

Role Strain and Perceived Needs:  
A Sample of Elderly Spouse Caregivers

by

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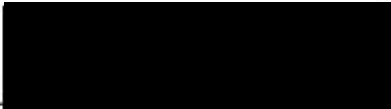
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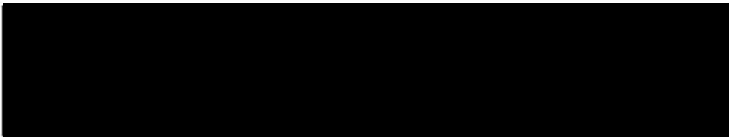
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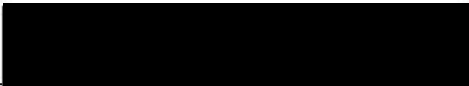
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## Chapter I

### Introduction

Families caring for their elderly members have received increased attention in recent years. This is due, in part, to the rise in the number and overall proportion of individuals aged 65 and over, a population trend that is expected to continue through the year 2050 (U. S. Bureau of the Census, 1984).

Another reason for the focus on family caregiving is the fact that as people age there is a dramatic increase in the likelihood that they will suffer some degree of physical and/or mental impairment (U. S. Department of Health, Education, & Welfare, 1978). With this increase in impairment there is a greater probability that the older person will require some level of assistance from his or her family. Family caregivers have been shown to play a significant role in preventing institutionalization of the impaired elderly person (Brody, Poulshock, & Mascioachi, 1978; Shanas, 1979). It is the elderly spouse who is frequently the primary caregiver (Johnson, 1983; Shanas et al., 1968).

This study examined the nature of the elderly spouse caregiver role in the caregiver-care receiver relationship. Specifically, the gender and the length of time caregiving were addressed as variables that



have potential effects upon new roles that develop, the phenomena of role strain, and the perceived needs of the caregiver for nursing care.

### Review of the Literature

A selective review of the literature was done on studies which relate to transition of the spouse caregiver. This literature is summarized in Table 1 according to the variables of gender, length of time caregiving, negative consequences of caregiving, and perceived needs. An overview of the caregiving literature, with particular emphasis on gender of the caregiver and length of time caregiving, will be provided. This overview will be followed by a review of studies of the negative consequences of caregiving, and the perceived needs of the caregiver in relationship to nursing.

### Overview of the Caregiving Literature

Gerontological, sociological, and psychological literature, as well as nursing literature, are addressed in this review. Nurse authors and researchers have contributed important work independently (Archbold, 1982; Worcester & Quayhagen, 1983) and collaboratively with other disciplines (Caserta, Lund, Wright, & Redburn, 1987; Chenoweth & Spencer, 1986; Fitting, Rabins, Lucas, & Eastham, 1986; Given, Collins, & Given, 1988). Sociologists and

Table 1

## A Chronological Review of the Caregiving Literature According to Variables of Interest

Study	Sample	Gender of Caregiving	Length of Time Caregiving	Negative Consequences of Caregiving	Perceived Needs
Shanas, Townsend, Wedderburn, Friis, Mijloh, & Stenouwer (1968)	National samples of approximately 2,500 persons aged 65 and older in each of the following countries: Denmark, Britain & United States. Area probability sampling used.	X			
Zarit, Reever, & Bach-Peterson (1980)	Non-randomized samples of 29 caregivers of persons with dementia. Majority of caregivers (n=25) were female and spouses (n=18).			X	
Johnson & Catalano (1981)	167 childless and non-childless elderly receiving family support.			X	
Cantor (1983)	111 low income elderly caregivers, including 37 spouses. Majority of caregivers were women.			X	
Johnson (1983)	Non-random sample of caregivers of 167 post-hospital stay persons aged 65 and over. Majority (55%) of caregivers were women.	X		X	
Robinson (1983)	Developed role strain index with a sample of 81 caregivers providing care to post-hospitalized patients aged 65 and over. Thirty-eight percent of caregivers were spouses.			X	
Archbold & Stewart (1984)	Developed a role strain measure for a study of 103 caregivers and their post-hospitalized care receivers.			X	
Ward, Sherman, & LaGory (1984)	1185 elderly aged 60 and over, 61% of whom were female.				X

Table 1 (continued)

Study	Sample	Gender of Caregiving	Length of Time Caregiving	Negative Consequences of Caregiving	Perceived Needs
Snyder & Keefe (1985)	117 caregivers to disabled and frail adults. Majority of sample were female spouses.		X		
Fitting, Rabins, Lucas, & Eastham (1986)	Non-random sample of spouse caregivers included 28 men and 26 women.	X		X	
George & Gwyther (1986)	Family caregivers (n=510) of older, memory-impaired adults. Majority (71%) were women.			X	
Zarit, Todd, & Zarit (1986)	Non-random sample of 46 husband and wife caregivers.	X		X	
Caserta, Lund, Wright, & Redburn (1987)	597 caregivers who were predominantly female and over age 60.				X
Haley, Levine, Brown, & Bartolucci (1987)	Non-random sample of 54 family caregivers of elderly parents with dementia. Eighty percent of caregivers were women, and 26% were spouses.			X	
Stone, Cafferata, & Sangl (1987)	Data drawn from informal caregivers survey, a component of 1982 National Long Term Care Survey.	X	X		
Sheenan & Nuttall (1988)	Non-random sample of 98 caregivers (86% of which were women) to elderly relatives. Majority of caregivers were female (80%) and adult children (n=75).			X	
Noelker & Bass (1987; 1989)	Data derived from a larger sample of 614 caregiving families. Quota sampling performed for substra of geographic area, rate, and generational configuration.				X
Quayhagen & Quayhagen (1988)	58 city dwelling family caregivers of Alzheimer's patients. Non-random sample included 43 spouse caregivers.	X		X	

psychologists have participated most extensively in the area of research regarding caregiving to older persons.

Although an abundance of caregiving research has occurred over the past decade, it is the work done over the past 20 years which is explored in order to show the evolution of our understanding of family caregiving. Early work focused on who family caregivers were (Shanas et al., 1968) and defined the family caregiver experience (Brody, 1981; Shanas, 1979; Treas, 1977). The components of caregiving, as experienced by different types of family caregivers, have also been explored (Archbold, 1982; Brody, Johnsen, Fulcomer, & Lang, 1983; Horowitz, 1985; Stoller, 1983). Finally, several studies have attempted to delineate the roles caregivers perform (Archbold, 1982; Clark & Rakowski, 1983; Horowitz, 1985).

The experiences and associated conflicts of adult children caring for a frail parent have been explored by several authors (Archbold, 1982; Horowitz, 1985; Stoller, 1983). This included the negative effects of caregiving (Fengler & Goodrich, 1979) which became identified as caregiver burden (Zarit, Reever, & Bach-Peterson, 1980), role strain (Cantor, 1983; George & Gwyther, 1986), and/or the stress of caregiving

(Quayhagen & Quayhagen, 1988). Pivotal work by Montgomery, Gonyea, and Hooyman (1985) further defined caregiver burden to include subjective and objective experiences. Several authors have developed scales to measure caregiver strain or burden (Montgomery et al., 1985; Poulshock & Deimling, 1984; Robinson, 1983; Zarit, Reever, & Bach-Peterson, 1980). Much of the study of burden has focused on caregivers of demented elderly persons (Caserta et al., 1987; Fitting et al., 1986; George & Gwyther, 1986; Zarit et al., 1980).

It must be noted, however, that role strain and caregiver burden are not clearly differentiated in the literature. Research has been done to describe the relationship between burden and role strain, chiefly by Poulshock and Deimling (1984), who see role strain as a component of caregiver burden. For purposes of this literature review, caregiver burden is viewed as the more global concept and role strain is seen as a specific aspect of burden. The majority of research has focused on burden. However, role strain is of primary interest to this investigator. The term "negative consequences of caregiving" is used as the umbrella term throughout this review of the literature.

A classic study was performed by Shanas and her colleagues (1968) which identified the hierarchical nature of family caregiving. They found that the

primary caregiver was usually a wife or, if the wife was not available, an adult daughter. In the absence of both, another relative assumed the major caregiver responsibility. Shanas (1979) refuted the myth that the elderly are alienated from their families, particularly their children.

The role of family caregivers has been illuminated by several authors. The reduced number of descendants to whom an older person may turn to for assistance has been identified as a factor that influences caregiving (Treas, 1977). The increasing number of older persons and the large-scale entry of women into the work force has been discussed in terms of the phenomenon of mid-life women caught in the middle of family needs (Brody, 1981). Subsequent work by Brody et al. (1983) indicated that older women had the least favorable attitudes toward equality in gender roles, but a large majority of all generations were in favor of sharing traditionally female tasks, such as child care, parent care, and household tasks. Stone, Cafferata, and Sangl (1987) confirmed the previous research findings that informal caregivers are predominantly female, that a sizeable proportion are over age 65, and a minority use formal services.

The caregiving experience has been shown to be a dynamic one. Stone et al. (1987) sampled a large

number of caregivers (N=2201) to develop a description of caregivers of the frail elderly in the United States. Forty-four percent of the caregivers had been caring for the care receiver for 1 to 4 years, 20% had been caregivers for 5 years or more, 18% for less than a year, and 16% were no longer caregiving by the time they were interviewed.

Another study which addressed the length of time the caregiver-care receiver relationship had been in effect was carried out by Snyder and Keefe (1985). These researchers found that over half of their sample had been caregivers for more than 5 years, and one-fourth had been caregivers for 2 to 5 years. The remaining caregivers reported a caregiving period of less than two years. A two-year follow-up on spouse caregivers of demented older persons found that only half of the care receivers were still at home with their caregiver. Recently, work has begun to address service knowledge (Ward, Sherman, & LaGory, 1984), utilization of community services (Caserta et al., 1987) and the unmet needs of the caregiver (Snyder & Keefe, 1985).

In summary, family caregiving to elderly members has received a great deal of empirical attention, particularly in the past decade. With the exploration of family caregiving, the phenomenon of caregiver role

strain, or burden, has been identified and described in depth. Also, the perceived needs and service awareness of the caregiver has begun to be explored. The elderly spouse caregiver, who is most often a woman, is involved in a dynamic interaction with the care receiver.

Literature relating to the variables of interest will be addressed in this review. These variables include gender of the caregiver, length of time caregiving, negative consequences of caregiving, and perceived needs. Since studies relating to gender of the caregiver and length of time caregiving were described in the overview, literature on the phenomenon of negative consequences of caregiving (NC of C) will be addressed next.

#### Exploration of the NC of C

A great deal of work has been done on burden experienced by caregivers of elderly persons. This section of the review will address studies on the NC of C, stress and the NC of C, other factors on the NC of C, caregiver gender and the NC of C.

Nature of NC of C. Three studies concerning the nature of the NC of C and caregiver burden will be reviewed. Cantor (1983) conducted a descriptive study of the impact of caregiving on the caregiver's life. Data was collected on a nonprobability sample of 111



low income elderly caregivers in New York City. A three-point scale to measure strain included emotional, physical, and financial concerns. Reliability and validity of the interview measure was not stated. Cantor found that the closer the bond between the caregiver and care receiver, the greater the amount of role strain.

From her analysis, Cantor (1983) proposed that spouses might be the highest risk caregiving group as opposed to caregiving children. Strain was found to be more likely associated with women (who were the majority of caregivers in the study) and with persons who were worried about the caregiving situation. Also, the more time and effort the caregivers spent in giving assistance, the more likely they experienced a resultant disruption and negative impact on their personal lives.

A second study addressed support systems in relation to their effect on role strain. Johnson and Catalano (1981) compared social support systems of a non-random sample of childless and nonchildless elderly (N=167). The interview schedule included measures of objective support, quality of help received, and extent of strain. Reliability and validity of the measures was not addressed. Content analysis of the subjective experiences of the caregivers was performed on the data

from the open-ended interviews. The investigators found that spouse caregivers provided more comprehensive care for a longer period of time with less strain as compared to adult child caregivers. It was the presence of a spouse, as opposed to a child, that prevented institutionalization.

A third study relating to the nature of caregiving was conducted by Zarit et al. (1980). They interviewed a non-randomized sample of caregivers of persons with dementia in order to identify sources of burden. The Kahn Mental Status Questionnaire (MSQ), Face Hand Test (FHT), Jacobs' Mental Status Test, and Lawton's Physical and Instrumental Activity of Daily Living Scales were administered to 58 caregivers and care receivers. The degree of burden was measured with a 29-item self-report inventory that was based on prior research and the clinical experience of the investigator. Only the validity of the MSQ and FHT were addressed. These researchers found that the frequency of family visits had an inverse effect upon the caregiver's feeling of burden. The severity of behavioral problems was not associated with higher levels of burden.

Both Robinson (1983) and Archbold and Stewart (1984) developed tools which measure role strain. A panel design methodological study was performed by

Robinson (1983) to validate questions used to detect strain in caregivers. Of the questions asked, 10 were identified in a previous survey study and 3 were formulated from a literature review. These questions were tested with 85 caregivers. Cronbach's alpha was calculated to assess internal consistency among the items, the coefficient alpha was .86. Construct validity was examined by analyzing the relationship between a number of criterion variables and the Caregiver Strain Index Score. Robinson found that neither gender of the caregiver, relationship of the caregiver to the care receiver, health of the caregiver, nor living arrangement of the caregiver were significantly related to caregiving strain scores. She concluded that this index could be used to predict caregivers at risk.

The interview schedule developed by Archbold and Stewart (1984) also addresses role strain. The tool draws from the literature and the existing instruments as well as the clinical experience of the investigators. It measures many dimensions of 18 constructs, one of which is caregiving role strain.

Archbold and Stewart (1988) addressed the following aspects of caregiver role strain: Role Strain related to Direct Care (reliability information not available), Role Strain from Caregiver Role

Expectations (alphas ranged from .45 -.53, average inter-item correlations ranged from .22-.30), Caregiver Role Strain from Lack of Resources (alphas ranged from .77-.78, average inter-item correlations ranged from .35-.36), Role Strain from Economic Burden (alphas ranged from .74-.77, average inter-item correlations ranged from .40-.49), Caregiver Role Strain from Worry (alphas ranged from .83-.84, average inter-item correlations ranged from .34-.36), Caregiver Role Strain from Tension in the Caregiver/Care Receiver Relationship (alphas ranged from .86-.91, average inter-item correlations ranged from .61-.71), Caregiver Role Strain from Role Conflict (internal consistency reliability not available), and Global Role Strain (alphas ranged from .76-.78, average inter-item correlations ranged from .45-.50). These researchers used an interview schedule made up of fixed response and open-ended questions.

Stress and NC of C. Three studies which address stress and NC of C will be reviewed next. George and Gwyther (1986) studied the physical and mental health, financial resources, and social participation of family caregivers ( $N=510$ ) of older memory-impaired adults. The majority of the persons (71%) in the sample were women. Most caregivers were either spouses or adult children ranging in age from 21 to 90.

The survey included multiple indicators for the four well-being dimensions: physical health, mental health, financial resources, and social participation. Physical health was measured by the number of physician visits in the past six months and self-rated health.

A checklist of psychiatric symptoms, a measure of affect, and a single-item measure of life satisfaction were used. The presence of psychotropic drug use during the past six months was obtained by caregiver report of medications taken. Pfeiffer's Short Psychiatric Evaluation Schedule was used to measure psychiatric symptoms associated with stress ( $\alpha=.85$ ) and Bradburn's Affect Scale was used to measure the ratio of positive to negative affect ( $\alpha=.89$ ). Financial resources were measured by household income and a multi-item scale measuring respondents' subjective assessments of their economic well-being ( $\alpha=.85$ ). Social participation was also measured using both objective and subjective measures. The subjective assessments were combined by the authors to form a scale measuring satisfaction with social activities ( $\alpha=.79$ ).

Compared to normative data, caregivers averaged nearly three times as many stress symptoms, had considerably lower levels of positive balance and life satisfaction, and reported substantially lower levels

of participation than the comparison samples for all the objective indicators of social activities except church attendance. Moreover, a substantially higher proportion of caregivers (28%) reported using psychotropic drugs than the comparison sample. All of the well-being indicators except one, the caregiver's number of doctor visits in the past six months, were significantly related to the perceived need for more social support. And, as expected for all of the significant relationships, those caregivers who did not need more social support reported higher well-being than those who desired more assistance from their friends and kin.

Another study which addressed stress and caregiver strain was conducted by Haley, Levine, Brown, and Bartolucci (1987). A total of 54 family caregivers of elderly dementia patients comprised the nonrandom sample. These caregivers completed interviews and questionnaires assessing the severity of patient impairment, caregiving stressors, caregiver appraisals, coping responses, social support and activity, and caregiver outcomes.

Stressors were measured by the Mini-Mental State Test, the Activities of Daily Living Scale, the Instrumental Activities of Daily Living Scale, a shortened version of the Memory and Behavior Problems

Checklist, and caregivers' report of the duration of patients' cognitive impairment and of the amount of the care receiver's care for which they were personally responsible. The caregivers also provided subjective appraisals for each stressor they identified. The Health and Daily Living Form was used to measure coping responses and social support and activity. Reliability and validity of these measures was not addressed.

Caregiver outcomes were measured with the Beck Depression Inventory, which they reported as having good reliability and validity. The researchers also used the Life Satisfaction Index-Form Z, which they reported has good validity, and a Self-Health Rating Scale, which they reported has a strong correlation with objective measures of health and ability to predict caregiver mortality.

The stressors showed little relation to outcome variables, other than a significant positive relationship between patient impairment on the Instrumental Activities of Daily Living Scale and caregiver depression scores. Demographic variables also showed little relation to caregiver outcome, although older individuals reported poorer health.

Measures of caregiver appraisal and coping responses were consistently related to caregiver outcome. A caregiver's appraisal of the patients'

behavioral problems and disability as highly stressful, and appraisals of him/herself as lacking in self-efficacy to manage these problems, were significantly related to higher levels of caregiver depression. The coping response scales were also consistently related to caregiver outcome. Information seeking was related to better health outcome, and consistency in affect was related to better outcome on both health and life satisfaction, while emotional discharge was related to higher levels of caregiver depression. The relative weakness of the relationship between the severity of objective caregiving stressors and caregiver outcomes was consistent with prior published findings (Zarit et al., 1980).

Other factors influencing the NC of C. Sheenan and Nuttall (1988) examined the influence of interpersonal conflict, affection, and distress concerning dependency and caregiving satisfactions in predicting caregiver strain. A non-randomized sample of 98, predominantly female (86%), family caregivers to impaired elderly relatives were accessed. The questionnaire was self-administered and was repeated in six months. This measurement tool included an Activity of Daily Living Scale, a Memory and Behavior Problems checklist, and scales which assessed the caregiver's reaction to the elder's impairment. In addition, three



subscales of the Hopkins Symptom Checklist, a scale of Psychological Problems of the Caregiver, an Affection and Satisfaction with Caregiving and Interpersonal Conflict Scale, and a Personal Strain and Negative Emotion Scale, were administered. Reliability and validity of these measures was not addressed.

Caregivers providing greater amounts of care reported more strain in their role,  $r=.28$ ,  $p < .007$ . However, the use of formal services to supplement the care provided was unrelated to caregiver strain. Overall, the variables most strongly associated with negative emotions were all of the subjective factors (e.g., conflict, affection, satisfaction with caregiving). The measures of objective impairment, the Activities of Daily Living, and the Memory and Behavior Problems scales, were associated with greater negative affect. Also, the strength of their association was weaker than that of subjective factors.

The results of the study support the conclusions from previous investigations which highlight the important role that subjective factors play in explaining the negative consequences of caregiving. Together these findings support Brody's (1985) conclusion that the problems associated with caregiving largely reflect the interpersonal and intrapsychic tensions of the caregiving situation.

In summary, it is clear from this review of literature that the NC of C, or role strain and burden, has been identified in family caregiving situations. It is not clear, however, which family caregivers experience the most NC of C. The next section will describe the literature which has attempted to identify the relationship of caregiver gender to the negative consequences of caregiving.

#### Caregiver gender and the NC of C

Three studies regarding gender and role strain will be discussed next. Johnson (1983) non-randomly sampled 167 post-hospital individuals aged 65 years and older. The majority of these caregivers were women (55%). She found that the most comprehensive and unstressful support was provided by the spouse. Caregiving husbands were reported as having less strain, and were more likely to seek formal assistance regarding care provision than wives. Johnson attributed this finding to the husbands' low involvement in domestic activity. She suggested that shared functions between relatives may be more common when males are caregivers.

A two-year longitudinal study was performed by Zarit, Todd, and Zarit (1986) on a non-random sample of husbands and wives who were caregivers for a spouse with dementia. The purpose was to identify factors affecting the course of caregiving, especially the

decision to institutionalize, and to determine if differences between husbands and wives found at the initial testing remained stable over time. The sample in the original study was comprised of 33 wives and 31 husbands who were caring for their spouses. At the two-year follow-up interview, 43 caregivers remained in the study. The interview was comprised of measures given to subjects at Time 1, along with a series of questions for caregivers who had placed their relative in a nursing home. Items from Zarit et al.'s (1980) Burden Interview, for which adequate reliability and validity was reported, were used.

Time 1 burden scores were compared for subjects who had placed their spouse in a nursing home and those who had kept the care receiver at home. Initial burden was significantly higher for those caregivers who had placed the care receiver in a nursing home  $t(42) = 2.23, p < .05$ ). The correlation between the mental status score and burden was in the opposite direction than expected; when care receivers made more logical responses caregivers reported more burden. Burden experienced by women decreased significantly from time 1 scores  $t(16) = 4.31, p < .001$ ). The women who had placed their spouse scored higher on the burden measures at time 1 than time 2. Additionally, men and women who had placed their spouse in a nursing home

reported significantly more tolerance for memory and behavior problems (Men,  $t(19) = 2.87$ ,  $p < .010$ ; Women,  $t(16) = 4.07$ ,  $p < .001$ ).

These findings suggest that the caregivers' ability to cope with problem behaviors actually increased over time, even as the disease progressed. Although the husband caregivers reported less burden than did wives at Time 1, this difference was no longer apparent in the two-year follow-up.

Gender and role strain was also examined by Fitting et al. (1986). They compared spouse caregivers of persons with dementia on measures of burden, family environment, social networks, psychological adjustment, demographic data, and feeling about the dementing illness. The non-random sample included 28 men and 26 women. Zarit et al.'s (1980) Burden Interview was used, with no reliability or validity information described. The male and female caregivers did not differ significantly on their burden. Two-way analysis of variance using sex and age of caregivers as independent variables yielded no statistically significant results.

Although each of these three studies included nearly equivalent numbers of male and female caregivers, their findings were inconclusive. Johnson (1983) found statistically significant differences

according to gender, while Zarit et al. (1980) and Fitting et al. (1986) did not find differences according to gender for caregivers to elderly spouses with dementia.

Caregiver stress and gender were two of the variables explored in a study of families of Alzheimer's patients by Quayhagen and Quayhagen (1988). Of the sample of 58 caregivers, 74% were spouses, with more wives ( $n=26$ ) than husbands ( $n=17$ ). These researchers analyzed coping patterns, management stimulation strategies, support factors, and the interrelationship of these variables within three caregiver groups (i.e., male spouses, female spouses, and adult children).

Well being was assessed according to life satisfaction, perceived physical health, and emotional health. The three measures used to assess well being included the 13-item Life Satisfaction Index Z, and a global self-rating scale to measure perceived physical and emotional health. The intercorrelations among these three well-being scales ranged from .48 to .60, with a standard coefficient alpha of .79.

Caregiver stress was measured by the Memory and Behavior Problems Checklist ( $\alpha=.78$ ). Coping was assessed by a modified version of the Coping Strategies Inventory which had Cronbach's alpha coefficients

ranging from .57 to .79. A taxonomy of cognitively stimulating activities for the patient was used to assess the management strategies of the caregiver. Reliability and validity information for this measure was not reported.

Caregiver respite time was measured by the number of hours per week that the family caregiver was free of direct family responsibility for the dementia patient. A modified form of Cohen's Dimensions of Social Support Scale was used to measure emotional and informational support received from family, friends, and colleagues (alphas=.95 and .81, respectively; interscale correlation=.85).

The three caregiver groups differed in the type of behaviors they found stressful. More wives ( $M=84.6\%$ ) than husbands ( $M=53.0\%$ ) or daughters (53.3%) found embarrassing acts of the care receiver stressful. A large majority of the daughters (93.3%) found bathing the care receiver stressful, but this was less so for husbands (58.8%) and wives (57.7%). The care receiver's difficulty in staying alone was also a problem for more daughters (93.3%) than for husbands (58.8%) or wives (46.2%). Significant chi square results were found for each of these relationships. Care receiver behaviors found to be stressful for all three groups of family caregivers also included

incontinence, asking repetitive questions, difficulty cooking, and handling money.

Perceived needs of the spouse caregiver will be addressed next as it is an additional variable of interest in this study. Four articles relating to caregiver needs will be explored in this section.

#### Perceived Needs of the Caregiver

First, two studies will be addressed which focused on caregiver identification of a need for assistance with the caregiving role. Snyder and Keefe (1985) examined the needs for additional social service programs associated with family caregiving. They sampled 117 caregivers for disabled and frail adults who were accessed through support-type organizations. Three-fourths of the caregivers were spouses. A 21-item self-report questionnaire was designed to elicit information about the caregiver and the care receiver. A three-point Likert scale was constructed to determine the functional level of the disabled adult. Almost 70% of the caregivers reported that their health had been negatively affected because of their caregiving responsibilities.

A statistically significant relationship was found between the level of disability of the disabled adult and the presence of health problems in the caregiver,  $r=13$ ,  $p<.01$ . Also, the longer the persons had been

caregiving the more they reported health problems,  $r=.13$ ,  $p<.10$ . The longer persons had been caregiving the more likely they were to receive assistance from family members and friends,  $r=.14$ ,  $p<.10$ . More than 90% of caregivers indicated the need for respite from caregiving.

Two thirds of the caregivers in the sample had used home health services and 80% reported receiving at least one type of social service. However, data revealed that caregivers who had been caregiving for the longest were the least likely to report receiving social services,  $r=-.26$ ,  $p<.01$ .

Limitations to the study were the fact that the majority of the caregivers in the sample lived in a large metropolitan area which was rich in social services. Also, many of the caregivers were already connected with programs which serve the needs of family caregivers. Hence, the caregivers in the sample may have been more sophisticated in their knowledge and use of social services than the average caregiver and more likely to use supportive social services due to their proximity to the metro area. Problems associated with the self-report method for data collection may further limit the reliability of the study.

The needs of caregivers of dementia victims were studied by Caserta et al. (1987). The caregivers



(N=597) were predominately female, married, white and over 60 years of age. The measurement tools included questions concerning the identification by caregivers of community services.

Respite-oriented services were perceived as the most needed and also most utilized. Both the need and the ill person's level of impairment played a role in whether or not services (when known to be available) were utilized. The level of caregiver burden was also related to utilization of services. Those who were not yet ready to utilize community services had lower burden scores while the other non-utilizers reported burden levels similar to utilizers.

These findings might not be replicated in studies which also sample caregivers who do not already use some sort of social service. Additionally, the types of services the caregivers used and expressed an interest in were related to the specific needs of caregivers of persons with dementia, such as respite and day care services. These services are particularly helpful in relieving the caregiver of stress related to management of behavioral problems of the care receiver with dementia.

The impact of service utilization and service discontinuance for family caregivers of the frail elderly is related to the subject of perceived needs.

Montgomery et al. (1985) collected data approximately one year after a change in state policy. The change had involved the loss of in-home chore services. The impact on families providing care for older relatives was addressed. These researchers found that the presence or absence of chore services was not significantly associated with the extent of caregiver involvement. They pointed out, however, that an assessment of impact of any single service is not adequate without examining the overall context of service utilization.

Another area related to the perceived needs of the spouse caregiver is knowledge of available services. Ward et al. (1984) investigated the association between informal ties and service knowledge in a large sample ( $N=1185$ ) aged 60 and over. The questionnaire used was developed for the study. Also, the 17-item Philadelphia Geriatric Center Morale scale was used as a general measure of subjective well-being ( $M=51.9$ ,  $SD=9.2$ , range=23-68, Cronbach's  $\alpha=.85$ ). The findings indicated that the more financially, educationally, and occupationally advantaged subjects were somewhat more knowledgeable about services. The media was found to be the most common source of information. Few respondents were found to use telephone or visiting services, meal programs, legal

services, visiting nurses or home health aides, or special transportation programs. Of these five itemized services, nursing services were used most (9%). Specific nursing needs were not addressed.

In summary, the studies by Montgomery et al. (1984) and Ward et al. (1984) indicate the relationship of caregiver roles to the caregiver's perception of needs. How perceived needs of the caregiver could be met through formal services, as well as the adequacy of services provided were addressed by these studies.

Factors related to causation of caregiver need for services were explored in two studies which used subsamples of a large data set (Bass & Noelker, 1987; Noelker & Bass, 1989). Both studies sought to expand on the Andersen model of service use. Quota sampling was used, and both subsamples included an approximately equal number of spouses to adult children, and men to women.

Research by Bass and Noelker (1987) addressed the predisposing, enabling, and need characteristics of both the primary caregiver ( $N=586$ ) and the elderly care receiver. The two measures of service use included asking the primary caregiver about the use of in-home nursing or aide service during the past six months for specific tasks, and asking the primary caregiver about the number of hours a week that nursing and aide

services were used for 14 tasks.

Predictors of service included household income, sex, age, and relationship to the elder. In addition, three dimensions of family support for caregiving were included. These were a four-item index of the caregiver's perception of how close and supportive family members are to each other ( $\alpha=.80$ ), the number of health care tasks with which other family members assist the elder, and the number of family members and friends who assisted the elder with personal care. Three variables were used to measure caregiver need, including a five-item index of reported activity restrictions due to caregiving ( $\alpha=.80$ ), whether the caregiver perceived a change in his or her physical health because of caregiving, and an additive measure of caregiving burden.

Noelker and Bass (1987) found that the use of in-home nursing or aide services for the elderly was related to high care-related stress effects in the primary caregiver. Also, enabling factors and elder-caregiver predisposing factors also had some effect. The amount or volume of service use, however, was determined largely by the enabling factors, especially household income, while elder need characteristics contributed little to explaining the amount of service use.

In the second study, Noelker and Bass (1989) categorized caregivers ( $N=519$ ) according to the type of service provider use by the caregiver. Family caregivers were categorized according to the following: dual specialization (caregivers and service providers assisting with completely separate tasks), supplementation (from formal service providers), kin independent (where no formal help was used), and formal service specialization (where the service was sole provider in at least one task).

Predictor variables included predisposing factors (care recipient's age and race, caregiver's gender and age); enabling factors (including household income, family support, and number of family and friend helpers); care recipient need (including incontinence, number of chronic conditions, paralysis, and diagnosed mental impairment); and caregiver need, including a five item index of restrictions ( $\alpha=.80$ ) and change in physical health and task burden ( $\alpha=.70$ ).

Kin independence was found to be predicted by lower levels of physical impairment in the care recipient and care-related health change in the primary caregiver. However, higher levels of physical impairment and care-related health change were predictive of formal service specialization. Female caregivers and those reporting decreased socialization

because of caregiving were more commonly found in the supplementation type. Dual specialization was more characteristic of male (husband) primary caregivers, those with higher care-related stress, and care recipients who were less functionally impaired.

These two studies contribute to our understanding of the predictors of caregiver service use, particularly according to caregiver gender. However, whether these patterns of service use are stable over length of time caregiving was not addressed.

#### Conclusion

When an elderly person becomes ill, the family provides the majority of care. It is the spouse who frequently provides that care. Caregiving can have negative consequences, including role burden or strain. These negative consequences have profound effects on the caregivers, especially on spouses, who are usually elderly and may also have impaired health. It is not clear whether there are differences in caregiving role strain based on the gender of spouse caregivers.

This study examined the relationship between gender and length of time caregiving on the role strain experienced by caregivers to elderly spouse. The effects of these two variables on caregiver role strain and perceived needs were also explored.

### Conceptual Framework

The transition of the elderly husband and wife into the caregiver-care receiver relationship is described using role theory. A component of this theory, role strain, is also addressed since it describes the potential negative effects of this relationship. The perceived needs of the caregiving spouse are, in part, based on his or her role strain. These needs indicate potential areas for nursing intervention.

#### Role Theory

The conceptual framework is based on the interactionist approach to role theory. From this perspective, role refers to a set of behaviors which emerge from the interaction of the individual in a social system (Lindesmith & Strauss, 1968; Turner, 1956).

Role incumbent is defined as the person who is enacting a particular role. The counterrole incumbent or significant other is the person who interacts with the role incumbent around a particular role. The interactionist framework stresses the reciprocal interrelationships between roles as each person adjusts his or her behavior and reactions to what he or she thinks the other is going to do. Role, in this sense, is conceptualized as a way of coping with an implied

other role (Turner, 1956) or as a relationship between what we do and what others do (Lindesmith & Strauss, 1968).

In its social interactive context, a role requires a counterrole to reinforce and complement it. Changes in one person's role necessitate complimentary and reciprocal changes in significant others roles. Conversely, any role transition by significant others requires changes in the role incumbent's roles also.

The stability of the interaction is influenced by the degree of role reciprocity. Reciprocity implies that the person in the counterrole also has obligations to the role incumbent. The roles are interdependent, and each role incumbent has rights and duties in relation to the other. Gouldner (1960) states that reciprocity is a mutually gratifying pattern of exchange. What one individual receives from the other requires some return, so that giving and receiving are mutual acts.

Role development is a dynamic interactive process. In this framework, roles are not learned singly, but rather in pairs or sets. Merton (1957) defines a role set as an ensemble of roles comprising the functional relationship of all roles that an individual carries out at one time. For instance, a caregiver may also perform wife, mother, and neighbor roles.



Sarbin (1968) identified six antecedents to effective and valid role enactment. First, the person must learn the role expectation, or the obligations, privileges, rights, and duties of the position he or she occupies. Secondly, the individual must be able to position him or herself accurately in the role structure, or social situation. This depends on his or her ability to identify and interpret cues arising from the behavior of others. Once the person enacts a role, role demands or constraints on the choice of role behaviors are introduced. These demands are rooted in cultural norms, and their violation may carry heavy sanctions. The fourth antecedent to effective role enactment is the role-taking aptitude, or the degree of motor and cognitive skills the individual has acquired to facilitate role enactment. Consistency of the characteristics of the self and of the role also help determine the effectiveness of role enactment. Finally, reinforcement properties of the audience are antecedents to role enactment. Audiences serve two functions: providing cues helpful to the person in locating his/her role and providing social reinforcements or sanctions.

The processes involved in the role development described above occur throughout the lifetime of the individual. They are particularly evident when the

individual experiences role transitions, which are the movement into or out of roles in a social system. Meleis (1975) points out that role transition represents a change in role relationships, expectations, or abilities. Role transition requires the individual to incorporate new knowledge, alter his or her behavior and thereby change his or her definition of him or herself in the social context (Meleis, 1975). Role transitions may mean the acquisition of a new role, the loss of a role or the concurrent loss and acquisition of roles.

Thornton and Nardi (1975) state that role acquisition is a developmental process and involves an increasing awareness of implicit as well as explicit expectations. These expectations encompass attitudes, values, knowledge and skills in addition to behavior. Until such awareness and knowledge is obtained, the individual acquiring the new role may have difficulty in the conceptualization and/or performance of a role. Meleis (1975) uses the term role insufficiency to describe behavior and sentiments affiliated with any felt disparity in fulfilling role obligations or expectations of self and/or significant others in the situation. Role insufficiency may result from poor role definition, the inner dynamics of role relationships, or merely from inadequate knowledge of

role behaviors, sentiments or goals.

### Role Strain

Role strain, according to Goode (1960), is the difficulty in performing obligations associated with a role. It has been defined as the negative consequences of performing a role, and is a potential occurrence in the caregiving situation. The individual who is subjected to stress will attempt to utilize personal resources and problem-solving processes to manage the environment and decrease role strain (Kahn, 1978). If a negative experience occurs and strain ensues which is not reduced, other adaptive responses may be employed. Role conflict develops when role expectations are incompatible with available resources for their fulfillment or incompatible with the individual's own values and beliefs about what is appropriate to the roles (Kahn, 1978)

The concept of person-environment fit was proposed by French, Rodgers, and Cobb (1974). The concept is defined as goodness of fit between the needs of the person and the supplies of the person's environment, and between the abilities of the person and the demands of the environment. The basic premise of this concept is that an inadequate fit between the individual and situational characteristics will lead the individual to be dissatisfied with his or her roles. In the case of

the caregiver, he or she may then demonstrate symptoms of strain and ill health.

#### Perceived Needs of the Caregiver

Needs are the human requirements calling for a response that makes human survival and development possible in a given society (Masini, 1980). Boettcher (1985) proposes that wellness in late adulthood is enhanced by an expanded awareness of needs and the location of means to satisfy those needs. Primary and formal groups are identified as need satisfiers which change in order to adapt to evolving needs. The goal is improved dignity and quality of life for the elderly when access to resources is readily available.

The needs the caregiver perceived as necessary to adequately care for the care receiver were addressed in this study. The identification of the caregiver's perceived needs that provides direction for nursing care in the arrangement of supportive services for the family.

#### Transition in the Marital Relationship

The transition of the elderly spouse into the caregiver role is depicted in Figure 1. During the initial phase the marital dyad is functioning in an established pattern. Most often the couple is post-retirement, and they have settled into patterns of behavior which usually are not disrupted by demands

such as employment and parenting. Frequently, the couple has been in the relationship for a long period of time. The marriage has often created a system of specialized knowledge and skills (Green, Osterweis, & Solomon, 1984). Family roles have become established, and the expectations and performances have become integrated to the point that the individuals have become comfortable with them (Goode, 1960).

At some point, for medical reasons, one spouse may require assistance and support. This period is termed destabilization (see Figure 1). Deterioration of a chronic illness, acute exacerbation of an illness, or onset of a life-threatening illness may be causes of the spouse's debilitation. The impaired spouse's illness renders him or her unable to continue to carry out all of the roles he or she had previously been able to do. When the other spouse, who is the "healthier" of the two, takes on the caregiver role the caregiver-care receiver relationship begins. The destabilization period often brings with it a transition in the enactment of previous roles and the assumption of new roles by the spouse caregiver.

At this time, the pre-established roles and functions carried out by both members undergo reorganization. Who performs which of the roles changes, and new roles develop. The reassignment of

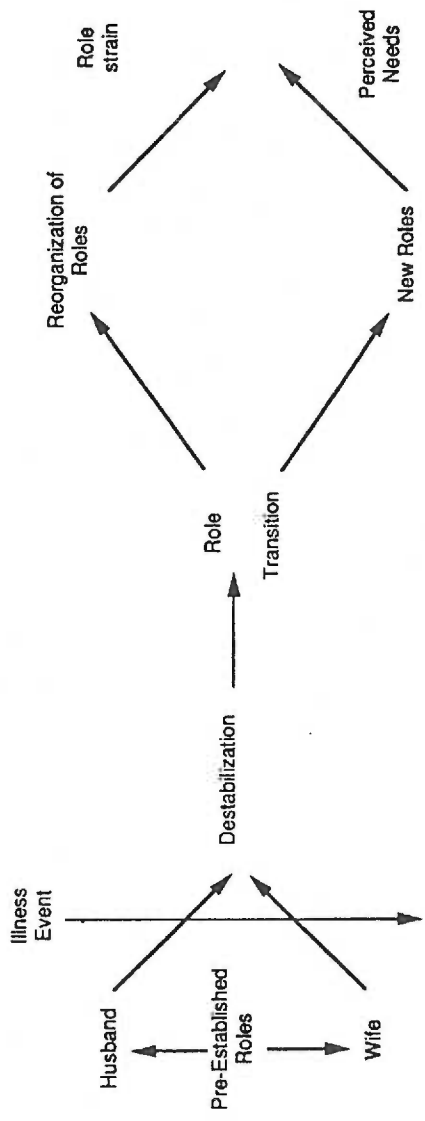


Figure 1. Transition in the Elderly Marital Relationship

roles and the acquisition of new roles may result in difficulty in performing these many obligations. The result may be the subjective experience of role strain. Additionally, the caregiver may perceive areas where he or she needs assistance from outside of the dyad to fulfill his or her role obligations (see Figure 1).

Roles have been operationalized in a variety of ways. The work of Bowers (1987) served as the foundation for operationalizing roles in this conceptual framework. Bowers categorized these roles as: anticipatory, preventive, supervisory, instrumental, and protective. This classification can be applied to the activities and behaviors of the marital dyad throughout the pre-event period to the adjustment to the illness of the impaired spouse. A description of Bower's definition of each category is included in Table 2.

Prior to the illness event, these behaviors or roles might be performed by either or both of the spouses. Anticipatory behavior involves decisions or behaviors based on potential needs of the other spouse. This includes the shared understandings of the others' needs which do not require verbal verification. The preventive behaviors are directed at health promotion and prevention of illness, injury, and deterioration in physical and mental statuses. Supervisory activities

Table 2

An Application of Bowers' (1987) Caregiver Behaviors to Elderly Spouses

Category	Bowers' Example	Pre-illness Phase	Post-illness Phase
Anticipatory	Caregiver avoids shared understandings with care receiver, anticipates possible needs. Mental event or perception.	Eg: Unspoken desire of wife to live close to medical center "just in case".	Eg: Wife decides not to carry out previous plans to do volunteer work due to concern over leaving ill husband alone.
Preventive	Caregiver focuses on preventing illness injury, complication, and physical and mental deterioration in the care receiver.	Eg: Husband insists that his wife have monthly blood pressure monitoring at local senior center.	Eg: Husband places grab bar on bath tub to prevent his disabled wife from falling while bathing.
Supervisory	Active and direct involvement of the caregiver. Includes "arranging for, checking up, making sure, setting up, and checking out" behaviors. May be done with or without the care receiver's awareness.	Eg: Wife prepares a meal ahead of time for her husband when she knows she will not be home in time for supper.	Eg: Wife sets up medications and makes sure her husband takes them on time.
Instrumental	Hands-on caregiving. Includes "assisting, providing, and giving". Purpose is to maintain the care receiver's physical integrity and health status.	Eg: Husband drives for his wife whenever she has errands to run.	Eg: Husband bathes his ill wife every morning.
Protective	Caregiver protects care receiver from that which was not or could not be prevented. Caregiver prevents threats to care receiver's self image; prevents him or her from awareness that he or she is being taken care of.	Eg: Wife commends husband for attempting to fix leaking pipes even though he was unsuccessful.	Eg: Wife does not tell her husband about his repeated urinary incontinence at bedtime.



include making arrangements for, checking up on, and setting things up for the other spouse. The instrumental functions of the individuals include all the tasks of daily living involved in maintaining current function, such as personal hygiene, house upkeep, food preparation and consumption, transportation, and socialization. Examples of the five categories are provided in Table 2.

### Research Questions

The research questions are derived from the review of the literature and the conceptual framework.

1. What changes occur in the assignment of preestablished roles when the caregiver-care receiver relationship is assumed? Are there differences according to the gender of the caregiver, the length of time caregiving and/or according to the interaction between gender and length of time caregiving?
2. What is the degree of caregiver role strain? Are there differences according to the gender of the caregiver, the length of time caregiving, and/or according to the interaction between gender and length of time caregiving?
3. What are the perceived needs of the caregiver with the assumption of the caregiver-care receiver relationship? Are there differences according to the gender of the caregiver, to the length of time caregiving and/or according to the interaction between gender and length of time caregiving?

## Chapter II

### Methods

A descriptive design was used to examine the relationship between gender and length of time caregiving to roles, role strain, and perceived needs of the caregiver. A one time interview was conducted with a convenience sample ( $N=29$ ) of caregivers to frail older persons. A description of the sample, interview guide, and procedures for identifying subjects and securing subjects follows.

#### Sample

Subjects were identified between September, 1988 and February, 1989 through a university affiliated medical center (i.e., inpatient units and an out-patient family practice clinic), two community hospitals (i.e., a home health agency, and a caregiver education and support program), and through an ad in a senior newspaper.

The original plan was to secure 10 subjects in each of four groups: husbands caring for their wives less than 6 months, husbands caring for their wives more than 6 months, wives caring for their husbands less than 6 months, and wives caring for their husbands more than 6 months. Due to time constraints and the difficulties experienced in securing subjects the project was stopped after 4 months of data collection.

Subjects included 4 husbands caring for their wives for three years or less, 5 husbands caring for their wives more than three years, 11 wives caring for their husbands three years or less, and 9 wives caring for their husbands more than three years.

Demographic information on the caregivers and care receivers is provided in Table 3. Overall, the average caregiver's and care receiver's ages were in their early 70's and their marriages were long term. Generally, while care receivers' illnesses had spanned several years, subjects had been caregivers for a shorter period of time.

Male and female caregivers differed according to several demographic variables, although the differences were not significant as measured using t-tests. Female caregivers were older than their male counterparts ( $\bar{M}=73.05$ ,  $SD=9.16$ , and  $\bar{M}=68.56$ ,  $SD=7.65$ , respectively), were married longer ( $\bar{M}=41.25$ ,  $SD=11.58$ , and  $\bar{M}=37.33$ ,  $SD=13.27$ , respectively), and had been caregivers for a longer period of time ( $\bar{M}=87.40$ ,  $SD=114.09$ , and  $\bar{M}=59.56$ ,  $SD=52.09$ , respectively).

The length of time the subject had been a caregiver also affected these demographic variables, although the differences were not significant as measured using t-tests. Subjects who had been caregivers for three years or less were older than

**Table 3****Demographic Information**

Category	$\bar{x}$	sd	range
Age			
Caregiver	71.66	8.84	60–90
Care receiver	74.38	9.60	56–92
Years married	40.03	12.03	12–65
Length of care receiver illness ( <i>in months</i> )	109.31	118.37	4–492
Length of time caregiving ( <i>in months</i> )	78.41	99.15	2–422

those who had been caregivers for more than three years ( $M=72.47$ ,  $SD=9.64$ , and  $M=70.79$ ,  $SD=8.16$ , respectively), but they had not been married as long as the latter group ( $M=37.13$ ,  $SD=13.42$ , and  $M=43.14$ ,  $SD=9.89$ , respectively).

### Interview Guide

The interview guide included background data regarding the caregiver and care receiver (see Appendix A). Role transition for the caregiver spouse was measured through closed ended questions. An existing measure of role strain (Robinson, 1983) and a modified version of the interview guide developed by Archbold and Stewart (1984) were used. Finally, an additional modification of Archbold and Stewart's interview guide measured service use and perceived needs of the caregiver. Open ended questions were also used to expand on the modified scale. The interview guide was pilot tested on two persons who meet the criteria for inclusion in to study to assess the clarity and accuracy of the questions and to confirm the time it took to complete the guide.

Background data. Demographic and illness-related data including age, marital status, living arrangements, and information related to diagnoses of the care receiver were collected from clinic or agency records when available. This information was obtained

from the caregiver at the beginning of the interview if the information was not available in the patient records.

Role transition. Questions were developed by the researcher to measure the transition from preestablished roles to the reorganization of roles and acquisition of new roles. These items addressed the kinds of behaviors that either spouse carried out prior to and after the onset of the caregiver-care receiver relationship. They were categorized according to Bowers' (1987) caregiver behaviors and include instrumental, anticipatory, preventive, supervisory and protective behaviors. The operationalization of the caregiver behaviors for the purposes of this study were evaluated for face validity by four gerontological nurses.

The instrumental behaviors, labeled caregiver tasks, were measured with a modified version of Archbold and Stewart's (1988) Direct Care Scale. The scale contained 38 items arranged into eight subscales: personal care; housekeeping; protection; transportation; financial, legal and health decisions; handling of behavior problems; medically related behaviors; and behaviors related to providing little extras. Average inter-item correlations and coefficient alphas for the subscales were calculated

for data collected by Archbold and Stewart at six weeks ( $N=103$ ), six months ( $n=98$ ), and nine month ( $n=94$ ) after the hospitalization which triggered the caregiver-care receiver relationship. At Time 1, the inter-item correlations were as follows: personal care .81-.84; housekeeping .69-.78; protection .65-.66; transportation .41-.55; financial, legal, and health decision making .66-.67; behavior problems .67-.71; medically related .31-.56; and, little extras .43-.44. The coefficient alphas for the Direct Care Scale at Time 1 and Time 3 were .86 (Archbold & Stewart, 1988).

The questions regarding caregiving tasks first asked who did each specific task (caregiver, other, and/or care receiver), and the item was scored according to whether each of the persons performed the task (yes=1, no=0, or not applicable=-9). Next the caregiver was asked whether he or she performed the role prior to becoming a caregiver (yes=1, no=0), another person performed the role (yes=1, no=0), or whether it was not applicable (-9).

Change scores were computed by subtracting the current caregiver performance score from the past caregiver performance score. Therefore, loss of a role was indicated by a positive number, addition of a role was indicated by a negative number, and no change in role performance was indicated by a zero.



Open ended questions for each of the anticipatory, preventive, supervisory, and protective behaviors were asked after an example of each behavior was described (see Appendix A). A score (yes=1, no=0) was derived from the question asking whether the caregiver noted a change in performance of each behavior.

Role strain. Robinson's (1983) Caregiver Strain Index (CSI), which was developed for a face-to-face interview, was adapted for use in this study for telephone interviews. This tool was chosen because it is brief and easy to use. The 13 items addressed the caregivers' perception of difficulties in helping the impaired spouse at the time of the interview. The caregiver is asked whether he or she experiences the stressor (yes=1, no=0).

Robinson (1983) reported the Cronbach's alpha coefficient as .86 for a sample of 81 caregivers between the ages of 22 to 83. The scale was also internally consistent (alpha=.83) for the spouse caregivers ( $n=31$ ). Robinson also obtained evidence of construct validity in three areas: ex-patient characteristics, subject perceptions of care-taking relationship by the caregivers, and emotional health of caregivers. Robinson proposed that positive responses to seven or more items on the index would indicate a greater level of stress.

The Cronbach's alpha for the CSI was .68 and the average inter-item correlation was .148 when computed for this study's sample (N=29). The Cronbach's alpha increased slightly if either the item measuring sleep (alpha=.70) or work adjustment (alpha=.68) was deleted.

Perceived needs. Perceived needs were measured with a modified version of Archbold and Stewart's (1988) Help in Caregiving Index. The measure included a closed and open ended questions, and a list of potential services.

The first closed end question asked whether there was some kind of help the caregiver would like to have in the home (scored: yes=1 and no=0), and an open ended question was used to allow the caregiver to elaborate if the response was yes.

The caregiver's perception of what was necessary to provide assistance to the care receiver was also measured. The caregiver was asked which of a list of services she or he was using (yes=1 and no=0), and which services he or she had used in the past 18 months. The list of services was based on the work of Archbold and Stewart (1988). Reliability and validity data was not available. Definitions of the services were included in the interview guide in case the subject needed an explanation of a particular service.

The final close ended questions addressed nursing

services the caregiver thought he or she could have used. When the caregivers responded yes to a question, then an open ended question allowed the subject to elaborate.

### Procedure

The procedure is described in terms of the methods for identifying potential subjects and the methods for securing participation. All procedures were carried out by the researcher, with assistance from hospital and agency staff where mentioned.

Identifying potential subjects. Criteria for inclusion of an elderly spouse caregiver in the study included that he or she: was the primary caregiver for a spouse who resided in the same home, provided the impaired spouse with assistance with two or more activities of daily living, and lived within 40 miles of the researcher. All persons who met these criteria and were willing and able to participate were interviewed.

Initially, subjects were going to be obtained through discharge planners at the university affiliated medical center (UAMC). Although two elderly patients and their spouses were identified as potential subjects during a five week period, they did not meet criteria for inclusion. The researcher then identified potential subjects through the UAMC out-patient family

practice clinic, a caregiver education and support program, a home care agency, and the senior community at large. Due to the diversity in agencies utilized to secure subjects, the methods for identification of potential subjects also varied (see Table 4 for a description of the procedures used).

In the family practice clinic, potential subjects were identified by computer search, followed by a chart review to assess whether the caregiver met study criteria. The one subject identified was sent an initial contact letter (see Appendix B) and subsequently consented to participate.

Staff nurses at the home care agency assisted the researcher in identification of spouse caregivers who met the study criteria. An initial contact letter (see Appendix B) was sent out to 26 caregivers to establish contact and to describe the nature and purpose of the study. The letter also notified the subject that he or she would receive a phone call within seven days for arrangement of the interview. Of these 26 potential subjects, 11 consented to participate. The reasons given for not participating included: time constraints ( $n=11$ ), not meeting the study criteria ( $n=2$ ), and unreachable by telephone ( $n=1$ ).

The audience at a monthly caregiver education forum was addressed by the researcher on two occasions

Table 4

**Procedures for Identification of Subjects**

Procedure	Hospital Inpatient Units	Outpatient Family Practice Clinic	Home Care Agency	Caregiver Education and Support Program		Senior Newspaper
				Education Program	Respite Program	
Computer search for care receiver's by diagnosis		X				
Chart review	X	X				
Conferences with individual staff nurses	X		X			
Discharge planning rounds	X					
Advertisement in publication						X
Face to face contact with caregiver and care receiver	X					
Initial contact letter		X	X	X	X	
Return postcard					X	
Follow-up phone call to arrange interview		X	X		X	X
Number of subjects	0	1	11	0	15	2

to recruit subjects. Despite the use of handouts describing the study and one inquiry, no subjects were obtained.

Assistance from the caregiver respite program affiliated with the forum was also solicited. Initial contact letters were sent by program staff with the program's monthly billing statement (see Appendix B). Of 54 persons contacted, 21 returned postcards indicating an interest in further information about the study. Of the 20 respondents who disclosed their names and phone numbers to the researcher on the post cards, 15 agreed to participate, 2 did not meet study criteria, and 3 refused to participate due to time constraints.

An ad was also run in a local senior monthly newspaper for two months. The ad briefly described study criteria and a phone number was listed in order to obtain further information. Of the three respondents, two consented to participate in the study, while one did not meet study criteria.

For all subjects, a telephone call was made to establish contact, describe the interview, determine willingness to participate and to arrange an interview. A script was utilized to insure that accurate information was provided to the potential subject (see Appendix C). Code numbers were used for each subject

to enhance confidentiality. Only the researcher had access to the names of the subjects.

To increase the efficiency of contacting all respondents possible, the time periods for calling were varied (Dillman, 1978). The interviews were scheduled to start on Monday or Tuesday afternoons. If there was no answer by the third call, those numbers were called on weekday and weekend mornings, with priority given to times when the subjects reached had specifically requested to be called back. For those numbers where there still was no answer, early evening calls were made before the household was considered unreachable. These steps were repeated until all subjects were identified.

Procedure for securing subjects. The researcher answered any questions about the study that the spouse had during the initial telephone contact. In addition, the researcher determined the spouse's willingness to participate. If the spouse was unwilling, no further contact was made. If the spouse was willing, the researcher verified the correctness of the demographic information, that the caregiver was providing care to the care receiver, and that the caregiver was able to hear and understand the researcher well enough to complete the interview. The caregiver was then asked whether he or she wanted to participate in the

interview via telephone, or if preferred, a face-to-face. While eight subjects chose the telephone interview, the majority ( $n=18$ ) chose the face-to-face method. The telephone interview was included in order to increase the response rate of subjects by decreasing the time and hassle involved in participating and to make the study less costly (Dillman, 1978).

An appointment was then made for the actual interview. A consent form (see Appendix D) was completed at the start of the interview. The researcher used the interview guide (see Appendix A) to collect data from the caregivers, either via telephone or in person.

Human subjects clearance was obtained and permission to conduct the study was secured from the researcher's institution and from the hospitals that housed the caregiver education and support program and home care agency. The decision to participate or not participate was treated confidentially. Code numbers were assigned to subjects, and identifying information was kept separate from the data.



## Chapter III

### Results

This chapter describes the results of the study. Included are the findings for the three research questions.

1) What changes occur in the assignment of preestablished and new roles when the caregiver-care receiver relationship is assumed?

Are there differences according to the gender of the caregiver, the length of time caregiving and/or according to the interaction between gender and length of time caregiving?

#### Caregiving Tasks

The measurement of roles included the preestablished roles as well as the new roles of the caregiving spouse to meet the care receiver's needs. Change in the assignment of roles was addressed under the entire set of roles.

The caregiving tasks were measured by 38 activities which were collapsed into eight subscales. Table 5 displays caregiver responses regarding task performance at the time of the interview and prior to the assumption of the caregiving role.

The majority of caregivers were performing protective behaviors, but had not done so previously. For example, 59% of the caregivers assisted the care

**Table 5**  
**Percentage of People who Manage Particular Care Needs of the Care Receiver Now**  
**and in the Past**

Item	Now				Past		
	caregiver	care receiver	other	not applicable	caregiver	other	not applicable
<b>Protection</b>							
Walk	10 (59%)	6 (35%)	2 (12%)	12 (41%)	2 (7%)	1 (4%)	26 (90%)
Keep an eye on	26 (96%)	0 (0%)	5 (19%)	2 (7%)	7 (24%)	3 (10%)	19 (66%)
Protect from falls	22 (96%)	2 (9%)	4 (17%)	6 (21%)	3 (10%)	0 (0%)	26 (90%)
Check up on	27 (100%)	0 (0%)	4 (15%)	2 (7%)	2 (7%)	1 (4%)	26 (90%)
<b>Transportation</b>							
Shopping	27 (96%)	2 (7%)	2 (7%)	1 (4%)	18 (62%)	4 (14%)	7 (24%)
Accompany care receiver shopping	8 (100%)	0 (0%)	0 (0%)	21 (72%)	4 (14%)	1 (3%)	24 (83%)
Takes care receiver to medical appointments	24 (92%)	0 (0%)	3 (12%)	3 (10%)	12 (41%)	4 (14%)	13 (45%)
Takes care receiver to other places	15 (88%)	1 (6%)	5 (29%)	12 (41%)	8 (28%)	0 (0%)	21 (72%)
<b>Financial/legal decision making</b>							
Health care decisions	24 (86%)	2 (7%)	2 (7%)	1 (4%)	11 (38%)	5 (17%)	13 (45%)
Legal matters	28 (97%)	2 (7%)	1 (4%)	0 (0%)	15 (52%)	1 (4%)	13 (45%)
Banking	28 (97%)	2 (7%)	1 (4%)	0 (0%)	14 (48%)	2 (7%)	13 (45%)
Fix things/odd jobs	22 (81%)	1 (4%)	13 (48%)	2 (7%)	15 (52%)	4 (14%)	10 (34%)
Complete necessary forms	28 (97%)	1 (4%)	0 (0%)	0 (0%)	13 (45%)	2 (7%)	14 (48%)
Helps make financial decisions	27 (96%)	2 (7%)	0 (0%)	1 (4%)	14 (48%)	2 (7%)	13 (45%)

Table 5 continued on next page

Table 5 (continued)

Item	Now				Past		
	caregiver	care receiver	other	not applicable	caregiver	other	not applicable
<b>Behavior problems</b>							
Manage crying	9 (100%)	0 (0%)	1 (11%)	20 (69%)	3 (10%)	0 (0%)	26 (90%)
Manage paranoia or suspiciousness	7 (100%)	0 (0%)	0 (0%)	22 (76%)	1 (4%)	0 (0%)	28 (97%)
Manage aggressive behavior problems	12 (100%)	0 (0%)	1 (8%)	17 (59%)	3 (10%)	0 (0%)	26 (90%)
Listen to repetitive questions	10 (91%)	1 (10%)	0 (0%)	18 (62%)	3 (10%)	0 (0%)	26 (90%)
Watch for wandering	5 (100%)	0 (0%)	1 (20%)	24 (93%)	0 (0%)	0 (0%)	29 (100%)
Remind care receiver of who (care receiver and caregiver is) and where (care receiver is)	9 (100%)	0 (0%)	0 (0%)	20 (69%)	1 (3%)	0 (0%)	28 (97%)
<b>Personal Care</b>							
Feed	9 (33%)	19 (70%)	1 (4%)	2 (7%)	0 (0%)	1 (4%)	28 (97%)
Lift	14 (67%)	7 (33%)	5 (24%)	8 (28%)	1 (4%)	0 (0%)	28 (97%)
Bathe	22 (79%)	4 (14%)	9 (32%)	1 (3%)	3 (10%)	0 (0%)	26 (90%)
Incontinence care	20 (91%)	3 (14%)	2 (9%)	7 (24%)	2 (7%)	2 (7%)	25 (86%)
Teeth	10 (46%)	11 (50%)	4 (18%)	7 (24%)	0 (0%)	1 (4%)	28 (97%)
Dress	25 (89%)	5 (18%)	5 (18%)	1 (4%)	2 (7%)	1 (3%)	26 (90%)
Get up at night	18 (90%)	2 (10%)	1 (5%)	9 (31%)	2 (7%)	0 (0%)	27 (93%)
Skin care	22 (85%)	2 (8%)	8 (31%)	3 (10%)	0 (0%)	0 (0%)	29 (100%)
Toilet	14 (61%)	9 (39%)	2 (9%)	6 (21%)	2 (7%)	0 (0%)	27 (93%)
Hair Care	18 (64%)	5 (18%)	11 (39%)	1 (3%)	1 (3%)	0 (0%)	28 (97%)

Table 5 continued on next page

Table 5 (continued)

Item	Now				Past		
	caregiver	care receiver	other	not applicable	caregiver	other	not applicable
<b>Medication</b>							
Medication (management)	24 (86%)	3 (11%)	2 (7%)	1 (3%)	3 (10%)	5 (17%)	21 (72%)
Pain (control)	19 (86%)	5 (23%)	0 (0%)	7 (24%)	6 (21%)	2 (7%)	21 (72%)
<b>Housekeeping</b>							
Meal preparation	27 (93%)	2 (7%)	4 (14%)	0 (0%)	18 (62%)	2 (7%)	9 (31%)
Change bed linens	24 (83%)	2 (7%)	5 (17%)	0 (0%)	19 (66%)	2 (7%)	8 (28%)
Light housekeeping	25 (86%)	1 (4%)	6 (21%)	0 (0%)	18 (62%)	2 (7%)	9 (31%)
<b>Little Extras</b>							
Sit and spend time with care receiver	26 (90%)	1 (4%)	7 (24%)	0 (0%)	13 (45%)	1 (3%)	15 (52%)
Participate in leisure activities with care receiver	24 (89%)	3 (11%)	4 (15%)	2 (7%)	12 (41%)	1 (3%)	16 (55%)
Physical contact	25 (100%)	0 (0%)	3 (12%)	4 (14%)	16 (55%)	1 (3%)	12 (41%)

receiver with walking, and 12% of care receivers were assisted by someone other than the care giver. Thirty-five of the care receivers were able to assist themselves with walking, and in 41% of the cases assistance with walking was not applicable. In the past (prior to becoming a caregiver for the care receiver), 7% of the caregivers assisted the care receiver with walking, 4% of care receivers received assistance from another person, and in 90% of the cases, assistance to the care receiver with walking was not applicable.

Transportation related activities were carried out by the caregiver to assist the impaired spouse. For most caregivers, shopping was the only transportation related activity carried out prior to becoming a caregiver. Most reported doing the care receiver's shopping alone, but in four of these cases, caregivers stated they had done shopping together with their spouse prior to becoming the caregiver. Of those who received assistance in taking the care receiver to other places, it was most often a child who assisted them (n=4).

For nearly half of the caregivers, financial and legal decision making activities were not a problem for the care receiver before the caregiver-care receiver relationship was assumed. The majority of caregivers

reported the performance of these activities now.

Behavior problems, when present, were most often managed solely by the caregiver. But for the majority of the caregivers this was not a problem ("not applicable" range: 59 to 93%). Behavior problems were also not a problem in the past. For the caregivers, the most frequent behavior problem was aggressive behavior ( $n=12$ ), followed by listening to repetitive questions ( $n=10$ ).

While the majority of caregivers did not assist the spouse with personal care before becoming the caregiver, most assisted the caregiver to some degree currently. The exception was feeding and oral care, which the care receiver was still able to do (70% and 50% respectively). When caregivers received assistance from others with personal care, it was in the areas of hair care (39%), bathing (32%), skin care (31%), and lifting the care receiver (24%). Three caregivers reported using a hooyer lift to assist with transferring the care receiver. Dressing techniques included cuing the care receiver by laying his or her clothes out ( $n=2$ ).

Prior to the assumption of the caregiving role, subjects did not find medication related activities a problem in most of the cases. Currently, 86% caregivers reported assisting the care receivers with

medications and pain management.

While housekeeping activities were performed by subjects prior to becoming caregivers, a greater majority reported current performance of these activities for the care receiver. Caregivers ( $n=2$ ) also identified activities related to pulmonary hygiene as part of their caregiving role. This included tracheostomy care, assessment of oxygen, and cleaning the care receiver's nebulizer.

#### Main and Interaction Effects on Caregiving Tasks

Two-way analysis of variance was used to determine the effect of the independent variables of gender and length of time caregiving on the dependent variables of caregiving tasks. The results are included in Tables 6 and 7. In the overall caregiving tasks scale, for example, females who were caregivers for less than three years (short term) had a mean score of  $-2.70$  ( $SD=.1.33$ ), whereas male short term caregivers had a mean of  $-2.35$  ( $SD=.1.09$ ). The F ratio for sex of the caregivers was  $.52$  ( $p>.50$ ), and thus male and female caregivers did not differ significantly in how their performance of caregiving tasks had changed.

No significant differences were found in the subscales of transportation, protection, medication-related, financial and legal decision making, behavior problems, or little extras. For housekeeping tasks,

Table 6

Effect of Gender and Length of Time Caregiving on Caregiver Tasks, Caregiver Behaviors, Role Strain, and Service Use

Scale	Female (n=20)		Male (n=9)		Length of time caregiving		F	sd	sd	F
	$\bar{x}$	sd	$\bar{x}$	sd	$\leq 3$ yrs. (n=15)	$> 3$ yrs. (n=14)				
Caregiver tasks	-2.70	1.33	-2.35	1.09	.52	-2.70	1.28	-2.48	1.27	.03
Protection	-.64	.35	-.56	.24	.35	-.68	.32	-.54	.31	.35
Transportation	-.23	.34	-.39	.28	1.62	-.32	.31	-.23	.36	.07
Financial/legal decision making	-.50	.38	-.28	.35	2.56	-.40	.37	-.46	.40	1.11
Behavior problems	-.31	.20	-.17	.17	2.93	-.32	.21	-.20	.16	2.52
Personal care	-.58	.30	-.49	.28	.59	-.56	.29	-.55	.30	.07
Medication related	-.60	.31	-.56	.39	.11	-.60	.39	-.57	.27	.01
Housekeeping	-.01	.30	-.65	.41	22.90*	-.08	.35	-.35	.50	5.16*
Little extras	-.45	.32	-.26	.28	2.09	-.40	.31	-.38	.34	.001
Caregiver behaviors	2.50	1.00	1.89	1.27	1.61	2.47	1.13	2.14	1.10	.70
Role strain	6.60	3.07	8.67	1.23	4.18*	7.80	2.76	6.64	2.79	.93
Current service use	2.85	1.79	2.33	1.58	.61	2.53	1.73	2.86	1.75	.37
Past service use	4.25	2.02	4.00	2.00	.10	4.47	1.81	3.86	2.18	.005

\*p<.05



Table 7

Interaction Effects of Gender and Length of Time Caring on Caregiver Tasks, Caregiver Behaviors, Role Strain, and Service Use

Scale	Interaction of gender and length of time caregiving						F		
	Female ≤ 3 yrs. (n=11)		Female > 3 yrs. (n=9)		Male < 3 yrs. (n=4)			Male > 3 yrs. (n=5)	
	$\bar{x}$	sd	$\bar{x}$	sd	$\bar{x}$	sd	$\bar{x}$	sd	
Caregiver tasks	-2.99	1.30	-2.35	1.36	-1.90	.88	-2.72	1.19	2.06
Protection	-.75	.32	-.50	.35	-.50	.29	-.60	.22	1.91
Transportation	-.32	.33	-.11	.33	-.31	.24	-.45	.33	1.74
Financial/legal decision making	-.52	.37	-.48	.41	-.08	.10	-.43	.42	1.64
Behavior problems	-.35	.23	-.26	.15	-.25	.17	-.10	.15	.16
Personal care	-.62	.28	-.54	.34	-.42	.32	-.56	.26	.76
Medication related	-.64	.39	-.56	.17	-.50	.41	-.60	.42	.42
Housekeeping	.03	.23	-.06	.38	-.37	.48	-.87	.18	2.55
Little extras	-.45	.30	-.44	.38	-.25	.32	-.27	.28	.01
Caregiver behaviors	2.55	.93	2.44	1.13	2.25	1.71	1.60	.89	.37
Role strain	7.46	3.08	5.56	2.88	8.75	1.50	8.60	1.14	.68
Current service use	2.73	1.74	3.00	1.94	2.00	1.83	2.60	1.52	.05
Past service use	4.91	1.38	3.44	2.46	3.25	2.50	4.60	1.52	3.20

significant relationships were found for gender,  $F(1,28) = 22.90, p=.0001$ , and length of time caregiving,  $F(1, 28) = 5.16, p=.03$ . Both male ( $M=-.65, SD=.41$ ) and long term caregivers ( $M=-.35, SD=.51$ ) reported greater change in the performance of housekeeping tasks than did female ( $M=-.01, SD=.30$ ) or short term caregivers ( $M=-.08, SD=.35$ ). However, there was not an interaction effect for gender and length of time caregiving on changes in the assignment of housekeeping tasks.

#### Caregiving Behaviors

The more subtle caregiving actions were measured in four subscales of anticipatory, preventive, supervisory, and protective caregiving behaviors. Yes/no responses were derived from open-ended questions on these subscales.

Four caregivers had difficulty comprehending the example given with the anticipatory behaviors. Nonetheless, most (79.31%) caregivers reported anticipation of care receiver needs for things without telling the care receiver this. Two caregivers reported using a strategy of "jogging" the spouse's memory to get the care receiver to do a specific task. The majority (62%) reported not having anticipated the care receiver's needs prior to becoming a caregiver, while 100% of subjects who did not anticipate spouse

needs after the spouse became ill did not do so before. Seven caregivers reported development of habits, routines, and automatic behaviors to anticipate the care receiver's needs. Transition in the spouses' abilities was reported by five caregivers who pointed out that the care receiver had been able to anticipate his or her own needs in the past.

Preventive behaviors were reported by 93.10% of caregivers, and for most (75.86%), this had changed from before the care receiver's illness. Most frequently cited were the prevention of falls ( $n=15$ ), diet related ( $n=7$ ), and medication management ( $n=2$ ). Eight caregivers reported that the care receiver was self-sufficient prior to assumption of the caregiving role.

Supervisory behaviors were reported by 93.10% of caregivers, and 86.21% stated they had performed these prior to the assumption of the caregiving role. Supervision of the care receiver's medications was reported by 9 caregivers, while 5 stated they supervised their spouses' diets. For six caregivers, the totality of the supervisory activities was apparent. As one subject stated, "That's my job-all of it!". A change in supervisory behaviors with the assumption of the caregiving role was actually a change in the degree or intensity of supervision.

The majority of caregivers (58.62%) denied current performance of protective behaviors, nor did they report protective behaviors prior to the assumption of the caregiving role. This was influenced by the care receiver's awareness of his environment, and the caregiver's desire to maintain openness in the relationship. As one caregiver stated, "We've never kept things from each other".

#### Main and Interaction Effects on Caregiving Behaviors

In the area of caregiving behaviors, anticipatory, supervisory, protective and preventive behaviors were combined for the two-way analysis of variance. No significant results were found (see Tables 6 and 7).

#### 2) What is the degree of caregiver role strain?

Are there differences according to the gender of the caregiver, the length of time caregiving, and/or according to the interaction between gender and length of time caregiving?

#### Role Strain

Scores for each of the 13 indicators of role strain were combined to obtain one score. Overall, the degree of role strain for the 29 spouse caregivers was moderate ( $M=7.24$ ,  $SD=2.79$ ).

#### Main and Interaction Effects on Role Strain

The relationship between gender and length of time caregiving on caregiver role strain was examined with

two-way analysis of variance. The results are presented in Tables 6 and 7. Significant differences in the degree of role strain were found between men and women,  $F(1, 28) = 4.18, p < .05$ .

- 3) What are the perceived needs of the caregiver with the assumption of the caregiver-care receiver relationship?  
Are there differences according to the gender of the caregiver, to the length of time caregiving and/or according to the interaction between gender and length of time caregiving?

#### Perceived Needs

More than half of the caregivers ( $n=15$ ) wanted help in caring for their spouse. Of the 14 subjects who did not think there was help they could use, 3 verbalized concerns about their future needs as caregivers. The totality of the caregiving role was a concern for three caregivers, as one stated, "Who else is going to come in 24 hours a day and wait on him hand and foot?". Of the subjects wanting help, 10 requested respite. It is important to note, however, that four of these expressed concern that respite be provided by persons the caregiver could trust to adequately meet the care receiver's needs. Respite was needed while the caregiver was gone, either while the care receiver remained at home or stayed in a nursing care center.

Past and present service use was measured by an itemization of 17 services (see Table 8). The majority of caregivers were not using services but 21 (72%) had used a home health nurse, 15 (58%) had used a home health aide in the past 18 months, and 16 (55%) had used respite in the past 18 months. Of those currently using services, the home care nurse was used most (42%), followed by chore services (38%), homemaker/housekeeper (35%), and respite (35%).

A concern was expressed by five caregivers about available transportation services for the care receiver. Although only 24% reported using such a service now, 41% had used a transportation service in the past. Problems expressed by five subjects included the care receivers having to wait a long time and becoming chilled, driver/vehicle operation problems, and prohibitive prices to such services as taxis and ambulances.

Most ( $n=21$ ) caregivers did not identify services that a nurse could help them with. Advice and answering health related questions were identified by 4 of the 8 caregivers wanting nursing interventions. Monitoring of care receiver condition was desired by three caregivers. The perception of a potential for future needs from nurses were expressed by three caregivers.

**Table 8**  
**Present and Past Use of Services**

Type of Help	Now		Past 18 Months	
	Yes	No	Yes	No
Home health nurse	12 (42%)	17 (59%)	21 (72%)	8 (28%)
Home health aide	10 (35%)	19 (66%)	15 (58%)	14 (48%)
Homemaker/housekeeper	10 (35%)	19 (66%)	8 (28%)	21 (72%)
Transportation service	7 (24%)	22 (76%)	12 (41%)	17 (59%)
Delivery service for groceries	0 (0%)	29 (100%)	0 (0%)	29 (100%)
Chore service	11 (38%)	18 (62%)	12 (41%)	17 (49%)
Friendly visitor service	0 (0%)	29 (100%)	0 (0%)	29 (100%)
Daycare/adult day health	4 (14%)	25 (86%)	5 (17%)	24 (83%)
Respite care	10 (35%)	19 (66%)	16 (55%)	13 (45%)
Social worker	5 (17%)	24 (83%)	11 (38%)	18 (62%)
Meal service	1 (4%)	28 (97%)	5 (17%)	24 (83%)
Therapy for care receiver's arms/legs	4 (14%)	25 (86%)	10 (35%)	19 (66%)
Phone reassurance	1 (4%)	28 (97%)	0 (0%)	29 (100%)
Block nurse	0 (0%)	29 (100%)	0 (0%)	29 (100%)
Advice nurse	2 (7%)	27 (93%)	3 (10%)	26 (90%)
Speech therapist	1 (4%)	28 (97%)	3 (10%)	26 (90%)
Mental health services	0 (0%)	29 (100%)	0 (0%)	29 (100%)

The concept that caregivers had regarding the role of nursing influenced five caregivers responses. These ranged from a lack of awareness of what nurses do to the interpretation of nursing activities as only the traditional "skilled" tasks such as changing a feeding tube or giving shots. One caregiver stated, "That's the toughest question in the world as I have no comparison". While another caregiver reported on the many things the home care nurses have taught her, she expressed frustration with the need to assume nursing tasks as "I wasn't prepared to be a nurse".

#### Main and Interaction Effects on Service Use

Two-way analysis of variance was used to determine the effects of gender and length of time caregiving on service use by the caregiver. No significant differences were found between male and female or between short and long term caregivers in the current or past use of formal services (see Tables 6 and 7).



## Chapter IV

### Discussion

This section will address the major findings, the implications for nursing, and the limitations of the study. Finally, recommendations will be made for future research.

#### Major Findings

Four major findings will be discussed. These include the effect of caregiver gender on change in the performance of housekeeping tasks, and the lack of caregiver performance of protective behaviors. Additionally, the relationship of caregiver gender to role strain, as well as the perceived needs of the caregiver for respite, nursing advice, and health-care information will be discussed. Verification of the conceptual framework will be discussed at the end of this section.

#### Caregiving Tasks

While caregivers generally gained roles in each of the eight subscales (protection, transportation, financial and legal decision making, behavior problems, personal care, medication related, housekeeping and little extras) with the assumption of caregiving, the independent variables of gender and length of time caregiving demonstrated significant effects for only one of the subscales. Statistically significant

differences were found in the performance of housekeeping tasks between male and female caregivers, and short and long term caregivers. Men and long term caregivers experienced greater change with the addition of roles.

Since women tend to perform the majority of housekeeping roles in the traditional marital relationship, the change according to gender is not surprising. It would be reasonable to expect that with the decline in the health of the female care receiver, the male caregiver would perform more of the housekeeping tasks such as meal preparation and bed making.

#### Caregiving Behaviors

The most interesting finding regarding caregiving behaviors was the lack of performance of protective behaviors by the majority of the spouse caregivers sampled. While most of the caregivers reported the performance of anticipatory, preventive, and supervisory behaviors, this was not true for protective behaviors. Conversely, adult child caregivers in Bowers' (1987) sample viewed protective caregiving as the most important type of care provided.

The nature of the caregiver-care receiver relationship as experienced by a spousal as opposed to parent-child dyad may explain some of the discrepancy

between these two studies' findings. Bowers (1987) identified that an important component in protective behaviors for the adult child caregiver was the avoidance of the parent (care receiver's) perception of role reversal. Prior to the onset of the care receiver's illness, however, normal spousal interaction focuses on a mutual exchange of information. Therefore, the maintenance of openness and the avoidance of illusions in the marital relationship may have been more important to the spouse caregivers in this study than the potential benefits of protective caregiving behaviors.

This study's finding regarding spouse performance of protective caregiving behaviors may have been influenced by the extraneous variable of care receivers' mental status. Although the care receivers' mental status was not measured in this study, it might be hypothesized that optimally functioning care receivers do not require caregiver performance of protective behaviors.

#### Role Strain

Caregiver gender was significantly related to the degree of role strain,  $F(1,28)=4.18, p<.05$ . Male caregivers experienced a greater degree of role strain ( $\bar{M}=8.66, SD=1.22$ ) than female caregivers ( $\bar{M}=6.60, SD=3.06$ ). This result does not concur with the

findings of Johnson (1983), who found less role strain in caregiving husbands, and those of Fitting et al. (1986) and Zarit et al. (1986) who found no difference in role strain according to gender of the caregiver. Since these findings are inconclusive, one may hypothesize that factors other than gender may have a stronger relationship to caregiver role strain.

#### Perceived Needs

The results of this study's analysis of caregiver needs paralleled those of previous researchers, and indicated a further need for nursing interventions. Caregiver identification of respite services as the most needed service were similar to the findings of Caserta et al. (1987). The finding that a minority of caregivers were using formal services is consistent with the results of Stone et al.'s (1987) analysis of data from a national survey.

No significant differences were found in current or past service use according to gender or length of time caregiving. The influence of past and present use of services probably had some effect on the fact that only a slight majority of caregivers identified a current need for assistance. The past use of nursing and respite services, but current preference for respite services, may indicate that home health nursing services were not perceived to be as helpful as basic

relief from caregiving. The qualifying information that some of the caregivers provided indicated the caregivers' ability to articulate with increasing specificity just what type of intervention would be helpful.

While most caregivers did not identify services that a nurse could help them with, some indicated an interest in caregiving advice and the provision of health related information from nurses. Caregivers' interest in advice and health related information specific to the caregiving situations is an area currently undergoing research. Archbold and Stewart (personal communication, April, 1989) have designed an intervention that provides an advice nurse for family caregivers.

#### Verification of the Conceptual Framework

The findings of this study provide verification of the conceptual framework. Also, the need for modification of the accompanying model (see Figure 1, p. 39) has been implicated. Spouse caregivers were generally in long term marriages, indicating the probable existence of preestablished roles. Transition in the marital relationship, due to the care receiver's illness and subsequent development of the caregiver-care receiver relationship, was verified by the overall gains in spouse caregiving tasks with the assumption of

the caregiving role.

Although this study did not find significant differences in the performance of most tasks or behaviors according to length of time caregiving, a longitudinal study may provide evidence of a greater number of significant differences in gains and losses of roles. As Thornton and Nardi (1975) point out, role acquisition is a developmental process. Therefore, the dynamic nature of role strain and perceived needs, which were depicted in Figure 1 as outcome variables, warrants exploration. The potential effects of role strain on perceived needs, and of perceived needs on role strain, could be depicted in a modified version of the model.

#### Implications for Nursing

The clinical significance of the study's findings will be addressed in terms of the changes in caregiver roles, role strain and use of services. Finally, the importance of nursing-focused caregiving research will be discussed.

#### Changes in Role Performance

Nurses working with elderly spouse caregivers need to understand the global nature of caregiving. This study's finding that caregivers gained roles in each of the eight subscales of caregiving tasks verified this. It is also important for nurses to understand the

assumption of the caregiving behaviors of anticipation, prevention, and supervision. This includes the subtle nature of the increase in the degree of performance of these behaviors with the development of the caregiving role.

It would also be important to address role loss as well as role assumption. Future research into preestablished versus new roles could address this change and help identify these issues.

#### Role Strain

The global quality of caregiving for elderly spouses illuminates the development of caregiver role strain. Additionally, factors such as stress related to role performance, and potentially unrealistic expectations of those providing assistance in caregiving, may explain the hesitancy of spouse caregivers to pursue intervention by formal services.

The dynamic nature of caregiving may account for the lack of significant differences between length of time caregiving on changes in tasks and role strain. Nurses need to focus on the needs of the caregiver and care receiver as the care receiver's health may vacillate.

The significant differences were found in changes in the performance of housekeeping tasks for male and long term caregivers. However the nurse needs to

assess whether these groups of spouse caregivers, influenced by caregiver income, need and desire linkage with housekeeping services.

Differences were found according to the performance of protective caregiving behaviors by elderly marital partners as compared to elderly parents and their adult children. Therefore, nurses need to understand these differences to achieve effective intervention with family caregivers.

#### Perceived Needs

The findings regarding the use of services by spouse caregivers indicated several areas of concern for nurses. Since spouse caregivers had often used home health nursing services but indicated a current preference for respite services, nurses need to evaluate care given in the home and how to provide it within restrictive reimbursement regulations. While caregiver use of advice and block nurse programs was small, increased development of these and other nursing services for caregivers needs to be addressed. As our aging population continues to increase, we will be increasingly accountable for efficient means of assisting family caregiving.

Additionally, spouse caregiver communication of specific concerns regarding respite interventions demonstrates the implications of past exposure to such



services. This illuminates areas for refinement of current services as well as development of new ones. Respite care programs, for example, could attempt to elicit from caregivers some of the more subtle behaviors of their role so that they can better assist in meeting family needs and expectations.

As caregivers themselves, nurses have unique expertise in understanding the caregiving role. In this way nurses can best identify how to more efficiently and effectively support the spouse caregiver's definition of caregiving.

#### Limitations

Generalizability of the findings are limited by the fact that a small convenience sample was used. Limitations to generalizability include characteristics of the sample, such as homogeneity of race and underrepresentation of male caregivers, as well as lack of information regarding caregiver income, religion, and educational background. Such factors could have influenced comprehension of the questions asked in the interview, as well as the subjects' knowledge of and accessibility to services.

An additional limitation is the new measures used in the study. There is a need for additional work on the measures of roles, role change, and perceived needs of the caregiver to evaluate the reliability and

validity of these measures.

A third limitation is that the assumptions of ANOVA were violated (eg., that gender of the caregiver and duration of caregiving function independently). Finally, the unequal numbers of subjects for each cell (ie., shortterm female caregivers, longterm female caregivers, shortterm male caregivers, and longterm male caregivers) cause the usual partitioning of the sums of squares to be unsuccessful. Also, the solution chosen to compensate for the unequal cell sizes, unique variance, is a conservative approach to finding main factor effects.

#### Directions for Future Research

Further exploration of the spouse caregiving role will be addressed according to the variables of gender, length of time caregiving, role strain and perceived needs. Also, sampling issues and the need to further develop the new measures in this study will be discussed.

While research findings regarding the caregiving role according to caregiver gender remain inconclusive, further research might focus on less explored areas. Length of time caregiving is a variable which has undergone little empirical analysis, especially in longitudinal research. While this study was cross sectional and depended upon caregiver recall, a

longitudinal study would be more reliable.

Longitudinal research would allow for direct assessment of how caregiving changes with the passage of time.

Although not well differentiated from the concepts of caregiving burden and caregiving stress, role strain remains an important variable of caregiving role performance. Further research could explore how preestablished and new role development impact role strain and perceived needs for nursing services.

Some caregivers identified a desire for more information regarding caregiving, including the "on-call" type of availability of an advice nurse. Interventions targeted for caregivers need to be systematically developed and evaluated.

Further exploration is needed into caregivers' understanding of nursing's abilities in the provision of care to the elderly spouse. Also, research should address caregiver perceptions of how nursing could best assist them with the caregiving role.

Large sample size is important in drawing conclusions regarding the general population of elderly spouse caregivers. Sample size was not a critical factor in the results of this study. A sample of 120 subjects would have been necessary to obtain significant findings for the effect of gender and length of time caregiving on all of the scales with the

exception of the housekeeping tasks and role strain scales.

Difficulty accessing the sample was a limiting factor in this study. Since few of the caregivers sampled chose the telephone method of interview, this may not be a method to pursue with an elderly population. Factors such as hearing loss, the constancy of caregiving duties, and hesitancy in giving information to strangers over the phone may have influenced the actual number of subjects who opted for this method.

Finally, further work needs to be done toward the refinement and additional testing of the new measures used in this study. This includes the measure of caregiving behavior, as well as the open and closed ended questions regarding perceived needs for services.

The legitimacy of Bowers' (1987) conceptualization of three (anticipatory, preventive, and supervisory) of the four caregiving behaviors was indicated in this study's findings. The majority of caregivers reported performance of anticipatory, preventive, and supervisory behaviors. Spouse caregivers did not seem to identify with Bowers' concept of protective behaviors.

Some of the caregivers ( $n=4$ ) expressed difficulty understanding the definition of anticipatory behavior

as presented in the interview. This finding indicates a need for further evaluation of this item. Additionally, several caregivers indicated that the performance of anticipatory, preventive, and supervisory behaviors had changed only in degree and intensity with the adoption of the caregiving role. However, the direction and degree of the change was not addressed in this study.

## Chapter V

### Summary

An increase in the proportion and overall number of individuals aged 65 and over is a trend projected to continue through the middle of the next century. As people age there is an increased likelihood that they will require some assistance from their family. It is the elderly spouse who is often the primary caregiver.

A descriptive correlational study was conducted to explore the nature of elderly spouse caregiving. The effects of gender and length of time caregiving on changes in roles, the phenomena of role strain, and the perceived needs of the caregiver were examined.

Role theory was chosen as the conceptual framework for this study. The sample consisted of 20 female and 9 male caregivers to elderly spouses. Measures of performance of and change in caregiving tasks and caregiving behaviors, role strain, and perceived needs of the caregiver were used. A one time telephone or face-to-face interview was conducted.

The small convenience sample limits generalizability of the study's findings. Also, the need for further development of the new measures of roles, role performance, and perceived needs of the caregivers is a limitation to the use of these findings.

While caregivers reported an overall change in the performance of caregiving tasks, significant relationships were found only for men and long term caregivers in changes in the performance of housekeeping tasks. Spouse caregivers reported a lack of performance of protective caregiving behaviors, which differed from previous research with adult children. A significant relationship was found between gender and role strain, with greater role strain in the male caregivers. While slightly more than half of the caregivers reported current use of formal services to assist in caregiving, some caregivers indicated an interest in respite services, as well as caregiving advice, and the provision of health related information.

According to the results of this study, nurses need to understand the comprehensiveness of the caregiving role. This would require that the nurse assess each individual caregiving situation, including performance caregiving tasks and behaviors, as well as role strain. Nurses also need to be aware of the potential differences which exist between spouses and adult children in the performance of the caregiving role, especially in relation to protective behaviors.

Additional research is needed in the variables of length of time caregiving, role strain, and

particularly in the perceived needs from nursing.

Also, further development of the new measures used in this study is needed.



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Appendix A

Caregiver ID \_\_\_\_\_

SPOUSE CAREGIVING  
QUESTIONNAIRE

Investigator: Mary Therese Rasch  
5238 N.E. Flanders  
Portland, OR 97213  
(503) 231-0504

(COMPLETE AT START OF INTERVIEW)

(CODING)

1. Date of Interview \_\_\_\_\_  
2. Time Interview Began \_\_\_\_\_

(COMPLETE AFTER INTERVIEW)

3. Sex of Caregiver [1] Female [2] Male I1 \_\_\_\_\_  
4. Caregiver Age \_\_\_\_\_ Years I2 \_\_\_\_\_  
(CALCULATE USING  
"Date of Interview"  
MINUS "Date of Birth";  
RECORD IN YEARS)  
5. Sex of Care Receiver [1] Female [2] Male I3 \_\_\_\_\_  
6. Diagnosis of Care Receiver \_\_\_\_\_ I5 \_\_\_\_\_  
\_\_\_\_\_  
8. When Diagnosed \_\_\_\_\_ MM/YY I6 \_\_\_\_\_  
9. Time Interview Ended \_\_\_\_\_  
10. Length of Interview \_\_\_\_\_ I7 \_\_\_\_\_  
(CALCULATE USING "Time  
Interview Ended" MINUS  
"Time Interview Began",  
RECORD IN MINUTES)  
11. Site of Interview [1] Home [2] Telephone I8 \_\_\_\_\_  
[3] Other  
Specify \_\_\_\_\_

Caregiver ID \_\_\_\_\_

During this interview, I will be asking you questions about your (husband/wife) Mr., Mrs., Ms. (INSERT FAMILY NAME OF CARE RECEIVER). When I do so, how would you like me to refer to (him/her) using (his/her) first name, family name, or as your (husband/wife):  
\_\_\_\_\_.

I will be writing your responses down during the interview. Please feel free to stop me if something is not clear or if you have questions. Also, you do not have to answer all of these questions, and you can stop the interview at any time. All of your responses will remain confidential.

Some of the choices of answers I give you may not be exactly the response you would choose, and for some of the questions you may want a more thorough explanation than what I ask for. However, to move through the interview, which is quite long, it will help if you can select from the options I give you. At the end of the interview, there will be time for you to tell me about anything that I may not have covered in the questions I will have asked.

\*\*\*\*\*  
Demographic Information  
\*\*\*\*\*

(QUESTION)	(RESPONSE)	(COMMENTS)	(CODING)
1. How many years have you and (CARE RECEIVER) been married?	_____ Years and Fraction of Years [-77] NA		D2_____
2. What is the date of your birth?	_____DD/MM/YY [-77] NA		D3_____
3. What is the date of (CARE RECEIVER'S) birth?	_____DD/MM/YY [-77] NA		D4_____
4. When was (CARE RECEIVER) first diagnosed with (his/her) predominant illness?	_____MM/YY		D5_____
5. How long has (CARE RECEIVER) not been feeling well?	_____Mos. &/or Yrs.		D6_____
6. How long have you been providing care or helping care for (CARE RECEIVER)?	_____Mos. &/or Yrs.		D7_____

Caregiver ID \_\_\_\_\_

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\*\*\*\*\*  
REVISED ARCHBOLD/STEWART NATURE OF THE CAREGIVING ROLE  
\*\*\*\*\*

The next set of questions is pretty long. The information, however, is very important to this study as I want to have a good idea of what things you do to take care of (CARE RECEIVER).

People who care for their spouse often provide different kinds of help. I am going to read you a list of types of help which are often given to a husband or wife. Some of these types of help might not apply to your situation, while some will. I would like to find out who provided care when spouse became ill, who does now or if this does not apply to your situation.

(ASK THE FOLLOWING QUESTIONS FOR EACH TYPE OF HELP.)

Caregiver ID\_\_\_\_\_

QUESTION 1: (For each type of help, ask Col. 1 & Col. 2 in sequence.)

Who (READ TYPE OF NEED FROM LIST)?

(If no, code column 1 as n/a and column 3 as -77)

Did you do \_\_\_\_\_ for CARE RECEIVER prior to becoming his/her caregiver?

	CG	Other	CR	N/A	Yes	No	Not a problem
A. Does shopping and errands for (CARE RECEIVER)?	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
B. Assists (CARE RECEIVER) with walking [for example, do you have to give (him/her) your arm or get (him/her) a walker]	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
C. Keeps an eye on (him/her) to make sure (he/she) is safe	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
D. Assists (CARE RECEIVER) with his/her medications or shots	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
E. Feeds (CARE RECEIVER)	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
F. Protects (CARE RECEIVER) from falls	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
G. Helps make major decisions about (CARE RECEIVERS) health care. (For example, surgery or a change in treatment)	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
H. Handles (CARE RECEIVERS) crying spells or does he/she not have that problem	[1]	[2]	[3]	[0]	[1]	[0]	[-77]

Caregiver ID \_\_\_\_\_

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Who (READ TYPE OF NEED FROM LIST)?

Did you do  
for  
CARE RECEIVER  
prior to becoming  
his/her  
caregiver?

(If no, code column 1 as n/a and column 3 as -77)

I. Lifts or transfers (CARE RECEIVER) from one place to another [for example, do you lift him/her out of a chair or transfer him/her from a bed to a chair]	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
J. Has to accompany (CARE RECEIVER) as he/she does shopping and errands	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
K. Assists (CARE RECEIVER) with bathing or washing	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
L. Has to handle (CARE RECEIVERS) paranoia or suspiciousness, or does he/she not have that problem	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
M. Sits and spends time with (CARE RECEIVER)	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
N. Cleans up if (CARE RECEIVER) is incontinent of urine or stool	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
O. Has to handle (CARE RECEIVERS) aggressive behavior problems [for example, his/her yelling, abusive language, hitting] or does he/she not have these problems	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
P. Prepares meals or helps prepare meals for (CARE RECEIVER)	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]

## Who (READ TYPE OF NEED FROM LIST)?

(If no, code column 1 as n/a and column 3 as -77)

## Did you do \_\_\_\_\_ for CARE RECEIVER prior to becoming his/her caregiver?

Who (READ TYPE OF NEED FROM LIST)?	CG	Other	CR	N/A	Yes	No	Not a problem
Q. Has to listen and answer repetitive questions that (CARE RECEIVER) asks	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
R. Takes care of (CARE RECEIVERS) dentures, or brushes his/her teeth	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
S. Helps (CARE RECEIVER) get legal matters attended to	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
T. Has to watch (CARE RECEIVER) in case he/she wanders off	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
U. Assists (CARE RECEIVER) with dressing and undressing	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
V. Has to get up at night to help (CARE RECEIVER)	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
W. Assists (CARE RECEIVER) with bank and financial matters	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
X. Has to remind (CARE RECEIVER) who he/she is, where he/she is, or who you are	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
Y. Has to check in on (CARE RECEIVER) to make sure he/she is OK	[1]	[2]	[3]	[0]	[1]	[0]	[-77]
Z. Takes (CARE RECEIVER) to medical appointments	[1]	[2]	[3]	[0]	[1]	[0]	[-77]

Caregiver ID \_\_\_\_\_

105

Who (READ TYPE OF NEED LIST)?

(If no, code column 1 as n/a and column 3 as -77)

Did you do \_\_\_\_\_ for CARE RECEIVER prior to becoming his/her caregiver?

	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
AA. Takes (CARE RECEIVER) to other places, such as to friends' homes, to church, or to restaurants							
BB. Checks (CARE RECEIVERS) skin and applies lotions							
CC. Fixes things and does odd jobs to maintain (CARE RECEIVERS) house							
DD. Participates in leisure activities with (CARE RECEIVER) to help meet his/her needs for those activities. [For example, watching TV together, playing games, listening to music]							
EE. Changes (CARE RECEIVERS) bed linens							
FF. Helps (CARE RECEIVER) use the toilet or bed pan							
GG. Assists (CARE RECEIVER) in completing necessary forms such as tax forms							



Caregiver ID \_\_\_\_\_

106

Who (READ TYPE OF NEED FROM LIST)?

(If no, code column 1 as n/a and column 3 as -77)

Did you do for CARE RECEIVER prior to becoming his/her caregiver?

HH. Does things for (CARE RECEIVER) like holds hands or rubs his/her back because they think he/she needs physical contact	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
II. Helps (CARE RECEIVER) make major financial decisions	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
JJ. Has to handle (CARE RECEIVERS) pain	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
KK. Does light housekeeping for (CARE RECEIVER)	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
LL. Assists (CARE RECEIVER) with hair care and shampooing	CG [1]	Other [2]	CR [3]	N/A [0]	Yes [1]	No [0]	Not a problem [-77]
MM. Is there anything missing from this list?	[1] Yes [0] No Other						

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Caregiver ID \_\_\_\_\_

107

\*\*\*\*\*  
APPLICATION OF  
BOWERS CAREGIVER BEHAVIORS  
\*\*\*\*\*

The next set of questions deal with things you may do for (CARE RECEIVER) but not think about. For some people, though, these things take up a lot of time and mental energy. Please think about each question and respond (as you think appropriate).

(QUESTION)                      (RESPONSE)                      (COMMENTS)                      (CODING)

1. Anticipatory

Many times people who are caring for an ill spouse anticipate the husband/wife's needs for things, but do not tell the spouse this. For example, a wife who is caring for her husband may choose to sleep at a hotel close to the hospital where her husband is hospitalized "just in case" husband needs urgent care.

a. Do you do this now?

B1a \_\_\_\_\_

b. If yes, have you always done this?

B1b \_\_\_\_\_

c. If no, did you do this before your (husband/wife) became ill?

B1c \_\_\_\_\_

Caregiver ID \_\_\_\_\_

108

(QUESTION)

(RESPONSE)

(COMMENTS)

(CODING)

2. Preventive

a. Are there things you do for (CARE RECEIVER) to prevent (him/her) from getting sicker or having an accident? For example, a husband who takes care of his wife may leave night lights on in the bedroom and bathroom to help the wife see her way to the bathroom at night.

B2a \_\_\_\_\_

b. Has this changed from the way it was before (CARE RECEIVER) became ill?

B2b \_\_\_\_\_

3. Supervisory

Some people may spend time doing less formal tasks for their spouse. These include things like setting up the spouse's pills, checking up on a spouse when (he/she) is in the bathroom, making sure spouse sticks to (his/her) prescribed diet, or checking out how the spouse feels that day.

a. Do you do any of these types of things?

B3a \_\_\_\_\_

b. Has this changed from before (CARE RECEIVER) became sick?

B3b \_\_\_\_\_

Caregiver ID \_\_\_\_\_

109

(QUESTION)

(RESPONSE)

(COMMENTS)

(CODING)

4. Protective

Some spouses protect their (husband/wife) of knowing about things that they think will bother him or her. For example, a husband may not tell his wife that she was incontinent of stool in her bed as he knows this would bother her or tell his wife she forgot to turn the stove off and burnt the food.

a. Have you found you protect/prevent (CARE RECEIVER) from knowing she/he is being taken care of or has done something you think would bother him?

B4a \_\_\_\_\_

b. Has this changed from before (CARE RECEIVER) became ill?

B4b \_\_\_\_\_

Caregiver ID \_\_\_\_\_

\*\*\*\*\*  
 AN ADAPTATION OF  
 ROBINSON'S ROLE STRAIN INDEX  
 \*\*\*\*\*

Sometimes caregivers experience difficulties in taking care of their spouse. I would like to learn more about the things you do for (CARE RECEIVER) which you find hard to do.

I am going to read a list of things which other people have found to be difficult in helping out someone who lives at home. Would you tell me if any of these apply to you?

(QUESTION)	(RESPONSE)	(COMMENTS)	(CODING)
1. Is your sleep disturbed (e.g. because (CARE RECEIVER) is in and out of bed or wanders around at night)?	[1] Yes [0] No		R1 _____
2. Is it inconvenient to take care of (CARE RECEIVER) (e.g. because helping takes so much time or it's a long drive over to help)?	[1] Yes [0] No		R2 _____
3. Is it a physical strain (e.g. because of lifting (CARE RECEIVER) in and out of a chair); effort or concentration is required?	[1] Yes [0] No		R3 _____
4. Is it confining (e.g. helping restricts free time or cannot go visiting)?	[1] Yes [0] No		R4 _____
5. Have there been family adjustments (e.g. because helping has disrupted your routine; there has been no privacy)?	[1] Yes [0] No		R5 _____

Caregiver ID \_\_\_\_\_

(QUESTION)	(RESPONSE)	(COMMENTS)	(CODING)
6. Have there been changes in personal plans (e.g. had to turn down a job, or could not go on vacation)?	[1] Yes [0] No		R6_____
7. Have there been other demands on your time (e.g. from other family members)?	[1] Yes [0] No		R7_____
8. Have there been emotional adjustments (e.g. because of severe arguments)?	[1] Yes [0] No		R8_____
9. Has some behavior been upsetting (e.g. because of incontinence; (CARE RECEIVER) has trouble remembering things; or (CARE RECEIVER) accuses people of taking things)?	[1] Yes [0] No		R9_____
10. Is it upsetting to find (CARE RECEIVER) has changed so much from his/her former self (e.g. he/she is a different person than he/she used to be)?	[1] Yes [0] No		R10_____
11. Have there been work adjustments [(e.g. because of having to take time off) (either paid or unpaid work)?]	[1] Yes [0] No		R11_____
12. Is it a financial strain?	[1] Yes [0] No		R12_____
13. Do you feel completely overwhelmed [(e.g. because of worry about (CARE RECEIVER) concerns) about how you would manage)?]	[1] Yes [0] No		R13_____

Caregiver ID \_\_\_\_\_

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\*\*\*\*\*  
PERCEIVED NEEDS  
\*\*\*\*\*

(QUESTION)	(RESPONSE)	(COMMENTS)	(CODING)
1. Is there some kind of help you think you would like to have in caring for (CARE RECEIVER)?	[1] Yes [0] No		PN1 _____
2. If yes, what is it?			
3. I am going to read you a list of services that some people use to help care for their spouse. For each one, I will ask (a) if you use the service now or (b) if you have used the service within the past 18 months			
Do you use:		Have you used:	
	NOW	PAST 18 MOS.	
A. Home Health nurse	[1] Yes [0] No	[1] Yes [0] No	PN3 _____
B. Home Health aide or personal care service	[1] Yes [0] No	[1] Yes [0] No	PN4 _____
C. Homemaker or housekeeping services	[1] Yes [0] No	[1] Yes [0] No	PN5 _____
D. Transportation service	[1] Yes [0] No	[1] Yes [0] No	PN6 _____
E. Delivery service for groceries	[1] Yes [0] No	[1] Yes [0] No	PN7 _____
F. Chore service	[1] Yes [0] No	[1] Yes [0] No	PN8 _____
G. Friendly visitor service	[1] Yes [0] No	[1] Yes [0] No	PN9 _____

Caregiver ID\_\_\_\_\_

(QUESTION)	(RESPONSE)	(COMMENTS)	(CODING)
Do you use:		Have you used:	
	NOW	PAST 18 MOS.	
H. Daycare/adult day health	[1] Yes [0] No	[1] Yes [0] No	PN10____
I. Respite care	[1] Yes [0] No	[1] Yes [0] No	PN11____
J. Social worker	[1] Yes [0] No	[1] Yes [0] No	PN12____
K. Meal service	[1] Yes [0] No	[1] Yes [0] No	PN13____
L. Therapy for arms/legs	[1] Yes [0] No	[1] Yes [0] No	PN14____
M. Phone reassurance	[1] Yes [0] No	[1] Yes [0] No	PN15____
N. Block nurse	[1] Yes [0] No	[1] Yes [0] No	PN16____
O. Advice nurse	[1] Yes [0] No	[1] Yes [0] No	PN17____
P. Speech therapist	[1] Yes [0] No	[1] Yes [0] No	PN18____
Q. Mental health services	[1] Yes [0] No	[1] Yes [0] No	PN19____
4. Finally, I would like to know if there are any services you think a nurse can help with now that you are not receiving.	[1] Yes [0] No		PN21____
5. If yes, what are these?			PN22____



Caregiver ID \_\_\_\_\_

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TEAR OFF BOTTOM HALF AND FILE IMMEDIATELY AFTER INTERVIEW

That is all the questions I have for you. Thank you for your time and willingness to let me interview you today. A summary of the results of this study will be available in June 1988. Would you like me to send you a copy of this summary?

\_\_\_\_\_ Yes                      \_\_\_\_\_ No

Name \_\_\_\_\_

Address \_\_\_\_\_

\_\_\_\_\_

DEFINITIONS OF SERVICES

115

<u>Name of Service</u>	<u>Definition</u>
1. Home Health nurse	RN/LPN who makes home visits
2. Home Health aide or personal care service	Person who assists with ADL's and with homekeeping/meals
3. Homemaker services	Person who does <u>only</u> housekeeping or meals
4. Transportation service	As it sounds
5. Delivery service for groceries	Ditto
6. Chore service	Service for larger household chores (e.g., windows, painting)
7. Friendly visitor	Volunteer who just comes to visit
8. Daycare/adult day health	Older person goes to a daycare center
9. Respite care	In-home relief, or short stay in hospital/nursing home
10. Social worker	As it sounds
11. Meal service	Loaves & Fishes or public meals offered out of high rises, senior centers or churches
12. Therapy for arms/legs	OT or PT
13. Phone reassurance	Someone who calls regularly to check upon person
14. Block nurse	Only 1 in Portland
15. Advice nurse	Phone number to nurse to ask advice
16. Speech therapist	ST/speech pathologist

Appendix B

October 3, 1988

To: Staff Nurses

From: Therese Rasch, RN, BSN

I am a graduate nursing student at \_\_\_\_\_. I'm in the process of data collection for my thesis "Role Strain and Perceived Needs of Elderly Spouse Caregivers" and would like your assistance in this process.

After contacting potential subjects here in the hospital, I will interview subjects (who are the spouses of the patients) once they return home. This will be a one-time interview which will take approximately one hour.

I will be attending discharge planning rounds on your unit to access names of potential subjects for my study. In addition to this, if you have a patient between the ages of 60 and 90, who will be returning home soon to live with a spouse, and lives no further than 60 miles from Portland, please leave a message for me either in this envelope or at home (I have an answering machine). My home phone number is (503) 231-0504. My advisor is Jane Kirschling, Associate Professor, Department of Family Nursing, extension 8382.

Thank you for your time and assistance!

January 12, 1989

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Dear Family Member:

My name is Therese Rasch. I am a registered nurse and a graduate student at the Oregon Health Sciences University in the School of Nursing in Portland. I am doing a research study with family members who provide care to an ill spouse. I want to find out what it is like to provide that care. If you are a male caregiver, and your spouse is 60 years of age or older, I would like to ask you to participate in this study. Taking part in the study is voluntary and will in no way affect the services that you presently receive, or may receive in the future, from the \_\_\_\_\_ or the Oregon Health Sciences University.

If you decide to participate, there will be one interview lasting approximately 45 minutes. You may choose to be interviewed over the phone or in person. Breaks will be worked into the interview but you may take additional rest periods at any time. You may withdraw from the study at any time prior to or during the interview. Your comments will be treated with utmost confidentiality. After the interview you may request a summary of the findings from the study.

The staff from \_\_\_\_\_ will not be informed of your decision to participate or not participate in the study. If you choose to participate in this study, please fill your name, address, and phone number at the bottom of this sheet, and return it to me at the break. I will call you within a week to answer any questions and set up an appointment for the interview. You may also direct any questions to my advisor, Dr. Jane Kirschling, at 279-8382. Thank you for your time and consideration.

Sincerely,

Therese Rasch, RN, BSN

-----  
\_\_\_\_\_  
Name

\_\_\_\_\_  
Street, City, Zip Code

\_\_\_\_\_  
Phone Number



THE OREGON  
HEALTH SCIENCES UNIVERSITY

119

3181 S.W. Sam Jackson Park Road, EJSN, Portland, Oregon 97201 (503) 279-8382

*School of Nursing  
Department of Family Nursing*

Dear Family Member:

My name is Therese Rasch. I am a registered nurse and a graduate student at the Oregon Health Sciences University (OHSU) in the School of Nursing in Portland. I received your name from the Family Practice Clinic at \_\_\_\_\_. I am doing a research study with family members who provide care to an ill spouse. I want to find out what it is like to provide that care. Your participation in this study will allow me to gain this understanding which can be shared with other health care professionals. Taking part in the study is voluntary and will in no way affect the services that you presently receive, or may receive in the future, from

If you decide to participate, there will be one interview lasting approximately 45 minutes. You may choose to be interviewed over the phone or in person. Breaks will be worked into the interview but you may take additional rest periods at any time. You may withdraw from the study at any time prior to or during the interview. Your comments will be treated with utmost confidentiality. During the interview your comments will be placed on data sheets and assigned an identification number. Results of the study will be presented in group form so that you will remain anonymous. After the interview you may request a summary of the findings from the study.

The staff from the Family Practice Clinic at \_\_\_\_\_ will not be informed of your decision to participate or not participate in the study. I will call you within a week to answer any questions and ask you if you are willing to be interviewed. If you have any questions about this research, please feel free to contact my advisor, Dr. Jane Kirschling, at 279-8382. Thank you for your time and consideration.

Sincerely,

Therese Rasch, RN, BSN  
Graduate Nursing Student  
The Oregon Health Sciences University

*Schools  
Schools of Dentistry, Medicine, Nursing*

*Clinical Facilities  
University Hospital  
Doernbecher Memorial Hospital for Children  
Crippled Children's Division  
Outpatient Clinics*

*Special Research Division:  
Vollum Institute for  
Advanced Biomedical Research*



THE OREGON  
HEALTH SCIENCES UNIVERSITY

3181 S.W. Sam Jackson Park Road, EJSN, Portland, Oregon 97201 (503) 279-8382 120

*School of Nursing  
Department of Family Nursing*

Dear Family Member:

My name is Therese Rasch. I am a registered nurse and a graduate student at the Oregon Health Sciences University in the School of Nursing in Portland. You have been identified as a caregiver through the \_\_\_\_\_ Respite Care Program. I am doing a research study with family members who provide care to an ill spouse. I want to find out what it is like to provide that care. It is important that health care professionals understand what families are experiencing and provide help according to their needs. Your participation in this research study will allow me to gain this understanding which can be shared with other health care professionals. Taking part in the study is voluntary and will in no way affect the services that you or your spouse presently receive, or may receive in the future, from \_\_\_\_\_ or the Oregon Health Sciences University.

If you decide to participate, there will be one interview lasting approximately 45 minutes. You may choose to be interviewed over the phone or in person. You may withdraw from the study at any time prior to or during the interview. Your comments will be treated with utmost confidentiality. During the interview your comments will be placed on data sheets and assigned an identification number. Results of the study will be presented in group form so that you will remain anonymous. Once the results of the study are compiled, participants will receive a report of the findings.

If you would like more information concerning the study, please check the "yes" box on the attached postcard. If you are not interested in participating in the study at this time, please check the "no" box on the postcard. Whichever option you choose, I would greatly appreciate your returning the postcard to \_\_\_\_\_ at the Caregiver Respite Program by January 1, 1989. If you select the "yes" option, I will call you after January 1, 1989 to answer any questions you may have and arrange an interview if you choose to participate in the study. In the interim, please feel free to contact my advisor, Dr. Jane Kirschling, at 279-8382 with any questions. Thank you for your time and consideration.

Sincerely,

Therese Rasch, RN, BSN

*Schools  
Schools of Dentistry, Medicine, Nursing*

*Clinical Facilities  
University Hospital  
Doernbecher Memorial Hospital for Children  
Crippled Children's Division  
Outpatient Clinics*

*Special Research Division:  
Vollum Institute for  
Advanced Biomedical Research*

Appendix C



SCRIPT FOR USE OF INTERVIEW GUIDE  
WITH TELEPHONE INTERVIEW

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- A. Version one: For first telephone contact with subject who also agrees to be interviewed at the same time.

1.

Hello, my name is Therese Rasch, and I am a graduate nursing student from the Oregon Health Sciences University. Can I speak with (POTENTIAL SUBJECT)? (AWAIT AFFIRMATIVE ANSWER, AND/OR FOR POTENTIAL SUBJECT TO COME TO THE PHONE. REPEAT FIRST SENTENCE OF SCRIPT AS NECESSARY). I mailed you a letter about 7 days ago concerning a small research study I am conducting. Did you receive that letter? (AWAIT RESPONSE. IF LETTER NOT RECEIVED, DESCRIBE THE CONTENTS OF THE LETTER. IF LETTER RECEIVED, CONTINUE.) Do you have time to discuss the study now? (AWAIT RESPONSE. IF POTENTIAL SUBJECT REFUSES TO CONTINUE, ATTEMPT TO RESCHEDULE TELEPHONE CONVERSATION. THANK POTENTIAL SUBJECT FOR HIS/HER TIME, AND HANG UP. IF RESPONDENT AGREES, CONTINUE).

2.

The study I am conducting is with Spouse Caregivers of elderly persons. The purpose of the study is to find out more about the experience of caring for an ill spouse. Do you have any questions for me about the study at this time? (PAUSE AND ALLOW POTENTIAL SUBJECT TO RESPOND, THEN CONTINUE). I would like to set up a time to conduct the interview. I can perform the interview either over the telephone, or in-person. Which would you prefer? (ALLOW THE POTENTIAL SUBJECT TO RESPOND. IF HE/SHE CHOOSES AN IN-PERSON INTERVIEW, SCHEDULE THE INTERVIEW AT THIS TIME. IF HE/SHE CHOOSES A TELEPHONE INTERVIEW, OFFER THE OPTIONS OF EITHER AN INTERVIEW AT THIS TIME OR AT A LATER DATE. IF HE/SHE CHOOSES THE LATTER, SCHEDULE THE TELEPHONE INTERVIEW AT THIS TIME. IF THE FORMER IS CHOSEN, CONTINUE). In order to ensure that you understand what this study entails, I will read to you a verbal consent form at this time, after which I will ask you to tell me if you agree to participate in this study. (PAUSE AND ALLOW OPPORTUNITY FOR RESPONSE. THEN FOLLOW BY READING THE TELEPHONE INTERVIEW CONSENT FORM. AFTER COMPLETING THE CONSENT FORM, DETERMINE AGREEMENT TO CONTINUE. IF HE/SHE DISAGREES, THANK HIM/HER FOR HIS/HER TIME AND HANG UP). CONTINUE IF POTENTIAL SUBJECT AGREES. Now we can start the interview. (ALLOW SUBJECT TO RESPOND, THEN CONTINUE BY READING THE INTERVIEW GUIDE AND MARKING RESPONSES).

- b. Version two: For second telephone interview for purpose of conducting interview.

1.

123

Hello, this is Therese Rasch, the Graduate Nursing Student from the Oregon Health Sciences University. Is this still a good time to carry out the telephone interview we had arranged? (ALLOW POTENTIAL SUBJECT TO RESPOND. IF THIS IS NOT A GOOD TIME, ATTEMPT TO RESCHEDULE, THANK HIM/HER AND HANG UP. IF HE/SHE AGREES TO THE INTERVIEW AT THIS TIME, CONTINUE FROM POINT A., 2).

Appendix D

INFORMED CONSENT  
 CONSENT TO ACT AS A SUBJECT FOR RESEARCH AND INVESTIGATION  
 IN PERSON INTERVIEW

You are being asked to participate in the study, "Role Strain and Perceived Needs: A Sample of Elderly Spouse Caregivers", under the direction of Mary Therese Rasch, RN, BSN. The purpose of the study is to find out more about the experience of caring for an ill spouse. You are one of forty spouses of persons aged 60 to 90 in the Portland area who are participating in this study.

Participation in this study involves being interviewed one time. This interview may take up to one hour. While you may benefit from an increased understanding of your needs in being a caregiver, potential risks to you include any emotional discomfort at awareness of these needs, as well as the risk of mild fatigue from the interview process.

Do you have any questions regarding the study? If so, please address these to Ms. Rasch at this time. You may also address any additional questions to Ms. Rasch by telephone at (503) 231-0504.

You may refuse to participate in the study at any time without affecting your relationship with or treatment at the

Your responses to the interview will be strictly confidential. You do not have to answer all questions. Information will not become part of your spouse's medical record, and the answers you give will be seen only by the research staff. Your name will not appear on any written or recorded data. Data will be identifiable by code number only. Please remember that you can withdraw from this study at any time. Do you agree to participate in this study? (Principal Investigator will check response).

Yes  
 No

\_\_\_\_\_  
 Subject Name

\_\_\_\_\_  
 Investigator Signature

\_\_\_\_\_  
 Date

INFORMED CONSENT 126  
CONSENT TO ACT AS A SUBJECT FOR RESEARCH AND INVESTIGATION  
IN PERSON INTERVIEW

You are being asked to participate in a study with Family Caregivers under the direction of Mary Therese Rasch, RN, BSN. The purpose of the study is to find out more about the experience of caring for an ill spouse.

Participation in this study involves being interviewed one time. This interview may take up to one hour. The investigator is not aware of any known risks or discomforts that may result from this research. There may not be any benefit to you except the chance to talk about your experience.

I need to point out that \_\_\_\_\_, as an agency of the state, is covered by \_\_\_\_\_ Liability Fund. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of \_\_\_\_\_ its officers, or employees. If you have further questions, please call \_\_\_\_\_ at \_\_\_\_\_. It is not expected that you will suffer injury. This is a required statement for all research conducted through

Do you have any questions regarding the study? If so, please address these to Ms. Rasch at this time.

You may refuse to participate in the study at any time without affecting your relationship with or treatment \_\_\_\_\_.

Your responses to the interview will be strictly confidential. You do not have to answer all questions. Information will not become part of your medical record, and the answers you give will be seen only by the research staff. Your name will not appear on any written or recorded data. Data will be identifiable by code number only. Please remember that you can withdraw from this study at any time.

Do you agree to participate in this study? (Principal Investigator will check response).

Yes  
 No

\_\_\_\_\_  
Subject Name

\_\_\_\_\_  
Investigator Signature

\_\_\_\_\_  
Date

**INFORMED CONSENT  
 CONSENT TO ACT AS A SUBJECT FOR RESEARCH AND INVESTIGATION  
 IN PERSON INTERVIEW**

You are being asked to participate in a study with Family Caregivers under the direction of Mary Therese Rasch, RN, BSN. The purpose of the study is to find out more about the experience of caring for an ill spouse.

Participation in this study involves being interviewed one time. This interview may take up to one hour. The investigator is not aware of any known risks or discomforts that may result from this research. There may not be any benefit to you except the chance to talk about your experience.

Do you have any questions regarding the study? If so, please address these to Ms. Rasch at this time.

You may refuse to participate in the study at any time without affecting your relationship with or treatment at \_\_\_\_\_ . It is not the policy of \_\_\_\_\_, or any other agency funding the research project in which you are participating, to compensate or provide medical treatment for human subjects in the event the research results in physical injury. You should further understand that should you suffer any injury from the research project, compensation will be available only if you established that the injury occurred through the fault of \_\_\_\_\_, its officers or employees or your physician. Further information regarding this policy may be obtained from the Office of Research Administration at 229-7218.

Your responses to the interview will be strictly confidential. You do not have to answer all questions. Information will not become part of your medical record, and the answers you give will be seen only by the research staff. Your name will not appear on any written or recorded data. Data will be identifiable by code number only. Please remember that you can withdraw from this study at any time.

\_\_\_\_\_

I have read and understand the foregoing and agree to participate in the study.

\_\_\_\_\_ Yes  
 \_\_\_\_\_ No

\_\_\_\_\_

Subject Name

\_\_\_\_\_

Investigator Signature

\_\_\_\_\_

Date

INFORMED CONSENT  
 CONSENT TO ACT AS A SUBJECT FOR RESEARCH AND INVESTIGATION  
 TELEPHONE INTERVIEW

You are being asked to participate in a study with Family Caregivers under the direction of Mary Therese Rasch, RN, BSN. The purpose of the study is to find out more about the experience of caring for an ill spouse.

Participation in this study involves being interviewed one time. This interview may take up to one hour. The investigator is not aware of any known risks or discomforts that may result from this research. There may not be any benefit to you except the chance to talk about your experience.

Do you have any questions regarding the study? If so, please address these to Ms. Rasch at this time.

You may refuse to participate in the study at any time without affecting your relationship with or treatment at \_\_\_\_\_ . It is not the policy of \_\_\_\_\_, or any other agency funding the research project in which you are participating, to compensate or provide medical treatment for human subjects in the event the research results in physical injury. You should further understand that should you suffer any injury from the research project, compensation will be available only if you established that the injury occurred through the fault of \_\_\_\_\_, its officers or employees or your physician. Further information regarding this policy may be obtained from the Office of Research Administration at 229-7218.

Your responses to the interview will be strictly confidential. You do not have to answer all questions. Information will not become part of your medical record, and the answers you give will be seen only by the research staff. Your name will not appear on any written or recorded data. Data will be identifiable by code number only. Please remember that you can withdraw from this study at any time.

Do you agree to participate in this study? (Principal Investigator will check response).

Yes  
 No

\_\_\_\_\_  
 Subject Name

\_\_\_\_\_  
 Investigator Signature

\_\_\_\_\_  
 Date

INFORMED CONSENT 129  
CONSENT TO ACT AS A SUBJECT FOR RESEARCH AND INVESTIGATION  
TELEPHONE INTERVIEW

You are being asked to participate in a study with Family Caregivers under the direction of Mary Therese Rasch, RN, BSN. The purpose of the study is to find out more about the experience of caring for an ill spouse.

Participation in this study involves being interviewed one time. This interview may take up to one hour. The investigator is not aware of any known risks or discomforts that may result from this research. There may not be any benefit to you except the chance to talk about your experience.

I need to point out that the \_\_\_\_\_ as an agency of the state, is covered by \_\_\_\_\_. If you suffer any injury from the research project, compensation would be available to you only if you establish that the injury occurred through the fault of \_\_\_\_\_, its officers, or employees. If you have further questions, please call \_\_\_\_\_ at \_\_\_\_\_. It is not expected that you will suffer injury. This is a required statement for all research conducted through \_\_\_\_\_.

Do you have any questions regarding the study?  
You may refuse to participate in the study at any time without affecting your relationship with or treatment at \_\_\_\_\_

Your responses to the interview will be strictly confidential. You do not have to answer all questions. Information will not become part of your medical record, and the answers you give will be seen only by the research staff. Your name will not appear on any written or recorded data. Data will be identifiable by code number only. Please remember that you can withdraw from this study at any time.

Do you agree to participate in this study? (Principal Investigator will check response).

Yes  
\_\_\_\_\_ No

Subject Name \_\_\_\_\_

Investigator Signature \_\_\_\_\_

Date \_\_\_\_\_



INFORMED CONSENT  
 CONSENT TO ACT AS A SUBJECT FOR RESEARCH AND INVESTIGATION  
 INTERVIEW

You are being asked to participate in the study, "Role Strain and Perceived Needs: A Sample of Elderly Spouse Caregivers", under the direction of Mary Therese Rasch, RN, BSN. The purpose of the study is to find out more about the experience of caring for an ill spouse. You are one of forty spouses of persons aged 60 to 90 in the Portland area who are participating in this study.

Participation in this study involves being interviewed one time. This interview may take up to one hour. While you may benefit from an increased understanding of your needs in being a caregiver, potential risks to you include any emotional discomfort at awareness of these needs, as well as the risk of mild fatigue from the interview process.

Do you have any questions regarding the study? If so, please address these to Ms. Rasch at this time. You may also address any additional questions to Ms. Rasch by telephone at (503) 231-0504.

You may refuse to participate in the study at any time without affecting your relationship with or treatment at the

Your responses to the interview will be strictly confidential. You do not have to answer all questions. Information will not become part of your spouse's medical record, and the answers you give will be seen only by the research staff. Your name will not appear on any written or recorded data. Data will be identifiable by code number only. Please remember that you can withdraw from this study at any time. Do you agree to participate in this study? (Principal Investigator will check response).

Yes  
 No

\_\_\_\_\_  
 Subject Name

\_\_\_\_\_  
 Investigator Signature

\_\_\_\_\_  
 Date

## Abstract

Title: Role Strain and Perceived Needs: A Sample of Elderly Spouse Caregivers

Author: Mary Therese Rasch

Approved: 

Jane M. Kirschling, R.N., D.N.Sc., Associate Professor, Thesis Advisor

A descriptive correlational study was conducted to explore the effects of gender and length of time caregiving on changes that occur in the assignment of preestablished roles, role strain, and the perceived needs of the caregiver. Although much research has been carried out regarding the caregiving role and the negative consequences of caregiving, less explored areas include differences among caregiving groups according to length of time caregiving and perceived needs of the caregiver for nursing intervention. Also, differences according to gender among spouse caregivers to elderly persons are not clear in the literature.

Role theory served as the foundation for the conceptual framework. The sample consisted of 20 female and 9 male caregivers to elderly spouses. The caregivers ranged in age from 60-90. Measures of the performance of and change in caregiving tasks and caregiving behaviors, role strain, and perceived needs of the caregiver were used. Each subject was interviewed one time, either in person ( $n=20$ ) or over

the telephone ( $n=9$ ).

Limitations of the study included the small convenience sample and the use of cross sectional data. Also, the need for additional methodological work on the new measures of roles, role performance, and perceived needs of the caregivers is acknowledged as a limitation.

The findings included some significant relationships in the performance of caregiving tasks. For housekeeping tasks, significant relationships were found for gender,  $F(1,28)=22.90$ ,  $p=.001$  and length of time caregiving,  $F(1,28)=5.16$ ,  $p=.03$ . Both male ( $M=-.65$ ,  $SD=.41$ ) and long term caregivers ( $M=-.35$ ,  $SD=.51$ ) reported greater change in the performance of housekeeping tasks than did female ( $M=-.01$ ,  $SD=.30$ ) or short term caregivers ( $M=-.08$ ,  $SD=.35$ ). The caregiving spouses reported a lack of performance of protective caregiving behaviors, which contrasted with previous research with adult children.

A significant relationship was found between gender and role strain, with men experiencing greater role strain,  $F(1,28)=4.18$ ,  $p<.05$ . While slightly more than half ( $n=15$ ) of the caregivers reported current use of formal services to assist in caregiving, some caregivers indicated an interest in respite services, as well as caregiving advice, and the provision of

health related information.

This study is an additional piece in the growing body of literature concerning spouse caregivers to the elderly. Particular to the nature of caregiving, nurses need to understand the assumption of the caregiving behaviors of anticipation, prevention, and supervision. Nurses also need to consider the potential for differences in the performance of protective caregiving behaviors by elderly marital partners as compared to adult children caring for their elderly parents. While this study found some interesting differences in the performance of caregiving tasks and protective caregiving behaviors, the nurse needs to assess the individual caregiving situation before applying the study's findings.