Motivation for Caregiving in Family Members Caring for Older People

Ву

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ABSTRACT

Title:

Motivation for Caregiving in Family Members Caring for Older People

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The purpose of this Master's Research Project was to identify motivational factors that influence a family member to assume the role of caregiver for an older relative who had been discharged from the hospital with a chronic illness, or to continue in the role of caregiver over a period of time. The conceptual framework was derived from parts of role theory and a search of the literature which resulted in the creation of the Personal, Familial, and Socio-Cultural Domains and the categories of Attachment, Reciprocation, Preparedness, Economic Constraints, Caregiver Availability, Personal Philosophy, Family Responsibility, Moral Standards of Behavior, and Cultural Role Assignment. The caregiver was viewed as an actor playing out a role according to a script interpreted through identification with the categories and the three domains.

The project was designed to analyze a portion of the data from the Caregiver Relief Study (CRS) (Archbold & Stewart, 1988). Content Analysis was used for this project to analyze qualitative data from the responses to three questions that were taken from the Family Caregiver Inventory (FCI) (Archbold & Stewart, 1986) during interviews with the caregiver dyads at 6 weeks ($\underline{n} = 103$) and again at 9

months post-hospital discharge ($\underline{n} = 78$). The qualitative data were quantified using frequency counts and rankings.

Data analysis resulted in the categories of Attachment, Family Responsibility, Personal Philosophy and Moral Standards of Behavior receiving the highest rankings among caregivers at both time periods. The percentage of responses that pertained to the categories of Reciprocation and Moral Standards was greater from among the caregivers who were interviewed at 9 months than from among those who were interviewed at 6 weeks.

Limitations of the study pertained to use of an existing database and analysis based on the responses from primarily one question. Other limitations included a dichotomous rating of the responses for either the presence or absence of factors within each category, and not controlling distinctions between caregivers who had assumed or continued in the role.

Implications within the clinical setting include the relevance of understanding the reasons why a family member decides to assume the role of caregiver, understanding the caregivers' beliefs about the quality of the relationship shared with the care receiver, and beliefs about family responsibility as factors that may influence successful caregiving outcomes. The results imply a need for more studies that explore the reasons why a family member decides to assume the role or to continue in the role of caregiver.

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CHAPTER 1

INTRODUCTION

Population and Growth Rate

According to the 1990 U.S. Census Report, Americans age 65 or older represent 12.5% of the total population (U.S. Bureau of the Census: Current Population Reports, Special Studies, 1992). The population is aging. The number of persons aged 65 years or over is projected to more than double by the middle of the next century to nearly 69 million. By 2040, the number of persons aged 65 years or older could exceed the number of persons under the age of 20. The oldest old age group—85 years and older—is expected to be the fastest growing part of the elderly population, projected to more than double from 3 million in 1990 to 8 million in 2030. By 2050, this group is expected to increase to over 15 million, to represent 5% of the total population (U.S. Bureau of the Census: Current Population Reports, Special Studies, 1992).

Health of Older People

More than four out of five people aged 65 and over are living with at least one chronic condition and frequently experience multiple chronic health conditions which may effect their functional abilities (Committee on Aging, 1991). As people get older, they tend to experience more health/functional problems. The percentage of people reporting difficulty with at least one personal care activity rises from 5.9%

for people 65-69 years of age to 34.5% for people 85 years or older (Committee on Aging, 1991).

The Role of Caregiver

As functional ability deteriorates, family members—often spouses or adult children—frequently find themselves in the position of juggling the needs of a dependent parent or spouse with other competing obligations both within and outside the family structure. Hing and Bloom (1990) found that out of the 5 million functionally dependent persons age 65 years or older who received home care, 67% received only informal care, which they defined as unpaid assistance that was provided by family, friends, or neighbors.

Depending on the level of functional and/or cognitive disability of the dependent relative, the family caregiver may be required to assist an older relative with a wide range of everyday tasks necessary for personal care and the maintenance of independent living. Caregiving activities may include bathing, dressing, toileting, feeding, shopping, transportation, handling personal finances, meal preparation, doing housework, giving medication, and answering the telephone (Hing & Bloom, 1990; Liu, Manton, & Liu, 1985; Macken, 1986; Stone, Cafferata, & Sangl, 1987).

Using data from the 1982 Informal Caregivers Survey (ICS) Stone et al., (1987) found that the majority of caregivers were female (71.5%), and were adult daughters (28.9% of all caregivers) or wives (22.7% of all caregivers). Husbands comprised almost 13% of all caregivers. One quarter of caregivers were aged 65 to 74, and 10.1% were aged 75 or over. Almost three quarters of the caregivers in the ICS study lived with the care recipient and provided assistance 7 days a week (80%)

with activities that included personal hygiene (66%), moving about (46%), administering medication (53%) and housekeeping tasks (80%).

The Effects of Caregiving

As the elderly population continues to grow older, the pool of family caregivers is aging as well. The caregiver's mental and physical resources may be stretched to meet the needs of the care recipient and other competing family- and work-related obligations. The role of caregiver for a dependent family member may be made more complex by the caregiver's personal limitations, including chronic health conditions that lead to self-assessment of their health as being lower than their age peers (Schulz, 1990). Stone et al. (1987) found that one third of the caregivers rated their health as fair or poor.

The stresses associated with caring for a family member who is functionally and/or cognitively impaired can result in decreased quality of physical health (Abel, 1991) or mental health (Baillie, Norbeck, & Barnes, 1988; Cohen & Eisdorfer, 1988; Robinson, 1989); loss of income (Committee on Aging, 1991; Stone et al., 1987), or financial drain (Archbold, 1980); strained relationships within the family (Johnson & Catalano, 1983; Pratt, Schmall, Wright & Cleland, 1985); social isolation (Archbold, 1980; Graham, 1983); and feeling overwhelmed (Chenoweth & Spencer, 1986).

Feelings of subjective and/or objective burden (Montgomery, Gonyea, & Hooyman, 1985; Zarit, Todd, & Zarit, 1986), correlates of burden (Poulshock & Deimling, 1984; Zarit, Reever, & Bach-Peterson, 1980), measurement of burden (Zarit et al., 1980), predictors of burden (Robinson, 1990), and burden and coping

strategies (Pratt et al., 1985) are representative of the many research studies that have focused on the burdens associated with caregiving.

Other studies have explored the stress (Baillie et al., 1988; Quayhagen & Quayhagen, 1988) and the strain (Archbold et al., 1990; Cantor, 1983; Given, Collins, & Given, 1988). The role of caregiver is known to be associated with negative mental health effects on spouse caregivers (Prucho & Resch, 1989), including depression (Cohen & Eisdorfer, 1988; Robinson, 1989). The relationship between mental and physical health is notable among older people (Committee on Aging, 1991). A growing body of knowledge indicates the significance between mental health effects and the course of illness among older persons, including impaired function of the immune system (Kiecolt-Glaser, Dura, Speicher, Trask, & Glaser, 1991).

One aspect of caregiving that is not well understood is what compels someone to undertake such a demanding role, or to continue in the role despite tremendous hardships. While a few researchers have investigated factors that influence an individual to assume the role of family caregiver (Cantor & Hirshorn, 1988; Guberman, Maheu, & Maille, 1992; Horowitz & Shindelman, 1983; Ikels, 1983) or to continue living with and caring for an older person (Hirschfield, 1983), our understanding of factors that are present to motivate an individual to assume the role of family caregiver remains incomplete.

<u>Significance</u>

Results from previous studies have led to a broad level of understanding by specialists in the field of aging about caregivers and the factors that may influence

their response to caregiving. However, current research needs to broaden its understanding of the complexities associated with the role of caregiver by attending to the diversity found among caregivers and the meaning that the individual caregiver gives to the role. Much of caregiving research has embedded the role of the caregiver within the care recipient's level of dependency to arrive at a description that reflects the needs of the <u>care receiver</u> rather than of the <u>caregiver</u>. The body of caregiving knowledge needs to be broadened to encompass the perceptions of the caregiver, including reasons why they chose the role. Knowledge of the reasons why a family member chooses to assume the role of caregiver may enable the clinician to structure clinical interventions and use strategies that target the subjective preferences of the caregiver, having the potential to reduce the degree of burden perceived by the caregiver (Gwyther, 1992).

The role of the family caregiver is complex and has the potential to be physically, emotionally, and financially draining on the caregiver and on other members of the family as well. Because of the complexities that are associated with the role of family caregiver, isolation of the factors that motivate someone to become a caregiver for an elder relative who has been discharged from the hospital, and to continue in the role in spite of hardships, is needed. This focus served as the overall goal of inquiry for this Masters Research Project (MRP).

CHAPTER 2

REVIEW OF THE LITERATURE

The purpose of this literature review is to present a comprehensive analysis of the existing level of knowledge about the factors that motivate someone to assume the role of family caregiver. The review will conclude with the conceptual framework for this project.

The literature review is divided into three sections. The first section will summarize research that directly pertains to motivation as it relates to the role of family caregiver. The second section summarizes the research about motivation and caregiving behaviors in general. The final section will present the contribution of role theory to the development of the conceptual framework used for this project.

Motivation and the Role of Family Caregiver

A computer search of the research literature using Medline, Knowledge Finder, and the Social Science Citation Index, 1982-1992, combined with a manual search, revealed five research or review articles that related directly to the concept of motivation and the role of caregiver for an impaired family member (Cantor & Hirshorn, 1988; Guberman et al., 1992; Hirschfield, 1983; Horowitz & Shindelman, 1983; Ikels, 1983). The purpose of this review is to compare and contrast the findings between the articles as they pertain to motivation and the role of caregiver for an older relative. Please refer to Table 1 for specific details about each study.

Table 1
Summary of Caregiving Studies With Direct References to Motivation

| Author & Date | Purpose | Framework | Measures | Findings | Relevance |
|----------------------------------|--|--|---|---|---|
| Cantor & Hirshorn (1989) | To describe the factors that motivate people of different generations to assist one another | Exchange Theory Caregiver Framework 1. Need for assistance 2. Values and attitudes intrinsic to family 3. Societal and personal factors that mediate familial response 4. Response domain includes nature and circumstances under which care is provided | Review of Literature | 1. Psychological attachments: love, hate, affection, intimacy, nurturance, positive and negative aspects of dependency 2. Intergenerational or family solidarity 3. Interactions between norms of family expectations and societal norms, including appropriate relationships between generations | Contributes to definition of motivation from the perspective of interaction and relationships between generations within the family structure. Indicates relevance of family relationships, family relationships, feelings of attachment to the definition of motivation. |
| Guberman, Maheu, & Maille (1992) | Descriptive analysis to identify what factors or motives intervene and determine a family's (woman's) decision to care for a dependent relative with the objective to problematize family caregiving as a social | Conceptual Framework Motives defined as those elements that play a role to assume the role of primary caregiver. Actions often originate not from within but from the situation in which individuals find | In-depth personal interviews. Non-random sample of 40 caregivers of nonspousal kin; range 30–80 years, majority 45–65 years. Care receivers: Mentally ill relatives mostly adult children (16); one | Fourteen Factors Primary: 1. Love, maternal feelings, feelings of family ties 2. Inadequacy of institutional or community resources 3. Profound need to help other | Phenomological approach identifies factors that motivate female relatives to become caregivers. Data analysis not given. Generalizability limited to sample. Subjects are residents of Quebec. Findings |

Table 1 (Continued)

| Author & Date | Purpose | Framework | Measures | Findings | Relevance |
|--------------------|---|--|--|---|---|
| | act rather than look at the specifics of caregiving in relation to an illness, handicap, or age group | themselves. Motives relating to values and feelings reflect an internalization of dominant societal norms. | mother; one brother-in- law frail elderly kin (24) | 4. Feelings of duty and obligation 5. Imposition of the decision by the dependent person 6. Women's socioeconomic dependency Secondary: 7. Unavailability of other family members | may reflect bias from Canadian health care system. 40% of sample are parent caregivers for disabled child. Caregivers' non-spousal methods of control not given. Findings reflect subjective perceptions of caregivers. |
| | | | | 8. Anti-institutional feelings 9. Caregiving arrangement 10. Religious feelings 11. Caregiver's personal characteristics 12. Belief in healing process 13. Dependent person's health 14. Family tradition | |
| Hirschfield (1983) | To present the concept mutuality, as a factor identified in a previous study about home care | Field methodology grounded theory; in- depth intense interviews structured | OARS Multidimensional Functional Assessment Questionnaire OMFAQ | Mutuality described as the caregiver's ability to find gratification in the relationship with | Results suggest that caregivers may be motivated to role of caregiver if they |

Table 1 (Continued)

| Author & Date | Purpose | Framework | Measures | Findings | Relevance |
|---------------|--|--|---|--|---|
| | versus institution- alization, and how it influences a family caregiver to continue living with and caring for an old person with irreversible senile brain disease, as opposed to institutionalization. | on adaptation and management to caregiver and to care receiver | (cited), in-depth focused questionnaires, and participant observation. Determine rating and coding for caregiver and care receiver. High interrater reliability observations; sales for morale, tension, management ability, and mutuality done with face validity and factor analysis, using Z scores to compose scale scores and determine range. Non-random sample of 30 demented elderly and 30 family caregivers from urban Western United States; two-thirds of caregivers were spouses; one-third | the impaired person and meaning from situation, and the caregiver's ability to perceive the impaired person as reciprocating by virtue of his/her existence. Interrelationship between mutuality and management (I = .63) and mutuality and morale (I = .58) show moderate correlation; Pearson's I between mutuality and tension shows negative correlation (I =58). Caregiver's attitude to institutionalization shows very high negative correlation with caregiver with caregiver | perceive a high level of mutuality about their relationship with the care receiver, and from the meaning they derive from the caregiving situation. |
| | | | were adult-child caregivers; 27% of caregivers were male. | $ \underline{n} = 30 $. Statistical significance level not given. | |

Table 1 (Continued)

| Author & Date | Purpose | Framework | Measures | Findings | Relevance |
|--------------------|--|---|---|--|---|
| ●Shindelman (1983) | To examine the influence of affection and reciprocity on the caregiving behavior of 203 caregivers for frail, elderly relatives. | Exchange Theory is implicit with definition of variables. Reciprocity is conceptualized as credits earned by the older relative for past help given to the caregiver—an obligation. Affection is defined as the quality of the relative relationship as perceived by the caregiver, as measured by the degree of positive feelings or closeness felt by the caregiver towards the caregiver towards the care recipient. | In-depth, structured interviews given to 203 primary caregivers for older relatives receiving day care or home services from one of four agencies in New York City. Data drawn from larger study. Caregivers: adult children (65%); spouses (9%); other relatives (26%). Age: range 22-85 years, M = 55. Care receiver: female (80%); widowed (67%); over 75 years (66%); moderately impaired ADL function. Four scales derived to operationalize constructs: 1. Caregiving involvement: Objective level of time and task commitment to help | Affection: Most reported being close to the care receiver (52%). However, 15% reported not very or not close at all; 21% could never confide in care receiver. Indicative that affective ties are not a necessary component to initiate caregiving. Providing care seems to draw the dyad closer but make the day-to-day interaction more difficult. 71% reported feeling very close as opposed to 58% who did so before the illness. Reciprocity: Most nonspouse caregivers (71%) believed their relative could always be counted on for help; 54% believed the care receiver had made many sacrifices for | Identification of familial obligation (filial responsibility), affection and reciprocity as source of motivation among caregivers for frail elderly relatives as determined by the perceptions of the caregivers. |
| | | | June of the state | | |

Table 1 (Continued)

| Author & Date | Purpose | Framework | Measures | Findings | Relevance |
|---------------|---------|-----------|---------------------------|--|-----------|
| | | | older relative. | them. Motivators to | |
| | | | Cronbach's alpha .82 | become caregiver | |
| | | | for 12-item scale. | included familial | |
| | | | 2. Caregiving | obligation (58%); | |
| | | | consequences: | affection (51%); and | |
| | | | Perception of problems | reciprocity (17%). | |
| | | | encountered in | Correlation between | |
| | | | caregiving experience | reciprocity and | |
| | | | operationalized with | caregiver involvement | |
| | | | open-ended and | indicates that | |
| | | | fixed-choice questions. | caregiver's perceptions | |
| | | | Internal consistency | of past help influence | |
| | | | reliability .88; validity | their decision to give | |
| | | | coefficient .73. | care ($I = .20$, | |
| | | | 3. Affection: The | p < .01). Correlation | |
| | | | degree of positive | between affection and | |
| | | | feelings towards the | both caregiver | |
| | | | care receiver. Scale | involvement and | |
| | | | alpha, .79; correlation | caregiver consequences | |
| | | | with interviewer's | indicates that the | |
| | | | global rating of | degree of positive | |
| | | | affection, .82. | feeling for the care | |
| | | | 4. Reciprocity: | receiver is related to | |
| | | | Measured with 10-item | the amount of care | |
| | | | scale of caregiver's | involvement by the | |
| | | | perception of extent | caregiver ($\underline{\mathbf{r}} = .21$, | |
| | | | and importance of past | p < .01), and the | |
| | | | help from care | degree of positive | |
| | | | receiver, given to | feeling for the care | |

Table 1 (Continued)

| Findings | receiver is negatively correlated to the caregiver's perception of the caregiving experience in terms of the emotional strain and adverse effects (T =19, p < .01). | appears to follow rules that transcend cultural tr | among siblings; caregiver, with greatest motivation |
|---------------|---|--|--|
| Measures | nonspouse caregivers rece only to avoid bias from corr marital relationship. care Internal consistency of the reliability, .62, expecorrelated with global the tratings at .75. | Genealogy of 123 elderly (60 and over) of Irish ancestry and 119 elderly of Chinese ancestry, had lived in United States between 1960 and 1980 (37 families of Irish ancestry and 53 ext, on ancestry and 53 entity, family families of Chinese child, families of chinese ancestry); family childre groupe in widow community. 1. D Sex, on child, families of other widow community. 3. Si Least i | amor |
| Framework | | Ethnological approach | |
| Purpose | | To explore reasons for the emergence of particular children from among their siblings to assume the role of caretaker for an older parents. | |
| Author & Date | | Ikels (1983) | |

Table 1 (Continued)

| Relevance | emphasis on cultural diversity. |
|---------------|--|
| Findings | with a particular child to assume role. Affectional bonds seldom cited as causal factors in caretaker selection. |
| Measures | |
| Framework | |
| Purpose | |
| Author & Date | |

With the exception of the article by Cantor and Hirshorn (1988) that was drawn from a review of family caregiving literature, the studies of motivation for caregiving research were descriptive/exploratory in design (Guberman et al., 1992; Hirschfield, 1983; Horowitz & Shindelman, 1983; Ikels, 1983). The studies gathered data through in-depth interviews with non-random convenience samples of family caregivers that ranged in size from 30 (Hirschfield, 1983) to 203 (Horowitz & Shindelman, 1983). Respondents were primarily spouses (Hirschfield, 1983) or adult child caregivers (Horowitz & Shindelman, 1983; Ikels, 1983); or were grouped as caregivers for non-spousal kin (Guberman et al., 1992). Care receivers were grouped as demented elderly (Hirschfield, 1983); elderly people moderately impaired in activities of daily living (ADLs) (Horowitz & Shindelman, 1983), or mentally ill relatives (Guberman et al, 1992). Rather than grouping people as either caregiver or care receiver, Ikels (1983) used a genealogy to explore the reasons for the emergence of a particular child as caregiver for a parent among elderly people of Irish or Chinese ancestry and their families. Perceptions of the caregivers about providing care for a family member provided the focus for the majority of studies.

Motivational factors identified from these studies that pertain to the role of family caregiver included psychological attachments, intergenerational solidarity, and societal norms (Cantor & Hirshorn, 1988); religious beliefs and moral values including a personal need to help others (Guberman et al., 1992); or a personal choice (Ikels, 1983). Other factors included characteristics of the caregiver, including gender, availability of the caregiver, for example, marital status, geographic proximity, and/or participation in the work force (Guberman et al.,

1992; Ikels, 1983). Caregiving arrangements included living arrangements and/or help from other members of the family (Guberman et al., 1992; Ikels, 1983). The dependent person's state of health (e.g., level of autonomy, socioeconomic concerns, and anti-institutional feelings) were also identified as motivational influences (Guberman et al., 1992).

The concept of affect as it pertained to the caregiver's feelings about the care receiver was included as a motivational factor in four of the articles reviewed.

Guberman et al. (1992) grouped all responses that referred to affect and determined a caregiver's decision to assume the role of caregiver into the category of love and feelings of family ties. The authors included in this category feelings of lifelong attachment, reciprocity, and filial attachment.

Likewise, in an effort to identify the motivating factors that promote intergenerational assistance between adult children and their elderly parents, Cantor and Hirshorn (1988) created a category they called psychological attachments. Feelings of love, hate, intimacy, affection, nurturance, and the positive and negative effects of dependency gleaned from a review of the literature, were grouped into this category.

Horowitz and Shindelman (1983) identified affection as a motivating factor and defined it as the caregiver's perception of the quality of the caregiver-older relative relationship and to the positive feelings felt by the caregiver towards the care receiver. The authors found that among the caregivers who participated in their study, affection was the second most frequently cited motivational factor (51%) after familial obligation (58%).

However, caregiving can and does take place in the absence of affection as a causal factor. Ikels (1983) noted that affectional bonds were seldom given as causal factors in caretaker selection, and Guberman et al. (1992) noted that some caregivers denied that they had any particular feelings of affection for the care receiver. Horowitz and Shindelman (1983) noted that 15% of caregivers from their study reported being not very or not close at all to the care receiver.

Closely related to factors that define affect is the concept of mutuality. Hirschfield (1983) defined mutuality as the caregiver's ability to find gratification in the relationship and/or meaning in the situation; and the ability of the caregiver to perceive the care receiver as reciprocating by virtue of their existence. In a study that explored factors that influenced a family member to continue to provide care for their mentally impaired older spouse or parent, Hirschfield found that high levels of mutuality were associated with the caregiver continuing to provide home care as opposed to institutionalization. In addition to mutuality, Hirschfield noted the effects of management ability, the caregiver's morale, and tension that was reflected in the caregiver's perception of unmet needs on the caregiver's continued provision of home care.

Cantor and Hirshorn (1988) used Exchange Theory to define the concept of family or intergenerational solidarity as the extent and nature of interaction between family members (associational solidarity); the degree of positive sentiment, warmth, closeness, emotional gratification (affectual solidarity); and the amount of agreement among family members of values and opinions (consensual solidarity). Attitudes towards filial and familial responsibility and the appropriate role of individuals to

meet the needs of elderly family members, termed norms of responsibility, interact with the broader societal values associated with morals, ethics, and religious values. These attitudes towards filial responsibility are intertwined with the societal norm that children have an obligation to assist their parents or other elder members (Cantor & Hirshorn, 1988).

Horowitz and Shindelman (1983) used the term familial obligation interchangeably with filial responsibility to describe the parameters of this motivating factor and included the concept of duty. Similarly, Guberman et al. (1992) used the term family tradition to describe the adult child caregivers who were motivated to assume the role as a reflection of family values and a function of how they had been raised. Other caregivers reported feelings of obligation to provide care for the elderly parent as a result of having been appointed caregiver by the dependent parent (Guberman et al. 1992).

In describing the process of caretaker selection among elderly Chinese and Irish families, Ikels (1983) included the interplay between cultural values and parental expectancy regarding the selection of the child who will assume responsibility for their care and gender of the child. In addition to gender, other determining factors included proximity, the child who owes the parent a special debt, and the child with the least competing obligations.

Reciprocity was defined as an obligation stemming from past help given by the care receiver to the caregiver and motivating the caregiver to assume the role as a means to repay the older relative for past services (Horowitz & Shindelman, 1983). The authors described reciprocity in terms of gratitude for a past service and

a desire to give something back. Horowitz and Shindelman (1983) found that most non-spouse caregivers believed their relative could always be counted on for help, and 54% believed that their relative had made many sacrifices for them. However, caregivers who were interviewed by Guberman et al. (1992) associated obligations stemming from reciprocity with negative connotations that included expressions of guilt, indebtedness, duty, and resignation. Cantor and Hirshorn (1988) suggested that reciprocity is a two-way exchange where assistance except in cases of severe disabilities flows between the child and the parent.

Guberman et al. (1992) noted the caregiver's faith in the healing process as a motivating factor that provided hope among parents of mentally ill children. Among caregivers who cited being motivated by a profound need to help others, the authors observed the significance of providing care to others through the caregiver's perception of feeling useful. Caregivers who were motivated by this factor described the role as giving meaning to their lives and referred to caregiving as a vocation or a calling. The authors suggested that caregiving for these individuals seemed to be related to their sense of self and feelings of responsibility to others.

Motivation and Caregiving in General

Twenty-six articles were found that pertained to motivation and to caregiving in general. Five articles that were published between 1962 and 1981 are included because of their relevance to establishing the significance of the family as a kinship system and as a source of mutual assistance (Adams, 1968; Shanas, 1979; Sussman & Burchinal, 1962) and to show the pertinence of filial or familial responsibility to the role of family caregiver (Archbold, 1980; Brody, 1981). For clarification, the

articles have been grouped into three sections. The first section reviews articles that equate motivation with the kinship system. The second section includes articles that relate motivation to the caregiver's appraisal of the role. The final section includes articles about motivation and familial or filial responsibility. Please refer to Table 2 for specific details about the following studies.

Kinship System

The significance of the family as a source of assistance between generations is made very clear (Adams, 1968; Brody, Poulshock, & Masciocchi, 1978; Shanas, 1979; Stoller & Pugliesi, 1989). Patterns of family involvement suggest mutual expectations (Shanas, 1979; Sussman & Burchinal, 1962) of assistance between generations (Adams, 1968) and familial responsibility (Brody et al., 1978; Shanas, 1979) as motivational factors. Closely related to familial responsibility is the concept of obligation which was described as occurring either with or without strong affectional ties (Adams, 1968); as an expression of love through the fulfillment of a family obligation (Stoller & Pugliesi, 1989); or as a moral obligation that resulted from mutual expectations (Sussman & Burchinal, 1962). Finally, caregiving that was motivated by the fulfillment of a need to care and as a source of satisfaction to the women who provide the care (Stoller & Pugliesi, 1989) was identified as a factor of motivation.

Caregiver Appraisal

Among the 14 articles that were included in this section, 8 of the studies were descriptive in design (Bowers, 1987; Cantor, 1983; Chenoweth & Spencer, 1986; Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken, 1991; Harvath,

Table 2

Summary of Caregiving Studies With Inferences to Motivation

| Author & Date | Purpose | Measures | Findings | Relevance |
|--|--|---|---|--|
| KINSHIP SYSTEM Adams (1968) | Summarization of aspects of kin involvement with residents of one urban place. | Interview and observations among intergenerational kin. | 1. Relations with kin should be generalized with respect to specific kin category and not to total | 1. The inclusion of mutual affection, obligation, and frequent contacts in conjunction with willingness |
| | | | 2. Parents are objects of positive concern, including frequent contacts, readiness to help, strong feelings of affection and obligation. | 2. The inclusion of obligation without strong affectional ties among adult children for parents. |
| | | | 3. Mutual affection and obligation dominate the relationship between parents and their adult children, basic concern focusing on each other's welfare | assistance between generations. 4. Females play a more dominant role in the kin network than males with |
| | | | 4. Regardless of the strength of the affectional bond, general obligation compels the adult child to maintain frequent contact. | expression of closer affectional bonds and more frequent contact with all kin. |
| Brody, Poulshock, & Masciocchi (1978) | To identify key variables that help to explain why some elderly persons who | 1. Two-stage sampling design to generate a sample of chronically ill/disabled | 1. Differential levels of functioning ability did not predict placement of the | The involvement of family members, specifically spouse or children, to |

Table 2 (Continued)

| ose ill or |
|--|
| disabled live in the community and others are institutionalized; working 2. Development of with the assumption that living arrangements and living with family might bathing, toileting, grooming, |
| elderly individual. and bladder control, and paralysis. Using a 3-point scale range 8-24, with 8 indicating no assistance required; 9-23, show moderate assistance; and 24 requiring full aid. 3. Key demographic data |
| 4. Random sample, $\underline{n} = 140$ from institutions; $\underline{n} = 46$ from community. |
| The family as a social support system; determined by family care for the lederly members in time of illness; the frequency of visiting patterns. |

Table 2 (Continued)

| Relevance | persons as best they can. Suggests familial responsibility as a motivating factor as a result of mutual expectations. | Outcomes suggest motives: 1. Fulfillment of need to care as a source of satisfaction by women who provide the care. 2. Caregiving viewed as an expression of love for an older family member or through the fulfillment of family obligation. 3. Enhance a caregiver's feelings of mastery; caregiving viewed as a challenge rather than as a burden. |
|---------------|--|---|
| Findings | older persons to live outside of institutions. 2. The emotional bond between older persons and their children is the most important factor governing the relationship between them and not joint living arrangements. 3. It is important to older persons to have regular visitors who show concern. | Findings included: 1. None of the caregivers' other roles influenced burden. 2. Helpers who reported positive relationships with older person were less likely to report burden regardless of the level of care provided. 3. Caregivers who assessed the older person's health positively were slightly less likely to feel burdened. |
| Measures | | Personal interviews with a panel of elderly people and their caregivers from Time 2 (1986). Measures included: 1. Caregiver burden: 13-item summated rating based on four previously used measures of burden. 2. Caregiver well-being: a. Center for a. Center for Bpidemiologic Studies Depression Scale—depression. b. Langer Index—psychological stress |
| Purpose | | To determine the effect of multiple roles on caregiver burden and well-being of family caregivers who provided informal care to elder relatives (spouses excluded) who were community-based. |
| Author & Date | | Stoller & Pugliesi (1989) |

Table 2 (Continued)

| Relevance | | Findings suggest mutual expectations and moral obligations could be relevant as factors that contribute to motivation of family members to provide caregiving assistance to |
|---------------|---|---|
| Findings | 4. Daughters or other family caregiver living with the older person did not report greater burden than other caregivers. 5. Caregivers who negatively assessed the health of the older person reported more symptoms of depression and stress than did caregivers who assessed the older person's health positively. 6. Well-being was undermined by problematic relationships between the caregiver and the older person. | Findings include: 1. Major activities that link the network are mutual aid and social activities. 2. Mutual aid can take many forms, including |
| Measures | (I = .82 between two measures of well-being). 3. Measures of social support: Socioemotional support: Socioemotional support, 7 items indicate contacts outside family and friendship networks. 4. Instrumental support: 8 dichotomous items indicate others help the caregiver or provide direct care themselves. 5. Cantril ladders used to: a. Elicit caregivers' assessments of elderly person's health and the quality of the relationship between the dyad. b. Rate the importance of a number of roles other than caregiver. | Review of writings and research emerging from several disciplines about the functioning of the kin network. |
| Purpose | | To review relevant theory and research to dispel the notion of social isolation and social mobility of the nuclear family and show the functioning of the American kin family network and its |
| Author & Date | | Sussman & Burchinal (1962) |

Table 2 (Continued)

| Author & Date | Purpose | Measures | Findings | Relevance |
|------------------------------------|--|---|--|---|
| | help and service among kin members. | | exchange of gifts, services, advice. 3. Exchange of aid can flow between parents and child, siblings, or other members of the kin network. 4. Services performed include services to older persons such as shopping, providing shelter, escorting, shopping, performing household tasks, sharing of leisure time. 5. Service tasks are considered to be acts of filial and kin responsibility performed voluntarily as an expected part of the roles of children and other kin members. | members of their kin network. |
| CAREGIVER APPRAISAL—MEANINGFULNESS | MEANINGFULNESS | | | |
| Albert (1992) | Use of psychometric theory to assess open-ended items by rephrasing them using a close-ended format in a rephrasing validation study to assess the dimensions of a | Using data from an earlier study, material was converted into close-ended, 5-point Likert format to explore familial obligation and parental dependency, in | Included with the findings: 1. Caregivers who view their obligation to provide care from a communal framework are more likely to be satisfied as caregivers. | Findings suggest relevance of caregiver's perceptions and beliefs to influence reasons to assume the role and to continue providing |

Table 2 (Continued)

| Relevance | care over an extended n period of time. n are sgative ing. he are r their riod of sgiver ing) ry out | Mutuality, as it pertains to care the caregiver's perception of the quality of the lower relationship with the care |
|---------------|--|---|
| Findings | 2. Caregivers who describe their parent in terms of infantilization are more likely to have negative feelings about caregiving. 3. Caregivers with the communal orientation are more likely to care for their parent for a longer period of time. 4. Caregiver beliefs emerge from experience and influence how the caregiver perceives the role (e.g., burdensome or satisfying) and how long they carry out the role. | Findings included: 1. Strain from direct care increased tension, and global strain appeared lower |
| Measures | a sample of 214 caregivers. Sample all part of Philadelphia Geriatric Center caregiver registry. Additional data collected including predictors of attitudes towards obligation and dependency. Caregiver satisfaction, caregiver impact, and subjective burden derived from Lawton, Kleban, Moss, & Rovine (1989). Depression measured with CES-D Scale. Open-ended criteria for coding obligation: 1. Exchange orientation: Debt to parent emphasized; caregiver assumed role by default. 2. Communal orientation: Needs of parent emphasized; caregiver actively pursued the role of caregiver. | Family Caregiving Inventory consisting of two structured interview instruments, one for care receiver, one for |
| Purpose | belief system for familial caregivers. | How well mutuality and preparedness explain the variance in aspects of caregiver role strain, after |
| Author & Date | | Archbold, Stewart, Greenlick, & Harvath (1990) |

Table 2 (Continued)

| Author & Date | Purpose | Measures | Findings | Relevance |
|---------------|--|--|--|---|
| | controlling for predictors that are found to be related to role strain. | caregiver. 4-point response. Seven predictor variables including: mutuality, preparedness, gender of caregiver, spouse/ nonspouse, degree of functional and cognitive impairment, amount of direct care. Nine measures of role strain included strains from worry, direct care, lack of resources, role conflict, economic burden, mismatched expectations, increased tension, feelings of being manipulated, global strain. Cronbach's alpha > .70 for 9 out of 10 measures; administered at 6 weeks post hospital discharge and at 9 months. | when higher levels of mutuality and higher levels of preparedness were reported by caregivers. 2. Mutuality did not improve strain from worry, and it had a limited effect on reducing strain from lack of resources. 3. Preparedness did not improve strain from role conflict. 4. Mutuality explained a moderate to large amount of variance in six aspects of caregiver role strain at both interview periods, but had little effect on the strains associated with lack of resources, economic burden, and worry. | receiver, could be relevant as a factor that motivates an individual to assume the role of caregiver. Individuals who perceive a higher level of mutuality may feel more compelled to become caregiver for a family member than individuals who perceive lower levels of mutuality due to their perception of a poorer relationship with the care receiver. |
| Bowers (1987) | To reconceptualize caregiving activities distinguished by purpose rather than task to obtain a more accurate representation of the experience, work, | Grounded dimensional analysis using interview questions that evolved in response to emerging theoretical categories. | Analysis revealed five conceptually distinct caregiving categories: 1. Anticipatory 2. Preventive 3. Supervisory 4. Instrumental | Caregiving defined by the author as the meaning or purpose a caregiver attributes to a behavior rather than by the nature or demands of the behavior itself. Protective caregiving |

Table 2 (Continued)

| Author & Date | Purpose | Measures | Findings | Relevance |
|---------------|---|---|---|---|
| | and stress of an intergenerational caregiver. | * | 5. Protective care. Instrumental care only category that involves hands-on care. Remaining four categories reflect the caregiving experience and are not observable behaviors; represent what is termed invisible work of the caregiver. | considered by many caregivers as their most important and difficult type of caregiving; aimed to protect the patient from the consequences perceived by the care receiver's self-image. Results suggest relevance of quality of the relationship between the caregiver and the care receiver and the meaningfulness that the caregiver gives to caregiving as factors that may contribute to the motivation to become family caregiver. |
| Cantor (1983) | To show the diversity among informal caregivers of the fail elderly and how the caregiving experience affected their lives with respect to the strains associated with caregiving. Data are drawn from larger study, "The Impact of the Entry of the Formal | Interview both clients and their primary caregivers who were served by a major homemaker service in New York City at the time of commencement of homemaker service and after termination of the service $(\underline{n} = 111)$. | Findings included: 1. Caregivers were primarily spouses (33%) or children (36%). 2. Slights over half of the spouses were male. 3. Care receivers were primarily frail older persons who were female; over half lived alone; one-third lived | Relevance of the caregiver's perception of the quality of the relationship with the care receiver suggests a factory that may influence a family member to assume the role of caregiver. Strength of family ties that is confirmed with family involvement suggests that |

Table 2 (Continued)

| Relevance | family responsibility may induce an individual to become caregiver. | 1. Results suggest that for some caregivers, the motivation to assume the role of caregiver is due to the individual's perception that there are no other |
|---------------|---|---|
| Findings | with a spouse; half were aged 75 years or older; 73% were rated on the Townsend Index of Functional Incapacity as severely impaired. 4. 70% or more of all caregivers currently felt very close to the care receivers (<u>n</u> = 111). 5. 65.8% of all caregivers felt they got along very well with the care receiver. 6. Feeling close to the person being cared for was felt to be a precursor to assuming the task. 7. The importance of family ties and the sense of responsibility towards other members. | Among the findings relevant to motivation: 1. In response to questioning about major problems faced by the caregiver and the family in providing care: |
| Measures | | 1. Questionnaire developed based upon the experiences and problems of families in the Greater Ann Arbor Chapter of the Alzheimers Disease and Related Disorders |
| Purpose | Organization on the Internal Support System of Older Americans." | To explore the experiences of families providing care for a relative diagnosed with dementia from the time of the earliest recognition of symptoms of dementia |
| Author & Date | | Chenoweth & Spencer (1986) |

Table 2 (Continued)

| . ! | Author & Date | Purpose | Measures | Findings | Relevance |
|-----|------------------|--|--|---|--|
| | | throughout the course of the disease. | Association. Comprised of open-ended, yes/no questions and checklists, 24 pages, completed by 289 caregivers. 2. Telephone interviews about diagnostic procedures and issues about institutionalization completed by 13 caregivers. 3. Contents of data coded into categories. | a. 25% cited the constant need for supervision or the impaired person's need for complete physical care ($\underline{n} = 79$). b. 11% cited concern about financial costs particularly in regard to nursing home costs. A few caregivers noted that financial constraints did not allow them any option but to provide in-home care. 2. 72% of the respondents cited feeling overwhelmed and the 24-hour care being too difficult as the reason for the decision to institutionalize their family member ($\underline{n} = 152$). | alternatives due in part to financial constraints. 2. For some caregivers, the decision to institutionalize a family member is motivated by the perception of feeling overwhelmed about the caregiving situation. |
| Ö | Cicirelli (1988) | Development of an instrument to measure filial anxiety among adult children as they anticipated parental decline. Two-component theory of anxiety and life-span theory of attachment used to define | Field testing of 13-item instrument on adult children of elderly parents randomly selected from population list of adult children of elderly parents provided by community organizations (N = 71). Factor analysis | Findings included: 1. Adult children with resources of a better job and education felt less anxiety about taking on the role of caregiver. 2. Adult children who were internally motivated | Findings suggest relevance of the adult child's appraisal of the caregiving situation and of the relationship with the care receiver's factors that may influence or inhibit the individual response to assume the role of |

Table 2 (Continued)

| Purpose filial anxiety and to explain |
|---|
| ţ, |
| attachment (defined as an caregiver, and Filial Anxiety emotional or affectional bond between two people) assume the role of caregiver, and Filial Anxiety bond between two people) the adult child's anxiety |
| behavior ttempt to otional bond |
| Protective behavior is FAA and .61 for FAB over demonstrated in helping a 2-week period with a subgroup $(n = 30)$. Variety |
| or tests measured validity including: Strength of attachment—Rubin Love Scale; adult child's perception of parent's declining health—checklist |
| of 42 symptoms known to adult child and 11 items that probed mobility of parent. |
| 1. To examine how much A review of existing evidence is present to show |

Table 2 (Continued)

| Relevance | family members for their impaired elderly relative is motivated by factors that include feelings of affection for the elderly person, a desire to repay past services or help provided by the older person; and a response to the sense of family responsibility as a moral value. |
|---------------|---|
| Findings | 1. Informal caregiving remains at a high level with little evidence to support the belief that families are becoming less willing or less able to provide home care for their elderly impaired family members. 2. Primary motivations for family caregivers to provide home care for their impaired elderly relatives include a sense of family responsibility, feelings of affection, and reciprocation for past help. 3. Families who provide care based on a sense of family responsibility alone face burnout. 4. Families are less motivated to provide care for their elderly relative if they believe the care level is greater than they can provide or if they believe the care will interfere with other family duties or is emotionally disruptive. |
| Measures | research on family caregiving. |
| Purpose | that American families are less able to provide home care for disabled elderly relatives. 2. To determine what, if any, impact government support or incentives would have on family caregiving. 3. To determine whether it would make any difference what kind of government support was offered. |
| Author & Date | |

Table 2 (Continued)

| | eptions, at is sgiving rs that ssuming r and ver to over a time. | |
|---------------|--|----------------------------|
| Relevance | Findings suggest relevance of caregiver's perceptions, and the meaning that is assigned to the caregiving experience as factors that may contribute to assuming the role of caregiver and enabling the caregiver to continue in the role over a sustained period of time. | |
| Findings | 5. Financial concerns were rare as a determinant to provide care. Response categories were grouped into four major themes: 1. Loss and provisional and ultimate meaning. 3. Caregiving resources. 4. Responsibilities of caregiver powerlessness included the caregiver's underlying choice to assume the role and provide care out of a sense of duty, responsibility, and obligation (43 %). In order to find meaning in caregiving, caregivers make personal choices, value the positive aspects of caregiving, search for provisional and ultimate | meaning. Caregivers valued |
| Measures | Interview comprised of a structured format and included quantitative and qualitative questions given to family caregivers who provided home care for a relative with a dementia. Seven open-ended questions probed the caregiver for subjective responses to how they felt about their lives, the most difficult and pleasant aspects of caregiving, what gives them hope, what they need most to provide care, and what are the good things in their lives (N = 94 caregivers). | |
| Purpose | To better understand the experience of caregiving by finding meaning through application of existentialism as an alternative theoretical paradigm. Meaning is defined as the caregiver's choice, values, and responsibility for right action and conduct that determine whether caregiving will have provisional or ultimate meaning. | |
| Author & Date | Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken (1991) | |

Table 2 (Continued)

| Relevance | | Results suggest that factors that may act to motivate an individual to assume the role of caregiver may be incorporated within the caregiver's own system of beliefs and perceptions that include the relationship with the care receiver. |
|---------------|--|---|
| Findings | caregiving, cherishing family and social relationships (63%); experiencing care recipient's love (48%); maintaining a positive relationship with the care receiver (33%); and memories of and accomplishments with others (16%). Caregivers derived ultimate meaning from reassurance through spiritual/religious beliefs (30%). | 1. Drawing on their previous research on family caregiving, the authors noted that some caregivers drew on a reflective process that encompassed the caregivers' own beliefs, perceptions, and strategies about the caregiving situation. 2. Local knowledge is embedded within the context of family culture and relationships. |
| Measures | | Local knowledge defined as information known to the caregiver that is unique to the care receiver and is essential to the recipient's care. Colonial knowledge defined as the nurse's scientific knowledge and skills that can be generalized across caregiving situations. |
| Purpose | | To present the concepts of local knowledge and colonial knowledge and describe their function in nursing practice with family caregivers for frail older people. |
| Author & Date | | Harvath, Archbold, Stewart, Gadow, & Kirschling (1992) [Unpublished manuscript] |

Table 2 (Continued)

| Relevance | | Caregiving perceptions of family traditions, religious values, modeling for one's own children, and reciprocity suggest factors related to the caregiver' belief system that may motivate a family member to assume the role of caregiver. |
|---------------|---|---|
| Findings | 3. Preparedness to provide care is a reflection of varied degrees of local and colonial knowledge. 4. Caregivers who reported the perception of higher levels of preparedness also reported lower levels of role strain. 5. Interventions need to be structured to incorporate both local and colonial knowledge. | An item pool consisted of five dimensions of caregiver appraisal including subjective caregiver burden, caregiving satisfaction, caregiving impact, caregiving mastery, and traditional caregiving. Exploratory factor analysis of the respite data revealed three strong items under traditional caregiving: appraisal about family traditions (63); religious values (69); modeling for |
| Measures | | Data gathered from two research projects: a respite study and an institutionalization study. Subjects for respite drawn from support groups for caregivers of impaired older people with dementing illness (N = 632 caregivers). Measures included: Multilevel Assessment Instrument (MAI); the Bradburn Affect Balance Scale; and the Center for Epidemiological |
| Purpose | | To increase the conceptual definition of burden as it pertains to the process of caregiving, using the term "caregiving appraisal" to include "all cognitive and affective appraisals and reappraisals of the potential stressors and the efficiency of one's coping efforts." |
| Author & Date | | Lawton, Kleban, Moss, Rovine, & Glicksman (1989) |

Table 2 (Continued)

| | Author & Date | Purpose | Measures | Findings | Relevance |
|------------------|-------------------------------------|---|--|---|--|
| | | | Studies Depression Scale. Measures relevant to caregiver appraisal were drawn largely from Burden Interview. The sample from the institutionalization study was drawn from families who had either applied for the admission of an impaired older person to a nursing home or were clients in a screen program for admission to a nursing home ($\overline{N} = 239$). Measures included interviews with identical content to those of the respite study. Diagnosis of the latter group included physically disabled and relatively few who were cognitively impaired. | one's own children to follow (72); and reciprocation with a factor loading of 39. Traditional caregiving was dropped from subsequent analyses because the authors did not feel that the factor fit with any other elements of their model of caregiving stress. Three factors confirmed included subjective burden, caregiving impact. | |
| Morris (1988) | Morris, Morris, & Britton (1988) | To identify the types of caregivers who are the most at risk for the development of strain or depression. | Review of research from related discipline including old age, psychiatry, and clinical and social psychology. | Caregivers most at risk include those who have a history of a poor relationship with the care receiver; a poor sense of being in control of their own reactions; and little social | Review of research indicates relevance of the caregiver's perception of the relationship with the care receiver, including the strength of the emotional bonds and the meaning the |

Table 2 (Continued)

| Relevance | person gives to the faregiving situation. | continuity in the closeness of the marital relationship, including the meaningfulness on to the caregiver, may be factors that motivate an individual to assume the role of caregiver. Ing Ing Ing Ing Ing Ing Ing In |
|---------------|---|---|
| Findings | support. People who experienced high levels of intimacy prior to the onset of dementia in their spouse, may undertake the role of caregiver out of a deep sense of affection and a desire to help or to repay the impaired for past help. | 1. Wives who were more gratified had more wellbeing ($I = .43$). 2. Well-being was correlated with gratification from social supports ($I = .47$), and gratification with having husband at home ($I = .38$). 3. Perceived change in marital closeness was associated with reduced gratification from caregiving and perceived continuity of the marital relationship was associated with greater gratification even among couples who were not close. |
| Measures | | Sample consisted of 50 wives caring at home for husbands with dementia. Data was collected during a 2-hour face-to-face interview. Measures included: 1. General Well-Being Index: internal consistency reliability, .94; test-retest reliability in five studies ranged from .50 to .86; high validity correlation with other scales sued to measure similar attributes of well-being. 2. Emotional Response to Stigmatization Scale was |
| Purpose | | To explore the rewards or gratifications and the frustrations derived by caregivers from the experience of caregiving. Hypothesis was that caregivers who experience greater gratification from caregiving will have higher general well-being than caregiving. Caregivers who experience less gratification from caregiving. Caregivers who experience greater frustration from caregiving will have lower well-being than caregivers who experience less frustration. |
| Author & Date | | Motenko (1989) |

Table 2 (Continued)

| Author & Date | Purpose | Measures | Findings | Relevance |
|---------------|---------|---|--|-----------|
| | | adapted; alpha coefficient, | 4. Wives who gave care | |
| | , | 3. Frustration with specific | out of reciprocity and tender loving care were highly | |
| | | aspects of caregiving was measured using items cited | gratified ($\underline{M} = 2.5$, $\underline{n} = 14$, tender loving care and | |
| | | from the literature. | $\overline{\mathbf{M}} = 2.0, \overline{\mathbf{n}} = 20,$ | |
| | | 4. Gratification was | reciprocity). Wives who | |
| | | measured using items cited | provided care out of | |
| | | from the literature. | responsibility had low | |
| | | Viers magnitud with 2 17 | grauncation ($\underline{\mathbf{M}} = 1.2$, $\underline{\mathbf{n}} = 16$) Page of | |
| | | item dementia symptom | Gratification index scores, 0 | |
| | | scale, adapted to severely | to 3, with 3 being most | |
| | | demented noncommuni- | gratified ($\underline{M} = 1.9$). | |
| | | cative, mute, or | | |
| | | nonambulatory; alpha | | |
| | | coefficient, .96. Questions | | |
| | | were asked about ADL | | |
| | | capacity, duration of | | |
| | | patient's miless, and the amount of supervision | | |
| | | perceived as needed. | | |
| | | 6. Hollingshead Index | | |
| | | measured socioeconomic | | |
| | | status. | | |
| | | 7. Change in marital status | | |
| | | was measured with the | | |
| | | Lopata Emotional Support Systems of Widow's Scale. | | |

Table 2 (Continued)

| Author & Date | Purpose | Measures | Findings | Relevance |
|------------------------------|--|---|---|--|
| | | 8. Caregivers were asked for the most important reason for taking care of their husband. | | |
| Phillips & Rempusheki (1986) | To explore caregivers' perceptions of their caregiving relationships using a grounded theory approach. | Data collected from sample of 39 caregivers for frail elderly from two locations—Midwest and Southwest—coded and analyzed using technique of constant comparative analysis. | Theoretical framework generated using symbolic interactionism social exchange theory, and dramaturgic theory as conceptual base. Five constructs emerged: 1. Personal identity of elder. 2. Image of caregiving. 3. Caregiver's role beliefs. 4. Caregiver's behavioral strategies. 5. Perceptions | 1. Personal identity of elder partially defined as the mental image the caregiver has of the elderly person that is comprised of past associations, present observations, and reconciliation with the past. 2. The caregiver's mental image of the elderly person directly effects how the caregiver perceives the elderly behavior, the caregiving situation, and the way in which the caregiver role. 3. The caregiver comes to the caregiving situation with a set of implicit standards that effect the caregiver and the family, and the caregiver's appraisal of the caregiving situation. |

Table 2 (Continued)

| Relevance | 4. Beliefs about family behavior, pride in the family and relationships, including obligations and responsibilities, comprise the caregiver's image about the caregiver's image about the caregiver is able to ascribe meaning to observations and to redefine role identities and the meaning of the relationship with the older person. 6. The above results suggest the importance of the caregiver's appraisal of the quality of the relationship with the care receiver along with the caregiver's system of beliefs about the role as factors that may compel a person to assume the role of caregiver. | Findings suggest the relevance of family |
|---------------|--|---|
| Findings | | 1. Family mutuality or shared responsibility was |
| Measures | | Content analysis about the ethical concerns of 116 |
| Purpose | | To explore the ethical |
| Author & Date | | Pratt, Schmall, & Wright (1987) |

Table 2 (Continued)

| Author & Date | Purpose dimensions of family caregiving. | Measures family caregivers to dementia patients in Oregon and Southwest Washington. | Findings cited by 24% (28) of caregivers as a contributor to the caregiving experience; described as a moral responsibility. | Relevance mutuality or responsibility, reciprocity, and the caregiver's perception of the care receiver's vulnerability as factors that could |
|---------------|--|---|--|---|
| | | | 2. Reciprocity was cited by 18% (21) as one source of moral obligation; described as repayment for what was given. 3. Reciprocity was suggested to give meaning to the sacrifices of caregiving and contribute to the sense of moral obligation along with the patient's vulnerability. | contribute to motivation to become caregiver for a family member. |
| AL RESPC | Familial or Filial Responsibility | | | |
| | Summary of basic strategies and organizational arrangements among six families providing care for an elderly parent who was one to two years poststroke. | Focused interviews with primary caregivers. | Among the findings: 1. Spouse/female children became the caregiver. 2. Decision among family members of who should become caregiver based on: | Criteria for caregiver role assignment among family members suggests relevance of family values and responsibility as factors that may contribute to the motivation of an adult child to assume the role of |

Table 2 (Continued)

| Relevance | caregiver for an impaired parent. | | Results suggest filial responsibility as a factor that may contribute to motivating a family member to assume the role of caregiver within the context of traditional family values. Within the context of traditional family values, the role of caregiver is assigned to the female as gender appropriate. |
|---------------|--|---|--|
| Findings | a. sibling who had previous role assignment of the oldest one. b. sibling considered to be the most responsible. c. sibling who was single d. sibling in closest proximity to the care receiver 3. Caregivers perceived their role as: | a. protective b. provision of physical/financial support c. provision of social support | Findings included: 1. The majority of all three generations of women endorsed the traditional value of filial responsibility to the aged. 2. The majority of each generation supported views about the sharing of tasks and responsibilities equally |
| Measures | | | Selected themes reported: 1. Women's attitudes toward family care of the aged and gender-appropriate roles. 2. Women's preferences for various service providers. 3. Data from substudy of attitudes of husbands of middle-generation women. |
| Purpose | | | A summarization of two research projects: 1. The Dependent Elderly and Women's Changing Roles, and 2. Women in the Middle and Care of the Dependent Elderly. Middle-generation women (<u>n</u> = 172) were drawn from larger study sample which |
| Author & Date | | | Brody (1981) |

Table 2 (Continued)

| Relevance | | Results suggest relevance of marital status of caregiver |
|---------------|--|--|
| Findings | between husbands and wives, men and women. 3. Analysis of the data by age and generation revealed that increasing age and belonging to the first generation correlated with the expectation that females were expected to fulfill caregiving and household tasks. 4. The majority of a substudy of husbands of the middle generation women $(\underline{n} = 79)$ endorsed family responsibility for the elderly and women's changing roles. 5. Attitudes about the sharing of responsibilities do not necessarily reflect behavior. 6. Women have deeply internalized values and do not always demand that men share. | Findings included: |
| Measures | Measurement data of correlations between age and type/amount of care and correlations between attitudes and work/nonwork status not given. | Adult children with disrupted marriages and a |
| Purpose | consisted of 433 women, representing 233 three-generation families. Goal of research to investigate the potential influences of demographic and lifestyle changes on the noninstitutionalized elderly and on their caregivers. | To explore how divorce, widowhood and remarriage |
| Author & Date | | Cicirelli (1983) |

Table 2 (Continued)

| Author & Date | Purpose | Measures | Findings | Relevance |
|---------------|--|---|---|---|
| | affect adult children's behavior toward elderly parents by: 1. Comparison of the amount of help provided to elderly parents by divorced, widowed, or remarried adult children. 2. Comparison of the amount of help provided by adult children with marriages intact and those with broken marriages. | living elderly parent over 60 years of age ($n = 141$). Adult children with intact marriages from a second data source ($n = 164$). T tests to test the difference between samples was statistically significant at .05 level. Sixteen types of services adult children provide to help elderly parents were categorized into primary, secondary, and tertiary services. To determine the amount of present help, all 16 services were rated with a 5-point scale. A 5-item adaptation of the Filial Expectancy Scale was used to measure filial obligation. Scores ranged from 50 to 25 with a high score indicative of grater sense of filial responsibility. Adult children's perceptions of parental need were rated on a 5-point scale for each of the 16 types of helping | 1. Percentages of adult children with disrupted marriages provided less help than adult children whose marriages were intact. The mean percentage of adult children with disrupted marriages providing some type of help: a. primary, 20.5%; b. secondary, 35.3%; c. tertiary, 10.0% As opposed to the mean percentage of adult children with intact marriages: a. primary, 26.5%; b. secondary, 48.5%; c. tertiary, 11.2% 2. Adult children with a marriag disruption perceived their elderly parents need for help significantly less (M = 24.60, SD = 9.70) than did adult children with marriages intact (M = 27.15, SD = 9.18), 1(303) = -2.35, p < .05. 3. Adult children with marrial disruption | along with competing responsibilities, e.g., job requirements, as factors that may limit the availability of a family member to assume the role of caregiver. |
| • | | THE PART TARES ALAND | | |

Table 2 (Continued)

| Findings | M = 16.16, SD = .357) showed significantly less filial obligation compared to adult children whose marriages were intact [M = 18.14, SD = 3.17) t(303) = -3.95, p < .01]. 4. When both groups were asked at what pint they could no longer provide care, 29% of adult children with intact marriages, compared to 16% of those with marital disruption, felt they could provide care under any circumstances. 5. Job responsibilities were cited by adult children with marital disruptions as the prime reason why help | Among the findings: 1. Raw scores from the Family Environment Scale indicated that men and women share similar women share similar service as factors that may perceptions about their scorial environments. |
|---------------|--|---|
| | $ \underline{M} = 16.16, \underline{SD} = .35 $ showed significantly leafilial obligation comparadult children whose marriages were intact $ \underline{IM} = 18.14, \underline{SD} = 3. $ $ $ | Among the findings: 1. Raw scores from (Family Environment Sindicated that men and women share similar perceptions about their social environments. |
| Measures | obtained by summing the responses for the 16 types of services. | 1. Family Environment Scale: used to measure whether the sex of the caregiver affected perception of the family environment. |
| Purpose | | To describe whether husbands and wives caring for spouses diagnosed with a dementing illness experienced the caregiving role in similar ways. ($N = 54$). |
| Author & Date | | Fitting, Rabins, Lucas, & Eastham (1986) |

Table 2 (Continued)

Author & Date

| Purpose | Measures | Findings | Relevance |
|---------|--|---|--|
| | 2. Burden Interview: used to measure the amount of burden felt by caregivers. 3. Minnesota Multiphasic Personality Inventory: used to generate psychological descriptions of people, specifically: a. scale 2—depression b. scale 4— psychopathic deviate c. scale 6—paranoia d. scale 7— psychosthenia Two additional measures: Wiggins depression and Ego strength were also used. 4. Measurement of functional impairment using 3-stage criteria derived from Sjogren, Sjogren, and Lundgren (1952, cited in Fitting, Rabins, Lucas, & | 2. Husband and wife caregivers for demented spouses experience similar degrees of burden; males, M = 18.29, SD = 12.77; females, M = 24.42, SD = 11.92. 3. Of the 47 subjects with children, 35 (73%) named a child as a confidante and 28 of these had at least a reciprocal relationship with a child. 4. Most of the caregivers had been married for more than 30 years and expressed a sense of duty and obligation to care for their spouse. 5. Husbands indicated a desire to reciprocate for the years their wives had been good homemakers and | mate. The role of children as confidante for the parent caregiver, suggests filial responsibility to interact with a parent in need and possibly influence a future decision made by the adult child to assume the role of caregiver for a parent. |
| | Eastham, 1986) 5. Measurement of extent/ strength of social networks a. Changes in marital relationship | mothers, reference to repay the nurturing they received throughout their marriage or feeling guilt as a result of perceptions about sacrifices made by wives. | |

Table 2 (Continued)

| Relevance | | Findings suggest relevance characteristics of the caregiver, including gender and marital status as well as the perception of traditional family values that pertain to filial responsibility as factors that may influence an adult child to feel motivated to assume the role of caregiver for their parent. Additional findings include the influence of the family structure as a factor that may motivate a son to assume the role of caregiver for a parent that might otherwise be assumed by a female member of the family. |
|---------------|--|---|
| Findings | | Findings included: 1. Male caregivers: a. 88% were only children. b. Children in male- only sibling networks, or c. Only geographically available child and d. Because there were no female siblings, tended to assume role by default. 2. Sons confronted similar caregiving situations as daughters most often caring for mother (85%), widowed (80%), over 75 years of age (73%), born outside the United States (60%), at least moderately impaired in ADL functioning. 3. Daughters were more likely to assist with specific hands-on assistance than sons. |
| Measures | b. Description of caregiving 6. Demographic data | In-depth structured interviews with adult child caregivers: male, <u>n</u> = 32; females, <u>n</u> = 99. 1. Caregiving involvement defined as objective level of time and task commitment; operationalized with 12-item scale. Alpha coefficient, .82. 2. Caregiving consequences defined as caregiver's perception of how caregiving has affected their social, emotional, and familial lives. Alpha coefficient, .88. 3. Family Caregiving livolvement—28-item measure of amount of assistance given to parent by all other relatives in family. Scale alpha, .87. 4. Spouse support—3-item scale measured degree |
| Purpose | | To present some of the findings from a study of 131 adult children who were caregivers for an older parent and to examine how adult sons perform and experience the role of caregiver compared to daughters. |
| Author & Date | | Horowitz (1985) |

Table 2 (Continued)

| Relevance | nore the ted on ance to parent to and did cantly ine ing red to re up ties o | itution Findings suggest the relevance of responsibility to the marital commitment and reciprocity for past actions in conjunction with the rultural assignment of |
|---------------|--|--|
| Findings | Compared to the caregiver daughters, more than three-fourths of the caregiver sons depended on their spouse for assistance to provide care for their parent (77% sons compared to < 49% daughters), and perceived their spouse as more supportive than did caregiver daughters. Sons were significantly more likely to deny the presence of any major problems about providing care (34% sons compared to 11% daughters), or to believe they had to give up anything because of caregiving responsibilities (32% sons compared to 60% of daughters). | Principle of Substitution operated as determinant of primary caregiver: a. married couple—a spouse b. widowed—a child |
| Measures | caregiver's spouse had positive attitude toward caregiving activities and positive attitude toward the older parent. Scale alpha, .73. 5. Service Utilization— Two measures for in-home services and for community-based services. 6. modification of OARS Multidimensional Functional Assessment Questionnaire to measure ADL level. Scale alpha, .91. | In-depth interviews with the patient (17%), the patient and a family member (30%) or the family member alone (53%). The primary caregiver was identified as |
| Purpose | | To analyze the patterns of family support for 167 post-hospital discharged elderly patients to determine whether the support is provided by one family |
| Author & Date | | Johnson (1983) |

Table 2 (Continued)

| Author & Date | Purpose | Measures | Findings | Relevance |
|---------------|--------------------|---|--|--|
| | a functional unit. | the spouse (45%), or a child (39%), with other family members assuming the primary role among the remaining families. measures of social contact and services provided by family members were categorized by kinship structure—spouse, child, or another relative. Outcomes of the care were measured by the rates of institutionalization, the levels of conflict and stress, and the attitudinal responses of each category of relationship. | c. married with children—spouse d. widowed or divorced with children—a child. A sibling was chosen if no children were available. 2. Married patients whose spouse was the caregiver were less likely to see a child weekly than were widowed patients. 3. Children were more than twice as likely to have daily contact with a widowed parent than with a married one. 4. A spouse provided the highest amount of overall support with a minimum of help from other family members. 5. Adult child caregivers provided less personalized care if the patient was married and were more apt to ask for help outside the family than was true with married couples. | primary caregiver based on the kinship system. Other factors that may compel a family member to undertake the role of caregiver include filial responsibility among the children of parent(s) in need. Finally, the caregiver's appraisal of the relationship with the care receiver may be a factor that motivates a family member to assume the caregiving role. |

Table 2 (Continued)

| Relevance | 8 | Data analysis not supplied measuring caregiver responses to decision to become a caregiver. Generalization of small, nonrandom sample limited to sample. Findings suggest feelings of love as possible factor that may motivate an individual to assume the role of caregiver. |
|---------------|--|--|
| Findings | 6. Providing care was described as stressful by 80% of the caregivers. Over 70% of the spouses reported they accepted the role without reservations, compared to 56% of the children who assumed the caregiving role (due to feelings of competing commitments from jobs and families on the part of the offspring). | Findings related to the decision to become a caregiver reflected the caregiver's responses to four questions about motivating factors, obstacles, and rewards they perceived. Main reason cited by men was a feeling of love for the person and feeling that if the situation was reversed, they would be cared for by the recipient. A few men stated that they felt obligated to |
| Measures | | Nonrandom sample selected from patient population of Geriatric Clinic of North Carolina Department of Family Nursing and from referrals from Alzheimer's support group. measures included in-depth interviews about demographics, caregiver, sfamily, the care receiver, caregiver activities, caregiver activities, relationship between the dyad. |
| Purpose | | To explore and describe the personal experiences of men who have assumed the role of caregiver for a demented relative at home $(\underline{n} = 12)$ compared with experiences of men who had placed a relative in a nursing home and acknowledged being the responsible party $(\underline{n} = 8)$. |
| Author & Date | | Mathew, Mattocks, & Slatt (1990) |

Table 2 (Continued)

| | enipose | Measures | Findings | Relevance |
|-----------------|---|---|---|---|
| | | Burden Interview and subscale from the Functional Dementia Scale about activities of daily living. | give the care and there was no one else available. | |
| Robinson (1990) | To investigate factors related to objective and subjective burden in wives who care for their husbands at home among 78 wives who were primary caregivers for husbands diagnosed with an irreversible dementia. Factors included: 1. The relationship between caregiver health, 2. Past marital adjustment, 3. Received social support to caregiving burden, 4. Socioeconomic status, and 5. Attitudes about asking for help. | Theoretical framework derived from Kahn and Antonucci's "goodness of fit" model in which caregiving burden is based on the degree of fit between the characteristics of the caregiver and the caregiving situation. Measures included: 1. Health of caregiver: a. self-rating 4-point scale measured caregiver's overall health. b. Louisville Health Scale measured caregiver's functional health with a 4-point scale; alpha coefficients, .82 to .89. 2. Marital Adjustment Test measured caregiver's perception of marital | Among the findings relevant to motivation: 1. Past marital adjustment was significantly and negatively related to subjective burden (<u>r</u> =44; <u>p</u> = .000), but not to objective burden. 2. Caregivers who reported better adjustment in their past marriage reported significantly lower subjective burden. 3. Caregivers with better past marital adjustment were found to desire less support and to receive less direct guidance. 4. Past marital adjustment as the best predictor of subjective burden and accounted for 20% of the total explained variance | Results suggest relevance of the caregiver's perception of the relationship with the care receiver as a factor that may contribute to the caregiver's decision to provide care for their impaired mate and to feel able to continue in the role over a sustained period of time due to lower feelings of subjective burden. |

Table 2 (Continued)

Author & Date

| Relevance | |
|-----------|--|
| Findings | |
| Measures | happiness one year before onset of her spouse's illness. 3. Received Social Support Inventory of Socially Supportive Behavior measured tangible and intangible forms of support; internal consistency reliability alpha coefficient, .93 and .94. 4. Semantic Differential Scale measured the caregiver's attitude toward asking for help from others. 5. Desire for More Help, a 4-item Likert scale, measured caregiver's desire for more help in the dimensions of emotional, physical help, information and directive guidance. 6. Caregiver Burden: a. 9-item inventory measured caregiver's appraisal of objective burden. b. 13-item inventory measured caregiver's |
| Purpose | |
| | |

Table 2 (Continued)

| Author & Date | Purpose | Measures | Findings | Relevance |
|-----------------------------------|---|---|---|--|
| | | appraisal of subjective burden. Internal consistency reliability for total scale reported to be .85 of a sample of 80 caregivers, and reliabilities of .70 for the subjective scale and .66 for the objective scale. | | |
| Selig, Tomlinson, & Hickey (1991) | To explore the dimensions of filial obligation through a review of the ethical literature and a presentation of three major philosophical views about the basis for filial duties as they pertain to adult child caregivers' perceptions of filial responsibility and caregiver stress and the implications for use in clinical practice. | Review of the literature including historical precedence; illustrated with case studies. Three philosophical views: 1. Parental reverence: ethical tradition. 2. Debt of gratitude: reciprocity. 3. Caregiving as an expression of friendship and love: Motive arises from love and friendship as opposed to role-based demands of debt and reciprocity. | All three views have limitations to creating an absolute obligation of filial responsibility. Historical precedence indicates that the rule to honor one's parents was not treated as an absolute filial obligation that overrode all other responsibility and obligations, including to one's spouse or children. Other social mechanisms may be able to meet parental need. Duties of indebtedness arise in response to favors arise in response to favors and favors must be freely | Rationale for three philosophical views suggests underlying principle to filial responsibility rests with caregiver's appraisal of relationship with care receiver and includes ethical traditions, feelings of reciprocity for past service or aid, and feelings of love and friendship for the parent. |

Table 2 (Continued)

| Relevance | | Findings suggest relevance of gender, marital bond, caregiver availability, and family responsibility as factors that may act to motivate an individual to assume the role of caregiver for a family member. |
|---------------|--|--|
| Findings | accepted in order to create a duty of reciprocity. 5. A parent who has performed the normal duties of parenthood in providing care for a child has not done a favor and does not require repayment. 6. Therefore, the appeal to past parental sacrifices beyond the call of duty does not support an absolute filial obligation, but rather a relative one. 7. Love and friendship can not be demanded, only hoped for and nourished. | Findings included: 1. Among elderly couples living alone or with others, over half of the caregivers were wives. 2. In households where an unmarried dependent older person lived with others, 8 out of 10 caregivers were female. |
| Measures | | 1. Unit of analysis is the caregiver/intrahousehold. 2. Structural criteria used to operationally define: home-care households. 3. Care receiver: impairment level measured with a 14-point Need for Assistance Scale. 4. Primary caregiver. Assignment determined by: |
| Purpose | | Adaptation of a secondary data analysis on a subsample drawn from the 1976 Survey of Income and Education (SIE) to examine the sociodemographic characteristics of caregivers in three distinct types of living arrangements; and to attempt to identify types of caregiving arrangements that |
| Author & Date | | Soldo & Myllyluoma (1983) |

Table 2 (Continued)

| | Purpose | Measures | Findings | Relevance |
|---------------|--|---|--|--|
| | appear to be structurally vulnerable to disruption and the most likely to benefit from social support. | a. assignment to remaining person living with care receiver. b. assignment by gender, marital bond, hierarchal structure of female kinship network. 5. Three types of caregiving arrangements: a. elderly couple living alone. b. elderly couple living with other. c. unmarried elderly living with other. | 3. The majority of caregivers were not themselves functionally impaired. 4. Nonelderly families providing home-care are self-selected, suggesting that the availability of a female relative to provide care may be due to her not entering or having withdrawn from the work force. 5. Families providing home-care to unmarried dependent relatives are the most vulnerable to dissolution, due to the conflicting demands between work outside the home and caregiving demands. | |
| Wilson (1989) | To use the method of constant comparative analysis to explore and describe the process of family caregiving for elderly relatives with Alzheimer's dementia from the | Open-ended interviews with subjects in their homes about greatest difficulties encountered, advice they would give to others, resources for support and direct help that were or would be important to deal | Analysis revealed that basic problem is dealing with negative choices. Caregivers attempted to cope through a three-stage process: a. Taking it one—taking on the responsibility | Results pertinent to motivation indicate that the caregiver's feelings of obligation and duty, anti-institutionalism feelings and viewing the need to provide care as no other option as factors that might contribute |

Table 2 (Continued)

| Relevance | to motivating an individual to assume the role of caregiver. | Generalization of findings limited due to small nonrandom sampling of participants who were candidates for rehabilitation. Relevance of the concept of responsibility and caregiver availability as motivational factors is suggested from the findings. |
|---------------|---|---|
| Findings | of caregiving for an impaired family member resulting in part from a sense of moral duty; as a last resort; of not knowing about resources; within a context of financial strain because many costs associated with home care are not reimbursable; and amid anti-institutional feelings. b. Going through it c. Turning it over | Findings included: 1. Family members believed that caregiving was their responsibility: a. by virtue of their relationship, or b. because no one else was available to provide the care. |
| Measures | better with difficulties and strains of caregiving. Ethnograph used with analysis. | Using a phenomenological approach, data was obtained through semistructured interviews conducted in the subjects' residences. Subject ($\overline{N} = 10$) were selected from individuals who had been discharged within the previous 2 months from a physical rehabilitation unit and required a caregiver. Caregivers were asked about the meaning of the activities |
| Purpose | perspective of the family caregiver ($\underline{N} = 20$). | To describe the activities that are performed by a caregiver for a relative who had been discharged from a physical rehabilitation program within the previous 2 months and the meaning of those activities to the role of the caregiver. |
| Author & Date | | Wood (1991) |

Table 2 (Continued)

| Relevance | |
|---------------|--|
| Findings | |
| Measures | they performed as the caregiver for an individual who had been discharged from a physical rehabilitation unit. |
| Purpose | |
| Author & Date | |

Archbold, Stewart, Gadow, & Kirschling, 1992; Motenko, 1989; Phillips & Rempusheki, 1986; Pratt, Schmall, & Wright, 1987). Two articles were methodological in content. Cicirelli (1988) developed an instrument to measure filial anxiety among adult children who anticipated parental decline. Utilizing psychometric theory to assess the dimensions of a familial caregiver belief system, Albert (1992) rephrased open-ended items using a close-ended format in a rephrasing validation study. Both studies indicated the importance of the caregiver's appraisal of the caregiving situation and of the caregiver's relationship with the care receiver (Cicirelli, 1988).

Using role theory, Archbold et al. (1990) used a longitudinal, correlational design to clarify how mutuality and preparedness explain the variance in aspects of caregiver role strain after controlling for predictors that are found to be related to role strain. Mutuality was defined by the authors as the positive quality of the relationship between caregiver and care receiver. Preparedness was defined as how well prepared caregivers believed themselves to be for the tasks and stress of the caregiving role. Viewing caregiving as a role, the authors were interested in how caregivers learned the role of caregiving and evaluated their ability as a caregiver.

Two articles reviewed the existing literature about research on family caregiving (Doty, 1986) and identification of the types of caregivers most at risk for the development of strain or depression (Morris, Morris, & Briton, 1988). Feelings of affection for the elderly person (Doty, 1986) or the strength of emotional bonds (Morris et al., 1988), a desire to repay past services or help provided by the older

person, and a sense of family responsibility as a moral value (Doty, 1986) are suggested as factors that influence a family member's decision to become caregiver.

Fourteen studies suggested the relevance of the caregiver's appraisal to motivate a family member to become a caregiver. Caregivers' perceptions (Adams, 1968; Archbold et al., 1990; Cantor, 1983; Farran et al., 1991; Harvath et al., 1992; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989; Morris et al., 1988) or appraisals (Cicirelli, 1988; Phillips & Rempusheki, 1986), and beliefs (Harvath et al., 1992; Phillips & Rempusheki, 1986) about their obligation to provide care for a family member are noted in the majority of the studies. The caregiver's perception of the quality of the relationship (Archbold et al., 1990; Bowers, 1987; Cantor, 1983; Cicirelli, 1988; Harvath et al., 1992; Morris et al., 1988; Motenko, 1989; Phillips & Rempusheki, 1986) with the care receiver is identified as another factor that may influence a family member to assume the role of caregiver for a relative.

In a study that explored the experiences of 289 caregivers for family members diagnosed with a dementia, Chenoweth and Spencer (1986) found that 11% of the respondents cited concern about financial costs, particularly in regard to nursing home placement, and noted that financial constraints did not allow them any option but to provide in-home care. From the findings, it would appear that for some caregivers the motive to provide care is due to their perception that there are no other available options, aggravated by financial strains.

Beliefs about family behavior, pride in the family and relationships that include obligations and responsibilities (Phillips & Rempusheki, 1986) and family mutuality or responsibility or reciprocity, emphasize the caregiver's appraisal from

the context of the family. In a descriptive study that explored the ethical dimensions of family caregiving among 116 family caregivers, family mutuality was cited by 24% of the caregivers as a shared or moral responsibility (Pratt et al., 1987). Reciprocity was described by the respondents (18%) as repayment for what was given, a moral obligation.

In a descriptive study that explored the rewards or gratifications and frustrations derived by 50 caregivers from the experience of caregiving, Motenko (1989) noted wives who gave care out of reciprocity and tender loving care were highly gratified. Wives who provided care out of responsibility had low gratification. Findings suggest the relevance of reciprocity as a motivator that is defined by the caregiver's appraisal of the caregiving situation and the relationship with the care receiver.

Findings from a study that used grounded dimensional analysis to describe caregiving by the meaning or purpose of the behavior (Bowers, 1987), suggests relevance of the meaning that the caregiver assigns to caregiving relative to individuals who assume the role of family caregiver. Farran et al. (1991) defined meaning as the caregiver's choice, values, and responsibility for the right action and conduct that determine whether caregiving will have provisional or ultimate meaning.

Farran et al. (1991) applied existentialism to understand the experience of caregiving in a descriptive study in which 94 caregivers were interviewed about how they felt about their lives, aspects of caregiving, and aspects of their lives. The authors found that caregivers valued the relational aspects of caregiving: cherished

the family and social relationships (63%), experienced the care recipient's love (48%), maintained a positive relationship with the care recipient (33%), and appreciated the memories of and accomplishments with others (16%). Caregivers derived ultimate meaning from reassurance through spiritual/religious beliefs (30%).

To expand the concept of burden as it pertains to the process of caregiving, Lawton et al. (1989) used the term caregiving appraisal to include all cognitive and affective appraisals and reappraisals of the potential stressors and the efficiency of one's coping. An item pool that consisted of five dimensions, and included traditional caregiving was subjected to factor analysis. Although the dimension was later discarded because the authors did not feel that the factor fit with other elements of their model of caregiving stress, factor loadings of appraisal about family traditions (63), religious values (69), modeling for one's own children to follow (72), and reciprocation (39) suggest that caregivers' perceptions of family traditions, religious values, modeling and, to a lessor extent, reciprocation, are factors that may motivate family members to assume the role of caregiver.

Familial or Filial Responsibility

The concept of responsibility was inferred as a factor that might contribute to an individual's decision to assume the role of family caregiver either as filial responsibility (Brody, 1981; Fitting, Rabins, Lucas, & Eastham, 1986; Horowitz, 1985; Johnson, 1983; Selig, Tomlinson, & Hickey, 1991) or familial responsibility (Archbold, 1980; Fitting et al., 1986; Soldo & Myllyluoma, 1983; Wood, 1991) among the 12 articles reviewed for this section. Three of the articles found that caregiving was performed in part because no one else was available to do it

(Mathew, Mattocks, & Slatt, 1990; Wood, 1991) or there were no other options, and the caregiver viewed the responsibility as an obligation (Mathew et al., 1990) or a moral duty (Wilson, 1989). In addition, Wilson (1989) noted that caregivers cited anti-institutional feelings as a reason for providing care in the home as opposed to nursing home placement.

In contrast, Fitting et al. (1986) found that familial responsibility to provide care for a spouse was motivated by a perceived obligation or duty by the caregiver to care for the impaired spouse and to reciprocate (Selig et al., 1991) for the years the spouse had nurtured them or had made sacrifices for them. The caregiver's perception of the quality of the relationship with the care receiver (Robinson, 1990; Selig et al., 1991) was suggested as a factor that may contribute to the caregiver's decision to provide assistance, as well as feelings of love for the care receiver (Mathew et al., 1990; Selig et al., 1991).

Familial or filial responsibility was influenced by traditional family values (Archbold, 1980; Brody, 1981), ethical traditions (Selig et al., 1991), and in conjunction with the cultural assignment of primary caregiver based on the kinship system (Johnson, 1983). The criteria for role assignment among family members was motivated by female gender (Archbold, 1980; Brody, 1981; Horowitz, 1985; Soldo & Myllyluoma, 1983), spouse or child (Archbold, 1980; Brody, 1981; Horowitz, 1985), marital status of the caregiver (Archbold, 1980; Cicirelli, 1983; Horowitz, 1985), the marital bond (Soldo & Myllyluoma, 1983) or the marital commitment (Johnson, 1983), and any competing responsibilities (Cicirelli, 1983), including caregiver availability (Soldo & Myllyluoma, 1983). In addition, role

assignment was motivated by the presence or absence of female siblings within the family structure (Horowitz, 1985). Archbold (1980) noted that role assignment was determined by the sibling who was perceived to be the most responsible, or had a previous role assignment of the oldest one and/or was in the closest proximity to the care receiver.

To summarize, a review of the caregiving research literature suggests motivational factors that might influence a family member to assume the role of caregiver. Factors identified from the literature allude to motivation about caregiving in association with the caregiver's personal beliefs about the role, ties with the family system, and the influence of social norms and cultural expectations on the caregiver's appraisal and decision to assume the role.

Conceptual Framework

This project used data from a study that used role theory and among its findings identified a variable of motivation that was recognized as important for understanding the role of caregiver (Archbold et al., 1990). However, the variable was not measured in the study. For this project some of the theoretical perspectives derived from role theory (Thomas & Biddle, 1986) were used to conceptualize motivation for caregiving.

Role Theory

Role theory focuses on understanding the many facets of human behavior through observation and examination of the human response to the roles people play (Thomas & Biddle, 1986). The authors used the analogy of actors in a play performing their roles from a script to illustrate the dimensions of role theory.

Individuals (actors) in society occupy positions (roles) and their role performance is determined by: social norms and rules (a social script), by the role performance of others, by reactions from those who observe and react (the audience), and by the individual's own capabilities and interests which will in turn influence how the role is played. The behavior of the individual is considered in terms of how it is influenced by the rules and demands of others, sanctions for nonconformance, and by the individual's own understanding and system of beliefs about what is expected (Thomas & Biddle, 1986). Role theory was used for this project about motivation to characterize how the caregiver as an actor interprets the script for the play and decides to play the role. The interpretation of the script is representative of the caregiver's appraisal of the caregiving situation, or the play, and is acted out according to judgments that are influenced by the individual's personal beliefs about the caregiving situation, the values and expectations that are associated with the family or kinship system, and the standards that form the framework for the cultural and societal norms (the rules of the script).

Domains for Caregiver Motivation

From a review of the literature, I identified three separate domains that pertain to motivation and to the family member's appraisal of the caregiver role and labeled the domains Personal, Familial, and Socio-Cultural. The Personal Domain encompasses the individual's personal beliefs about the role of caregiver. Categories identified for the Personal Domain include Attachment, Reciprocation, Preparedness, Economic Constraints, Caregiver Availability, and Personal Philosophy. The Familial Domain reflects judgments made by the individual about caregiving that are

based on influence from family beliefs and expectations. The category identified for the Familial Domain is Family Responsibility. The Socio-Cultural Domain reflects standards that represent social and cultural norms and influences the system of beliefs and values adhered to by the individual and the family that are represented by the other two domains. The two categories that represent the Socio-Cultural Domain are Moral Standards of Behavior and Cultural Role Assignment. Please refer to Table 3 for a summary of the categories and factors for each of the domains.

Motivation for Caregiving

Motivation to assume the role of family caregiver reflects the caregivers appraisal of a family member's unmet need, and includes an evaluation of the circumstances surrounding the situation and appraisal of the nature and quality of the relationship with the person in need. The resulting judgment to provide caregiving assistance is influenced by the caregiver's personal beliefs, the expectations and beliefs that originate from the family, and the standards associated with social norms and cultural expectations.

Research Questions

The following research questions were posed for this project:

- 1. What factors do caregivers for older relatives who have been discharged from the hospital and require assistance with daily living activities report as having motivated them to assume the role of caregiver?
- 2. What factors do caregivers for older relatives who have been discharged from the hospital and require assistance with daily living activities report as having motivated them to continue in the role of caregiver over time?

Table 3

Summary of Domains and Categories of Motivation

| Category PEDSONAI DOMAIN | Definition | Factors | Citations |
|--------------------------|---|--|---|
| Attachment (A) | Positive emotions and feelings for the care receiver and the caregiver relationship that reflect the caregiver's perception of the relationship shared with the care receiver. | Relevance of the quality of the relationship shown by expressions of love or affection, caring, or feeling close, high levels of intimacy, interdependency. A01, A11 | Adams (1968); Archbold, Stewart, Greenlick, & Harvath (1990); Bowers (1987); Cantor (1983); Cantor & Hirshorn (1988); Cicirelli (1988); Doty (196); Guberman, Maheu & Maille (1992); Harvath, Archbold, Stewart, Gadow, & Kirschling (1992); Horowitz & Shindelman (1983); Johnson (1983); Mathew, Mattocks, & Slatt (1990); Morris, Morris, & Britton (1988); Motenko (1989); Phillips & Rempusheki (1986); Selig, Tomlinson, & Hickey (1991); Stoller & Pugliesi (1989) |
| Reciprocation (B) | Belief of need and/or desire for caregiver to repay for services or attention from the care receiver. | Positive reciprocity perceived as personal desire to repay care receiver for services or assistance. B01, B11 | Doty (1986); Fitting, Rabins, Lucas, & Eastham (1986); Hirschfield (1983); Horowitz & Shindelman (1983); Ikels (1983); Johnson (1983); Morris, Morris, & Britton (1988); Pratt, Schmall, & Wright (1987); Selig, Tomlinson, & Hickey (1991). |

Table 3 (Continued)

| Category | Definition | Factors | Citations |
|----------------------------|---|--|---|
| | | Negative reciprocity refers to actions taken by the caregiver based on feelings of guilt, indebtedness, or resignation. B02, B12 | Guberman, Maheu, & Maille (1992); Wilson (1989). |
| Preparedness (C) | Perception of readiness or ability to assume role | Care management ability or previous experience as caregiver. C01, C11 | Archbold (1980); Hirschfield (1983) |
| | | Perception of care receiver's health status and/or vulnerability. C02, C12 | Guberman, Maheu, & Maille (1992); Pratt, Schmall, & Wright (1987) |
| Economic Constraints (D) | Actions determined by perception of financial resources | Institutionalization; provision of home care to avoid costly alternative care. D01, D11 | Chenoweth & Spencer (1986); Guberman, Maheu, & Maille (1992); Wilson (1989) |
| | | Dependency of caregiver on care receiver's income. D02, D12 | Guberman, Maheu, & Maille (1992) |
| Caregiver Availability (E) | Perception of absence from competing demands, including the status of other relationships, presence of dependents, participation in labor force, geographic proximity to care | Adult-child caregiver's marriage intact, without conflict; spousal assistance. E01, E11 | Cicirelli (1983); Horowitz (1985) |
| | receiver, and availability and/or willingness of others to become caregiver. | | |

Table 3 (Continued)

| Citations | Guberman, Maheu, & Maille (1992) | Cicirelli (1983); Soldo & Myllyluoma (1983) | Guberman, Maheu, & Maille (1992; Soldo & Myllyluoma (1983) | Horowitz (1985); Ikels (1983) | Chenoweth & Spencer (1986); Guberman, Maheu, & Maille (1992); Wilson (1989); Wood (1991) | Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken (1991); Ikels (1983); Stoller & Pugliesi (1989) | Farran, Keane-Hagerty, Salloway, Kupferer, & Wilken (1991); Guberman, Maheu, & Maille (1992); Lawton, Kleban, Moss, Rovine, & Glicksman (1989) |
|------------|--|--|---|---|--|--|--|
| Factors | Caregiver divorced or widowed. E02, E12 | No other dependents. E03, E12 | Participation in labor force. E04, E14 | Geographic proximity to care receiver. E05, E15 | No one else available; no one else able or willing to assume role; role assumed by default; a last resort. E06, E16 | Personal choice; decision produces feelings of satisfaction, or feelings of mastery. F01, F11 | Personal decision-making supported by own philosophical or spiritual beliefs. F02, F12 |
| Definition | | | | | | Personal choice to assume role of caregiver that produces feelings of satisfaction and/or feelings of mastery; or is determined by the caregiver's personal philosophy or spiritual beliefs. | |
| Category | | | | | | Personal Philosophy (F) | , |

Table 3 (Continued)

| Category | Definition | Factors | Citations |
|---------------------------------|---|---|--|
| | | Anti-institutional feelings determined by negative beliefs about placement in nursing home. F03, F13 | Guberman, Maheu, & Maille (1992) Wilson (1989) |
| FAMILIAL DOMAIN | | | |
| Family Responsibility (G) | Beliefs and values shared among family members that support role assignments and successful role performance among its members and binds its members together with a shared purpose and feelings of unity and belonging; family ties. | Familial responsibilities, expectations, obligations, beliefs about family behavior including: family pride, marital commitment, filial responsibility. G01, G11 | Adams (1968); Archbold (1980); Brody (1981); Brody, Poulshock, and Masciocchi (1978); Cantor (1983); Cantor & Hirshorn (1988); Doty (1986); Fitting, Rabins, Lucas, & Eastham (1986); Horowitz (1985); Horowitz & Shindelman (1983); Johnson (1983); Phillips & Rempusheki (1986); Pratt, Schmall, & Wright (1987); Shanas (1979); Soldo & Myllyluoma (1983); Stoller & Pugliesi (1989); Sussman & Burchinal (1962); Wood (1991) |
| SOCIO-CULTURAL DOMAIN | | | |
| Moral Standards of Behavior (H) | Moral or ethical rules that are accepted by members of society and adhered to without question, e.g., ethical traditions, traditional religion, or governing rules. | Moral obligation, moral duty, or moral responsibility embedded in traditional family values and/or traditional religious values to influence the behavior of family members. H01, H11 | Brody (1981); Guberman, Maheu, & Maille (1992); Horowitz (1985); Johnson (1983); Lawton, Kleban, Moss, Rovine, & Glicksman (1989); Pratt, Schmall, & Wright (1987); Selig, Tomlinson, & Hickey (1991); Soldo & Myllyluoma (1983); |

Table 3 (Continued)

| Citations | Sussman & Burchinal (1962); Wilson (1989) | Archbold (1980); Brody (1981); Horowitz (1985); Ikels (1983); Johnson (1983); Soldo & Myllyluoma (1983) | Guberman, Maheu, & Maille (1992); Ikels (1983) |
|------------|--|--|--|
| Factors | | Family/kinship structure. 101, 111 | Parental expectation. 102, 112 |
| Definition | | Designation of role based on cultural traditions and social norms. | |
| Category | | Cultural Role Assignment (I) | |

CHAPTER 3

METHODOLOGY

Description

This project was designed to analyze a portion of the data from the Caregiver Relief Study (CRS), a longitudinal correlational study of family caregivers for care receivers recently discharged from a hospital (Archbold & Stewart, 1988). Content analysis was used for this project to analyze qualitative data obtained from responses to three questions that were taken from the Family Caregiver Inventory (FCI) (Archbold & Stewart, 1986) during interviews with the caregiver dyads at 6 weeks and again at 9 months post-hospital discharge. The qualitative data were quantified using frequency counts and rankings.

Sample

The accessible population consisted of 243 families who belonged to a health maintenance organization (HMO) in the Pacific Northwest (Archbold et al., 1990).

All care receivers were 65 years or older and had been discharged during 1986 from a hospital that was a part of the HMO.

Selection criteria included the need by the care receiver for assistance with at least one personal care activity including: medications or injections; bathing, shampooing, or dressing; walking, shopping, or errands; or household chores. The caregiver was required to be at least 18 years of age and able to speak English (Archbold et al., 1990).

The sample, drawn systematically from hospital discharges, consisted of 103 caregivers and care receivers. Caregivers were primarily female (68%), white (97%), married (82%), and between ages 65-74 years (34%). Approximately a quarter (24%) of the caregivers had completed high school; 26% had attended college; and 14% had graduated from college. The modal income for the 98 caregivers who reported it was \$15,000 to \$24,999. Four caregivers reported they did not know their income level, and one caregiver refused to answer. The average caregiver reported his/her income adequacy to be "enough with a little left over." When asked about their health, 72% perceived their health to be about the same as the previous year; and compared to others, 48% of caregivers perceived their health to be good. At the 6-week interview, 38% of the caregivers had been providing care for less than 1 year; 37% had been providing care from 1 to 4.9 years; and 25% had been providing care for 5 years or more. Although 84% of the caregivers reported they had no children dependent on them, 15% of the caregivers reported that they also provided care for another sick person (Archbold & Stewart, 1988).

Care receivers were primarily female (61%), white (98%), married (54%), between the ages of 75 and 84 years (45%) with a mean age of 80.1 years, had attended high school (24%) and had completed high school (22%). Twenty-five care receivers or caregivers responding to the proxy interview did not know their own or the care receiver's income. Among the 78 care receivers and care givers who responded, 16% had a modal income between \$6,000 and \$9,999; 16% reported a modal income between \$10,000 and \$14,999. Care receivers tended to live with their spouse or partner (57%) or with children (23%) (Archbold & Stewart, 1988).

Almost half (42%) of the caregiver/care receiver dyads had been living together for 40-59 years; and one dyad (1%) had been together for 60 years and over (Archbold & Stewart, 1988).

At the 9-month interviews, 78 dyads remained in the study (Archbold et al., 1990). Among these, 76 were in an ongoing caregiving situation, and two care receivers were institutionalized. Sample loss included 16 care receivers who were deceased, two caregivers who were deceased, six who refused to be interviewed, and one who was too ill to be interviewed (Archbold & Stewart, 1988).

Family Caregiving Inventory

The Family Caregiving Inventory (FCI) is composed of multiple measures of key aspects of caregiving that are designed to measure caregiving variables (Archbold & Stewart, 1986). Interspersed with the close-ended measures are several open-ended qualitative questions. This study used data from three of those questions which were asked at the 6-week and 9-month interviews. The FCI was administered in the form of two structured interviews, one for the caregiver and one for the care receiver, at 6 weeks and again at 9 months post-hospital discharge.

The following items were taken from the caregiver form of the FCI for content analysis for this project. The questions that were administered at 6 weeks are labelled with an "A" preceding the item. The questions that were administered at 9 months are labelled with a "C" preceding the item.

1a. (A109) There are lots of reasons why people take care of other people.

Could you tell me what your reasons were for starting to take care of (Care

Receiver)? If Caregiver states he/she has taken care of the care receiver for a long time ask: What are the reasons you are continuing to take care of (Him/Her)?

- 1b. (C109) There are lots of reasons why people take care of other people. could you tell me what your reasons are for continuing to take care of (Care Receiver)?
- 2. (A120, C120) Thank you very much for sharing your thoughts and ideas with me. Your answers to our questions have been very helpful. I wonder, in conclusion, if there is any advice you would give to other persons who are considering becoming caregivers like yourself?
- 3. (A121, C121) Are there any other questions you'd like to ask or comments you'd like to make?

The responses to these items described the caregivers' appraisals of the caregiving experience and included how they viewed their role as caregiver and their relationship with the care receiver. Analysis of the responses to these questions was used to identify motivational factors for caregiving that have been cited in the literature and to look for other motivational factors that have not yet been cited.

Coding Form

Findings from review of the literature resulted in the creation of nine categories. The Personal Domain included the categories of Attachment, Reciprocation, Preparedness, Economic Constraints, Caregiver Availability, and Personal Philosophy. The Familial Domain contained one category that was called Family Responsibility. The Socio-Cultural Domain contained two categories called Moral Standards of Behavior and Cultural Role Assignment. Twenty factors,

identified from the literature were assigned to the appropriate categories and were included on the coding form. Please refer to Table 4 for the Motivation for Caregivers Coding Form.

The categorical scheme underwent several revisions as the result of discussions with expert coders who were members of the faculty. For example, in the Personal Domain, two factors under <u>Attachment</u> were merged into one factor that included "expressions of love and affection" and "relevance of the quality of the relationship with expressions of feeling close." The concept of mutuality was thought to be encompassed within the factor and was dropped as a separate factor.

In the category <u>Reciprocation</u>, the phrase "past" services was dropped, because it was felt to restrict the full meaning of reciprocation. <u>Reciprocation</u> was later revised to include two separate factors, "Positive Reciprocity" and "Negative Reciprocity," to elicit a more accurate meaning for the caregivers' responses about reciprocity.

Under <u>Preparedness</u>, "Health of the Caregiver" was dropped after consideration about the appropriateness of the factor as a motivator to either assume the role of caregiver or to continue in the role. The wording for <u>Care Management Ability</u> was changed to read <u>or previous experience as caregiver</u>," rather than INCLUDING previous experience as caregiver.

Under <u>Economic Constraints</u>, the "Cost of Institutionalization" as a motivator was combined with the "Cost of In-home Care." The wording used for the example was changed from "unable to afford cost of nursing home care" to read "to avoid

Table 4

Motivation for Caregivers Coding Form

| | # | |
|-----|--------|------|
| ID# | Coder, | Date |

Instructions:

- 1. Circle the appropriate response for the presence (1) or absence (0) of each factor.
- 2. Complete the Other category for any factors that cannot be coded with the existing factors.
- 3. If responses to questions A109, A120, or A121 indicate a continuation of the role, code as Continue and not Assume.
 - 4. All responses will be coded only once dependent on Continue or Assume.
- 5. Responses to questions A or C 120 and A or C 121 have to be specific linkage to motivation; when in doubt, do not code. 6. Use within time to understand responses, but not across time.

| | Respon | se rating to conti | Response rating to assume role or to continue in role | ne role Ie | | |
|---|--------|-----------------------|---|---------------|------|--|
| | Assume | ıme | Continue | inue | | |
| | Yes | No | Yes | No | Code | |
| PERSONAL DOMAIN | 3 | | | | | |
| A: Attachment | | | | | | |
| A01/A11: | - | 0 | | C | A01 | |
| Relevance of the quality of the relationship shown by expressions of love or affection, caring, feeling close, high levels of intimacy; interdependency. Example: I love him; I care for him. | · | , | • | > | | |

Table 4 (Continued)

| | Respon | se rating to conti | Response rating to assume role or to continue in role | ne role | | |
|--|--------|-----------------------|---|----------|-----|------|
| | Ass | Assume | Con | Continue | | |
| | Yes | No | Yes | No | Ü | Code |
| C02/C12: Perception of caregiver's health status and/or vulnerability. Example: He can't be left alone; he's gone downhill; he needs me to look after him. | | 0 | T | 0 | C02 | C12 |
| D: Economic Constraints D01/D11: Institutionalization Example: Provision of home care to avoid costly alternative care. | | 0 | - | 0 | D01 | D11 |
| D02/D12: Dependency of caregiver on care receiver's income. Example: Caregiver dependent on support of care receiver's income. | _ | 0 | - | 0 | D02 | D12 |

Table 4 (Continued)

| | Respon | Response rating to assume role or to continue in role | to assun | ne role le | | |
|--|--------|---|----------|---------------|-----|------|
| | Assı | Assume | Cont | Continue | | |
| | Yes | No | Yes | No | Ö | Code |
| E: Caregiver Availability | | | | | | |
| E01/E11: Adult-child caregiver's marriage infact | П | 0 | | 0 | E01 | E11 |
| Example: Adult-child marriage without conflict; spousal assistance. "He helps her while I fix supper." | | | | | | |
| E02/E12: | _ | 0 | - | C | E02 | H12 |
| Caregiver divorced or widowed. <u>Example</u> : Caregiver's unmarried status increases her availability. | | | •> | | | |
| E03/E13: | _ | 0 | 1 | 0 | E03 | E13 |
| No other dependents. <u>Example</u> : Not responsible for other dependent children or adults. | | | | | | |
| E04/E14: | 1 | 0 | П | 0 | E04 | E14 |
| Participation in labor force. Example: Increased availability to be caregiver if not holding a job. | | | | | | |

Table 4 (Continued)

| | Respon | se rating to contir | Response rating to assume role or to continue in role | ne role le | | |
|--|--------|------------------------|---|---------------|-----|------|
| | Assume | me | Continue | inue | | |
| | Yes | No | Yes | No | Co | Code |
| E05/E15: Geographic proximity to care receiver. Example: Geographic location | 1 | 0 | - | 0 | E05 | E15 |
| E06/E16: No one else available. Example: No one else able or willing to assume role; role assumed by default; a last resort. | - | 0 | 1 | 0 | E06 | E16 |
| F: Personal Philosophy F01/F11: Personal choice. Example: Decision produces feelings of satisfaction or mastery, "I want to help"; "Helping her makes | 1 | 0 | - | 0 . | F01 | F11 |
| F02/F12: Personal decision-making supported by own philosophical or spiritual beliefs. Example: Expressions about meaning derived from the role; or expressions of faith. | - | 0 | - | 0 | F02 | F12 |

Table 4 (Continued)

| | Respon | se rating to conti | Response rating to assume role or to continue in role | ne role le | | |
|---|--------|-----------------------|---|---------------|-----|------|
| | Assume | ıme | Cont | Continue | | |
| | Yes | No | Yes | No | CO | Code |
| F03/F13: Anti-institutional feelings. Example: Actions determined by negative beliefs about placement of care receiver in nursing home. | - | 0 | 1 | 0 | F03 | F13 |
| FAMILIAL DOMAIN | | i.º | | | | |
| G: Family Responsibility | | | | | | |
| G01/G11: Family responsibilities, expectations, obligations, beliefs about family behavior, including family pride, marital commitment, filial responsibility. Example: He's my husband. She's my mother. Our family looks out for each other. | 1 | 0 | | 0 | G01 | G11 |

Table 4 (Continued)

| | Respon | Response rating to assume role or to continue in role | to assur | ne role Je | | |
|--|--------|---|----------|---------------|-----|------|
| | Assume | ıme | Con | Continue | | |
| | Yes | No | Yes | No | 0 | Code |
| SOCIO-CULTURAL DOMAIN | | | | | | |
| H: Moral Standards of Behavior | | | | | | |
| H01/H11: | , | C | _ | C | H01 | H111 |
| Moral obligation, moral duty, or moral responsibility embedded in traditional family values and/or traditional religious values to influence the behavior of family members. Example: Children are morally obligated to look after their parents. | . = | | | • | | |
| I. Cultural Role Assignment | | | | | | |
| Family kinship structure. Example: Role assignment that is based on gender, | 1 | 0 | -4 | 0 | 101 | 111 |
| role of family position. | | | | | | |
| I02/I12: Parental expectation. | _ | 0 | 1 | 0 | 101 | 112 |
| Example: Role assignment that is based on parental designation. | | | | | | |

| Caregiver ID# |
|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|---------------|
| | | | | | | | | | | | | |
| 1: | 2: | 3: | 4: | 5: | 9: | 7: | 8: | 6: | 10: | 11: | 12: | 13: |

Table 4 (Continued)

O: OTHER

costly alternative care," to broaden the definition and to clarify the meaning of the factor.

Under <u>Caregiver Availability</u>, "Absence of marital conflict" and "Presence of caregiver's spouse for caregiver assistance" were combined for the purpose of clarification. The wording in "Absence of other dependents" was clarified to read "No other dependents." For similar reasons, the wording of "Limited or non-participation in the labor force" was changed to read "Participation in the labor force."

In an effort to be more sensitive to the meaning of the subject's response, the category Personal Philosophy underwent several revisions. The factor "Personal choice" was divided into two factors. The first factor, "Personal Choice," was associated with feelings of satisfaction and mastery. Later revisions clarified the meaning of the factor with the inclusion of the word "decision" that produces "feelings of satisfaction or mastery."

The second factor was called "Personal fulfillment" in conjunction with philosophical or spiritual beliefs." The word religious was added and later dropped because of it's close tie with the word spiritual which was considered to be more inclusive. "Personal fulfillment" was later changed to read "Personal decision making" because fulfillment was not considered to be a necessary part of an individual's decision that is supported by his/her philosophical or spiritual belief.

The example that accompanied "Anti-institutional feelings" was changed from beliefs that the caregiver can provide higher quality care than care given in a nursing home to actions determined by negative beliefs about placement of care

receiver in nursing home to more accurately reflect the meaning of anti-institutional feelings.

The category <u>Personal Burden</u> was deleted because it was too similar to other categories already identified. The factor "No other choice" was placed under <u>Caregiver Availability</u> and the wording was changed to "No one else available." The factor "Feelings of guilt, indebtedness, or resignation" was moved to <u>Reciprocity</u> and became the example for the factor "Negative reciprocity."

In the Familial Domain, the category <u>Family Ties</u> was changed to <u>Family Responsibility</u>, because it was felt that the latter was more representative of the meaning for the category. Within this category, "Filial responsibility" was merged with the factor "Family responsibilities" because of the lack of exclusiveness between the two factors. Finally, "Marital commitment" was deleted from the **Socio-Cultural Domain** and placed in the **Familial Domain** under the category <u>Family Responsibility</u>. Although influenced by the moral standards associated with the **Socio-Cultural Domain**, actions determined by "Marital commitment" reflect beliefs about family behavior and belong with "Family responsibilities."

In the Socio-Cultural Domain, the category Standards of Behavior was changed to Moral Standards of Behavior to more clearly define the domain. The term "traditional religious values" was added to the factor "Moral obligation, moral duty" to reflect the influence of traditional religious values on the individual's decision to become caregiver. The example "children should honor their parents" was changed to read "children are morally obligated to look after their parents" to clarify the meaning for this category.

The categorical scheme was pre-tested with six cases using three coders to assess for inter-rater reliability, including consistency in identifying the units to be categorized and consistency in assigning units to categories (Waltz, Strickland, & Lenz, 1991). The minimum acceptable inter-rater reliability was set at 80% agreement. After initial training, rater check resulted in inter-rater reliability at 96.6%. Rater reliability was checked throughout the coding process, with regard to questionable or ambiguous data bits, through discussions held with expert coders who were members of the faculty. Content that could not be coded or was ambiguous was discussed with coders from the faculty. After resolving any differences, content that still could not be coded was kept separate and categorized as "Other."

Procedure

Data were treated with respect for issues of confidentiality and privacy with regard for basic ethical principles and in keeping with prior informed consent obtained from the participants at the time of the initial research study. Handling of the data maintained the anonymity of the subject and assured minimal risk.

Categories were assigned a letter, for example, A: Attachment,

B: Reciprocation and so on. Factors were assigned a two-digit number that was preceded by the categorical letter (A01). Factors were numbered in sequence (e.g. 1, 2, 3, etc.) and according to whether they pertained to the 6-week interview (<u>0</u>1) or the 9-month interview (<u>1</u>1).

The sampling unit consisted of the questions selected for this project and the caregivers' responses. The response to each question was generally one to three sentences in length.

The procedure involved a separate analysis of individual words or clusters of words in each sentence with the coding system derived from motivation factors identified from the literature. Content analysis consisted of analysis of individual words or clusters of words in each sentence using the coding system derived from motivational factors identified from the literature.

Responses were coded based on the presence of words or clusters of words that had a similar meaning to those in the coding system, specifically as the response pertained to assuming the role or continuing in the role of caregiver. In the event a data bit did not fit a category, it was kept separate from the other categories and evaluated for the possibility of creating a new category that had not yet been identified. All responses were coded only once. If responses to questions A109, A120, or A121 indicated a continuation of the role, they were coded as continue and not assume. Data bits that did not specifically pertain to motivational factors were not coded. Responses were interpreted and coded as they pertained to within time and not to across time, for example, A109 to A120 and not A109 to C109.

Analysis involved quantifying the existence and frequency of each coded factor at the 6-week time period and again for the data analyzed from the 9-month period. Data management utilized the Crunch Statistical Package. Verification of data entry (100%) was done prior to running frequency counts.

Analysis Plan

The goal of the analysis plan was to answer the research questions posed for this project. Research question one, identification of motivation factors to assume the role of caregiver, was answered by computing the percentage of caregivers giving responses to questions A109, A120, and A121 that were coded into each motivational category. The second research question about motivation factors to continue in the caregiving role was answered by computing the percentage of caregivers giving responses to questions C109, C120, C121 and to the responses to A109, A120, and A121 if the responses applied to the continued role of caregiving and not to assuming the caregiver role, that were coded into each motivational category.

Analysis consisted of describing the frequencies of motivation factors in all the categories with the use of descriptive statistics that included frequency counts, percentages, and rank ordering, from the data gathered at the two separate time periods. The results were analyzed with respect to the relative frequency of occurrence of one factor over another, and to the similarities between motivation categories identified in the literature and those detected from the data analysis. Furthermore, in an effort to identify factors that contributed to sustained caregiving, analysis was directed to look for changes over time in the frequencies of motivation factors and the dominance of a particular category.

CHAPTER 4

RESULTS

The data was analyzed using the Crunch Statistical Package to obtain frequencies, percentages and rankings for each factor. Please refer to Table 5 for details of the frequencies, percentages, and rankings of each factor within the categories in response to the interviews conducted at 6 weeks and at 9 months. The sample size for the data bits coded from the 6-week interviews was 103; for the 9-month interviews, sample size was 78. Results of the data analysis will be presented according to each domain and category and will begin by answering the first research question—identification of factors that motivated the caregivers to assume the role—followed by results that applied to answering the second research question—identification of factors that motivated caregivers to continue the caregiver role. For the sake of clarity, the domains are shown in bold print, categories are underlined, and factors are enclosed in quotation marks.

Research Ouestion 1

The Personal Domain contained six categories Attachment, Reciprocation,

Preparedness, Economic Constraints, Caregiver Availability, and Personal

Philosophy, with frequency counts that ranged from 45 (Attachment, "Relevance of the quality of the relationship") to 1 (Caregiver Availability, "Participation in the labor force"). Attachment was ranked number one (44%) for "Relevance of the

Table 5

Table of Frequencies to Assume Caregiver Role or to Continue Role

| | | Assume role $(\underline{n} = 103)$ | role 03) | | | Continue role $(\underline{n} = 78)$ | role 78) | | 1 1 |
|---|------|-------------------------------------|-------------|------------|------|--------------------------------------|----------|------|-----|
| | Code | Frequency | % | Rank | Code | Frequency | 8 | Rank | 1 |
| Personal Domain | | | | | | | | | |
| Attachment Relevance of the quality of the relationship | A01 | 45 | 44 | - | A11 | 28 | 36 | 1.5 | |
| Reciprocation Positive reciprocity | B01 | 6 | 6 | ∞ | B111 | 6 | 12 | 4.5 | |
| Negative reciprocity | B02 | 0 | | | B12 | 0 | | | |
| Preparedness | č | t | t | i c | i | , | | | |
| Care management ability Perception of care receiver health | G G | - 41 | - 41 | و. د. ۸ | 55 | 1 0 | (* | 111 | |
| Economic constraints | } | | |) | | 1 | 1 | C: (| |
| Institutionalization | D01 | 7 | 7 | 9.5 | D11 | 2 | 3 | 9.5 | |
| Dependency of caregiver on care receiver income | D02 | 0 | | | D12 | 0 | | | |
| Caregiver availability | | | | | | | | | |
| Adult-child caregiver marriage intact | E01 | 0 | | | E11 | 0 | | | |
| Caregiver divorced or widowed | E02 | 0 | | | D12 | 0 | | | |
| No other dependents | E03 | 0 | | | E13 | 0 | | | |
| Participation in labor force | E04 | - | - | 13 | E14 | 0 | | | |
| Geographic proximity to care receiver | E05 | 2 | 2 | 11 | E15 | 1 | - | 11 | |
| No one else available | E06 | 12 | 12 | 9 | E16 | 4 | 2 | 6.5 | |
| | | | | | | | | | |

Table 5 (Continued)

| | | Assume role $(\underline{n} = 103)$ | role 03) | | | Continue role $(\underline{n} = 78)$ | role (8) | |
|--|------------|-------------------------------------|-------------|------|------------|--------------------------------------|-------------|------|
| | Code | Frequency | % | Rank | Code | Frequency | % | Rank |
| Personal Philosophy Personal choice | 00 | 0 | ç | · | ř | ć | • | |
| Personal decision-making | F02 | 5 | 6 4 | s 11 | F11 F12 | א ע | 12 | 8.5 |
| Anti-institutional feelings | F03 | 11 | 11 | 7 | F13 | 4 | · v | 6.5 |
| FAMILIAL DOMAIN | | | | | | | | |
| Family responsibility Family responsibilities/expectations/obligations | G01 | 43 | 42 | 2 | G11 | 28 | 36 | 1.5 |
| SOCIO-CULTURAL DOMAIN | | | | | | | | |
| Moral standards of behavior Moral obligation/moral duty | H01 | 15 | 15 | 4 | H111 | 14 | 18 | 3 |
| Cultural role assignment Family kinship structure Parental expectation | 101 102 | | | 13 | 111 | 1 0 | - | Ħ |
| | | | | | | | | |

quality of the relationship" shown by expressions of love, affection, or feeling close. "Personal choice" was ranked number three (18%) under the category Personal Philosophy. In the category of Preparedness, "Perception of the care receiver's health" ranked number five (14%). In the category Caregiver Availability, the factor "No one else available" ranked number six (12%). "Anti-institutional feelings" ranked number seven (11%) under the category Personal Philosophy.

Reciprocation as it applied to "Positive reciprocity" ranked number eight (9%).

Under Preparedness, "Care management ability" shared the rank of 9.5 (7%) with the category Economic Constraints/"Institutionalization." "Personal decision making" was ranked 11 (5%) under the category of Personal Philosophy.

In the **Personal Domain** the category of <u>Caregiver Availability</u> contained two factors with frequencies of 2 or less. The factors were "Geographic proximity to care receiver" (2%) and "Participation in labor force" (1%).

Three categories in the **Personal Domain** had factors with frequencies of zero. The category of <u>Caregiver Availability</u> had frequencies of zero for "Adult-child caregiver marriage intact," "Caregiver divorced or widowed," and "No other dependents." In the category of <u>Economic Constraints</u>, "Dependency of caregiver on care receiver's income" had a frequency of zero. Finally, in the category of <u>Reciprocation</u>, "Negative reciprocity" had a zero frequency.

The **Familial Domain** contained one category. <u>Family Responsibility</u> was ranked number two with a frequency count of 43 (42%) for motivation that pertained to feelings about "Family responsibilities, expectations, obligations, and

beliefs about family behavior including marital commitment and filial responsibility."

The Socio-Cultural Domain contained two categories, Moral Standards of Behavior and Cultural Role Assignment. The factor "Moral obligation, moral duty" under the category Moral Standards of Behavior ranked number four with a frequency count of 15 (15%). The two factors under Cultural Role Assignment each had a frequency count of one (1%) and ranked 13.

Research Ouestion 2

Total frequencies obtained for the categories that reflected caregivers responses at the 9-month interviews ranged from 28 to 0, and were noted among all six categories in the **Personal Domain**. Both the **Personal Domain** and the **Familial Domain** contained a category that shared the top rank of 1.5 with frequencies of 28 (36%). The two categories were <u>Attachment</u>/"Relevance of the quality of the relationship" and <u>Family Responsibility</u>/"Family responsibilities, expectations, obligations." The category <u>Attachment</u> was noted to be the only category to maintain the highest rank at both interview times.

Among the other categories in the **Personal Domain**, the categories of Reciprocation/"Positive reciprocity" and Personal Philosophy/"Personal choice" shared the rank of 4.5, (12%). Among the caregivers interviewed at 6 weeks, 9% of the responses had pertained to "Positive reciprocity" and 18% of the responses had pertained to "Personal choice."

<u>Personal Philosophy</u>/"Anti-institutional feelings" and <u>Caregiver</u> <u>Availability</u>/"No one else available" shared the rank of 6.5 (5%). Although the ranks were similar to those noted among the responses given at the 6-week interviews, the frequencies for both factors were considerably lower from among the caregivers interviewed at 9 months.

"Personal decision making" under the category of <u>Personal Philosophy</u> was rank ordered at number eight (4%) from the caregivers responses at the 9-month interviews. The frequency count for this factor was 3.

Categories in the **Personal Domain** that had frequencies of 2 or less comprised the remaining ordered ranks. <u>Preparedness</u>/"Perception of care receiver's health" (3%) and <u>Economic Constraints</u>/"Institutionalization" (3%) ranked 9.5 with frequencies of 2. Within the factor "Perception of care receiver's health," the percentage lowered by 11% when the responses of caregivers interviewed at 6 weeks were compared with the responses made by caregivers who had been interviewed at 9 months. Similar findings were noted with the factor "Institutionalization" which decreased by 4%.

Along with <u>Cultural Role Assignment</u>/"Family kinship structure," from the **Socio-Cultural Domain**, <u>Preparedness</u>/"Care management ability" and <u>Caregiver Availability</u>/"Geographic proximity to care receiver" from the <u>Personal Domain</u> shared the rank of 11, with frequencies of one (1%). Care management ability showed a difference of 6% from the responses given by caregivers interviewed at 6 weeks and those who were interviewed at 9 months.

Four categories had factors with zero frequencies: three in the Personal Domain and one in the Socio-Cultural Domain. The three categories from the Personal Domain had factors with zero frequencies at both the 6-week and the

9-month interviews. They included <u>Reciprocation</u>/"Negative reciprocity"; <u>Caregiver Availability</u> and the factors of "Adult-child caregiver marriage intact," "Caregiver divorced or widowed," and "No other dependents"; and <u>Economic Constraints</u>/"Dependency of the caregiver on the care receiver's income." Response was minimal to the category <u>Caregiver Availability</u>, "Participation in the labor force" from the interviews conducted at both 6 weeks and at 9 months. In the <u>Socio-Cultural Domain</u>, <u>Cultural Role Assignment</u>/"Parental expectation" had zero frequency among the responses of caregivers who were interviewed at 9 months.

Responses by the caregivers who were interviewed at 9 months resulted in ranking "Moral obligation, moral duty" from the category Moral Standards of Behavior (Socio-Cultural Domain) number three (18%). In addition, the responses resulted in Moral Standards of Behavior/"Moral obligation, moral duty," and Reciprocation/"Positive reciprocity," having a percentage that was 3% higher than among the responses made by caregivers interviewed at 6 weeks.

Other

Data bits that could not be coded with the existing categories were listed separately as Other on the coding form. Results from some of the data that was entered as Other suggested enough similarities in the responses to create four groups. Please see Table 6 for Grouped Data Bits.

The first group is called <u>The Natural Thing to Do</u> (4). All the data bits for this group were from the 6-week interviews (A109). The second group is called <u>Personal Characteristics Consistent With the Role</u>. Out of the four factors identified for this group two were from the 6-week interview (A109) and two were from the

Table 6

Grouped Data Bits

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The natural thing to do
     always known would do it, expected to do it (3)
    natural/normal thing to do (73)
    it's easy to do (79)
    it's the natural thing to do (80)
Personal characteristics consistent with the role
    I'm reliable (12)
    I think it's my disposition, I would take care of anyone who needed help (70)
    I'm very easy going (80)
    I like to feel useful too (88)
Concern for the care receiver
    because of a need to know that she is doing well and has the proper care (90)
    maintain his quality of life and dignity (15)
    primarily for his own happiness (22)
    because she wouldn't be happier anywhere else (25)
    for her peace of mind (52)
    sympathy involved in that (1)
    if the situation were reversed, I'd want him to take care of me (104)
Care receiver's feelings about nursing home
    she wouldn't go anyway (to nursing home) (36)
    she doesn't want to go to a nursing home (37)
    she being terrified of rest homes and the promise I made (66)
Other factors related to caregiver availability
    it snuck up on me doing one thing and then something else then everything (37)
    the only thing to do (69)
    I got nothing else to do (11)
Other factors related to social norms
    I expect someone to do this for me when I get that age (47)
    they would think I was wrong if I didn't take care of him . . . I worry about the
    criticism I'd get (70)
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9-month interview (C109). The third group is called <u>Concern for the Care</u>

<u>Receiver</u>. Out of the seven factors identified as belonging to this group, four were taken from the 6-week interview (A109) and three were from the 9-month interview (C109). The fourth group is called <u>Care Receivers Feelings about Nursing Homes</u>. Three factors obtained from the 6-week interviews (A109) were identified as belonging to this group.

Three factors were identified that are related to the category <u>Caregiver</u>

<u>Availability</u>, but because they do not fit the definition that was derived from the literature, were assigned to this category: Two responses were from the 6-week interview (A109) and one was from the 9-month interview (C109).

Two factors suggest relevance to <u>Social Norms</u>. Both factors were from the 6-week interviews and will be discussed more fully later in this paper.

To summarize, the following motivational categories/factors were identified from the 6-week interviews in descending order of percentage response:

- 1. Attachment/"Relevance of the quality of the relationship"
- 2. <u>Family Responsibility</u>/"Family responsibilities, expectations, obligations" including marital commitment and filial responsibility"
 - 3. Personal Philosophy/"Personal choice"
 - 4. Moral Standards of Behavior/"Moral obligation, moral duty"
 - 5. Preparedness/"Perception of the care receiver's health"
 - 6. Caregiver Availability/"No one else available"
 - 7. Personal Philosophy/"Anti-institutional feelings"
 - 8. Reciprocation/"Positive reciprocity"

- 9. Economic Constraints/"Institutionalization"
- 10. Preparedness/"Care management ability"
- 11. Personal Philosophy/"Personal decision making"
- 12. Caregiver Availability/"Geographic proximity to care receiver"
- 13. Caregiver Availability/"Participation in labor force"
- 14. Cultural Role Assignment/"Family kinship structure"
- 15. Cultural Role Assignment/"Parental expectation"

The following motivational categories/factors were identified from the 9-month interviews in descending order of percentage response:

- 1. Attachment/"Relevance of the quality of the relationship"
- 2. Family Responsibility/"Family responsibilities, expectations, obligations"
- 3. Moral Standards of Behavior/"Moral obligation, moral duty"
- 4. Personal Philosophy/"Personal choice"
- 5. Reciprocation/"Positive reciprocity"
- 6. <u>Caregiver Availability/</u> "No one else available"
- 7. Personal Philosophy/"Anti-institutional feelings"
- 8. Personal Philosophy/"Personal decision making"
- 9. <u>Preparedness</u>/"Perception of care receiver's health"
- 10. Economic Constraints/"Institutionalization"
- 11. Preparedness/"Care management ability"
- 12. Caregiver Availability/"Geographic proximity to care receiver"
- 13. Cultural Role Assignment/"Family kinship structure"

CHAPTER 5

DISCUSSION

The discussion will focus on an interpretation of the relevant findings among the categories in each domain with attention to the similarities and differences between the actual caregiver responses and findings from the literature. The chapter will conclude with the relevance of the findings to clinical practice and include suggestions for further studies.

Attachment

The categories of Attachment from the Personal Domain and Family

Responsibility from the Familial Domain appear to play important roles to motivate an individual to become a caregiver or to continue in the role. At the 6-week and the 9-month interviews, both categories received the highest number of responses, suggesting the effects of the caregiver's positive emotions and feelings for the care receiver and the beliefs and values shared among family members as important motivational factors. Numerous citations from the literature support the relevance of attachment (for example, Archbold et al., 1990; Cantor & Hirshorn, 1988; Guberman et al., 1992; Horowitz & Shindelman, 1983; Morris et al., 1988; Motenko, 1989). Findings from the category of Family Responsibility will be discussed more fully later in this paper.

Many of the caregivers expressed feelings of love and affection toward the care receiver in response to being asked about their reasons for assuming and/or

continuing to take care of the care receiver. Responses were often brief and to the point—"I love her," "my love for him . . .," "love," "because I care for her"—and were often expressed in conjunction with expressions related to filial responsibility or their marital commitment.

Reciprocation

In the category of <u>Reciprocation</u>, positive reciprocity was rated higher from among the caregivers who were interviewed at 9 months than from among the caregivers who were interviewed at 6 weeks. In addition to the category of <u>Reciprocation</u>, <u>Moral Standards of Behavior</u> was the only other category to be higher at the 9-month interview than at 6 weeks. The relevance of the findings from the latter category will be discussed later in this paper.

On the basis of the findings from the categories of Reciprocation and Attachment, it appears that caregivers who feel love and affection for the care receiver may also desire to provide care as a way to repay the care receiver for past services or assistance. Morris et al. (1988) noted that people who experienced high levels of intimacy prior to the onset of dementia in their spouse may undertake the role of caregiver out of a deep sense of affection and a desire to help or repay the impaired for past help: "He took care of my sister and I . . . least I can do for him"; "he's done for everyone else . . . now it's time to be there for him"; "because I love him, he gave up a lot of stuff for us."

<u>Preparedness</u>

<u>Preparedness</u>, as it pertained to "Care management ability" and "Perception of the care receiver's health," appeared to have less influence on the caregivers

interviewed at 9 months who were continuing to provide care, unlike feelings associated with Attachment, Reciprocity, Family Responsibility, and Moral Standards of Behavior that may influence an individual's decision to assume or to continue in the role of caregiver. Fewer respondents cited either their past experience as caregiver or their perception of their ability to care for the care receiver as a motivating factor at the 9-month interview.

In light of the findings among the previous categories of Attachment,

Reciprocity and Family Responsibility, it would appear that among those caregivers interviewed at 9 months who were continuing in the role, "Care management ability" was less of a motivating factor than were factors associated with the caregiver's perception of the quality of the relationship with the care receiver, their desire to repay the relative for past services, and their belief about behaviors that pertained to family responsibility. The findings from this study among the caregivers who were interviewed at 9 months may reflect the use of assistive services that may have been available to the families through their membership in the HMO.

In addition, the findings may reflect the caregiver's perception of a change in the health status in the care receiver resulting in either a decreased need for the caregiver's assistance, or the development of a caregiving routine and feelings of self-competence about their ability to provide care. Finally, the percentage of responses in this category at 9 months may have reflected the influence of other categories on motivation, including <u>Moral Standards of Behavior</u>.

The percentage of caregivers giving responses to "Perception of the care receiver's health" at the 9-month interviews was considerably lower than among those who responded to this factor at the 6-week interviews. These findings may reflect differences between the two groups of caregivers who were interviewed at 6 weeks and at 9 months, changes in the health status of the care receivers, or influence of the dominant categories of Attachment, Family Responsibility, Personal Philosophy, and Moral Standards of Behavior as factors of motivation.

On the basis of the findings, it appears that "Perception of the care receiver's health" and the caregiver's perception of his/her ability to provide care ("Care management ability") may be more important motivators when deciding whether or not to assume care for a family member than when deciding whether to continue as caregiver. Although perception of the care receiver's health status or vulnerability is documented in the literature (Guberman et al., 1992; Pratt et al., 1987), the sources do not distinguish the factors between caregivers who had assumed the role and those who were continuing.

Economic Constraints

"Institutionalization" (Economic Constraints) contributed less as a factor of motivation among caregivers who were interviewed as 9 months, than among those who had been interviewed at 6 weeks. Although the literature provides studies that documented concerns among caregivers about financial costs associated with institutionalization as opposed to home care (Chenoweth & Spencer, 1986; Guberman et al., 1992), findings from this study may reflect the level of education, income level of the sample, and membership of the subjects in a large HMO.

Furthermore, the predominance of Attachment, Family Responsibility, and to a lessor degree Personal choice and Moral Standards of Behavior, may have exerted more influence as factors of motivation than the issues that surrounded Economic Constraints among the caregivers who were interviewed at 9 months. Hirschfield (1983) found a negative correlation between mutuality, which was defined as the caregiver's ability to find gratification in the relationship with the impaired person and meaning from the caregiving situation, and institutionalization ($\underline{r} = -.90$).

"Dependency of the caregiver on the care receiver's income" was not given by the respondents as a motivating factor at either the 6-week or the 9-month interviews. Documentation of this factor in the literature (Guberman et al., 1992) may reflect a cultural norm that applies to the Canadian health care system and the 40 caregivers of nonspousal kin residing in Quebec, Canada.

Caregiver Availability

Out of the six factors identified in the category of <u>Caregiver Availability</u>, "No one else available" was the only factor to be identified as an important motivational factor among the caregivers interviewed at 6 weeks, but appeared to be considerably less important as a factor of motivation among the caregivers who were interviewed at 9 months. It appears that among caregivers who were interviewed at 6 weeks, their motivation may have been due to their perception that there was no one else who was willing or available to provide care for the dependent relative.

Caregivers whose responses at the 6-week interviews included "No one else available" as a motivating factor often included statements at the 9-month interview that pertained to a sense of responsibility or moral obligation. It would appear that

some of the caregivers may have been motivated to assume the role out of their perception of default and have been motivated to continue in the role out of a keen sense of filial responsibility or marital commitment and moral duty: "I was the only one available," and "responsibility that I feel I have to do"; "no one else will do it," and "so I'll do it as long as I can"; "I was stuck with it," and "husband and wife, we signed an agreement." The literature documents the variable as it pertains to a keen sense of moral duty (Wilson, 1989); by virtue of their relationship to the caregiver, that is, spouse (Wood, 1991); and as the result of no other options (Chenoweth & Spencer, 1986; Guberman et al., 1992).

Findings from the remaining five factors in this category showed few if any response as sources of motivation among caregivers in the sample at either the 6-week or the 9-month interviews. The lack of responses to these five factors suggests that among the caregivers sampled, issues pertinent to the marital status of the caregiver, the number of other dependents, participation in the work force, or geographic proximity to the care receiver made little if any contribution towards motivating the caregiver to either assume the role or continue as caregiver.

Personal Philosophy

The category of <u>Personal Philosophy</u>, with its three factors, contained the third largest number of responses, following the categories of <u>Attachment</u> and <u>Family Responsibility</u>, made by caregivers at both the 6-week and the 9-month interviews. "Personal choice" received the largest number of responses at both interviews followed by "Anti-institutional feelings" and "Personal decision making."

Overall findings from this category indicated the importance to motivation of the factors associated with an individual's personal philosophy including their beliefs about the meaning of the role, their spiritual beliefs, and the personal satisfaction that was derived from performing the role: "Because I wanted to"; "I could do it 24 hours a day . . .; "I don't want someone else taking care of her"; "wanted to do all I could"; "have a lot of faith in God."

In addition, it would appear from the responses of some of the caregivers at the 6-week interviews that assumption of the role of caregiver may have been motivated by strong feelings against placement of their relative in a nursing home: "She was in a nursing home . . . felt I could do more for her, give her better care"; "because I couldn't let her go into a nursing home"; "because I refuse to put him in a nursing home." As noted by the number of responses in the category of Moral Standards of Behavior, among the caregivers interviewed at both times, this finding may be a reflection of their beliefs about "Moral obligation, moral duty," coupled with stories about the quality of care provided in nursing homes. Wilson (1989) noted that among the 20 family caregivers interviewed, care was provided for their family member out of a keen sense of moral duty that was due in part to the "horror" stories the caregivers had heard about the poor quality of care in nursing homes.

Although the individual findings among the three factors for <u>Personal</u>

<u>Philosophy</u> were lower at 9 months, their total percentage remained substantial.

Results from the category <u>Personal Philosophy</u> implied that among some of the caregivers interviewed at 9 months, the importance of their personal beliefs about

the meaning they ascribed to the role and the feelings of satisfaction they derived from the role, influenced their decision to continue to provide care. In addition, their spiritual beliefs and their beliefs against placement of the care receiver in a nursing home appeared to contribute as motivating factors among some of the respondents interviewed at this time period.

Farran et al. (1991) noted that caregivers may find provisional meaning through the day-to-day tasks and experiences with their impaired family member and ultimate meaning or fulfillment by embracing their philosophical or spiritual beliefs. Guberman et al. (1992) observed that for some of the caregivers who participated in their study, the act of caring for others gave meaning to their lives and used the terms "vocation" or "calling" to describe the phenomena.

Judging from the number of responses in the categories of <u>Personal</u>

<u>Philosophy</u>, <u>Attachment</u> and <u>Family Responsibility</u>, it would appear that for a number of caregivers the decision to assume the role or to continue as caregiver may have been influenced by positive feelings and emotions for the care receiver and the meaning they derived from the caregiver role. In addition, beliefs about family behavior and familial responsibility may have contributed as a factor of motivation to either assume the role or to continue as caregiver.

Family Responsibility

Although the category of <u>Family Responsibility</u> in the **Familial Domain** has been briefly discussed, because of the large number of responses to this category from the caregivers who were interviewed at 6 weeks and those who were interviewed at 9 months, a more in-depth discussion is necessary. Among the

caregivers who were interviewed at 6 weeks and at 9 months, it would appear that beliefs and values that were associated with "Family responsibilities," including filial responsibility and marital commitment, were strongly supported and identified as factors of motivation. These findings are well supported in the literature (e.g., Adams, 1968; Archbold, 1980; Brody, 1981; Brody et al., 1978; Cantor, 1983; Fitting et al., 1986; Horowitz, 1985; Shanas, 1979; Stoller & Pugliesi, 1989; Sussman & Burchinal, 1962).

Although <u>Family Responsibility</u> and <u>Attachment</u> were the two dominant categories among caregivers interviewed at 6 weeks and again at 9 months,

Horowitz and Shindelman (1983) found that some caregivers expressed filial responsibility in the absence of affection. Similar findings were noted among the responses of some caregivers: "My duty as her husband" and "a responsibility"; "we are married and it makes it my responsibility to do it."

Caregivers often referred to family responsibility as it pertained to their marital commitment: "He's my husband"; "we're married . . . he's my husband"; "she's my wife." Filial responsibility was frequently indicated as a reason to provide care: "She's my mother, can't think of any reason why I wouldn't want to"; "he's my dad"; "because she's my mother."

Moral Standards of Behavior

Overall, of the three domains assessed for factors of motivation, the Socio-Cultural Domain contained the least number of responses from caregivers at either the 6-week or the 9-month interviews. However, the category Moral Standards of Behavior was one of only two categories (the other being

Reciprocation) that was rated higher among the caregivers who were interviewed at 9 months. Similar findings between moral obligation and reciprocity were noted by Pratt et al. (1987). In a study with 116 family caregivers about ethical concerns, the authors noted that reciprocity was suggested to give meaning to the sacrifices of caregiving and contribute to a sense of moral obligation.

On the basis of these findings, it would appear that although the perceptions associated with feelings of Attachment and Family Responsibility continued to be important factors of motivation, for many of the caregivers the influence of social norms and ethical values to beliefs about "Moral obligation" may have contributed to motivate some caregivers to either assume the role or to continue to provide care over a period of time. The initial decision to help may be influenced by feelings of love and affection along with sense of family responsibility. However, after a period of time the desire to help may be driven by feelings that include a sense of moral obligation and a debt of honor: "Because I feel I have to," "my duty," and "for my conscience."

Cultural Role Assignment

Caregivers did not identify either "Family kinship structure" or "Parental expectation" as important factors of motivation among the caregivers interviewed at either the 6-week or the 9-month interviews. The sources cited for these factors included ethnic cultures that were different from the sample drawn for this study (Guberman et al., 1992; Ikels, 1983).

The minimal response to this category may reflect the beliefs and values of the respondents who comprised the sample and the resulting effect on identifying factors of motivation. The lack of response in this category shows the need for nurse researchers to recognize the influence of both the ethnic and cultural diversity found among caregivers, as well as the effect that the form of health care practiced in a country might have on motivation and the role of caregiver.

Other

A total of 23 factors were identified by the caregivers that did not match the definitions given to the categories identified from the literature. An interesting finding among the 23 factors was that with a few exceptions, there was a positive quality to the responses about the role of caregiver.

Approximately one-third of the factors were from the caregivers who were interviewed at 9 months, with the balance coming from those participating in the 6-week interview. The factors shared enough similarities to be formed into four groups. The remaining five factors were grouped as being related to either Caregiver Availability or to Social Norms. Each group will be discussed separately. The Natural Thing to Do

Findings from among the four caregivers whose responses were grouped as The Natural Thing to Do generally shared the belief that providing care for a family member was an expected occurrence or "the natural thing to do." "Always known would do it, expected to do it"; "natural normal thing to do." From the responses, it would appear that assumption of the role of caregiver reflected beliefs about family behaviors including filial responsibility and responsibilities associated with the marital commitment.

Personal Characteristics Consistent With the Role

Four caregivers generally equated reasons why they were caregivers by describing their own personal characteristics. For example, caregivers replied "I'm reliable," "I'm very easy going." It would appear from their responses that some caregivers may be motivated to assume the role of caregiver due to a combination of preconceived notions about the qualifications associated with the role of caregiver, for example, one who is reliable and easy going, with a self-appraisal that encompasses beliefs about their ability to undertake the role. In keeping with role theory, the perceptions of some of the caregivers may have reflected how they interpreted their role from a script that is influenced by social norms and rules, the expectations of others, and the caregiver's own capabilities. The caregivers may perceive themselves as the most reliable, the most easy going and therefore the most qualified to provide care for the dependent person.

Concern for the Care Receiver

Findings from the responses of seven caregivers indicated the importance they placed on preserving the well-being of the care receiver and meeting their own need for reassurance that the care receiver was receiving proper care. With regard to preserving the care receiver's well-being, caregivers responded: "To maintain his quality of life and dignity"; "primarily for his own happiness"; "for her peace of mind." Another response that addressed the caregivers need for reassurance included, "because of a need to know that she is doing well and has the proper care."

It would appear from these findings that these caregivers may have been motivated to assume the role or to continue to provide care out of concern for the welfare of the care receiver and the need to reassure themselves that they were doing all they could to help. Further studies about motivation and caregiving might find a relationship between feelings of attachment, including beliefs about the quality of the relationship shared with the care receiver, and feelings of concern for the welfare of the care receiver that cannot be substantiated with the available data at this time.

Care Receiver's Feelings About Nursing Homes

The three responses made by the caregivers who were interviewed at 6 weeks appeared to reflect actions that had been partly determined by being sensitive to the care receiver's feelings about nursing home placement. Although assumptions cannot be substantiated due to the limited number of responses, it would appear that the decision to assume the role of caregiver was effected by the caregivers' perceptions about the quality of the relationship shared with the care receiver and feelings of closeness and familiarity that provided the caregiver with the insight to speak for the other. For example, one adult daughter replied, "she wouldn't go anyway." Beliefs about Family Responsibility may have contributed to the responses made by the caregivers as well. For example, a daughter-in-law responded, "She doesn't want to go to a nursing home . . . I'll do it as long as I can."

It would appear from the responses of these three caregivers that the motivation to assume the role of caregiver may have been determined in part out of

respect for the care receiver's feelings against placement in a nursing home. Future studies about motivation and the role of the caregiver should not overlook the importance of feelings of attachment, the quality of the caregiver's relationship with the care receiver, and beliefs about family responsibility as potential factors of motivation.

Other Factors Related to Caregiver Availability

Findings from the responses of three caregivers who were interviewed at 6 weeks appeared to indicate that for them taking on the role of caregiver was an event that had not necessarily been planned or expected, but rather something that had evolved over a period of time: "It snuck up on me doing one thing and then something else then everything." Other caregivers responded, "the only thing to do"; "I got nothing else to do."

Although the responses in this group were limited in number, the content of the responses suggested that factors other than those traditionally associated with competing demands for the caregiver's time may be included under the category of Caregiver Availability. From the responses of the caregivers who were interviewed at 6 weeks, it would appear that the motivation to assume the role of caregiver may have been determined in part by their perceptions of having the time to help the care receiver, the care receiver's health status or vulnerability, and their perception of the responsibilities associated with a gradual assumption of the role. Future studies about motivation and caregiving might benefit from an exploration of these factors.

Other Factors Related to Social Norms

The two responses that were placed in this group were from caregivers who had participated in the 6-week interviews and represented the Socio-Cultural Domain. It appeared from the content of the responses that the decision to assume the role of caregiver had been determined in part by the caregivers' personal expectations of the outcomes associated with taking on the caregiver role and the influence of social norms on the decision. It appeared from the response of one caregiver that assumption of the role of caregiver was viewed as a future investment: "I expect someone to do this for me when I get to be that age." The response from the second caregiver appeared to suggest motivation that was determined in part on the need for approval: "They would think I was wrong if I didn't take care of him . . . I worry about the criticism I'd get."

Although the number of responses that pertained to <u>Social Norms</u> was very limited, it would appear that for the two caregivers who made the responses the motivation to assume the role of caregiver was influenced in part by the social norms or rules that are a part of the <u>Socio-Cultural Domain</u> and effect the personal beliefs and subsequent actions taken by the caregivers. Future studies to determine the relevance of social norms to motivation among caregivers would be helpful.

Summary and Implications

To summarize, the categories of Attachment, Family Responsibility, and Personal Philosophy received the highest number of frequencies among family caregivers who were interviewed at 6 weeks ($\underline{n} = 103$) and again in response to the interviews that were conducted with those caregivers who remained in the study and

continued to provide care for a relative at 9 months ($\underline{n} = 78$). On the basis of these findings, it would appear that the caregivers' perceptions about the quality of the relationship with the care receiver, and strong beliefs about filial or familial responsibility or the marital commitment, were strong motivational factors and imply the influence of both the Personal Domain and the Familial Domain on motivation. In addition, it would appear that the caregivers' personal beliefs about the role of caregiver including feelings of satisfaction, his/her spiritual or philosophical beliefs, and feelings against nursing home placement, also contributed as relevant factors of motivation.

Other noteworthy findings included the high number of responses to the factors in the category of <u>Preparedness</u> among the caregivers interviewed at 6 weeks but not at 9 months. It would appear that beliefs about "Care management ability" and "Perceptions about the care receiver's health status" were more relevant as motivation factors among caregivers who had assumed the role.

Among the factors identified for the category of <u>Caregiver Availability</u>, only the factor "No one else available" appeared to be relevant as a factor of motivation among the caregivers who were interviewed at 6 weeks and to a lesser extent among those interviewed at 9 months. From the number of responses to this factor at 6 weeks, it would appear that <u>Caregiver Availability</u>, as it pertained to "No one else available," was more relevant as a factor of motivation among caregivers who had assumed the role.

From the number of responses to Moral Standards of Behavior, it would appear that feelings about "Moral obligation, moral duty" were relevant factors of

motivation among caregivers interviewed at both times. These findings indicate the influence of the standards that represent the social and cultural norms found in the **Socio-Cultural Domain** on the caregiver's beliefs and the motivation to provide care out of feelings about moral duty.

Reciprocation and Moral Standards of Behavior were the only two categories to increase in percentages among the caregivers who were interviewed at 9 months, suggesting influence of the standards from the Socio-Cultural Domain on the beliefs from Personal Domain. From the findings, it would appear that over time the desire to help the care receiver out of feelings of gratitude for past services and feelings about moral obligation both increased in relevance as factors of motivation.

To place the findings from this project in the proper prospective, it is necessary to identify some limitations. The first limitation pertains to use of the existing data base. This project was designed to employ Content Analysis to analyze three questions from the FCI (Archbold & Stewart, 1986) during interviews with the caregiver dyad at 6 weeks and again at 9 months post-hospital discharge, restricting both the results and the generalizability.

Interpretation of data results was further restricted due to the minimum number of responses to the questions that pertained to motivation. The majority of responses about motivation came from one question from the existing database that asked about the caregiver's reasons for assuming the care for the care receiver or wanting to continue to provide care. Future studies about motivation and caregiving would benefit from a larger database with a greater number of questions that surveyed additional reasons for caregiving. Controls for the length of time the

caregiver had been providing care, including precise definitions to more accurately distinguish caregivers who had assumed the role from those who were continuing in the role, would aid in the interpretation of the responses among caregivers both within time and across time.

Responses to the questions were limited to two points in time, 6 weeks and 9 months post-hospital discharged, limiting interpretation of the responses to the caregivers' perceptions about caregiving. Caregivers may have responded differently at another time. Future studies would benefit from exploring the role of caregiver and the factors that motivate them to continue the role over a longer period of time to see if and how motivation changes.

The findings from this project were limited to the sample which was primarily white, female, married, and belonged to a large HMO in the Pacific Northwest. Future studies that include family caregivers from other ethnic cultures are needed now, as the population, in addition to getting older, is becoming more ethnically diverse. Results from a study that focused on the cultural practices and beliefs among families from different ethnic cultures who are caring for a relative would provide a view of caregiving that has so far not been revealed in this population of predominately middle-class, white, and female caregivers.

Future studies would benefit from the addition of information about the religious practices among the families providing care for a relative to assess whether the <u>practice</u> of a religion acts as a factor of motivation, particularly among caregivers who provide care over a period of time. Constructing questions that

focus on the practice of religion may reveal factors of motivation that are more descriptive than questions about spiritual beliefs.

Although controls for response bias and transitory factors were included in the CRS (Archbold & Stewart, 1988), interpretation of the responses should nevertheless include consideration for transitory factors among the respondents, including such extraneous factors as environmental distractions, influence from other members of the family as well as stress, strain, or fatigue among the caregivers that may have influenced their subjective responses. In spite of controls, other considerations that may have biased the interpretation of the caregivers' responses include transcription errors in data entry and bias by the interviewer and/or the coder.

Analysis of the findings would have been more helpful with inclusion of the medical diagnoses of the care receivers. It is possible that among the caregivers who were continuing to provide care, some of the responses among the caregivers may have been a reaction to the care receiver's changed health status or to an alteration in the original medical diagnosis, resulting in a confounding of the interpretation of the responses between the two time periods.

Although the findings from this project cannot be generalized beyond the sample, they do suggest that among the sample of caregivers who participated in the study, personal beliefs about attachment, family responsibilities, and the meaning the caregiver derives from providing the care are involved with the decision to become a family caregiver. However, caregivers as a group are as diverse as every caregiving

situation. Just as they cannot be lumped together into a common pot, nor can any conclusions be drawn about findings from any of the categories.

The categories that were analyzed consisted of very broad definitions. The findings reflect data analysis that used a dichotomous response to indicate only whether each factor was present or absent. No attempt was made to analyze how much of each factor was present, how much the presence of each factor varied between caregivers either within time or across time, or whether other unknown factors were present to compel the caregiver to either assume the role or to continue but were not ranked.

Furthermore, it is important to interpret these findings as they relate to the particular group of caregivers who were surveyed. Another group of caregivers at another time may have responded in a very different manner. The categories that contained few, if any, responses were cited in the literature as factors of motivation among some caregivers. The lack of response among the respondents who participated in this study merely reflects the bias of the group sampled and should not be interpreted to mean those categories were any less important or worthy of more study. Within the clinical setting, the findings suggest the relevance for the clinician to have an understanding of the factors that motivate a family member to assume or continue in the role of caregiver for an older person. Beliefs about the role of caregiver, that include the quality of the relationship shared with the care receiver need to be identified and recognized as components of the caregiver's reservoir of strengths that may influence the caregiving outcome. The relevance of beliefs about family responsibilities suggests the importance of clinicians to view the

role of family caregiver as a component of the whole family unit. The clinician needs to recognize the strength of the values and beliefs of the family on the motivation of the family member to assume or to continue in the role of the caregiver and to include the family members in planning for the needs of the care receiver.

The findings from this study only hint at the reasons why a family member decides to become a caregiver, and raise more questions than were answered. The role of the caregiver is indeed very complex and has potential for outcomes that are as varied as the caregivers themselves. An outcome of this project has been the recognition that caregivers are motivated to provide care for a family member for a variety of reasons, many of which are determined by the caregivers' personal beliefs, beliefs about family responsibility and the influence of moral standards of behavior. It is hoped that these findings will provide the blueprint for future studies about motivation among family caregivers.

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