3) Not a problem
34. Restricted privacy due to caregiving
 (1) Serious problem
 (2) A problem, but not serious
 (3) Not a problem
35. Limits on social life due to caregiving
 (1) Serious problem
 (2) A problem, but not serious
 (3) Not a problem
36. Caregiving requires constant attention
 (1) Serious problem
 (2) A problem, but not serious
 (3) Not a problem
37. Caregiving hard on other relationships
 (1) Serious problem
 (2) A problem, but not serious
 (3) Not a problem

38. What is the probability of placing the person in a nursing home within the next year?

- (1) Certainly will be placed in nursing home
 (2) Probably will
 (3) Even chance
 (4) Probably will not
 (5) Certainly will not

39. How would you assess your strain from caregiving?

Little or none <-----> A great deal

- | | 1 | 2 | 3 | 4 | 5 |
|----------------------|-------|-------|-------|-------|-------|
| (1) Emotional strain | _____ | _____ | _____ | _____ | _____ |
| (2) Financial strain | _____ | _____ | _____ | _____ | _____ |
| (3) Physical strain | _____ | _____ | _____ | _____ | _____ |

Please assess the person's level of functioning and impairment in the following activities of daily living. (Please answer *all* items)

RESPONSE SCALE

1	2	3	4	5
NONE	MILD	MODERATELY SEVERE	VERY SEVERE	EXTREMELY SEVERE

PERSON NEEDS HELP/ASSISTANCE WITH:

- _____ 40. Eating, excluding cutting meat or buttering bread
 _____ 41. Getting out of bed or a chair
 _____ 42. Dressing or changing clothes
 _____ 43. Bathing in a tub or shower, at a sink or basin, or in bed, including getting in and out of the tub or shower
 _____ 44. Getting to or using the toilet, including helping with a bedside commode, catheter, colostomy bag, or diapers
 _____ 45. Cleaning up after bladder or bowel accidents
 _____ 46. Taking medications or giving injections
 _____ 47. Fixing meals or preparing special meals
 _____ 48. Doing laundry or day-to-day housework
 _____ 49. Shopping for food, clothing, medications, or other items
 _____ 50. Managing the person's finances, by writing checks or paying bills, but not including providing direct financial support
 _____ 51. Using the telephone
 _____ 52. Travelling, including leaving the house

53. Does the person have any cognitive or behavioral difficulties, such as forgetfulness, that affect his/her ability to perform any of the activities mentioned above in questions 40-52?

- (1) Yes, frequently
 (2) Yes, occasionally
 (3) No

54. What other kinds of help do you provide to the person? (Check *all* that apply)

- (1) Direct financial support
 (2) Assist with physical, occupational, or speech therapy, including supervision of exercises
 (3) Help with other medical treatments such as giving oxygen or changing bandages
 (3) Supervise for personal safety to prevent falls and injuries
 (4) Provide companionship
 (5) Arrange/coordinate outside help for person
 (6) Other (specify) _____

Please be open and candid in responding to the following statements:

55. I am just as happy as when I was younger

- (1) Agree
 (2) Disagree

56. My life could be happier than it is now

- (1) Agree
 (2) Disagree

57. These are the best years of my life

- (1) Agree
 (2) Disagree

58. I expect some interesting and pleasant things to happen to me in the future

- (1) Agree
 (2) Disagree

59. The things I do are as interesting to me as they ever were

- (1) Agree
 (2) Disagree

60. I feel old and sometimes tired

- (1) Agree
 (2) Disagree

61. Most of the things I do are boring or monotonous

- (1) Agree
 (2) Disagree

62. As I look on my life, I am fairly well satisfied

- (1) Agree
 (2) Disagree

63. I would not change my past life even if I could

- (1) Agree
 (2) Disagree

64. I have gotten pretty much what I expected out of life
 (1) Agree
 (2) Disagree
65. I have gotten more of the breaks in life than most of the people I know
 (1) Agree
 (2) Disagree

RESPONSE SCALE

1	2	3	4	5
ALMOST NEVER	ONCE IN AWHILE	SOMETIMES	FREQUENTLY	ALMOST ALWAYS

DESCRIBE YOUR MARRIAGE RELATIONSHIP NOW:

- _____ 66. We ask each other for help.
- _____ 67. When problems arise, we compromise.
- _____ 68. We approve of each other's friends.
- _____ 69. We are flexible in how we handle our differences.
- _____ 70. We like to do things with each other.
- _____ 71. Different persons act as leaders in our marriage.
- _____ 72. We feel closer to each other than to people outside our family.
- _____ 73. We change our way of handling tasks.
- _____ 74. We like to spend free time with each other.
- _____ 75. We try new ways of dealing with each other.
- _____ 76. We feel very close to each other.
- _____ 77. We jointly make the decisions in our marriage.
- _____ 78. We share hobbies and interests together.
- _____ 79. Rules change in our marriage.
- _____ 80. We can easily think of things to do together as a couple.
- _____ 81. We shift household responsibilities from person to person.
- _____ 82. We consult each other on our decisions.
- _____ 83. It is hard to identify who the leader is in our family.
- _____ 84. Togetherness is a top priority.
- _____ 85. It is hard to tell who does which household chores.

RESPONSE SCALE

1	2	3	4	5
DISSATISFIED	SOMEWHAT DISSATISFIED	GENERALLY SATISFIED	VERY SATISFIED	EXTREMELY SATISFIED

HOW SATISFIED ARE YOU:

86. With how close you feel to the rest of your family?
 87. With your ability to say what you want in your marriage?
 88. With your marriage's ability to try new things?
 89. With how often your spouse makes decisions in your marriage?
 90. With how much you argue with each other?
 91. With how fair the criticism is in your marriage?
 92. With the amount of time you spend with your spouse?
 93. With the way you talk together to solve your problems?
 94. With your freedom to be alone when you want to?
 95. With how strictly you stay with who does what chores in your marriage?
 96. With your spouse's acceptance of your friends?
 97. With how clear it is what your spouse expects of you?
 98. With how often you make decisions as a couple, rather than individually?
 99. With the number of fun things you and your spouse do together?
-

APPENDIX B

Table A. Demographic and Caregiver Variables

Type of Caregiver		
Type of caregiver	n	percentage
Spousal	44	51.8
Parental	41	48.2
Sample total	85	100.0

Age of Caregiver (percentage)						
Type of caregiver	n	<40	41-50	51-60	61-70	≥70
Spousal	44	0.0	6.8	18.2	27.3	47.7
Parental	41	22.0	19.5	41.5	17.1	0.0
Sample total	85	10.6	12.9	29.4	22.4	24.7

Marital Status (percentage)					
Type of caregiver	n	Single	Married	Widowed	Divorced/separated
Spousal	44	0.0	100.0	0.0	0.0
Parental	41	12.2	56.1	9.8	22.0
Sample total	85	5.9	77.6	4.7	10.6

Sex of Caregiver (percentage)			
Type of caregiver	n	Female	Male
Spousal	44	84.1	15.9
Parental	41	97.6	2.4
Sample total	85	90.6	9.4

Ethnicity of Caregiver (percentage)				
Type of caregiver	n	White	Black	Hispanic
Spousal	44	95.5	4.5	0.0
Parental	41	97.6	0.0	2.4
Sample total	85	96.5	2.4	1.2

Education Level of Caregiver (percentage)							
Type of caregiver	n	Elem.	Some H.S.	H.S.	Some college	College	Post college
Spousal	43	4.7	9.3	44.2	16.3	20.9	4.7
Parental	41	2.4	4.9	29.3	22.0	26.8	14.6
Sample total	84	3.6	7.1	36.9	19.0	23.8	9.5

Income Level of Caregiver (percentage)					
Type of caregiver	n	<\$15,000	\$15-24,999	\$25-34,999	>\$35,000
Spousal	41	31.7	36.6	19.5	12.2
Parental	40	27.5	25.0	32.5	15.0
Sample total	81	29.6	30.9	25.9	13.6

Number of Children Living in Household (percentage)

Type of caregiver	n	Q	Frequency		
			1	2	3
Spousal	44	84.1	11.4	2.3	2.3
Parental	41	68.3	19.5	2.4	9.8
Sample total	85	76.5	15.3	2.4	5.9

Number of Persons Cared For in Household (over 50 years of age) (percentage)

Type of caregiver	n	1	2	≥2
Spousal	42	90.5	9.5	0.0
Parental	41	80.5	17.1	2.4
Sample total	83	85.5	13.3	1.2

Health Assessment of Caregiver (percentage)

Type of caregiver	n	Excellent	Good	Fair	Poor	Mean	StDev.
Spousal	42	4.8	57.1	31.0	7.1	2.32	0.75
Parental	41	12.2	48.8	34.1	4.9	2.40	0.69
Sample total	83	8.4	53.0	32.5	6.0		

(scale: 1-4; 1-excellent, 4-poor)

Employment Status of Caregiver (percentage)

Type of caregiver	n	Currently employed	Not employed/retired
Spousal	41	19.5	80.5
Parental	41	53.7	46.3
Sample total	82	36.6	63.4

Length of Time Since Last Vacation (percentage)

Type of caregiver	n	≤6 mos.	6 mos.-1 year	1-2 years	≥2 years
Spousal	41	14.6	22.0	7.3	56.1
Parental	38	28.9	21.1	10.5	39.5
Sample total	79	21.5	21.5	8.9	48.1

Sex of Care-Receiver (percentage)

Type of caregiver	n	Female	Male
Spousal	44	15.9	84.1
Parental	41	87.8	12.2
Sample total	85	50.6	49.4

Age of Care-Receiver (percentage)

Sex of care-receiver	n	≤60	60-70	71-75	76-80	≥80
Female	43	2.3	11.6	14.0	25.6	46.5
Male	39	10.3	28.2	20.5	23.1	17.9

Percentage of Care-Recipients Who Are Spouses or Older Relatives of Caregivers

Type of caregiver	n	Mother	Father	In-law	Aunt/uncle	Husband	Wife
Spousal	44	0.0	0.0	0.0	0.0	84.1	15.9
Older relative	41	78.0	7.3	12.2	2.4	0.0	0.0

Length of Care (percentage)

Type of caregiver	n	0-6mos	7 mos.-1 years	1-3 years	≥3 years
Spousal	40	2.5	10.0	25.0	62.5
Parental	41	0.0	9.8	39.0	51.2
Sample total	81	1.2	9.9	32.1	56.8

Hours Per Week Spent Providing Care For the Care-Receiver by Different Caregivers

Type of caregiver	n	Mean hrs/wk	StDev.	Range	Mode
Caregiver	67	100.2	64.6	0-168	168 (n = 25)
Others living in house	70	2.9	7.3	0- 40	0 (n = 53)
Others outside of house	68	3.7	10.8	0- 60	0 (n = 50)
Paid outside help	72	13.5	25.4	0-120	0 (n = 44)

Satisfaction With Current Care Arrangements (percentage)

Type of Caregiver	n	1	2	3	Mean	StDev.
Spousal	37	37.8	29.7	32.4	1.95	0.84
Parental	37	24.3	32.4	43.2	2.19	0.80
Sample total	74	31.1	31.1	37.8	2.07	0.83

(scale: 1-3; 1-very satisfied, 3-not too satisfied)

Worry About Providing Sufficient Help (percentage)

Type of caregiver	n	1	2	3	4	Mean	StDev.
Spousal	41	53.7	26.8	12.2	7.3	1.73	0.94
Parental	38	31.6	55.3	5.3	7.9	1.89	0.82
Sample total	79	43.0	40.5	8.9	7.6	1.81	0.89

(scale: 1-4; 1-quite a lot, 4-not at all)

Assessed Quality of Relationship With Care-Receiver (percentage)

Type of caregiver	n	1	2	3	Mean	StDev.
Spousal	40	52.5	45.0	2.5	1.50	0.55
Parental	38	57.9	42.1	0.0	1.42	0.49
Sample total	78	55.1	43.6	1.3	1.46	0.52

(scale: 1-3; 1-we get along very well, 3-we do not get along well)

Probability of Placement in Nursing Home (percentage)

Type of caregiver	n	1	2	3	4	5	Mean	StDev.
Spousal	40	15.0	10.0	7.5	40.0	27.5	3.55	1.38
Parental	41	2.4	2.4	14.6	34.1	46.3	4.20	0.94
Sample total	81	8.6	6.2	11.1	37.0	37.0	3.88	1.22

(scale: 1-5; 1-certainly will be placed, 5-certainly will not)

Disability of Care-Receiver (n = 77)

	None	Mild	Mod. severe	Very severe	Extreme severe
Frequency	9	10	14	17	27
Percentage	11.7	13.0	18.2	22.1	35.0

Interference Index

(Composite score of Social Activity, Work, Spousal, Children, and Quiet Time) (score: 5-25)

Type of caregiver	n	Mean	StDev.	Scaled mean
Spousal	10	13.90	3.75	2.78
Parental	20	11.35	3.35	2.27
Sample total	30	12.20	3.69	2.44

(scale: 1-5; 1-most of the time, 5-never)

Interference with social activities outside the household (percentage)

Type of caregiver	n	1	2	3	4	5	Mean	StDev.
Spousal	36	55.6	19.4	13.9	5.6	5.6	1.86	1.18
Parental	36	47.2	19.4	19.4	11.1	2.8	2.03	1.17
Sample total	72	51.4	19.4	16.7	8.3	4.2	1.94	1.18

Work or job interference (percentage)

Type of caregiver	n	1	2	3	4	5	Mean	StDev.
Spousal	19	15.8	15.8	15.8	5.3	47.4	3.53	1.61
Parental	28	25.0	7.1	17.9	25.0	25.0	3.18	1.54
Sample total	47	21.3	10.6	17.0	17.0	34.0	3.32	1.55

Interference with time with spouse (percentage)

Type of caregiver	n	1	2	3	4	5	Mean	StDev.
Spousal	14	35.7	7.1	0.0	21.4	35.7	3.14	1.83
Parental	26	23.1	34.6	15.4	19.2	7.7	2.54	1.25
Sample total	40	27.5	25.0	10.0	20.0	17.5	2.75	1.48

Interference with time with children (percentage)

Type of caregiver	n	1	2	3	4	5	Mean	StDev.
Spousal	17	17.6	17.6	5.9	17.6	41.2	3.47	1.62
Parental	26	23.1	15.4	38.5	7.7	15.4	2.77	1.36
Sample total	43	20.9	16.3	25.6	11.6	25.6	3.05	1.46

Interference with quiet time or rest (percentage)

Type of caregiver	n	1	2	3	4	5	Mean	StDev.
Spousal	37	21.6	37.8	16.2	18.9	5.4	2.49	1.18
Parental	35	25.7	31.4	31.4	11.4	0.0	2.29	0.97
Sample total	72	23.6	34.7	23.6	15.3	2.8	2.39	1.09

Life Satisfaction (percentage)

Type of caregiver	n	Mean	StDev.
Spousal	43	3.86	2.78
Parental	39	4.38	2.64
Sample total	82	4.11	2.72

(scale: 0-11; higher scores indicate higher satisfaction)

Impact Index

(Composite score of Time With Family, Privacy, Social Life, Constant Attention, and Others)

(score: 5-15)

<u>Type of caregiver</u>	<u>n</u>	<u>Mean</u>	<u>StDev.</u>	<u>Scaled mean</u>
Spousal	34	9.88	2.93	1.98
Parental	38	9.47	1.98	1.89
Sample total	72	9.67	2.48	1.93

(scale: 1-3; 1-serious problem, 3-not a problem)

Interference with family time (percentage)

<u>Type of caregiver</u>	<u>n</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>Mean</u>	<u>StDev.</u>
Spousal	36	25.0	38.9	36.1	2.11	0.77
Parental	39	20.5	64.1	15.4	1.95	0.60
Sample total	75	22.7	52.0	25.3	2.03	0.70

Interference with privacy (percentage)

<u>Type of caregiver</u>	<u>n</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>Mean</u>	<u>StDev.</u>
Spousal	43	16.3	46.5	37.2	2.21	0.70
Parental	41	14.6	65.9	19.5	2.05	0.58
Sample total	84	15.5	56.0	28.6	2.13	0.65

Interference with social life (percentage)

<u>Type of caregiver</u>	<u>n</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>Mean</u>	<u>StDev.</u>
Spousal	44	47.7	38.6	13.6	1.66	0.71
Parental	40	35.0	57.5	7.5	1.73	0.59
Sample total	84	41.7	47.6	10.7	1.69	0.65

Caregiving requires constant attention (percentage)

<u>Type of caregiver</u>	<u>n</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>Mean</u>	<u>StDev.</u>
Spousal	42	38.1	40.5	21.4	1.83	0.75
Parental	41	26.8	56.1	17.1	1.90	0.66
Sample total	83	32.5	48.2	19.3	1.87	0.71

Interference with other relationships (percentage)

<u>Type of caregiver</u>	<u>n</u>	<u>1</u>	<u>2</u>	<u>3</u>	<u>Mean</u>	<u>StDev.</u>
Spousal	39	25.6	53.8	20.5	2.03	0.62
Parental	40	35.0	50.0	15.0	1.80	0.68
Sample total	79	30.4	51.9	17.7	1.87	0.68

Functionality (percentage)

<u>Type of caregiver</u>	<u>n</u>	<u>Bal.</u>	<u>Mid</u>	<u>Ext.</u>
Spousal	31	38.7	41.9	19.4
Parental	34	23.5	52.9	23.5
Sample total	65	30.8	47.7	21.5

(note: Bal.=balanced, Mid=mid-range, Ext.=extreme)

Strain Index

(Composite score of Emotional, Financial, and Physical Strain) (score: 3-15)

Type of caregiver	n	Mean	StDev.	Scaled mean
Spousal	37	11.22	3.63	3.74
Parental	35	9.74	2.98	3.25
Sample total	72	10.50	3.41	3.50

(Scale: 1-5; 1-little or none, 5-a great deal)

Emotional strain (percentage)

Type of caregiver	n	1	2	3	4	5	Mean	StDev.
Spousal	41	7.3	7.3	7.3	24.4	53.7	4.10	1.25
Parental	40	5.0	7.5	17.5	35.0	35.0	3.88	1.12
Sample total	81	6.2	7.4	12.3	29.6	44.4	3.99	1.19

Financial strain (percentage)

Type of caregiver	n	1	2	3	4	5	Mean	StDev.
Spousal	37	24.3	8.1	16.2	21.6	29.7	3.24	1.55
Parental	35	31.4	17.1	22.9	11.4	17.1	2.66	1.45
Sample total	72	27.8	12.5	19.4	16.7	23.6	2.96	1.53

Physical strain (percentage)

Type of caregiver	n	1	2	3	4	5	Mean	StDev.
Spousal	41	12.2	9.8	14.6	24.4	39.0	3.68	1.39
Parental	39	12.8	15.4	30.8	17.9	23.1	3.23	1.31
Sample total	80	12.5	12.5	22.5	21.3	31.3	3.46	1.37

Adaptability and Cohesion (adjusted scores) (frequency)

Type of caregiver	n	Adaptability		n	Cohesion	
		Extreme	Balanced		Extreme	Balanced
Spousal	31	54.8	45.2	31	61.3	38.7
Parental	32	46.9	53.1	33	60.6	39.4
Sample total	63	50.8	49.2	64	60.9	39.1

Sub-group raw scores adjusted dichotomously (low-high)

t-Test Results (Spousal vs. Parental)

Variable	df	t-Obs.
Age	83	-7.50***
Marital status	83	-5.60***
Employment	80	3.39**
Education	82	2.09*
Sex of caregiver	83	-2.21*

*p>0.05

**p>0.005

***p>0.001

Family Satisfaction

ANOVA (all groups)	df	MS	F
Between groups	2	21.96	0.14
Error	63	162.53	

Table B. Family Satisfaction (Caregiver Groups vs. Olson Sample Norm)

Type of caregiver	Mean	Significance
Spousal	38.28	t (32) = -3.59**
Parental	37.32	t (34) = -4.87***
Sample total	37.79	t (66) = -5.94***

**p>0.01

***p>0.001

(Olson sample: n = 2,056; mean = 47.00)

(scale: 14-70; high scores indicate higher satisfaction)

Table C. Correlations of Variables Among Caregiver Groups

Group	Variable 1	Variable 2	Pearson r
Sample	Cohesion	Adaptability	0.02
Spousal	Cohesion	Adaptability	-0.02
Parental	Cohesion	Adaptability	0.03
Sample	Family satisfaction	Functionality	0.28
Sample	Family satisfaction	Adaptability	-0.11
Spousal	Family satisfaction	Adaptability	-0.13
Parental	Family satisfaction	Adaptability	-0.08
Sample	Family satisfaction	Cohesion	0.51
Spousal	Family satisfaction	Cohesion	0.49
Parental	Family satisfaction	Cohesion	0.56
Sample	Family satisfaction	Impact index	0.43
Sample	Family satisfaction	Interference index	0.12
Sample	Family satisfaction	Strain index	-0.39
Sample	Functionality	Impact index	0.00
Sample	Functionality	Interference index	0.08
Sample	Functionality	Strain index	0.08
Sample	Life satisfaction	Family satisfaction	0.59
Sample	Life satisfaction	Functionality	0.14
Sample	Life satisfaction	Adaptability	-0.06
Spousal	Life satisfaction	Adaptability	0.00
Parental	Life satisfaction	Adaptability	-0.14
Sample	Life satisfaction	Cohesion	0.27
Spousal	Life satisfaction	Cohesion	0.27
Parental	Life satisfaction	Cohesion	0.27
Sample	Life satisfaction	Impact index	0.39
Sample	Life satisfaction	Interference index	0.30
Sample	Life satisfaction	Strain index	-0.52

Sub-group raw scores for Adaptability and Cohesion adjusted dichotomously (extreme-balance)

Table D. Functionality of Caregiver Groups

Sub-group	df	Chi-square
Functionality	2	$\chi^2 = 1.76$
Cohesion	1	$\chi^2 = 0.00$
Adaptability	1	$\chi^2 = 0.40$

Sub-group raw scores adjusted dichotomously (low-high)

Table E. Functionality (Caregiver Groups vs. Olson Sample Norm)

Type of caregiver	df	Chi-square
Spousal	2	$\chi^2 = 11.48^*$
Parental	2	$\chi^2 = 2.65$
Sample total	2	$\chi^2 = 10.54^*$

* p < 0.01

Table F. Cohesion (Caregiver Groups vs. Olson Sample Norm)

Type of caregiver	df	Chi-square
Spousal	1	$\chi^2 = 6.06^{**}$
Parental	1	$\chi^2 = 9.05^{***}$
Sample total	1	$\chi^2 = 4.34^*$

* p < 0.05

** p < 0.02

*** p < 0.01

Table G. Adaptability (Caregiver Groups vs. Olson Sample Norm)

Type of caregiver	df	Chi-square
Spousal	1	$\chi^2 = 23.15^*$
Parental	1	$\chi^2 = 11.71^*$
Sample total	1	$\chi^2 = 11.87^*$

* p < 0.01

Table H. One-Factor Analysis of Variance

Independent variable	Dependent variable	MS-treat	MS-error	df	F
Functionality	Family satisfaction	446.23	155.24	2, 58	2.87
	Life satisfaction	24.50	6.81	2, 61	3.60*

* p < 0.05

Table I. Impact of Caregiving According to Relationship

Caregiving impact	Scale range	Sample mean	Spousal Caregiver	Parental Caregiver	Significance
Caregiver health assessment (a)	1-4	2.36	2.40 (n=42)	2.32 (n=41)	t (81) = -0.55
Disability of care-receiver (a)	1-5	3.56	3.53 (n=40)	3.59 (n=37)	t (75) = -0.22
Caregiver worry about care (b)	1-4	1.81	1.73 (n=41)	1.89 (n=38)	t (77) = 0.81
Quality of relationship (c)	1-3	1.46	1.50 (n=40)	1.42 (n=38)	t (76) = -0.66
Satisfaction with arrangement (c)	1-3	2.07	1.95 (n=37)	2.19 (n=37)	t (72) = -1.26
Nursing home probability (d)	1-5	3.88	3.55 (n=40)	4.20 (n=41)	t (79) = -2.42**
Strain index (a)	3-15	10.50	11.22 (n=37)	9.74 (n=35)	t (70) = 1.86
Emotional strain	1-5	3.99	4.10 (n=41)	3.88 (n=40)	t (79) = 0.83
Financial strain	1-5	2.96	3.24 (n=37)	2.66 (n=35)	t (70) = 1.63
Physical strain	1-5	3.46	3.68 (n=41)	3.23 (n=39)	t (78) = 1.48
Impact index (b)	5-15	9.67	9.88 (n=34)	9.47 (n=38)	t (70) = 0.68
Family time interference	1-3	2.03	2.11 (n=36)	1.95 (n=39)	t (73) = -1.00
Privacy interference	1-3	2.13	2.21 (n=43)	2.05 (n=41)	t (82) = -1.13
Social life interference	1-3	1.69	1.66 (n=44)	1.73 (n=40)	t (82) = 0.46
Constant attention	1-3	1.87	1.83 (n=42)	1.90 (n=41)	t (81) = 0.44
Other relationships	1-3	1.87	2.03 (n=39)	1.80 (n=40)	t (77) = -0.96
Interference index (b)	5-25	12.20	13.90 (n=10)	11.35 (n=20)	t (28) = 1.74
Social interference	1-5	1.95	1.86 (n=36)	2.03 (n=36)	t (70) = 0.59
Work/job interference	1-5	3.32	3.53 (n=19)	3.18 (n=28)	t (45) = -0.74
Time with spouse	1-5	2.74	3.14 (n=14)	2.54 (n=26)	t (38) = -1.10
Time with children	1-5	3.05	3.47 (n=17)	2.77 (n=26)	t (41) = -1.48
Quiet time or rest	1-5	2.39	2.49 (n=37)	2.29 (n=35)	t (70) = -0.78
Life satisfaction (e)	0-11	4.11	3.86 (n=43)	4.38 (n=39)	t (80) = -0.87
Family satisfaction (e)	14-70	37.79	38.28 (n=32)	37.32 (n=34)	t (64) = 0.31

a High scores indicate greater distress/disability.

b Low scores indicate greater distress/disability.

c Low scores indicate higher satisfaction.

d Low scores indicate higher probability.

e High scores indicate higher satisfaction.

** p < 0.01.

APPENDIX C

HUMAN SUBJECTS APPROVAL FORM

PROJECT APPROVAL FORM
FOR ETHICAL REVIEW OF ACTIVITIES INVOLVING HUMAN SUBJECTS
IN QUESTIONNAIRES, INTERVIEWS, OBSERVATIONS, VIDEO & AUDIO TAPES, ETC.

1. Leif T. Swanson Family Studies
Principal Investigator Department

Functionality and Life Satisfaction in Multigenerational
Title of Project

Households

none
Name of Funding Agent None

2. SUPERVISING OFFICIAL

I certify that (1) facilities and personnel are available to the investigator for assuring the safety and well-being of human subjects involved; (2) I will be responsible for continuing surveillance of the proposed program with respect to the rights and welfare of human subjects; (3) no procedural changes relating to the human subjects involved will be allowed without prior review by the University Committee; (4) I am satisfied that the procedures to be used for obtaining informed consent comply with the spirit and intent of DHHS regulations; (5) I certify that the investigator is fully competent to accomplish the goals and techniques stated in the attached proposal; (6) the signed consent forms will be filed in the Departmental file and retained for a period of six years.

A. Christopoulos
Head of Department, Dean of the College, or comparable authority

Acting Director, School of Family & Consumer Resources
Title Date 1-30-89

3. ADVISING PHYSICIAN

(Signature needed only if project involves medical procedures and investigator is not a licensed physician.) I certify that I am a duly licensed physician of the state of _____ and that, acting as advising physician, I accept responsibility for any complications to human subjects that may arise from the procedures prescribed therein or used in this project.

Physician Date

4. DEPARTMENTAL REVIEW COMMITTEE

We/I have examined the proposal cited above, and find that the information contained therein is complete; that the scientific aspects of the project include appropriate provision for protecting the rights and welfare of the human subjects involved; and that the required forms have been filled out properly in accordance with the Institutional Assurance filed by the University of Arizona with the U.S. Department of Health and Human Services.

Minimal risk to human subjects: Human Subjects Committee review not required
 Possible risk to subjects: Human Subjects Committee review recommended.
 Subjects at risk: Human Subjects Committee review required.

Walter J. Han Feb 20, 1989
Chairman of Departmental Review Committee Date

5. HUMAN SUBJECTS COMMITTEE

The proposal above was approved on this date by the Human Subjects Committee.

Chairman Date

REFERENCES

- Adams, D. (1969). Analysis of a life satisfaction index. *Journal of Gerontology* , 24 , 470-474.
- The American Association of Retired Persons (1987). *A profile of older Americans* . Administration on Aging, U.S. Department of Health and Human Services, Washington, D.C.
- The American Association of Retired Persons & the Travelers Companies Foundation (1988). *National survey of caregivers* . Washington, D.C.
- Archbold, P. (1983). Impact of parent-caring on women. *Family Relations* , 32 , 39-45.
- Aronson, M. K., Levin, G., & Lipkowitz, R. (1984). A community-based family/patient group program for Alzheimer's disease. *The Gerontologist* , 24 (4), 339-342.
- Barrow, G. M. (1986). *Aging, the individual, and society* . West Publishing Company, St. Paul, Minnesota.
- Barusch, A. S. (1988). Problems and coping strategies of elderly spouse caregivers. *The Gerontologist* , 28 (5), 677-685.
- Brody, E. M. (1981). "Women in the middle" and family help to older people. *The Gerontologist* , 21 (5): 471-480.
- Brody, S. J., Poulshock, S. W., & Masciocchi, C. F. (1978). The family care unit: A major consideration in the long-term support system. *The Gerontologist* , 18 , 556-561.
- Cantor, M. H. (1983). Strain among caregivers: A study of experience in the United States. *The Gerontologist* , 23 (6), 597-604.
- Carnes, P. (1985). *Counseling sexual abusers* . CompCare Publications, Minneapolis, Minnesota.
- Caserta, M. S., Lund, D. A., & Wright, S. D. (1987). Caregivers to dementia patients: The utilization of community services. *The Gerontologist* , 27 (2), 209-214.
- Cath, S. H. (1970). *The geriatric patient and his family* . *The institutionalization of a parent: A nadir of life* . Paper presented at the 10th Annual Meeting of the Boston

- Society for Gerontological Psychiatry, Boston, Massachusetts.
- Chodorkoff, B. (1990). Providing psychotherapy in private practice. *Generations*, 14 (1), 27-30.
- Christianson, J. B. (1986). *Channeling effects on informal care, National Long Term Care Channeling Demonstration*, U.S. Department of Health and Human Services, U.S. Government Printing Office, Washington, D.C.
- Christianson, J. B., & Stephens, S. A. (1986). Informal care to the impaired elderly: Report of the national long term care demonstration survey of informal caregivers, *National Long-Term Care Channeling Demonstration*, U.S. Dept. of Health and Human Services, U.S. Government Printing Office, Washington, D.C.
- Clarke, J. (1984). The family types of schizophrenics, neurotics, and "normals." Unpublished doctoral dissertation. Family Social Science, University of Minnesota, St. Paul, Minnesota.
- Constantine, L. L. (1983). Dysfunction and failure in open family systems, I: Application of a unified theory. *Journal of Marriage and the Family*, 45, 725-738.
- Crossman, L., London, C., & Barry, C. (1981). Older women caring for disabled spouses: A model for supportive services. *The Gerontologist*, 21 (5), 464-470.
- Crystal, S. (1982). *America's old age crisis*. Basic Books, New York.
- Culfond, D. G., Olsen, J. K., & Block, M. (1979). Two generations of elderly in the changing American family: Implications for family service. In *Sourcebook on aging*. Marquis Academic Media, Chicago.
- Davies, H., Priddy, J. M., & Tinklenberg, J. R. (1986). Support groups for male caregivers of Alzheimer's patients. *Clinical Gerontologist*, 5 (3/4), 385-395.
- DeLaski-Smith, D. L. (1984). Housing the elderly: Intergenerational family settings. *Journal of Housing for the Elderly*, 2 (3), 61-70.
- Elrod, L. H. (1980). Housing alternatives for the elderly. *Journal of Family Law*, 18, 723-759.
- Fengler, A., & Goodrich, N. (1979). Wives of elderly men: The hidden patients. *The Gerontologist*, 19, 175-183.
- Florsheim, M. J., & Herr, J. J. (1990). Family counseling with elders. *Generations*, 14

(1), 40-42.

- Gallagher, D., Rose, J., Rivera, P., Lovett, S., & Thompson, L. W. (1989). Prevalence of depression in family caregivers. *The Gerontologist* , 29 (4), 449-456.
- Ganote, S. (1990). A look at counseling in longterm-care settings. *Generations* , 14 (1), 31-34.
- Garbarino, J., Sebes, J., & Schellenbach, C. (1985). Families at risk for destructive parent-child relationships in adolescents: *Child Development* , 55 , 174-183.
- George, L. K. (1980). *Role transitions in later life* . Brooks/Cole, Monterey, California.
- George, L. K. (1981). Subjective well-being: Conceptual and methodological issues. In C. Eisdorfer (Ed.), *Annual review of gerontology and geriatrics* (Vol. 2). Springer, New York.
- George, L. K., & Gwynter, L. P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. *The Gerontologist* , 26 , 253-259.
- Gilford, R., & Bengston, V. (1979). Measuring marital satisfaction in three generations: Positive and negative dimensions. *Journal of Marriage and the Family* , 41 (2), 387-398.
- Glasse, L., & Leonard, F. (1988). Policy from the older woman's perspective. *Generations* , 7 (3), 57-59.
- Hess, B., & Markson, E. (1980). *Aging and old age* . MacMillan Publishing Company, Inc., New York.
- Horley, J. (1984). Life satisfaction, happiness, and morale: Two problems with the use of subjective well-being indicators. *The Gerontologist* , 24 (2), 111-116.
- Horne, J. (1985). *Caregiving: Helping an aging loved one* , AARP, Washington, D.C.
- Horowitz, A. (1978). *Families who care: A study of natural support systems of the elderly* . Paper presented at the 31st scientific meeting of the Gerontological Society, Dallas, Texas.
- Horowitz, A., & Dobrof, R. (1982). *The role of families in providing long term care to the frail and chronically ill elderly living in the community* . Final report. Grant from the Health Care Financing Administration.

- Joreskog, K. G., & Sorbom, D. (1981). *LISREL V - estimation of linear structural equation systems by maximum likelihood methods*. International Educational Services, Chicago.
- Kahan, J. (1985). Decreasing the burden in families caring for a relative with a dementing illness: A controlled study. *Journal of the American Geriatrics Society*, 33 (10), 664-670.
- Katz, K. D. (1980). Elder abuse. *Journal of Family Law*, 18, 695-722.
- Killorin, E., & Olson, D. H. (1984). The chaotic flippers in treatment. In E. Kaufman (Ed.), *Power to Change: Alcoholism*. Gardner Press, New York.
- Kinney, J. M., & Stephens, M. P. (1989). Caregiving hassles scale: Assessing the daily hassles of caring for a family member with dementia. *The Gerontologist*, 29 (3), 328-335.
- Kivett, V. R., & Learner, R. M. (1982). Situational influences on the morale of older rural adults in child-shared housing: A comparative analysis. *The Gerontologist*, 22 (1), 100-106.
- Lawton, M. P. (1977). Morale: What are we measuring? In C. N. Nydegger (Ed.), *Measuring morale: A guide to effective assessment*. Gerontological Society, Washington, D.C.
- Lawton, M. P. (1983). Environment and other determinants of well-being in older people. *The Gerontologist*, 23, 349-357.
- Liang, J. (1984). Dimensions of the life satisfaction index A: A structural formulation. *Journal of Gerontology*, 36 (5), 613-622.
- Lund, D., Pett, M., & Caserta, M. S. (July 1985). *Institutionalizing dementia victims: Some caregiver considerations*. Paper presented at the 13th annual meeting of the International Congress of Gerontology, New York.
- Manton, K. G., & Liu, K. (1984). *The future growth of the long-term care population: Projections based on the 1974 National Nursing Home Survey and the 1982 Long-Term Care Survey*.
- Miller, D. B., Gulle, N., & McCue, F. (1986). The realities of respite for families, clients, and sponsors. *The Gerontologist*, 26 (5), 467-470.

- Mindel, C. H. (1979). Multigenerational family households: Recent trends and implications for the future. *The Gerontologist*, 19 (5), 456-463.
- Mindel, C. H., & Wright, R. (1982). Satisfaction of multigenerational households. *Journal of Gerontology*, 37 (4), 483-489.
- Montgomery, R. J. V., & Borgatta, E. F. (1989). The effects of alternate support strategies on family caregiving. *The Gerontologist*, 29 (4), 457-464.
- Neugarten, B. L. (1975). The future and the young-old (part ii). *The Gerontologist*, 15, 4-9.
- Neugarten, B. L., Havighurst, R. J., & Tobin, S. (1961). The measurement of life satisfaction. *Journal of Gerontology*, 16, 134-143.
- Newman, S., Morgan, J., Moras, R., & Postalan, R. (1976). *Housing alternatives of older people*, Institute for Social Research, University of Michigan, Ann Arbor, Michigan.
- Olson, D. H. (1985). Commentary: Struggling with congruence across theoretical models and methods. *Family Process*, 24, 203-207.
- Olson, D. H., & Killorin, E. (1985). Chemically dependent families and the Circumplex Model. Unpublished manuscript. Family Social Science, University of Minnesota, St. Paul, Minnesota.
- Olson, D. H., Russell, C. S., & Sprenkle, D. H. (1983). Circumplex model of marital and family systems: VI. Theoretical update. *Family Process*, 22, 69-83.
- Olson, D. H., Sprenkle, D. H., Russell, C. S. (1979). Circumplex model of marital and family systems: I. Cohesion and adaptability dimensions, family types, and clinical applications, *Family Process*, 18, 3-29.
- Olson, D. H., & Wilson, M. (1982). Family satisfaction. In D. Olson et al. (Eds.), *Family inventories*. Family Social Science, University of Minnesota, St. Paul, Minnesota.
- Parsons, R. J., & Cox, E. O. (1989). Family mediation in elder caregiving decisions: An empowerment intervention. *Social Work*, 34 (2), 122-126.
- Quayhagen, M. P., & Quayhagen, M. (1988). Alzheimer's stress: Coping with the caregiving role. *The Gerontologist*, 28 (3), 391-396.

- Reece, D., Walz, T., & Hageboeck, H. (1983). Intergenerational care providers of non-institutionalized frail elderly: Characteristics and consequences. *Journal of Gerontological Social Work* , 5 (3), 21-34.
- Robinson, B., & Thurnher, M. (1979). Taking care of aged parents: A family cycle transition. *The Gerontologist* , 19 (6), 586-593.
- Rodick, J. D., Henggeler, S. W., & Hanson, C. L. (1986). An evaluation of Family Adaptability and Cohesion Evaluation Scales (FACES) and the Circumplex Model. *Journal of Abnormal Child Psychology* , 14 , 77-87.
- Scharlach, A. E., & Boyd, S. L. (1989). Caregiving and employment. Results of an employee survey. *The Gerontologist* , 29 (3), 382-387.
- Scott, J. P. (1986). Families of Alzheimer's victims: Family support to the caregivers. *Journal of the American Geriatrics Society* , 34 (5), 348-354.
- Shanas, E., & Streib, G. F. (eds.). (1965). *Social structure and the family: Generational relationships* . Prentice-Hall, Englewood, N.J.
- Silliman, R. A. (1986). Families of elderly stroke patients: Effects of home care. *Journal of the American Geriatrics Society* , 34 (9), 643-648.
- Silliman, R. A., & Sternberg, J. (1988). Family caregiving: Impact of patient functioning and underlying causes of dependency. *The Gerontologist* , 28 (3), 377-382.
- Silverstone, B. (1979). Family relationships of the elderly: Problems and implications for helping professionals. *Aged Care and Services Review* , 1 (2), 1-9.
- Silverstone, B., & Hyman, H. K. (1982). *You and your aging parent: A guide to understanding emotional, physical, and financial needs* . Consumers Union, Mt. Vernon, N.Y.
- Soldo, B. J., & Myllyluoma, J. (1983). Caregivers who live with dependent elderly. *The Gerontologist* , 23 (6), 605-611.
- Spencer, G. (1984). *Projections of the population of the United States by age, sex, and race: 1983 to 2080* . U.S. Bureau of the Census, Current Population Reports, Series P-25, No. 952; Middle Series Projections.
- Toseland, R. W., & Rossiter, C. M. (1989). Group interventions to support family caregivers: A review and analysis. *The Gerontologist* , 29 (4), 438-448.

- Toseland, R. W., Rossiter, C. M., Peak, T., & Smith, G. C. (1990). Comparative effectiveness of individual and group interventions to support family caregivers. *Social Work* , 35 (3), 209-217.
- Treas, J. (1977). Family support systems for the aged: Some social and demographic considerations. *The Gerontologist* , 17 (6), 486-491.
- U.S. Senate Special Committee on Aging. (1986). *Aging America: Trends and projections (1985-1986 edition)* . In conjunction with the American Association of Retired Persons, the Federal Council on Aging, and the Administration on Aging.
- U.S. Social Security Administration. (1980). *Research and statistics note. No. 8.* Office of Research and Statistics, U.S. Department of Health and Human Services, U.S. Government Printing Office, Washington, D.C.
- Young, R. F., & Kahana, E. (1989). Specifying caregiver outcomes: Gender and relationship aspects of caregiving strain. *The Gerontologist* , 29 (5), 660-666.