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# An Assessment of Relationships between Actual and Perceived Caregiving Demand and Negative Impact Measures

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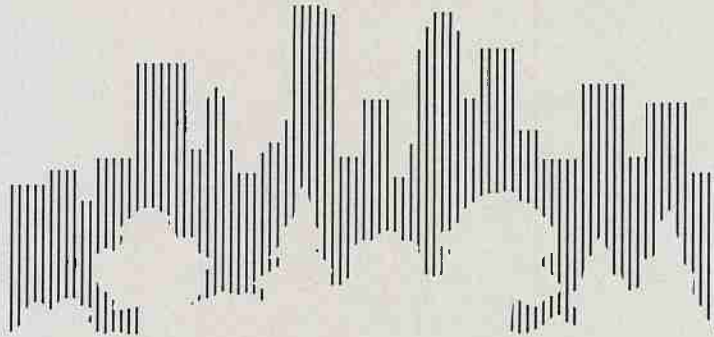
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## MASTERS IN SOCIAL WORK THESIS

Michele L. Mandrich

**An Assessment of Relationships  
between Actual and Perceived Caregiving Demand  
and Negative Impact Measures**

**MSW  
Thesis**

Thesis  
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An Assessment of Relationships between Actual and Perceived Caregiving Demand and  
Negative Impact Measures

Michele L. Mandrich

Submitted in partial fulfillment of  
the requirement for the degree of  
Master of Social Work

Augsburg College  
Minneapolis, Minnesota

1997

**MASTER OF SOCIAL WORK  
AUGSBURG COLLEGE  
MINNEAPOLIS, MINNESOTA**

**CERTIFICATE OF APPROVAL**

This is to certify that the Master's thesis of:

Michele L. Mandrich

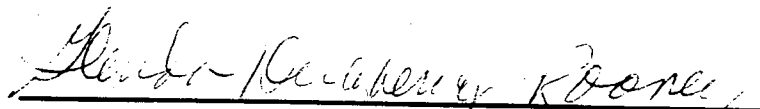
has been approved by the Examining Committee for the thesis requirement for the Master of Social Work Degree.

Date of Oral Presentation: November 25<sup>th</sup>, 1997

Thesis Committee:



Thesis Advisor: Dr. Sharon Patten



Thesis Reader: Dr. Glenda Dewberry Rooney



Thesis Reader: Iris Freeman, MSW

In honor of the memory of my father John and for my  
mother JoAnne who cared for him.

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Thank you, M.

## Abstract

Previous research has focused on the time spent and the tasks involved in caregiving and on care recipient characteristics in measuring caregiving demand and predicting negative impacts (Aneshensel, Pearlin, & Schuler, 1993; McKinlay, Crawford, & Tennstedt, 1995; Stull, Bowman, & Smerglia, 1994). However, the nature of the relationship between objectively measured caregiving demand and negative impacts for caregivers remains unclear. Researchers now note that assessing caregivers' perceptions of demand may be key in understanding negative impacts (Coverman, 1989; Litvin, Albert, Brody, & Hoffman, 1995; Loomis & Booth, 1995). This study assessed relationships between objective and subjective reports of caregiving demand and negative impact measures. Information about subgroups of caregivers and caregiving demand and negative impacts was also made available. The design involved a cross-sectional survey methodology that utilized means tests and correlation statistics for analysis. The findings indicate that caregiver's subjective reports of demand are positively associated with negative impacts while their objective reports are inversely associated with negative impacts. The findings also show that some subgroups of caregivers experience greater negative impacts than others. Implications for practice and policy are discussed.

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# An Assessment of Relationships between Actual and Perceived Caregiving Demand and Negative Impact Measures

## Introduction

The purpose of the present study is to contribute to the knowledge base regarding the experience of caregivers for older adults with disabilities. In particular, its purpose is to delineate possible relationships between caregiver reports of actual and perceived caregiving demand and measures of negative impacts.

Caregiving demand is typically determined by assessing the Activities of Daily Living score (ADL) for the care recipient and/or the amount of time and the numbers of tasks involved in providing care to the care recipients (Aneshensel, Pearlin, and Schuler, 1993; McKinlay, Crawford, and Tennstedt, 1995; Stull, Bowman, and Smerglia, 1994). However, the relationship between these assessments of caregiving demand and negative impacts for caregivers is not consistently supported in the literature (e.g., McKinlay et al., 1995; Lieberman and Kramer, 1991). This observation serves, in part, as the rationale of this study. While research findings strongly indicate that caregivers can experience great burden (Abel, 1990; Aneshensel et al., 1993; Brody, 1990) and that this burden tends to diminish when the care of the recipient is turned over to a formal system such as a nursing home (Aneshensel et al., 1993), what accounts for this initial burden is unclear. Thus, the question remains what accounts for caregiver burden if it is not actual caregiving demand? This study aims to provide information related to what, in addition to the time and tasks involved in caregiving, contributes to negative impacts.

Already toward this end, researchers have begun to argue that caregiver perceptions, or subjective evaluations of demand, rather than objective criteria, may be

key in understanding the negative aspects of the caregiving experience (Coverman, 1989; Loomis and Booth, 1995; McKinlay et al., 1995; Quittner, Opipari, Regoli, Jacobsen, and Eigen, 1992; Rankin, 1990). In addition to carrying out a daily regimen of tasks, caregivers most likely are coping with losses resulting from subtle or dramatic changes in a primary relationship, stress due to multiple roles, shock at the profoundness of their once independent spouse or parent's need, and bewilderment at the responsibilities that come with meeting that need (Brody, 1990; Olson, 1994). Experiences such as these tend to be expressed more frequently in the memoirs of caregivers than in quantitative research (Burack-Weiss, 1995; Gazner, 1994). For example, Bobbie Glaze Custer (1989) writes about the changes her husband has experienced because of Alzheimer's Disease and her response to them,

With the 24 hour vigil, I became totally exhausted--physically and emotionally. It became frightening living with this stranger who might push me or twist my arm, or throw things at the television. The loving gentle husband I once knew was no longer there. He became a shell that simply breathed (p.60).

Although these psychoemotional phenomena present themselves as a result of the caregiving situation, they cannot be assessed in time or by task, only in perception.

Negative impacts for caregivers, in particular, role captivity and personal negative impacts have been found to be strongly associated with negative impacts for care recipients, in particular, institutionalization (Aneshensel et al, 1995; McKinlay et al., 1995). However, caregiving demand has not been consistently found to be associated with the presence of these negative impacts. The implication in these findings is twofold. First, what accounts for severe negative impacts if not the day in and day out operations

of caregiving? Second, the relationship between the effects of caregiving on the caregiver and the subsequent consequences of these effects on the care recipient is underscored. Thus, it is worthwhile to examine the effects of caregiver perceptions on these particularly salient negative impacts.

Describing the relationships between actual (time demand involved in caregiving) and perceived (caregiver subjective evaluations) caregiving demand and negative impacts serves a greater purpose than to fill a gap in the research literature. The tendency of publicly funded programs and insurance companies to use criteria of actual caregiving demand to determine eligibility for services, such as in-home care is one such reason (Stone and Keigher, 1994). Because the literature does not confirm that actual caregiving demand criteria consistently and accurately assess the reality of caregiving individuals and families, other methods should be examined.

## Review of Literature

Theorists and researchers assert that cultural emphases, social and economic change, demographics, and political climates contribute greatly to the caregiving experience and its interpretation (Brody, 1990; De Beauvoir, 1972; Olson, 1994).

### Cultural Emphases and Social Change

Traditional American values dictate that the provision of help to disabled older adults is a family responsibility (Brody, 1990; De Beauvoir, 1969; Olson, 1994). This expectation can be viewed as a consequence of the broader American values of self-reliance, individualism, and personal responsibility (Olson, 1994). Advocating for changes in Medicare and Medicaid by recommending legislation that creates more stringent eligibility requirements while it decreases benefits to the impoverished illustrates this traditional view which is ultimately aimed at reducing the public, and increasing the personal response. However, researchers note that changes in social forces contribute to the efficacy of certain values and the degree to which they are rational. For example, Moen and Forest, (1994) state that "At present, societal norms, institutions, and practices have not kept pace with the shifting realities of contemporary life" (p.826).

And, according to Brody (1990),

Those values [responsibility of family for parent care] developed before the massive demographics trends....before the radical change in the number and proportion of older people in the population who lived to advanced old age, before the shift in the nature of their ailments dictated prolonged care, and before the fall in the birth rate. All of those trends combined to increase the demand for parent care while reducing the capacity of adult children to provide that care. Those developments occurred in

the context of broad socioenvironmental changes such as the phenomena of urbanization, industrialization, mobility, increasing educational levels, public economic support for the elderly, and inflation. At the same time, values about women's roles have been changing. The "new" values hold that it is acceptable, even desirable, for women to have more egalitarian roles with men. The most visible expression of the change has been women's greatly increased participation in the work force (p.54).

As these authors contend, an increase in longevity, a decrease in overall population growth and family size, and expectations for women to work, among other cultural factors, have changed over time. While it is not within the scope of this study to discuss all of the social and cultural factors that have changed and contributed to the experience of caregiving families, it is important to note that the expectation for family care is one that has not changed.

Demographics. According to Moen and Forest, (1994), "the contemporary focus on the problems of families in the childrearing phase disregards the fact that the United States is an aging society" (p. 825). And this statement is supported by a predicted unprecedented increase in the demographic makeup of the U.S. population of older adults in the next thirty years (Olson, 1994). For example, it is estimated that the number of persons over the age of 65 will double to approximately 65 million--one fifth of our nation's population being over the age of 65 by 2030 (Stone and Fletcher, 1988, as cited in Olson, 1994). Further, it is predicted that the number of those who are 85 and older is expected to quadruple in the same time span. By this time, the number of Americans over 65 will exceed the number of children under 18 (Moen and Forest, 1994). Although these



numbers are startling on their own, consideration of the potential needs of this population as it ages are even more so.

Research indicates (Brody, 1990; Olson, 1994; Rankin, 1990) that in addition to changes in the personal and social resources of contemporary family members are changes in the nature of health problems associated with later life. For example, older adults are afflicted by a greater number of chronic and progressively disabling conditions such as hypertension, diabetes, and arthritis as opposed to the more acute and reversible illnesses common in earlier phases of the life course. These chronic problems are precisely those that caregivers attend to in daily life.

The Administration on Aging (1997) estimates that in 1992, approximately 7.3 percent of people aged 65-69, 11.9 percent of people aged 70-74, and 22.5 percent of people aged 75-84 needed assistance in activities of daily living (ADLs) or Instrumental Activities of Daily Living (IADLs). ADLs are those activities that are essential and are performed daily, such as eating, hygiene cares, and toileting. IADLs are those activities that aid adults in remaining independent, such as transportation, mobility, and socialization activities. For those aged 85 and above, 42.3 percent of them needed assistance in one or more ADLs or IADLs. Since the age 85 and older population is growing at the fastest rate, rapidly increasing numbers of persons needing assistance in the coming decades can be expected. These numbers, coupled with evidenced changes in the structure of the American family such as a steady increase in the number of single-parent families and one-child families, in addition to lowered birth rates serve to point out that the older adults of the future will be less likely to have spouses and adult children available to care for them, or these spouses and adult children will have significantly less

support in doing so (Brody, 1985; Brody, 1990; Crystal, 1982).

### History of Research on the Caregiving Experience

Three decades ago, with a burdened health care system and unforecasted numbers of nursing homes filling up, researchers were urged to inquire into why American families were abandoning their older members (Brody, 1985). The assumption that abandonment was the cause of formalizing care was intimately tied to the American values of individualism and personal responsibility (Olson, 1994). Rather than bearing the bulk of care for a family member that was disabled, public policy analysts argued that families were looking to the public to provide financial and functional care (Brody, 1985). However, researchers found that caring for older adults with disabilities was a much more complex topic than was previously thought and that attributing institutionalization only to a lack of personal responsibility was inaccurate (Brody, 1985). Subsequently, articles on caregiving emerged (for review, see McCallion, Toseland, and Diehl, 1994).

The results of this research generally indicate that the caregiving experience should be viewed as a most complex, oftentimes painful and difficult family experience (Abel, 1990; Brody, 1990). And profiles of caregiving families indicate that it is wholly inappropriate to assume that most families willingly relinquish care of older adults with disabilities to institutions (Stone, Cafferata, and Sangl, 1987).

### Characteristics of the Caregiving Experience

Since the late 1960s, much has been learned about informal caregiving in terms of its prevalence, caregiver profiles, typical caregiving demands, and the implications of caregiving for both the giver and receiver.

Prevalence. Estimates indicate that family members provide 80% of all long-term care in the United States (Stone et al., 1987). In 1982, for example, Stone and Fletcher approximated that 2.2 million people aged 14 or older were providing unpaid assistance to 1.6 million noninstitutionalized people with disabilities who needed assistance with the most basic of activities of daily living (as cited in McCallion et al., 1994). However, if the estimate of the number of caregivers includes those that provide aid to older adults in order to help them maintain their independence in their community, the estimated population of primary caregivers increases to 4.2 million (Stone, 1991, as cited in McCallion et al., 1994). Moreover, if all potential caregivers are considered--that is, all individuals who have a spouse or parent(s) with a disability aged 65 or over--estimates range as high as 13.3 million (Stone and Kemper, 1989, as cited in McCallion et al., 1994). What can be gleaned from these statistics is that the vast majority of older adults with disabilities who continue to live outside of nursing facilities depend primarily upon their family members to help them do so.

Caregiver Profile. It has also been observed that caregiving tends to be provided by one family member who is usually female (Abel, 1990; Brody, 1990; Hooyman and Gonyea, 1995; Leira, 1994). Women represent over 70 percent of all caregivers, including adult daughters, wives, daughters-in-law, and sisters. Men represent approximately 30 percent of all caregivers, including husbands, sons, and brothers (Brody, 1990; Olson, 1994). Indeed, the perspective of some scholars is that family care is merely a euphemism for feminine care (Hooyman and Gonyea, 1995; Leira, 1994; Olson, 1994). As Brody states, "The widespread, powerful social value that *families* are responsible for the care of the old really means that *daughters* are the ones held responsible" (p.80, author's Italics).

Caregiving Demand. According to a national profile (Stone et al., 1987), 80 percent of caregivers assist their relatives seven days a week, averaging four hours a day. The type and amount of care provided at these times is highly variable from situation to situation depending upon the older person's needs and disability (Olson, 1994). Informal and formal caregiving demand are typically measured in terms of ADLs and IADLs (e.g., Aneshensel et al., 1993; Stull et al., 1994). Usually, the higher number of dependencies that one has in ADLs and IADLs measures, the greater the caregiving demand is for informal and formal supports.

This information is important in order to understanding the caregiving experience. Due to the cultural emphasis on self-reliance and the accountability of the family in the U.S., we can expect that family members will be providing the bulk of community-based care (Olson, 1994). And, for the most part, caregivers would not have it any other way.

Studies have shown that caregivers tend to prefer to provide care rather than to institutionalize the care recipient. (Brody, 1985; Brody, 1990; Buckwalter and Hall, 1987; Olson, 1994). This desire, oftentimes exercised by continuing to provide care for the care recipient despite negative consequences, can be attributed, in part, to cultural and personal values (Olson, 1994), guilt regarding abandonment (Brody, 1990), and fears related to the real and perceived conditions in nursing homes (Buckwalter and Hall, 1987).

### Implications for Caregivers and Care Recipients

While studies indicate that positive outcomes, such as a greater sense of mastery in the caregiver and enhancement of the caregiving relationship (Brody, 1990; Hooyman and Gonyea, 1995) can be advantages to providing informal care, the literature identifies

the potential for negative outcomes for caregivers far more often (Abel and Nelson, 1990; Brody, 1990; Hooyman and Gonyea, 1995; McCallion et al., 1994). The findings of these studies indicate that caregivers can experience an array of ill psychosocial effects such as clinical depression, a deterioration of health, a sense of social isolation and familial abandonment, and the perception of the deterioration of the caregiver/receiver relationship (McCallion et al, 1994; McKinlay et al., 1995; Stull et al., 1994). Negative effects for the care recipient can also be present and may include reduced quality of care, abuse and/or neglect, and institutionalization (Aneshensel et al., 1993; Lieberman and Kramer, 1991; McKinlay et al., 1995) which has been found to be associated with a decrease in the care recipient's longevity (Aneshensel et al., 1993).

Researchers have attempted to delineate the predictors of these negative outcomes. Consequently, articles on this topic prevail (McCallion et al., 1994). For example, some researchers have studied the characteristics of the caregiving relationship for possible associations with negative impacts. Some findings indicate that the physical needs and cognitive status of the care recipient (Purk and Richardson, 1994; Stull et al., 1994), the types and amount of care required (McKinlay et al., 1995) the health of the relationship between the giver and receiver, the length of the caregiving relationship, and whether the caregiver is a spouse or an adult child (Harris, 1993; Litvin, Albert, Brody, and Hoffman, 1995; Purk and Richardson, 1994) are linked to negative impacts for caregivers.

Other conditions that are associated with negative impacts are those that are not the direct result of characteristics of the caregiving relationship but nonetheless exacerbate it. Examples of these conditions include financial instability (Brody, 1990; Liberman and Kramer, 1990), lack of familial or community support (George and Gwyther, 1986;

Litvin et al., 1995; Monahan and Hooker, 1995), lack of formal supports [e.g., outpatient therapies, clinical supervision (Lieberman and Kramer, 1991)], dependent children in the home (Brody, 1990), marital status (Litvin et al.; 1995; Rankin, 1990), poor caregiver health (McKinlay et al., 1995) and employment responsibilities outside of the home (Barnes, Given, and Barnes, 1995; Brody, 1990). However, the factors listed here and their association with negative impacts can not be assumed to define the caregiving experience due to contradictory evidence.

For example, studies have shown that some of these factors, such as dependent children in the home (Spitze and Logan, 1990; Stull et al., 1994), care recipient characteristics (Aneshensel et al, 1993; Liberman and Kramer, 1990), marital harmony (Loomis and Booth, 1995; Spitze and Logan, 1990), and formal supports (Lieberman and Kramer, 1991) do not have a significant effect on negative impacts for caregivers and /or care recipients.

### Theoretical Frameworks

Several theories have been developed and utilized to describe the caregiving experience. A few of the questions that these theories address include, what influences a family member to provide care rather than to relinquish it to formal systems?; what consequences exist for both the caregiver and care recipient?; and what social, cultural, and psychological processes contribute to these outcomes? (Brody, 1990; Hooyman and Gonyea, 1995; Leira, 1994). Of these, the consequences of caregiving for the caregiver and care recipient and the predictors of these consequences have been the most extensively studied. Although several disciplines have taken particular approaches to caregiving, those of role theory (Coverman, 1989) and stress process theory (Pearlin and

Turner, 1987) are of particular interest to this study.

Both role theory and stress process theory draw a theoretical line between stressful factors 'inside' of the caregiving relationship and stressful factors 'outside' of the caregiving relationship and propose that both play a role in producing caregiver negative impacts (Coverman, 1989; Pearlin, Mullan, Semple, and Skaff, 1990; Pearlin and Turner, 1987). The 'inside factors' are comprised of the characteristics of the care recipient in terms of what types of care he or she needs (e.g., supervision, assistance with transportation, eating, or bathing) and how much time is required of the caregiver in order to meet those needs. The 'outside' factors are the roles that the caregiver attends to when he or she is not caring for the care recipient, such as being a parent, spouse, or an employee. These factors are referred to as caregiver "role combinations" (Coverman, 1989). However, the two theories differ in the explanation of how these two sets of factors can produce negative impacts.

Role theory proposes that negative impacts are a function of the caregiver's perceived conflict between caregiving demand and role combinations (Coverman, 1989). Stress process theory on the other hand, proposes that negative impacts are a function of an interaction between caregiving demand and role combinations over time (Pearlin et al., 1990). An analysis of role theory and stress process theory and each theory's view on the influence of caregiving demand on negative impact follows.

Stress Process. Stress process theory aims at explaining the lack of consensus in the caregiving literature (Pearlin and Turner, 1987) as to the predictors of negative impacts. The theory proposes that caregiver negative impacts are the result of an interaction between primary stressors (characteristics of the care recipient's needs and the tasks and

time required in meeting those needs), secondary stressors (factors outside of the caregiving situation, such as marriage or employment), and mediating factors (e.g., presence/absence of formal or social supports). As Pearlin et al. (1990) state in regards to stress process theory, "... the very notion of process forces attention on the relationships among the many conditions leading to personal stress and the ways these relationships develop and change over time" (p. 585). Further, stress process theory includes an intraphysic construct that is proposed to be representative of severe caregiver distress.

Role captivity. According to Aneshensel et al. (1993), there is another secondary stressor in addition to those typically studied with regard to the caregiving experience (i.e., marital status, and employment). Role captivity refers to situations in which people are unwilling actors of social roles. The authors poignantly illustrate why this complex stressor can manifest itself in a person's life:

The "over-socialized" conception of societal members assumes that we learn to want what we must do to seek the roles in which we eventually become incumbents. However accurate this portrayal is in general, it does not describe the fates of numbers of reluctant or rebellious social actors. It certainly is not consistent with the experiences of many caregivers.

Caregiving is not something people typically are socialized to desire, seek, or expect. Confronted with a need for care, many wives, husbands, daughters, and sons step forward to become caregivers. Others, however, find themselves responding more to powerful cultural expectations than to inner imperatives. Often people become caregivers by default; because they are women, not employed outside of the home, happen to live close by, and so on. Certainly there are people



who initially are reluctant or resentful who later become dedicated to the role; correspondingly, there are those who start out committed, but whose motivation wanes under the load. Regardless of the particular scenario by which one is channeled into the role, there are caregivers who become unwilling incumbents. Being captive of the role, we submit, can be better testimony to powerlessness in shaping one's own fate, a condition conducive to stress (p.67).

The consequences of being role captive can include "painful intrapsychic dislocation", an erosion of a sense of mastery, self-doubt, and a sense of loss of control" (p.55). And with specific regard to caregiving, the authors contend that caregiving responsibilities matter, but less than the fact that these responsibilities are experienced as "obligatory and inescapable, not as voluntary or optional" (p.56).

Investigations that have employed the stress process theory as a framework in the study of the caregiving experience include Aneshensel et al. (1993). In a large-scale longitudinal study an attempt was made to identify those conditions that lead to the institutionalization of care recipients with Alzheimer's Disease. Of particular interest to this study was the concept of role captivity--the extent to which caregivers are unwilling incumbents of this role--and the degree to which it may account for institutionalization.

Aneshensel and colleagues (1993) conceptualized primary stressors as those demands and tasks that are directly related to the caregiving situation which require daily attention, such as providing supervision, preventing potentially harmful action, performing hygiene maintenance tasks, dressing, feeding and instrumental tasks, such as paying bills and performing household chores. Secondary stressors, including role captivity, were defined as those problems that emerge in social roles, network relations,

and feelings about oneself as a result of the presence of primary stressors. Mediating factors in this study are conceptualized as those factors that interact with the primary and secondary stressors and which may influence the impact of these stressors upon placement decisions; they include social support, self-concept, and caregiver health. The authors predicted that associations between primary and secondary stressors (in particular, role captivity) and mediating factors would account for the institutionalization of care recipients.

The results of this study (Aneshensel et al., 1993) indicate that role captivity does indeed account for variance associated with subsequent institutionalization of the care recipient. In addition, role captivity remains relatively stable over time until it rapidly declines after institutionalization, which appears to support the relationship between the two. However, multivariate relationships between primary stressors, secondary stressors, and institutionalization were not evidenced. Thus, while role captivity in caregivers was evidenced and tended to lead to the institutionalization of the care recipient, the relationship between caregiving demand (primary stressor) and role captivity (secondary stressor) and institutionalization (outcomes) was not supported.

Another study that employed the stress process framework was conducted by McKinlay et al. (1995). This study also examined caregiving with the intention of delineating those factors that are associated with both negative outcomes for the caregiver and institutionalization of the care recipient. Again, primary stressors (actual tasks of caregiving), secondary stressors (problems that arise for the caregiver as a result of caregiving), and mediating factors (those conditions which influence the degree to which the primary and secondary stressors impact the caregiver) were analyzed in terms of the

caregiver's responses on four measures of negative impacts and on the consequences for the care recipient (McKinlay et al., 1995).

The findings of the study (McKinlay et al., 1995) indicate that overall, caregivers rated the personal impact (e.g., amount of privacy, sleep, and leisure time) of caregiving as the most negative and these ratings were two times as likely to be associated with subsequent institutionalization of the care recipient than other measures of negative impact (e.g., employment and family conflict). Primary stressors, in particular, the type and amount of care provided were also consistent predictors of negative impact, as higher ratings of personal impact were associated with providing care to a person with greater needs for care. This finding contradicts that of Aneshensel et al. (1993), who found that primary stressors, or caregiving demand was not associated with role captivity or other negative impacts.

A striking finding in this study, however, as the authors recognize (McKinlay et al., 1995) is that those caregivers who reported little or no negative impact were more likely to institutionalize the care recipient than those who reported greater negative impacts. What accounts for the latter group's perseverance in the helping role given their greater demands when their less burdened cohorts did not is unclear. One possible explanation offered by the authors is that caregivers do not always interpret their situation negatively. The authors state that a review of qualitative interviews with caregivers in their study show that caregivers oftentimes view their roles positively--gaining as well as giving--and want to continue in their role despite the potential for negative consequences. However, this hypothesis was not examined further.

Stress process theory aims at predicting negative outcomes for caregivers as well as

care recipients in terms of the relationships and interactions between primary and secondary stressors and mediating factors (Pearlin and Turner, 1987). While support exists for the theory with regard to the potential for role captivity (Aneshensel et al., 1993) and negative personal impacts (McKinlay et al., 1995) to predict institutionalizations, the nature of the relationship between caregiving demand, or primary stressors, and these outcomes is inconclusive.

### Role Theory.

Research that employs role theory as a framework in empirical studies of the caregiving experience utilize two constructs in explaining negative impacts for various populations, including caregivers (Coverman, 1989).

The first proposes that caregiver stress is a function of role strain--a caregiver's perception that two or more equally important forces (e.g., employment responsibilities and caregiving responsibilities) compete with equal magnitude for the caregiver's finite time and energy resources (Coverman, 1989). The second, role overload, proposes that the caregiver perceives him/herself to be consistently attending to two or more demanding forces. The important difference between the two constructs deals with subjective evaluation. Role strain is characterized by the individual's perception that a conflict exists between two or more role responsibilities, such as being a parent and a caregiver to a dependent adult. Thus, while an individual may evidence role overload, a perception of a conflict between those varying roles determines if indeed the individual is role strained. Research has shown that role overload does not necessarily lead to stress; rather, positive outcomes have been found to be associated with acting in multiple roles (Coverman, 1989; Marks, 1977). Conversely, it has been shown that the experience

of role strain can have negative consequences for the caregiver (e.g., Brody, 1990). These findings appear to support the importance of the individual's perceptions of experience in determining whether negative impacts result.

Thus, role theory, with regard to the caregiving experience, posits that providing care to a dependent parent or spouse in addition to fulfilling other roles may put the caregiver at risk for negative impacts due to perceptions of conflict (Brody, 1985; Brody, 1990; Lieberman and Kramer, 1991). As one researcher states with regard to role-strained adult daughter caregivers (Brody, 1990):

Whether or not they work outside of their homes, the dilemma of these women lies in trying to fulfill all of their roles---to respond to the competing demands and to sort out their priorities. Some of them suffer intensely and are bewildered by the situations in which they find themselves. The pressures they experience come not only from the multiple claims on their time and energy, but from the emotional aspects of their situations. There is a negative impact on the health and financial status of some these women, but the most severe and pervasive effects are emotional strains such as anxiety, depression, frustration, conflict, anger, feelings of guilt about not being able to "do it all", and stress from trying to do so (p.3).

Empirical studies have utilized the construct of role strain in explaining negative impacts. For example, Coverman (1989) conducted a study on the relationships between role overload, role strain, job satisfaction, and marital satisfaction for both men and women. A model was tested which posits that role conflict (strain) and overload affect job and marital satisfaction and that all four of these factors affect psychophysical symptoms of distress and well being. The findings indicate that role conflict decreases

job satisfaction and the marital satisfaction of men and increases women's psychophysical symptoms. The weakest effects observed in the model however, involve role overload. The effects of role overload on job and marital satisfaction tend to be small and inconsistent, suggesting that time expenditures do not strongly influence stress levels. Hence, the results indicate that in order for negative impacts to occur, a perception of conflict between roles needs to be present.

Litvin et al.(1995) examined perceptions of role strain in caregivers of dependent adults as a function of marital status. The investigators found that the caregivers who were married reported a higher incidence of perceived competing demands than the nonmarried caregivers. However, married respondents also indicated a greater source of socioemotional support than did their nonmarried cohorts. Thus, while multiple role obligations may enhance the probability of perceptions of conflict between these roles, the social support that is received by acting in these roles is apparently beneficial to the caregiver in coping.

Further, Rankin (1990) examined differences in perceptions of stress sources as a function of the type of caregiving relationship (spouse or adult daughter). Perceptions of stress sources were found to be different between the groups. While spouses tended to perceive their personal resources (e.g., physical abilities and financial situation) as the primary source of stress, adult daughters tended to perceive their primary source of stress as competing task demands outside of the caregiving relationship. Thus, the potential for differences between subgroups of caregivers in their responses to multiple roles and potential strain has been identified.

### Statement of the Problem.

Role theory contributes an important aspect to the literature on the caregiving experience and to the current study; that of perception or subjective evaluation of caregiving demand (Coverman, 1989). While previous studies into the caregiving experience have focused on the needs of the care recipient and the time and tasks involved in meeting these needs in order to predict caregiver negative impacts (Aneshensel et al., 1993; Stull et al., 1994), many have ignored the caregiver's perceptions of demand that may include, but may not be limited to the needs of the care recipient (Leira, 1994). The reviewed literature on role theory indicates that perceptions of role strain tend to be associated with differences in outcomes (Coverman, 1989; Litvin et al., 1995; Rankin, 1990). However, no studies have been conducted based on the potential relationship between perceived caregiving demand and negative impacts even though researchers have begun to argue for the examination of caregivers' subjective evaluations, or perceptions of demand.

Studies that indicate that caregivers do not tend to evidence negative impacts report that caregiver perceptions may be the key to understanding their experience rather than objective criteria. For example, in the study conducted by McKinlay et al. (1995), which assessed stress process theory and the relationships between caregiving demand, role combinations, and negative impact measures and subsequent institutionalization, it was found that those caregivers who reported the greatest negative impacts were less likely than those reporting few negative impacts to transfer caregiving responsibilities to another source. This finding contradicts the theoretical premise that increased caregiver distress leads to an increase in the probability for negative outcomes for the care

recipient, or institutionalization. A preliminary explanation for this data, offered by the authors, is that perhaps the perceptions of the caregivers did not correspond to their reports on objective measures. Or, perhaps these caregivers did not perceive their situations negatively. Other studies have also alluded to the possibility that caregiver perceptions may be important in understanding discrepancies in the literature.

In the study conducted by Rankin (1990), neither spouses nor adult children attributed their sources of stress to the dependency of the care recipient nor the time and tasks required in caring for them. Rankin conceptualizes these findings in the following way: "the total sum of roles and responsibilities associated with the mid-life phase of adult development, of which care to a disabled parent may be one, were found to be salient in understanding the experience of these caregivers" (p. 70).

In addition, Coverman (1989) argues for the inclusion of subjective measures in studies of role strain. She attends that studies into the impacts of role strain neglect to consider the sum of experiences that may go into the evaluations of caregiving demand, those experiences that cannot be possibly measured in terms of tasks and time.

Further, in a study conducted on the effects of dependent children in the home and caregiving responsibilities (Loomis and Booth, 1995), subjective measures were utilized to assess caregiving demand in relation to multigenerational caregiving effects (i.e., an increase in felt burden as a consequence of caring for both children and aged parents while maintaining work and marriage commitments). The authors argue that the subjective measures that they employed, although unlike those used in previous research, were appropriate because "...it [the subjective measure] indicates the potential that caregiving has to interfere with the time and energy requirements of other life areas,



regardless of the type of caregiving activity" (p.136).

Thus, it is unclear to what degree researchers can attribute responsibility to caregiving demand for negative impacts. Because measures of actual demand in terms of time and tasks or measures of ADLs and IADLs that have been utilized in previous studies (e.g., Aneshensel et al., 1993; Stull et al., 1994; Lieberman and Kramer, 1991) have not consistently yielded effects on negative impacts for caregivers, it may be that higher perceptions of caregiving demand may be more indicative of trouble (role captivity and/or negative personal impact) in a caregiving relationship. By examining associations between both actual demand and perceived demand on negative impact measures, more information will be available regarding the influence of caregiving demand on the caregiving experience. Thus, the hypotheses that will be examined in this study is: perceived caregiving demand is associated with negative impact measures such that higher perceived caregiving demand is associated with higher reports of role captivity and personal negative impact. The measures of negative impact in this study are utilized because of the strong association between role captivity, personal negative impacts and the disintegration of the caregiving relationship (Aneshensel et al., 1993; McKinlay et al., 1994). Seven independent variables will be included in the analysis in order to compare differences between subgroups of caregivers. These variables are age of care recipient, age of caregiver, gender of caregiver, living arrangement, relationship with care recipient, institutionalization, and multigenerational caregiving.

## Method

The present study was descriptive in nature. The intent was to gather data on the strength and direction of relationships between actual caregiving demand and the two negative impact measures (role captivity and personal negative impacts) and the strength and direction of the relationships between perceived caregiving demand and the two negative impact measures. The study was also designed to produce information about subgroups of caregivers with regard to caregiving demand and negative impacts. The design of the study involved a cross-sectional survey methodology and utilized both parametric and nonparametric means tests and correlation tests for data analysis.

### Hypothesis

The hypothesis in this study was that perceived caregiving demand would be associated with negative impact measures such that higher perceived caregiving demand would be associated with higher reports of role captivity and personal negative impacts. Actual caregiving demand (time demand) was analyzed with the intent of comparing those reports with those of perceived caregiving demand.

In addition, seven independent variables were analyzed with the actual and perceived caregiving demand measures and with the two negative impact variables in order to assess differences as a function of subgroup membership. These variables were age of care recipient, age of caregiver, gender of caregiver, living arrangement, relationship with care recipient, institutionalization, and multigenerational caregiving. However, no preliminary hypotheses were stated regarding these relationships since other studies have reported inconsistent results regarding the effects of these variables on caregiving demand and negative impacts (e.g., Brody, 1990; Stull et al., 1994).

### Participants

The sample utilized in this study was a convenience sample, obtained from a suburban county agency that provides social services. Permission to use mailing addresses of caregivers was obtained from the program coordinator (for letter of consent from the participating agency, see Appendix A; for letter of consent from the college's Institutional Review Board, see Appendix B). The sample included 140 caregivers.

Eligibility. The eligibility requirement for participation was that each participant considers him/herself to be a caregiver for an adult with a disability. Caregiver was defined as someone that helps an adult with a task(s) that he or she could not do alone. Adult was defined as a person that is at least 18 years old. Disability was defined as a condition that prevents the adult from performing one or more activities in daily life (for example, getting dressed, eating, cleaning the house, needing supervision) without help. It was explained to participants that the disability could be a physical disability (for example, needs help walking), a cognitive disability (for example, is forgetful), or both. The eligibility requirement was described in the cover letter that sample members received.

### Measures and Definitions

There were 7 independent variables in this study--age of care recipient, age of caregiver, gender of caregiver, living arrangement, relationship with care recipient, institutionalization, and multigenerational caregiving.

Independent Variables. The age of care recipient and age of caregiver variables were measured on the same 8 category interval scale [(18-25) (26-35) (36-45) (46-55) (56-65) (66-75) (76-85) (over 86)]. For the analysis, the caregiver age and care recipient age

variables were each recoded. The resulting recoded age variables had two levels: 65 years of age and under and 66 years of age and older. The gender of caregiver variable was measured on a nominal scale, the participants were instructed to circle male or female. The living arrangement variable was defined as whether the caregiver lives in the same household as the care recipient or not. Participants were asked to indicate their answer by circling yes or no. The relationship type variable was defined as whether the care recipient is the caregiver's spouse, parent, or other. Participants were asked to indicate their response by circling the answer that described them. For those participants who circled "other", a line was provided for them to indicate the nature of the relationship (the majority of the responses indicated a spousal or parental type of relationship; therefore, the "other" level of the relationship type variable was not included in the final analysis). The institutionalization variable was defined as whether or not the care recipient was living in a nursing/boarding care home. Participants were asked to indicate their answer by circling yes or no. Multigenerational caregiving was defined as the presence of dependent children in the home of the caregiver. Participants responded to this question by circling yes or no on the questionnaire.

Caregiving Demand Variables. The actual caregiving demand variable was conceptually defined as time demand and operationally defined as the number of hours caregivers spend each day providing care to the care recipient. Participants were asked, "How many hours do you spend providing care to the care recipient each day?", and were instructed to write the number in the space provided. This measure is at an interval/ratio level of measurement

Perceived caregiving demand was conceptually defined as caregivers' subjective

evaluations of the difficulty of their caregiving work. Participants were asked, "How would you describe your role as a caregiver?", after the following introduction:

For this question, I want you to think about the whole of your experience as a caregiver. In addition to the time that you spend providing care to the care recipient, I want you to consider the mental and emotional aspects of caregiving. After you consider these things, answer the following question by circling the answer that best describes you.

The participants indicated their response on a 5-point Likert scale by circling the number that best described their experience.

1            2            3            4            5  
*Not at all difficult*      *Somewhat difficult*      *Very difficult*

Perceived caregiving demand was treated as an ordinal scale in the analysis.

The caregiving demand variables served as dependent variables in the means tests and as criterion variables in the correlations tests of the analysis.

Dependent/Criterion Variables. Role captivity was conceptually defined as the degree to which caregivers feel incumbent of an unwanted role (Aneshensel et al., 1993). Role captivity was operationalized by assessing scores on three 3-point ordinal scales [ranging from "never true of me" (1) to "sometimes true of me" (2) and "usually true of me" (3)] that were utilized in previous research (Aneshensel et al., 1993). These scales include: 1) I wish I was free to lead a life of my own; 2) I feel trapped by the care recipient's illness or disability; 3) I wish I could just run away ( $\alpha = .83$ ). The role captivity variable, as measured on the three indices, served as dependent variables in the means tests and as a criterion variables in the correlations tests.

Personal negative impact was conceptually defined as the degree to which the personal time of caregivers is adversely affected by their caregiving responsibilities

(McKinlay et al., 1995). The personal negative impact variable was operationalized by assessing scores on six 3-point scales that were utilized in previous work (McKinlay et al., 1995) and then recoding. Caregivers were asked if they, as a result of caregiving, had experienced changes "for the worse" (3), "for the better (2)", or "no change (1)" in the following areas: sleep; health; leisure; privacy; financial situation; management of household chores. The recoding of the personal negative impact variable included subtracting out those scores that indicated a change for the better or no change at all, and then summing the resulting scores (those that indicate at negative impact in at least one of the domains) for each participant. This measure served as a criterion variable in the correlations tests and as an independent variable in the means tests. Personal negative impact is treated at an interval/ratio level of measurement in the analysis.

In addition to these questions, two other questions were asked of participants: the primary ethnic identification of the participant, and how long the participant had been providing care for the care recipient. This information was requested for the purpose of further assessing the characteristics of the sample.

### Materials

All sample members received a detailed cover letter (see Appendix C). The cover letter contained information relevant to anonymity, the selection process, the purpose of the study, the eligibility requirement for participation, the procedures of the study, the risks of participation, the benefits of participation, and the voluntary nature of the study.

All sample members received a questionnaire in the same envelope as the cover letter (see Appendix D). The questionnaire contained 21 questions relevant to demographic characteristics, the independent variables, caregiving demand, and negative

impacts.

A self-addressed stamped envelope was provided along with the cover letter and the questionnaire to all sample members. These envelopes were addressed to the researcher and the mailing address on them was a campus address at Augsburg College

### Procedures

The researcher prepared 140 sets of study materials (cover letter, questionnaire, and self-addressed and stamped envelope) and put them into mailing envelopes with postage. The program manager at the supporting agency addressed the envelopes with the addresses of the caregivers. The identity of all of the sample members was kept anonymous.

Sample members were informed of the expectations for participation in the study in the cover letter. All participants were asked to read the cover letter, understand their rights as research participants, and to answer the 21 questions contained in the questionnaire. All participants were asked to place the completed questionnaire in the self-addressed stamped envelope that was provided and to place it in the mail. All participants were asked to keep the cover letter for their records. It was explained to all participants that informed consent would be implied if a completed questionnaire was returned in the mail. For those sample members who chose not to participate in the study or for those who did not meet the eligibility requirement, the instructions were to put the blank questionnaire into the self-addressed stamped envelope and to return it in the mail. One mailing of the study materials took place on September 23, 1997 and three weeks was allowed for returns, data collection ending on October 14, 1997.

### Protection of Human Subjects

The precautions taken to minimize risks included: 1) All sample members were provided with a cover letter which oriented them to the nature of the study, the procedures, the benefits/risks, and the voluntary nature of the study; 2) All sample members were provided with a detailed cover letter which explains their rights, risks/benefits, and confidentiality; 3) No identifying information of any of the participants was available to the researcher and no identifying information was requested of the participating sample members; 4) The phone number of Dr. Sharon Patten was provided so participating participants can ask questions regarding their participation and/or to request a copy of the completed study; 5) All records were kept by the researcher in a locked file box; 6) Only the principal investigator has access to the locked file box; 7) The data will be promptly destroyed once the it has been entered into the computer, analyzed, and interpreted; 8) No identifying information was contained in the computer records; 9) No identifying information of any participants was contained in the final written manuscript; 10) All of this information was provided to sample members in the cover letter that appeared before the survey in the mailings.



## Results

The characteristics of the sample and the results of the analysis are reported below.

Sample Characteristics. Of the 140 participants who received the cover letter and questionnaire in the mail, 51 returned at least a partially completed questionnaire resulting in a response rate of 36 percent. Two participants filled out the questionnaire twice, once for each parent that they provided care for. Each question was recorded twice for both of these participants resulting in a total sample size of 53. Incomplete questionnaires were utilized in the analysis. Therefore, the sample sizes may differ in the analysis due to missing values. Five participants returned the questionnaire blank, indicating that they chose not to participate or that they did not meet the eligibility requirements (these returned questionnaires were not included in the total response rate).

The demographic characteristics of the sample are as follows.

Forty-seven of the participants were female (88.7%) and 6 were male (see Appendix E). Over half of the participants were between the ages of 56-75 (58.4%), although younger and older age groups were represented [14 were between the ages of 26 and 55 (13.2%) and 8 were between the ages of 76 and 85(15.1%)]. Caucasian was the predominant primary ethnic identification reported (94.3%), 1.9% indicated "other", and two participants did not respond. Forty-five participants did not have dependent children living with them (84.9%). Forty-three participants reported that they lived with the care recipient (81.1%). Twenty-nine participants indicated that they provided care for their spouse (54.7%), 20 participants were providing care for a parent (37.7%) and 7.5% of the sample indicated that they were providing care for an adult other than a spouse or parent. The number of years that caregivers indicated that they had been providing care to the

care recipient varied; the range was from 3 months to 25 years and one participant did not respond. The mean number of years spent caregiving was 5.8 years. Just over forty-seven percent of the participants indicated that the person they provided care for was female, while 52.8 percent indicated that the care recipient was male. Five care recipients were between the ages of 18 and 65 (9.4%), sixteen were between the ages of 66 and 75 (30.2%), 19 between the ages of 76-85 (35.8%), and 13 were 85 years of age or older (24.5%). Finally, of the 53 participants, 8 reported that the care recipient was living in a nursing/boarding care home at the time they filled out the questionnaire.

As a result of the low response rate and the lack of representativeness of the sample, the generalizability of the results of this study are limited.

#### Statistical Procedures

The first part of the statistical analysis conducted in this study involved computing correlation tests for actual and perceived caregiving demand and role captivity measures and personal negative impacts. A Pearson product-moment correlation test was performed for actual caregiving demand and personal negative impacts because both variables are or approximate an interval/ratio scale of measurement. A nonparametric correlation test, Spearman rank-order correlation, was utilized to test coefficients for perceived caregiving demand and role captivity measures and for perceived caregiving demand and personal negative impacts because perceived caregiving demand and the role captivity measures are treated as ordinal scales in this study.

The second part of the analysis involved performing tests for differences in mean actual caregiving demand and perceived caregiving demand as a function of independent groups (age of care recipient, age of caregiver, gender of caregiver, living arrangement,

relationship with care recipient, institutionalization, and multigenerational caregiving). For the actual caregiving demand measure, the t-test for independent groups was used and differences in means were assessed. For the perceived caregiving demand measure, the nonparametric Mann Whitney U test was used and differences in mean ranks were assessed.

Finally, t-tests for independent groups were conducted to test for differences in mean personal negative impacts as a function of the independent variables and the Mann Whitney U test was used to test for mean rank differences in role captivity as a function of these same variables.

#### Relationships between Actual Caregiving Demand and Role Captivity

A Spearman rank-order correlation addressed the relationship between rank scores on the actual caregiving demand and the role captivity indices (Table 1). An observed correlation was significant, suggesting that actual caregiving demand is related to caregivers' desire to lead a life of their own (RC1),  $r_s = -.33$ ,  $p < .05$ , such that as the number of hours of care increases the likelihood of experiencing a desire to lead one's own life decreases (Figure 1).

Table 1

#### Spearman rank-order correlations for role captivity and actual caregiving demand

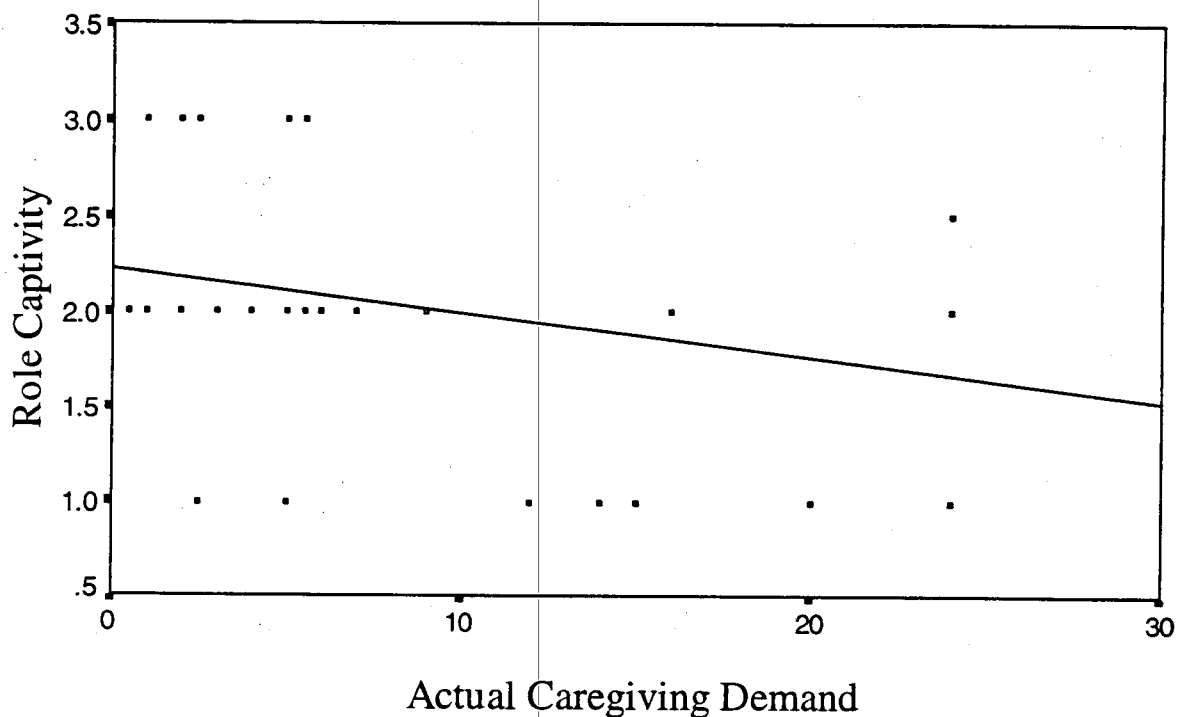
	N	RC1	RC2	RC3
Actual caregiving demand	44	-.33****	-.06	-.24

Note. RC1, RC2, and RC3 represent the individual measures of the role captivity variable, desire to lead own life, feel trapped by the care recipient's illness/disability, wish I could run away, respectively.

\*\*\*\* $p < .05$

Figure 1

The relationship between actual caregiving demand and role captivity: The desire to lead one's own life



Observed correlations between actual caregiving demand and the two other measures of role captivity (RC2 and RC3), although negative, were insignificant,  $p > .05$

Relationships between Perceived Caregiving Demand and Role Captivity

A Spearman rank-order correlation also addressed the relationship between perceived caregiving demand and role captivity (Table 2). Significant relationships were found between perceived caregiving demand and role captivity. Perceived caregiving demand and the feeling of being trapped by the care recipient's disability/illness (RC2) was found to be significant,  $r_s = .55$ ,  $p < .0005$ , such that as caregiver perceptions of demand increase feelings of being trapped by the care recipient's illness/disability

increase (Figure 2). Perceived caregiving demand and the feeling of wanting to run away (RC3) were also positively correlated,  $r_s=.57$ ,  $p<.0005$ . The relationship between perceived caregiving demand and the desire to lead one's own life (RC1), although positive, was insignificant,  $p>.05$ .

Table 2

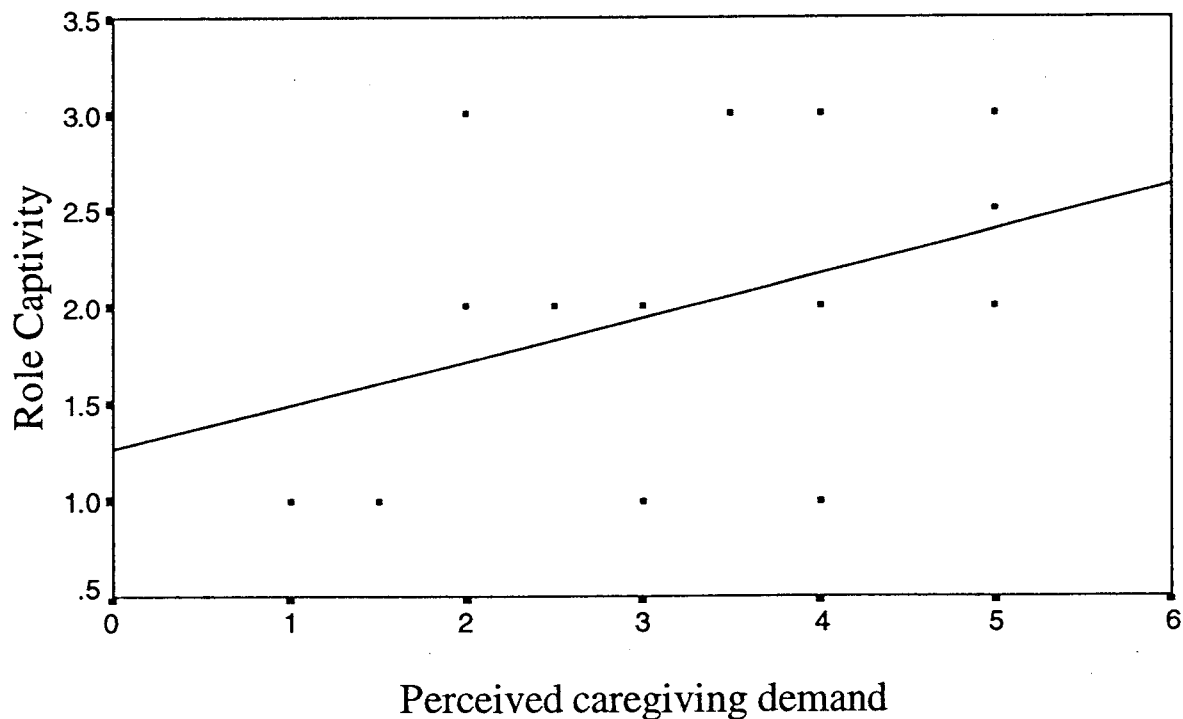
Spearman rank-order correlations for role captivity and perceived caregiving demand

	N	RC1	RC2	RC3
Perceived caregiving demand	52	.23	.55*	.57*

\* $p<.0005$

Figure 2

The relationship between perceived caregiving demand and role captivity: Feeling trapped by the care recipient's illness or disability



In order to test for relationships between actual caregiving demand and personal negative impacts, the scores that indicated a change for the better or no change at all as a result of caregiving were eliminated from the analysis and the resulting scores, those that indicate negative impact in one or more domains, were summed for each participant. This measure then served as the criterion variable in the following analysis.

A Pearson product-moment correlation addressed the relationship between the number of hours that caregivers provide care to care recipients and personal negative impacts (Table 3). This relationship was insignificant, thereby indicating that the number of hours that caregivers provide care to care recipients is not associated with the incidence of personal negative impacts in the areas of sleep, privacy, household management, finances, health, and leisure time,  $p > .05$ .

Table 3

Pearson product-moment correlations for actual and perceived caregiving demand and personal negative impacts

	N	Personal negative impacts
Actual caregiving demand	44	-.12
Perceived caregiving demand	52	.58*

\* $p < .0005$

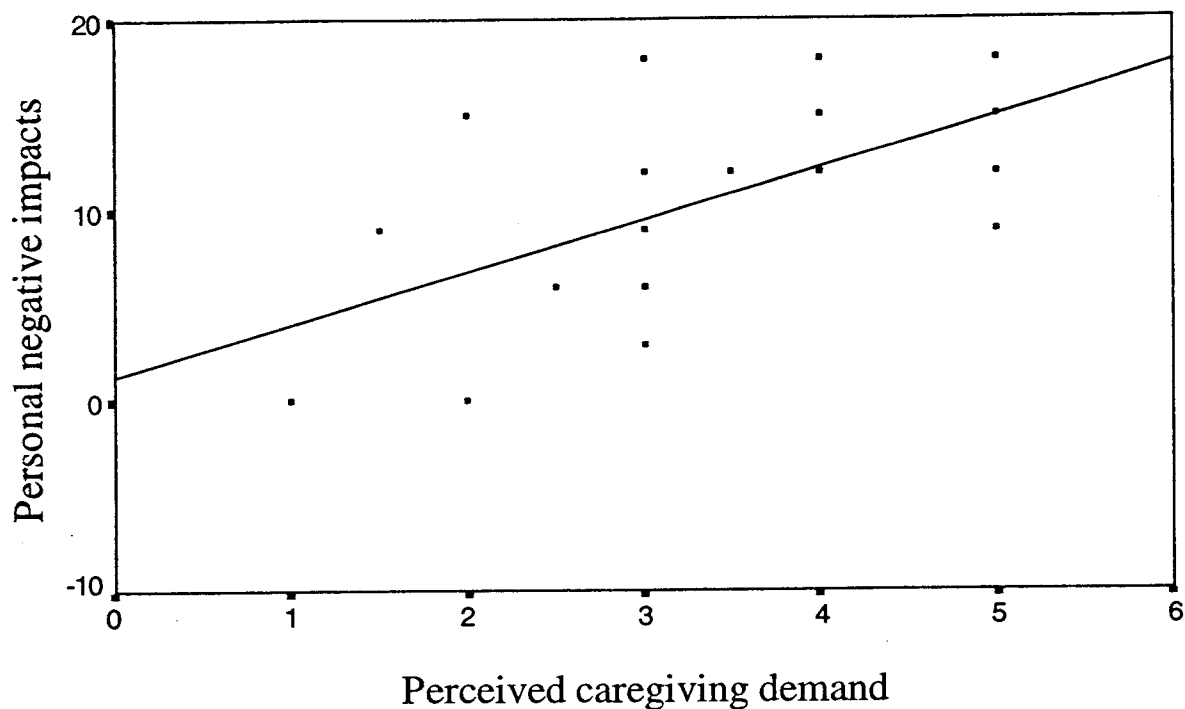
The Relationship between Perceived Caregiving Demand and Personal Negative Impacts

A Spearman rank-order correlation addressed the relationship between perceived caregiving demand and personal negative impacts (Table 3). Unlike actual caregiving demand, perceived caregiving demand was found to be associated with personal negative

impacts, such that as perceptions of caregiving demand increase, personal negative impacts increase,  $r_s=.58$ ,  $p<.0005$  (Figure 3).

Figure 3

The relationship between perceived caregiving demand and personal negative impacts



#### Subgroups of Caregivers and Actual Caregiving Demand

A series of t-tests for independent samples was run on the seven independent variables and actual caregiving demand (Table 4). Significant differences in mean actual caregiving demand were found for the gender of caregiver, living arrangement, and institutionalization subgroups.

A significant difference in mean actual caregiving demand was observed for caregivers who lived with the care recipient and caregivers who did not. Caregivers who lived with the care recipient tended to provide more hours of care ( $M=13.37$ ) than caregivers who did not live the care recipient ( $M=4.5$ ),  $t(43)=2.82$ ,  $p<.01$ . In addition,

caregivers who provide care to care recipients who live in nursing/boarding care homes provide significantly less numbers of hours of care ( $\underline{M}=2.50$ ) than caregivers who provide care to care recipients who do not live in nursing/boarding care homes ( $\underline{M}=13.32$ ),  $t(43)=-3.24$ ,  $p<.01$ . For this sample gender plays a role in the number of hours that the caregiver provides care. Male caregivers provided a significantly greater number of hours of care ( $\underline{M}=20.2$ ) than female caregivers ( $\underline{M}=10.3$ ),  $t(43)=-2.31$ ,  $p<.05$ . No other significant differences in mean actual caregiving demand were observed as a function of subgroup membership,  $p>.05$ .

Table 4

Mean actual caregiving demand scores by subgroup

	n	<u>M</u>
Gender****		
Male	5	20.20
Female	40	10.30
Multigenerational Caregiving		
Yes	6	13.92
No	39	11.01
Living Arrangement***		
Live together	35	13.37
Live separate	10	4.50
Institutionalization***		
Yes	8	2.50
No	37	13.32
Relationship Type***		
Spouse	26	13.19
Parent	15	8.73
Caregiver Age		
$\leq 65$	22	11.89
$\geq 66$	23	10.89



Care Recipient Age		
≤65	5	12.30
≥66	40	11.28

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\*\*\*p<.01

\*\*\*\*p<.05

### Subgroups of Caregivers and Perceived Caregiving Demand

A series of Mann-Whitney U tests were computed for the seven independent variables and perceived caregiving demand (Table 5). However, no significant differences in mean ranks of perceived caregiving demand were found as a function of age of care recipient, age of caregiver, gender of caregiver, living arrangement, relationship with care recipient, institutionalization, and multigenerational caregiving,  $p>.05$ .

Table 5

#### Mean rank perceived caregiving demand scores by subgroup

	n	mean rank
<u>Gender</u>		
Male	6	20.33
Female	47	27.85
<u>Multigenerational Caregiving</u>		
Yes	7	31.71
No	46	26.28
<u>Living Arrangement</u>		
Live together	43	26.45
Live separate	10	29.35
<u>Institutionalization</u>		
Yes	8	28.44
No	45	26.74
<u>Relationship Type</u>		
Spouse	29	24.52
Parent	20	25.70
<u>Caregiver Age</u>		
≤65	26	28.75

≥66	27	25.31
Care Recipient Age		
≤65	5	30.00
≥66	48	26.69

Note. No mean ranks were significantly different,  $p < .05$

#### Subgroups of Caregivers and Role Captivity

A series of Mann-Whitney U tests were run on the seven independent variables and the role captivity indices (Table 6). Significant differences in mean ranks of role captivity were found to be a function of caregiver age, gender of caregiver, living arrangement, type of relationship, and institutionalization.

Caregivers who were 65 years of age or younger reported a significantly higher mean rank (31.92) for the "desire to lead own life" measure (RC1) than caregivers who were 66 years of age or older (21.08),  $U=197.0$ ,  $p < .01$  (Figure 4). In addition, younger caregivers reported a significantly higher mean rank (32.67) for the "feel like running away" measure (RC3) than older caregivers (20.33),  $U=177.5$ ,  $p < .001$ .

Table 6

#### Mean rank of role captivity scores by subgroup

	n	RC1	RC2	RC3
Gender				
Female	47	27.85****	27.61****	27.88****
Male	6	13.80	16.10	13.50
Multigenerational Caregiving				
Yes	7	29.57	30.50	33.64
No	45	26.02	25.88	25.39
Living Arrangement				
Live together	42	24.81****	25.80	25.37
Live separate	10	33.60	29.45	31.25
Institutionalization				
Yes	8	35.25****	30.69	32.75

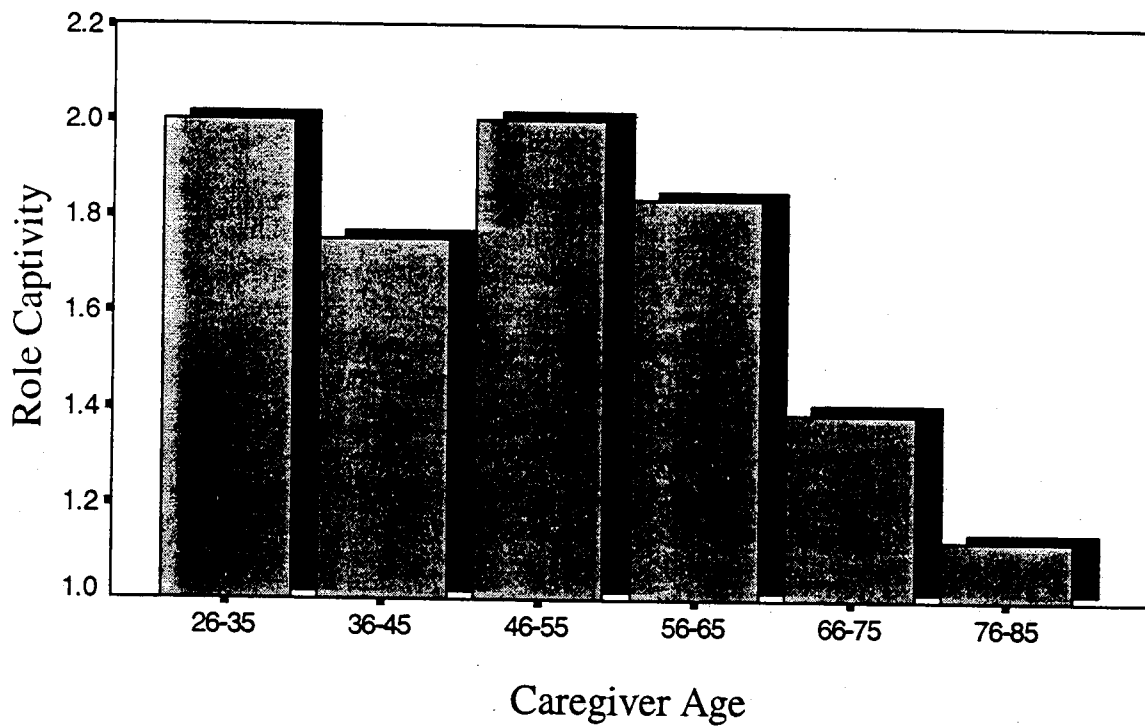
	n	RC1	RC2	RC3
No	44	24.91	25.74	25.36
Relationship Type				
Spouse	28	20.71***	21.82	21.14****
Caregiver Age				
Parent	20	29.80	28.25	29.20
≤65	26	31.92***	29.02	32.67***
≥66	26	21.08	23.98	20.33
Care Recipient Age				
≤65	5	27.00	25.00	34.90
≥66	47	26.45	26.66	25.61

\*\*\*  $p < .01$

\*\*\*\*  $p < .05$

Figure 4

Mean role captivity by caregiver age: Desire to lead own life.

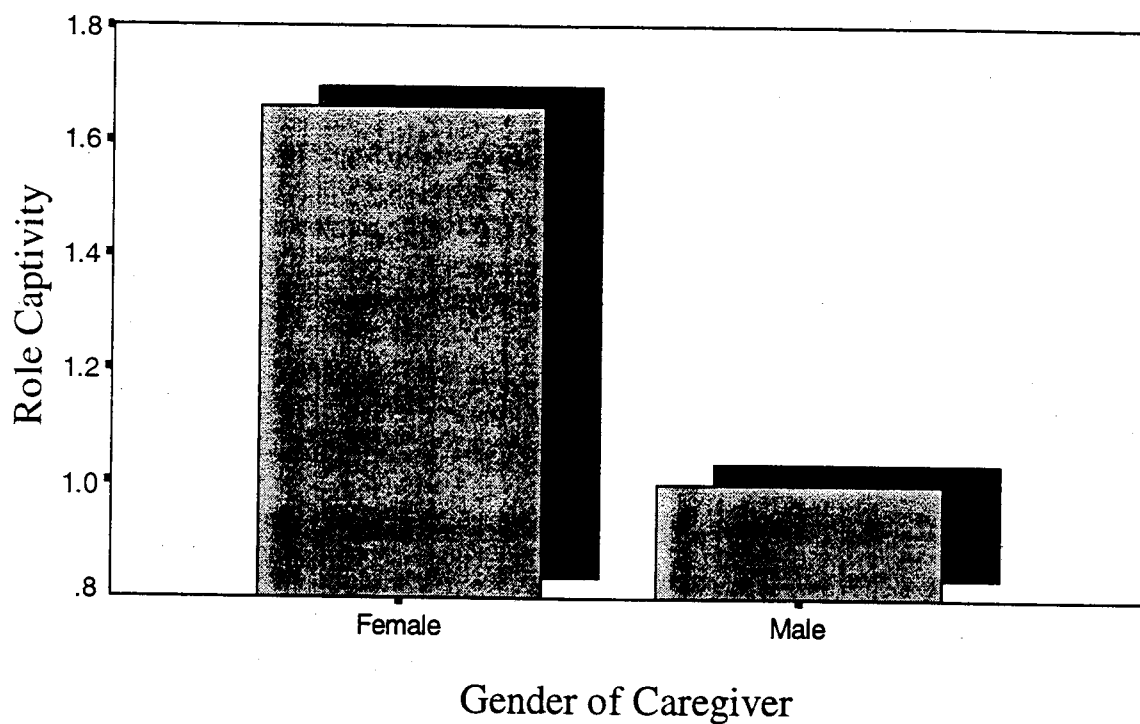


Gender played a role in differences in role captivity in that female caregivers

reported a significantly greater mean rank (27.85) for the "desire to lead own life" measure (RC1) than male caregivers (13.80),  $U=54$ ,  $p<.05$ . Female caregivers also reported a significantly greater mean rank (27.61) for the "feel trapped by the care recipient's illness/disability" measure (RC2) than their male counterparts (16.10),  $U=65.5$ ,  $p<.05$ . Finally, female caregivers reported a significantly greater mean rank (27.88) for the "wish I could run away" measure (RC3) than did male caregivers (13.50),  $U=52.5$ ,  $p<.05$  (Figure 5).

Figure 5

Mean role captivity by caregiver gender: Wish to run away



Whether caregivers lived with care recipients influenced differences in role captivity also. For instance, caregivers who did not live with care recipients reported a significantly greater mean rank (33.60) for the "desire to lead own life measure (RC1)

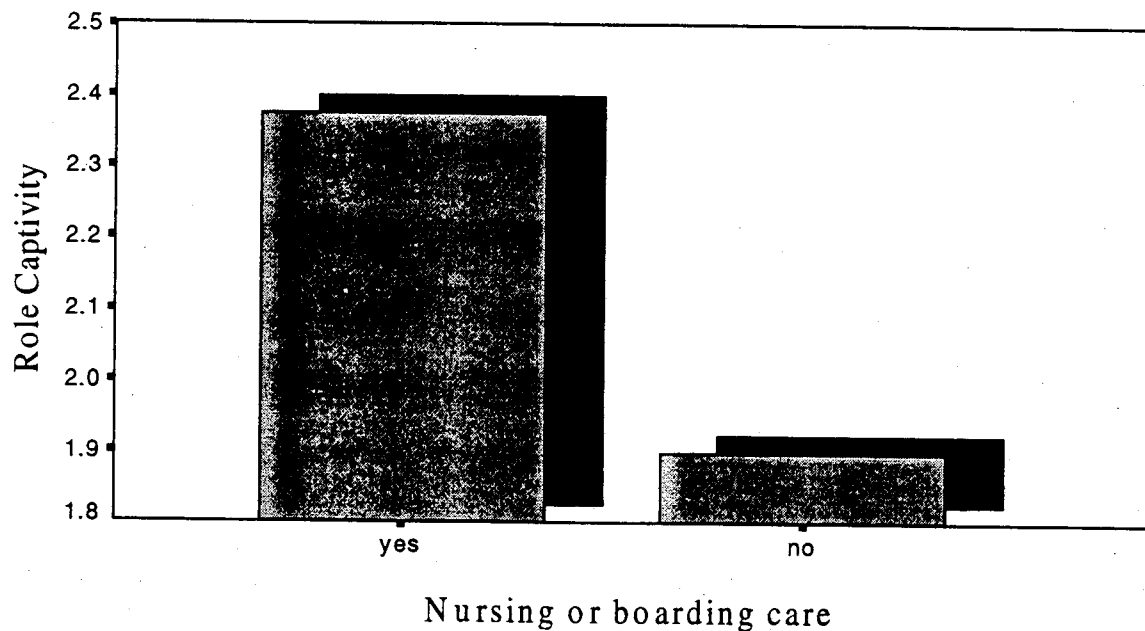
than caregivers who do live with care recipients (24.81),  $\underline{U}=139.0$ ,  $p<.05$ .

The type of relationship between caregivers and care recipients was associated with differences in role captivity. Caregivers who provided care to a parent reported a significantly greater mean rank (29.80) on the "desire to lead their own life" measure (RC1) than caregivers who provided care to a spouse (20.71),  $\underline{U}=174.0$ ,  $p<.01$ . Further, filial caregivers reported a significantly greater mean rank (29.20) for the "wish I could run away" measure (RC3) than did spousal caregivers (21.14),  $\underline{U}=186.0$ ,  $p<.05$ .

Whether care recipients resided in the community or in nursing/boarding care homes helped describe differences in role captivity also. Caregivers who provided care to care recipients who resided in nursing/boarding care homes reported a significantly greater mean rank (35.25) on the "desire to lead own life" measure (RC1) than caregivers who provided care to care recipients in the community (24.91),  $\underline{U}=106.0$ ,  $p<.05$  (figure 6).

Figure 6

Mean role captivity and institutionalization: Desire to lead own life



No other significant differences between subgroups of caregivers were detected for mean ranks of role captivity,  $p > .05$ .

### Subgroups of Caregivers and Personal Negative Impacts

The results of a series of t-tests for independent groups indicate that the age and gender of the caregiver influence differences in personal negative impacts (Table 7).

Caregivers 65 years of age and under reported significantly greater personal negative impacts ( $M=12.23$ ) than caregivers aged 66 and over ( $M=9.69$ ),  $t(50) = -2.02$ ,  $p < .05$  (Figure 7).

Table 7

### Mean personal negative impact scores by subgroup

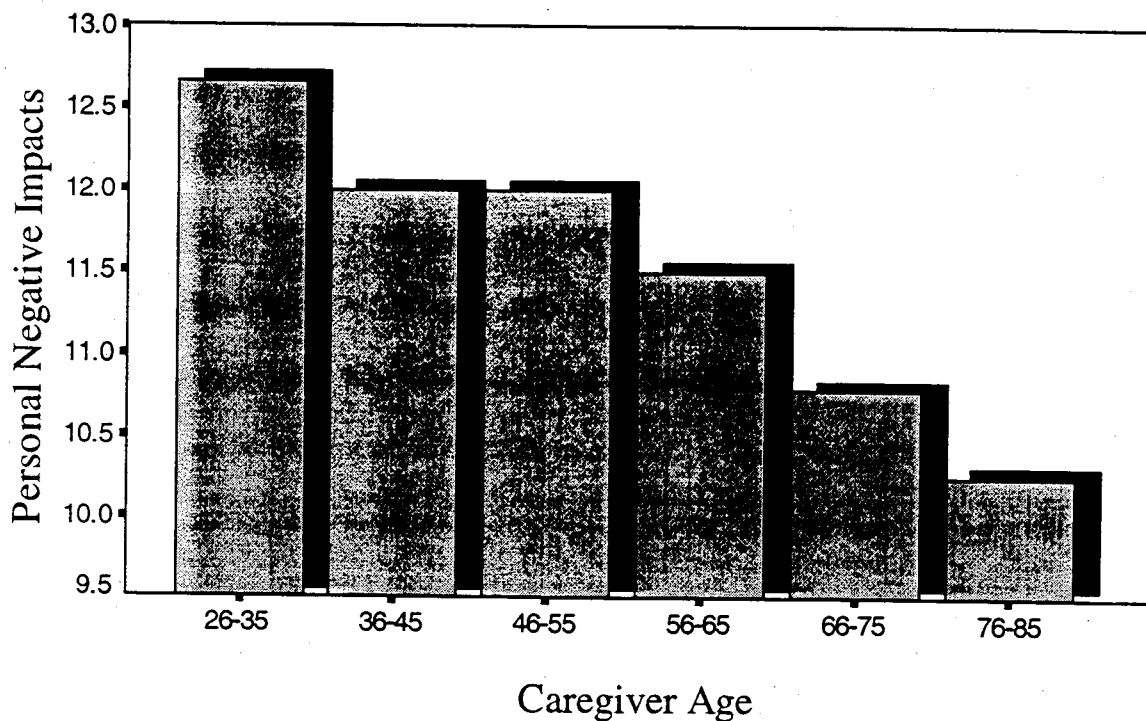
	n	<u>M</u>
Gender****		
Male	6	7.00
Female	47	11.48
Multigenerational Caregiving		
Yes	7	12.43
No	45	10.73
Living Arrangement		
Live together	42	10.43
Live separate	10	13.20
Institutionalization		
Yes	8	13.13
No	44	10.57
Relationship Type		
Spouse	28	9.96
Parent	20	12.15
Caregiver Age****		
$\leq 65$	26	12.23
$\geq 66$	26	9.69

Care Recipient Age		
≤65	5	14.40
≥66	47	10.60

\*\*\*\* $p < .05$

Figure 7

Personal negative impacts by caregiver age



The gender of the caregiver influenced the incidence of personal negative impacts also. In this sample, female caregivers reported significantly greater personal negative impacts ( $M=11.48$ ) than male caregivers ( $M=7.00$ ),  $t(50)=2.30$ ,  $p < .05$ .

No other significant differences were found between subgroups of caregivers and personal negative impacts,  $p > .05$ .

## Discussion

The hypothesis of this study was that perceived caregiving demand is associated with negative impact measures such that higher perceived caregiving demand is associated with higher reports of role captivity and personal negative impact measures. This hypothesis was developed after a literature search produced studies that indicated an inconsistent effect of objective measures of demand on outcome measures and other studies which recommended the examination of other possible methods of measuring demand in caregiving situations (Aneshensel et al., 1993; Coverman, 1989; Loomis and Booth, 1995; Rankin, 1990). The inconsistencies noted in the literature and the implications associated with them for the population that they study are great.

Although the results of this study do not show that objective measures of caregiving demand serve no purpose in determining the needs of caregiving families, they do call attention to the possibility that the logic behind a total reliance on objective criteria to predict negative impacts may be faulty, leading to inaccurate generalizations in both research and applied settings.

### Caregiving Demand and Negative Impacts

The findings show that perceptions of caregiving demand are indeed associated with negative impacts. Caregiver perceptions of demand are strongly associated with both role captivity and personal negative impacts as the positive linear relationships indicate. As the subjective evaluations of the burden of caregiving (the mental and emotional aspects in addition to the operations) increase, the likelihood of caregivers to experience the feeling of being incumbent by an unwanted role increases, as does the likelihood of experiencing negative impacts in sleep, leisure time, privacy, management



of household chores, finances, and health. Previous research (Coverman, 1989; Rankin, 1990) indicates that the perceptions of caregivers should be accounted for when determining the impact of difficult life experiences and the results of this analysis demonstrate a direct relationship between perception and outcome and thus provide support for further inquiry in this area.

A relationship between actual caregiving demand and negative impacts is detected as well, however in a contradictory direction than that of perceived caregiving demand. The number of hours that caregivers spend providing care to the care recipient is associated with a decrease in the likelihood of role captivity rather than an increase as intuition would predict. This finding is also inconsistent with findings of previous research. McKinlay et al. (1995) and Stull et al. (1994), for example, find that an increase in objectively defined caregiving demand is associated with reported negative impacts. The results of the current study add another possibility regarding the relationship between actual caregiving demand and negative impact measures. And what accounts for this negative relationship is unclear. One possible explanation that has been advanced is that an increase in actual caregiving demand may lead to an increase in familiarity, identification, and immersion into the caregiving role which culminates in more positive outcomes than negative impacts (e.g., McKinlay et al., 1995). However, this explanation is not intuitive, has yet to be tested experimentally, and tends to detract from more obvious possibilities, such as the inadequacy of objective measures in capturing the qualitative aspects of caregivers' experiences, a large part of which is subjectively evaluated each day by each individual caregiver.

The results of the analysis also indicate that the relationship between the number of

hours that caregivers provide care to the care recipient and personal negative impacts in the areas of sleep, leisure time, privacy, management of household chores, finances, and health, although inverse, is not significant. This finding contradicts that of McKinlay et al. (1995) who find that higher ratings on objective measures of demand are positively related to an increase in personal as well as other areas of negative impacts (e.g., work and family).

Thus, the subjective evaluations of caregivers regarding the difficulty of caregiving are positively related to both role captivity and personal negative impacts while the actual number of hours of care that caregivers provide is associated with negative impacts in such a way as to indicate a negative relationship or none at all.

By utilizing an objective measure of caregiving demand, comparisons can be made between the strength and direction of the relationships between actual and perceived caregiving demand and the measures of negative impacts. While the findings of this study add to the inconsistencies in the literature regarding the role that objective measures of demand play in the prediction of negative impacts for caregivers, the comparison that remains is that perceptions of caregiving demand and actual caregiving demand are two different realities that are associated with different outcomes. Or in other words, what caregivers do is only an element of what they experience.

Further, the lack of a positive relationship between the objective measure of demand and negative impacts implicates the methodology of current service reimbursement systems.

#### Subgroups and Differences in Actual and Perceived Caregiving Demand

Another goal of this study was to produce information regarding differences

between subgroups of caregivers in actual and perceived caregiving demand and negative impact measures. Several significant differences are observed.

Intuition supports that the caregivers who live with care recipients spend more hours each day providing care. This may occur because those caregivers who tend to live with care recipients do so because more care is required or because those caregivers who live with care recipients provide more hours of care simply because the living arrangement makes it possible or convenient. Intuition also predicts that caregivers who provide care to care recipients who live in institutions would provide a significantly fewer number of hours of care per day than caregivers who provide care to care recipients who continue to live in the community. However, as the previous results affirm common sense, the gender difference counters it. In this sample, the male caregivers provide twice the number of hours of care ( $M=20.2$ ) than female caregivers ( $M=10.3$ ). This finding is not common in the literature (Brody, 1990; Olson, 1994; Stone et al., 1987). It must be mentioned however, that female caregivers outnumbered (88%) male caregivers (11.3%) in the sample. Although the national estimate indicates that female caregivers make up 70% of all caregivers and the number of female and male caregivers in this study should not be expected to be equal, the percentage of males is still lower than the population predicts, thus the generalizability of the differences in the number of hours of care provided due to gender is limited.

Reports of the number of hours that caregivers spent caregiving do not differ due to the presence of dependent children in the home, the age of the caregiver or the age of the care recipient. Thus, in this sample, gender is the only factor that influences caregiving rates beyond what would be generally expected.

Differences in subjective evaluations of caregiving demand as a function of the independent variables are not observed. Differences in caregivers, such as gender, age, living arrangement, and whether children are present do not influence whether the caregiver perceives his/her situation as more or less difficult. Thus, while differences in caregiving experiences have been reported elsewhere between subgroups of caregivers such as employed and unemployed daughters (Barnes et al., 1995), male and female caregivers (Monahan and Hooker, 1995), spousal and filial caregivers (Rankin, 1990) with respect to a number of outcomes, differences in perceived caregiving demand are not evidenced as a function of subgroup differences in this study. One possible explanation for the absence of this effect is personality. Monahan and Hooker (1995) find that when spousal caregivers report greater perceived social support they also tend to report better health outcomes. Conversely, spousal caregivers who report negative perceived social support tend to report worse health outcomes. Furthermore, McKinlay et al. (1995) find that caregivers who report the least negative impacts due to their caregiving role are more likely to institutionalize the care recipient than those who report greater negative impacts. These two findings, although seemingly incongruent, point to the possibility that some people do not view their situations negatively, that personality type may play a role in this, and that one's perspective on their situation, rather than their age or gender, may bear a greater influence on outcomes.

#### Subgroups and Differences in Role Captivity and Personal Negative Impacts

The results also show that younger caregivers (those 65 years of age and under) are more likely to experience role captivity than older caregivers (those 66 years of age and older). This age difference is reported elsewhere. For example, Aneshensel et al. (1993)

find that younger caregivers experience role captivity to a greater extent than older caregivers. In addition, McKinlay et al. (1995) find that younger caregivers are more likely to report greater negative impacts than older caregivers. While it is not possible to explain this finding based on the available data, one hypothesis is that younger caregivers may experience greater role overload (caregiving in addition to raising children, employment, etc.) than older caregivers. However, as discussed in the literature review, role overload is not consistently associated with negative impacts unless the perception of a conflict is present (Coverman, 1989). Further, the effects of employment and multigenerational caregiving on caregiver negative impacts remain unclear (Barnes et al., 1995; Brody, 1990; Stull et al., 1994). Another possible way to account for this difference is in relationship type; the younger caregivers in this study also tend to be the filial caregivers in this study and the data indicate that the filial caregivers experience proportionately greater negative impacts than spousal caregivers.

The gender of the caregiver influences reports of role captivity and personal negative impacts as well. Specifically, female caregivers are more likely to experience role captivity and personal negative impacts than male caregivers. The greater frequency and impact of caregiving on women has been and continues to be a topic of great interest in theory and research (e.g., Brody, 1990). One contribution of this research is the theory of multigenerational caregiving that proposes that the additive effect of multiple responsibilities, including the nurturing and care of children in addition to employment, marriage, and eldercare has the potential to produce negative impacts in the lives of many caregiving women. However, studies of multigenerational caregiving produce inconsistent findings as to the effect and frequency of caring for two generations (Brody,

1990; Spitze and Logan, 1990; Stull et al., 1994). For example, the results of this study indicate that very few caregivers who are providing care to an adult with a disability are also providing care to a dependent child. Furthermore, these women (all of the caregivers who reported multigenerational caregiving were women) do not report significantly greater role captivity or personal negative impacts than their subgroup cohort. However, these observations fail to confirm that multigenerational caregiving does not occur with greater frequency in the population or without greater consequences. Nevertheless, a greater negative impact on women is suggested in the literature (Abel and Nelson, 1990; Brody, 1990) and supported in this study in spite of the fact that the male caregivers reported significantly greater actual caregiving demand rates.

The living arrangement of the caregiver and the care recipient also accounted for differences in reports of role captivity. Caregivers who live in a separate residence than the care recipient report significantly greater role captivity than caregivers who lived in the same residence as the care recipient. This finding is inconsistent with George and Gwyther (1986) who find that caregivers who live with care recipients tend to experience more negative impacts than caregivers who maintain separate residences. However, caregivers who live separately from the care recipient are attending to two households whereas caregivers who live with the care recipient are attending to only one, which may aid in reducing some types of negative impact. Another interpretation is in terms of the positive aspects of caregiving hypothesis (McKinlay, 1995) that has been advanced already. It may be that those caregivers who live with the care recipient have had the opportunity, due to close consistent contact, to more fully identify with the caregiving role and to experience the positive effects of it which, in turn, may decrease the

likelihood of experiencing negative impacts. However, this hypothesis has not been examined systematically within this theoretical framework. Another explanation is that caregivers who live separately from care recipients may be caring for someone that can still maintain a certain level of independence. In these cases the caregiving is focused in on supporting and/or supplementing that level of independence. If, due to a fall or the advance of a chronic illness, those supports and supplemental tasks performed by the caregiver are not sufficient to maintain the care recipient's position in society, this may cause an increase in the felt burden of the caregiver. And this occurs in addition to the demands of fulfilling separate commitments to their own household. Further, the increase in demand on the caregiver may be more than operational. Consider what the fall or the advance of the chronic illness means for the care recipient and the caregiver and consider the systemic effects on individual lives and relationships.

The type of caregiving relationship also influences negative impacts.. Filial caregivers are more likely to experience role captivity than spousal caregivers and these results are also found elsewhere. For example, this finding is consistent with Aneshensel et al. (1993) who find that adult-children caregivers are more likely than spouses to feel trapped by the caregiving role. A greater negative impact on filial caregivers, in particular daughters, than spousal caregivers is also evidenced in the study conducted by McKinlay et al. (1995) who find that negative impacts reach beyond personal impacts into work and family. However, differences in reports of personal negative impacts between filial and spousal caregivers do not reach significance in this study. Thus, filial caregivers tend to experience greater role captivity than spousal caregivers, but the groups do not differ in their experience of personal negative impacts. It appears from the

data that the filial caregivers were also the younger caregivers and the analysis shows that the younger caregivers reported significantly greater role captivity and personal negative impacts than older caregivers. However, a multivariate analysis was not performed to control for caregiver age.

Finally, caregivers who provide care to care recipients who reside in nursing/boarding care homes report significantly greater role captivity than caregivers who provide care to care recipients in the community. The effect of institutionalization on personal negative impacts does not reach significance such that the level of personal negative impacts reported by caregivers who provided care to care recipients who lived in the community and those who lived in formal care settings do not statistically differ. Thus, it appears that negative impacts persist despite institutionalization. This finding contradicts that of Aneshensel et al. (1993) who, with respect to their finding that institutionalization was related to a significant decrease in role captivity, state, "placement may be seen [by caregivers] as an effort to cope with a complex and enveloping life-situation that inherently resists ameliorative actions" (p.67). Unfortunately, according to the results of this study, negative impacts remain post-placement.

What accounts for this finding is unclear; however, Brody (1990), through her work with adult-daughter caregivers provides some explanation for why negative impacts may persist after institutionalization:

.... It is widely assumed that once such placement is made, children turn their backs to their parents and are relieved of responsibility and of the stress they have endured. Indeed, the myth assumes that this is the very reason for the placement. To the contrary,



adult children continue to be vitally interested in their parents, behave accordingly, and may experience a whole new set of strains (p.230).

These strains, although qualitatively different from those experienced in the home of the care recipient, are not necessarily less intense or pervasive. For example, caregivers may experience guilt and/or shame about having made the placement, and sadness and grief regarding the care recipient's initial feelings of despair and continued deterioration (Brody, 1990). In addition, caregivers of care recipients who live in formal care settings may experience strains related to witnessing poor care of the recipient, dealing with negative staff attitudes toward the care recipient and his/her family, the presence of other residents with more severe disabilities, fears of retaliation for making complaints, and uncertainty regarding a new caregiving role. In sum, the decision to place a family member into a nursing/boarding care home out of need can arouse negative impacts due to the presence of stressors related to the cessation of caregiving and the culture of some nursing home environments. Thus, as observed here, role captivity as an intrapsychic construct may be applied to caregiving situations across the spectrum of living arrangements, proximity, and intimacy.

Differences in role captivity are not evidenced however, as a function of multigenerational caregiving and care recipient age. The lack of effect of the presence of dependent children in the home on negative impacts in this study is inconsistent with some reports (Brody, 1990) and consistent with others (Stull et al., 1994) and helps close no gaps in the literature regarding this issue.

#### Limitations of the Study

There are limitations to the generalizability of the findings in this study. For

example, the sample utilized in the study was obtained purposively. The mailing addresses of a known number of caregivers were obtained for the purpose of gathering data on their responses to the questionnaire. Because the members of the sample were not randomly selected from the population, the external validity of the findings is limited. In addition, the sample size is small, only 36 percent of the sample returned completed questionnaires, and unrepresentative with respect to ethnicity and gender. These issues limit even further the potential that the findings of this study can be confidently generalized to the population of caregivers.

Another limitation of the study is the degree to which the predictor and criterion measures are reliable and valid. Although the alpha coefficient for the role captivity measures was available (Aneshensel et al., 1993), those for the personal negative impact measures, actual caregiving demand and perceived caregiving demand measures, were not. Further, pre-testing was not performed on the questionnaire. However, the exploratory nature of the study regarding the perceived caregiving demand measure may reduce the limitations of the study discussed with respect to pre-testing.

Finally, the results of the inferential statistics that were performed in the analysis may be weakened due to the sample size, the unequal numbers in the subgroups, and the nonparametric aspects of the analysis.

Thus, the degree to which one can be confident in the findings presented here is bounded due to issues of reliability, external validity, and violations of conditions and assumptions in statistical theory.

#### Recommendations for further Research

Research in role theory, in particular role strain and overload, has indicated that

individual perceptions play a role in the development and maintenance of negative impacts. The findings of this study support this. However, the measure used to assess perceived caregiving demand in this study was only a starting point. Research in the future should develop measures that can assess caregiver perceptions in general and more specific domains of perception, such as perceptions related to changes in the caregiver/receiver relationship, perceptions related to the synthesis of the history of the relationship, perceptions of the caregiver related to his/her self image, and perceptions related to the fulfillment of lifelong personal and/or cultural expectations. Research in this area may lead to even richer information about what leads one caregiver to experience negative impacts and another one to avert them, and whether or not these differences occur independently of objective reports of caregiving demand.

In addition, research should more specifically assess the role that perceptions may or may not play in stress process theory. The inconsistent effect of actual caregiving demand on negative impacts within this framework may be better understood by including subjective measures. This is especially so since, according to the findings of this study, the effect of institutionalization on role captivity is to increase its likelihood, rather than to decrease it as the theory asserts.

Given that the institutionalization of care recipients is associated with the presence of negative impacts, in particular role captivity and personal negative impacts (Aneshensel et al., 1993; McKinlay et al, 1995), and perceptions of caregiving demand is the greatest predictor of these negative impacts according to the current data, particular attention should be paid to these relationships in the future as they potentially illustrate great consequences for both caregivers and care recipients.

Finally, research should devote attention to the experience of caregivers for people who live in formal care settings. The finding that negative impacts persist despite institutionalization provides the foundation for such study.

### Implications for Practice

The implications of this study for family practice include identifying caregivers that are likely to experience negative impacts, disseminating information, and supplying needed resources.

As was indicated in this study, younger female caregivers who provide care to a parent are more likely to experience negative impacts, in particular role captivity, than older caregivers who provide care to a spouse. Although this does not mean that caregivers who fit the prototype are the only caregivers to experience negative impacts, practitioners may need to pay particular attention to those on their caseloads that do. This is essential not only for the wellbeing of the caregiver, but for the care recipient as well, as the incidence of role captivity and personal negative impacts is demonstrated to be associated with institutionalization (Aneshensel et al., 1993; McKinlay et al., 1995).

Knowledge is power. Informing caregivers of some typical scenarios, likely feelings, and common experiences that they too might encounter may assist caregivers in altering negative feelings about themselves and their performance. For example, the findings of this study indicate that caregivers who choose to seek formal care settings for the care recipient may not be able to expect a great reduction in negative impacts. Similarly, caregivers who provide care less frequently (due to seeking paid or unpaid help) may not be able to rely on lesser negative impacts. Lesser negative impacts may have more to do with individual perceptions. Thus, it is important that family

practitioners explore with caregiving families their expectations about the outcomes of the choices that they will make regarding the continuation or rearrangement of the caregiving relationship.

Finally, the above recommendations are predicated on the existence of quality accessible support services. Practitioners familiar with available resources for caregiving families as well as the nature of caregiving relationships and the common themes that run through them are essential as a support service.

### Implications for Policy

In 1969, Simone De Beauvoir wrote,

In the capitalist democracies, the aging of the population has raised new difficulties.... Not only are there many more aged people than there were, but they no longer spontaneously integrate with the community: society is compelled to decide upon their status, and the decision can only be taken at governmental level. Old age has become the object of a policy (p.222).

It could be said that today we are in a similar predicament. And this is due to many factors, some of which, like the Social Security Act of 1935, have already occurred. And others, like the consequences of the major demographic shift in the numbers of people of advanced ages that will occur in the next thirty years and the outcome of the country's ability to provide for the older generation's health care needs, have yet to occur. Further, many populations of older persons in America do not "spontaneously integrate" with society. Books entitled The Graying of the World: Who Will Care for the Frail Elderly realize this global reality (Olson, 1994). Unfortunately, old age is still the object of a policy.

The implications of this study for policy revolve around the finding that the number of hours that caregivers provide care to the care recipients is inversely related to negative impacts while perceptions of demand are positively related to negative impacts. The purpose these findings serve is as an illustration of the complexity of caregiving juxtaposed against the simplicity of the objective assessments that are used to decide whether caregivers and adults with disabilities are eligible for necessary services. It is possible, given the discrepant relationships between actual and perceived caregiving demand and negative impact measures discovered here, that the service reimbursement systems that caregivers and care recipients are the subjects of are highly simplified and over generalized. And great consequences of this reality for caregiving families exist.

For example, older adults with disabilities who have a family caregiver may be placed in formal care facilities because available and affordable services are inadequate. This occurs because adult day care centers are set up to provide services to people with disabilities who are 'higher functioning' (needs rate lower on the objective assessment) rather than to people with disabilities who have greater needs for care (needs rate higher on the objective assessment). Thus, an employed caregiver who wants to provide care for a family member with a complex disability at home may instead have to place him/her into a nursing facility because of the need to work and the lack of supportive community-based services. Another example is the limited reimbursement for home care services. Caregivers who cannot afford to pay privately for in-home care over the long term and who do not have available or willing family supports may be forced to institutionalize their family members even though they continue to desire to provide the care themselves. While it is rare that institutional care is considered ideal or even acceptable, this is where

the largest state and federal financial outlays are spent, rather than on informal caregivers or services that can support them. Given the cultural expectation for family care and the expense that it fields for the nation, public policy is severely lacking in its response.

Another area of concern for public policy involves the finding that the negative impacts associated with caregiving for some individuals are not eliminated with institutionalization. Program development and policy activity should respond in the areas of nursing home regulations and performance assurance, family support and family council development, in order to increase the quality of services and decrease the occurrence of persistent negative impacts for caregivers.

Finally, public policy should focus on monitoring the growing commercial interest in caregiving families because their existence is a consequence of the limited support provided to caregiving families. Private-sector case management is a growing phenomenon among families who do not qualify for public case management services. It is the responsibility of policy to provide resources toward the monitoring of these services so as to reduce the probability of exploitation.

### Conclusion

The outcomes for family members who provide care to adults with disabilities are not predicated only upon the number of hours required to complete caregiving tasks. The perceptions of caregivers, in addition to characteristics of the caregiving relationship are factors that also contribute to outcomes for caregivers and most likely, outcomes for the people that they provide care for. It is the responsibility of family and social policy to provide tangible aid to caregivers, thereby supporting and assigning value to the service of many individuals who care for family members at home within the context of family

globally defined. Indeed, as Moen and Forest (1995) state,

Informal family care of the ill and infirm is a tremendous social resource, one that prolongs their [people with disabilities] independence or augments the existing system of formal supports. But most health care providers and programs focus solely on the ailing individuals, not their caregivers. The importance of sustaining ties within and across generations needs to be high on the policy agenda of our aging society (p.827).

Indeed, enlightened policy must begin to be responsive to those needs of caregivers, and those of the people that they provide care for, that are disregarded in overly simplistic objective assessments that determine need and resulting aid in the second half of the life span.



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Appendix A: Letter of consent from the participating agency

# COUNTY OF ANOKA

## HUMAN SERVICES DIVISION

Community Social Services &  
Mental Health Department

Government Center • 2100 3rd Avenue • Anoka MN 55303-2264  
612-422-7000 • TDD: 612-323-6166 • Fax: 612-422-6987/612-422-6929

August 8, 1997

•Achieve  
83-4909

•Adult Mental Health  
422-7070

•Chemical Health  
422-7070

•Child Care Assistance  
717-7710

•Developmental Disabilities  
422-7175

•Family & Children's Services  
422-7125

•Interagency Early Intervention  
323-KIDS

•Licensing-Day Care  
422-7146


•Licensing-Foster Care  
422-7144

•Program/Placement Support  
422-7074

•Senior Services  
422-7070

•Volunteer Services  
422-7089

TO: Augsburg College Institutional Review Board

FROM: Carolyn Iverson   
Volunteer Coordinator

Our agency gives permission for our Respite Coordinator, Linda Hayen, to work with Michele Mandrich in distributing survey materials as a part of a master's thesis.

We understand that the individuals who will receive the materials will be identified through a database that can only be accessed by Linda. Therefore, the identity of all of the individuals who receive the materials will remain completely anonymous. I am aware that all individuals who decide to participate in this study will do so voluntarily and that they will be fully informed that their decision to participate or not to participate will not affect any relationships between themselves and Augsburg College or with this agency.

Appendix B: Letter of consent from the Augsburg College IRB

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**AUGSBURG**

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**C•O•L•L•E•G•E**

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September 18, 1997

Michael Schock, M.S.W., Ph.D.  
Chair, Institutional Review Board  
Augsburg College  
2211 Riverside Avenue  
Minneapolis, MN 55454

Dear Michele Mandrich,

I have received your revised IRB application. You have fully complied with the requirements of Augsburg's IRB. Therefore, you have full clearance from Augsburg College to proceed with your research. Your IRB number is 97-02-03. Please use this number in your cover letter. Also place this number on your survey. Finally, address all returns to your Augsburg Mail box #401 at 2211 Riverside MPLS, MNM 55454.

Good luck on this interesting research.

A handwritten signature in cursive script, appearing to read "Michael Schock". The signature is fluid and somewhat stylized, with the first name being more prominent.

Michael Schock, Ph.  
Chair IIB  
Augsburg College

Appendix C: Cover Letter

October, 1997

Dear Prospective Research Participant:

Hello, my name is Michele Mandrich and I am inviting you to participate in my research project concerning the experiences of caregivers for adults with disabilities. You were selected as a possible participant because your mailing address exists on the mailing list of caregivers in Anoka County. I am conducting this research as a part of my master's thesis at Augsburg College and have been granted permission by Anoka County to invite you to participate.

The purpose of this study is to examine the differences between what you do as a caregiver and how you feel about being a caregiver. Further, I am looking at how the similarities and differences between the two affect various aspects of your life.

The only eligibility requirement to participate in this research is that you consider yourself to be a caregiver for an adult with a disability. What I mean by caregiver is that you help an adult with a task(s) that he or she could not do alone. An adult is defined in this study as a person that is at least 18 years old. Disability is defined as a condition that prevents the adult from performing one or more activities in daily life (for example, getting dressed, eating, cleaning the house, needs supervision) without help. The disability can be a physical disability (for example, needs help walking) or a cognitive disability (for example, is forgetful) or both.

If you decide to participate in my study, I will ask three things of you. First, I ask that you read this letter and understand your rights as a research participant. Second, I ask that you answer the 21 true/false and multiple choice questions contained in the survey. Finally, I ask that you place the completed survey in the self-addressed stamped envelope that is provided and place it in the mail as soon as possible. Keep this letter for your records. Answering these questions should only take you approximately 10-15 minutes. There are no right or wrong answers to these questions.

I do not anticipate that there are any risks to you for participating in this research; however, the questions contained in the survey are personal in nature. Although the likelihood of any emotional discomfort is minimal, you have the right to decline to participate. A phone number will be provided at the end of this form for you to call if you experience any difficulties. You will not be penalized for deciding not to participate in this study and you can change your mind at any time.

There are no direct benefits to you for participating in this research. An indirect benefit will be your contribution to social science research on the experience of caregivers for adults with

disabilities. You will not be compensated for your decision to participate in this study.

The records of this study will be kept private. In any sort of report that I might publish, I will not include any information that will make it possible to identify you. Research records will be kept in a locked file; only I will have access to the records.

Your decision whether or not to participate in this study will not affect your current or future relationships with Augsburg College or with Anoka County. If you decide to participate, you are free to withdraw at any time without affecting those relationships and without any other penalty.

You may keep this form for your records. I will imply that you have read and understand the information contained in this form and that you agree to participate in this research if a completed survey is returned to me in the mail.

If you decide not to participate in this study or if you do not consider yourself to be a caregiver, please return the blank forms in the provided self-addressed stamped envelope.

Thank you for your contributions to social science research on the caregiving experience. If you experience any emotional difficulties as a result of participating in this study, you may call Anoka County First Call for Help for assistance, 612-783-4880, at no cost to you. If you have any questions about your participation in this research or if you would like a copy of this study once it is complete, you may contact Dr. Sharon Patten, my thesis advisor at Augsburg College, at 612-330-1723.

Sincerely,

Michele Mandrich  
Graduate Student  
Department of Social Work  
Augsburg College



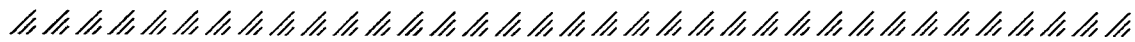
Appendix D: Questionnaire

**Thank you for agreeing to participate in my study. This survey should only take you about 10-15 minutes to complete.**

**Instructions**

**The instructions for answering each section of questions appear at the beginning of each section. Please know that the person that you provide care for is called the "care recipient" in this survey.**

**Thank you!**



For this section, please circle the answer that best describes you and the care recipient.

**1. Your gender:**

Male Female

**2. Your age:**

(18-25) (26-35) (36-45) (46-55) (56-65) (66-75) (76-85) (86 or older)

**3. Gender of care recipient:**

Male Female

**4. Age of care recipient:**

(18-25) (26-35) (36-45) (46-55) (56-65) (66-75) (76-85) (86 or older)

**5. Your primary ethnicity:**

African American

Asian American

Caucasian

Hispanic/Latino

Other (please specify): \_\_\_\_\_

**6. Do you have dependent children living with you?**

Yes No

**7. Do you live with the care recipient?**

Yes No

**8. Does the care recipient live in a nursing or boarding care home?**

Yes No

**9. What is your relationship with the care recipient?**

**He/She is my:**

Spouse\_\_\_\_\_ Parent\_\_\_\_\_ Other (please specify)\_\_\_\_\_

**10. How long have you provided care for the care recipient? (Please indicate in years, or if less than one year, in months) \_\_\_\_\_**

//////  
 For this question, write the number of hours each day that you spend providing care to the care recipient.

**11. How many hours do you spend providing care to the care recipient each day? \_\_\_\_\_**

//////  
 For this question, I want you to think about the whole of your experience as a caregiver. In addition to the time that you spend providing care to the care recipient, I want you to consider the mental and emotional aspects of caregiving. After you consider these things, answer the following question by circling the number that best describes your experience.

**12. How would you describe your role as a caregiver?**

1                      2                      3                      4                      5  
*Not at all difficult                      Somewhat difficult                      Very difficult*

For this section of questions, circle the answer that best describes your experience. There are three answer choices for each question.

**13. How would you describe changes in your health since you began caregiving?**

No change

Changed for the better

Changed for the worse

**14. How would you describe changes in your leisure time since you began caregiving?**

No change

Changed for the better

Changed for the worse

**15. How would you describe changes in your privacy since you began caregiving?**

No change

Changed for the better

Changed for the worse

**16. How would you describe changes in your financial situation since you began caregiving?**

No change

Changed for the better

Changed for the worse

**17. How would you describe changes in your management of household chores since you began caregiving?**

No change

Changed for the better

Changed for the worse

**18. How would you describe changes in your sleep since you began caregiving?**

No change

Changed for the better

Changed for the worse

**19. I wish I were free to lead a life of my own**

Never true of me

Sometimes true of me

Usually true of me

**20. I feel trapped by the care recipient's illness or disability**

Never true of me

Sometimes true of me

Usually true of me

**21. I wish I could just run away**

Never true of me

Sometimes true of me

Usually true of me

If there is anything else that you would like to communicate to me about your experience as a caregiver, you can do so in the space provided here.

**This is the end of the survey. Please place the survey in the provided self-addressed stamped envelope and place it in the mail as soon as possible.**

*Thank you very much for participating!*

Appendix E. Sample CharacteristicsParticipant Age

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
26-35	2.00	3	5.7	5.7	5.7
36-45	3.00	4	7.5	7.5	13.2
46-55	4.00	7	13.2	13.2	26.4
56-65	5.00	12	22.6	22.6	49.1
66-75	6.00	19	35.8	35.8	84.9
76-85	7.00	8	15.1	15.1	100.0
		-----	-----	-----	
Total		53	100.0	100.0	

Mean 5.208

Valid cases 53 Missing cases 0

Age of Care Recipient

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
18-25	1.00	1	1.9	1.9	1.9
46--55	4.00	1	1.9	1.9	3.8
56-65	5.00	3	5.7	5.7	9.4
66-75	6.00	16	30.2	30.2	39.6
76-85	7.00	19	35.8	35.8	75.5
over 85	8.00	13	24.5	24.5	100.0
		-----	-----	-----	
Total		53	100.0	100.0	

Mean 6.660

Valid cases 53 Missing cases 0

Dependent children in home

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
yes	1.00	7	13.2	13.2	13.2
no	2.00	46	86.8	86.8	100.0
		-----	-----	-----	
Total		53	100.0	100.0	

Mean 1.868  
 Valid cases 53 Missing cases 0

### Primary Ethnic Identification

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Caucasian	3.00	50	94.3	98.0	98.0
Other	5.00	1	1.9	2.0	100.0
	.	2	3.8	Missing	
		-----	-----	-----	
Total		53	100.0	100.0	

Mean 3.039  
 Valid cases 51 Missing cases 2

### Caregiver Gender

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Female	1.00	47	88.7	88.7	88.7
Male	2.00	6	11.3	11.3	100.0
		-----	-----	-----	
Total		53	100.0	100.0	

Mean 1.113  
 Valid cases 53 Missing cases 0

### Care Recipient Gender

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Female	1.00	25	47.2	47.2	47.2
Male	2.00	28	52.8	52.8	100.0
		-----	-----	-----	
Total		53	100.0	100.0	

Mean 1.528  
 Valid cases 53 Missing cases 0

**Living Arrangement**

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Live together	1.00	43	81.1	81.1	81.1
Do not live together	2.00	10	18.9	18.9	100.0
		-----	-----	-----	
Total		53	100.0	100.0	

Mean 1.189

Valid cases 53 Missing cases 0

**Nursing or boarding care**

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
yes	1.00	8	15.1	15.1	15.1
no	2.00	45	84.9	84.9	100.0
		-----	-----	-----	
Total		53	100.0	100.0	

Mean 1.849

Valid cases 53 Missing cases 0

**Relationship with Care Recipient**

Value Label	Value	Frequency	Percent	Valid Percent	Cum Percent
Spouse	1.00	29	54.7	54.7	54.7
Parent	2.00	20	37.7	37.7	92.5
Other	3.00	4	7.5	7.5	100.0
		-----	-----	-----	
Total		53	100.0	100.0	

Mean 1.528

Valid cases 53 Missing cases 0

**Number of years spent caregiving**

Value	Frequency	Percent	Valid Percent	Cum Percent
.03	2	3.8	3.8	3.8
.11	1	1.9	1.9	5.8
.12	1	1.9	1.9	7.7
1.00	3	5.7	5.8	13.5



1.40	1	1.9	1.9	15.4
1.50	3	5.7	5.8	21.2
2.00	3	5.7	5.8	26.9
3.00	4	7.5	7.7	34.6
3.50	2	3.8	3.8	38.5
4.00	6	11.3	11.5	50.0
5.00	8	15.1	15.4	65.4
7.00	3	5.7	5.8	71.2
8.00	2	3.8	3.8	75.0
9.00	2	3.8	3.8	78.8
10.00	4	7.5	7.7	86.5
12.00	2	3.8	3.8	90.4
13.00	1	1.9	1.9	92.3
15.00	1	1.9	1.9	94.2
16.00	1	1.9	1.9	96.2
19.00	1	1.9	1.9	98.1
25.00	1	1.9	1.9	100.0
.	1	1.9	Missing	
Total	53	100.0	100.0	

Mean 5.869

Valid cases 52 Missing cases 1

