Caregiving behaviors of families who place an elderly relative in a nursing home
by Cynthia Joy Walton

Abstract:
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Secondary analysis of the data using the qualitative method of content analysis was done. Data were read and reread to identify themes, recurring words or language, attitudes, and behaviors that were congruent with Bowers' categories. Face validity was obtained through a consensus of the thesis committee members.

Study findings support Bowers' model of preservative family caregiving. New dimensions of two categories emerged. The category of family connectedness was expanded to include the use of touch, assisting a family member with eating, and bringing a family member a special food they liked. Because Bowers' category of maintaining hope (of recovery) was narrowly defined, Herth's (1993) model of hope was incorporated into this category.

An expanded model is proposed that is particularly suited to the population of end-of-life care recipients. Future research should be directed toward using the expanded model to develop an instrument intended to quantitatively measure quality of care at the end of life.

CAREGIVING BEHAVIORS OF FAMILIES WHO PLACE AN

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by

Cynthia Joy Walton

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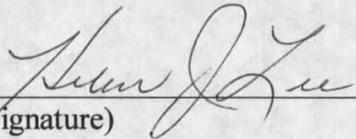Bozeman, Montana

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APPROVAL

of a thesis submitted by

Cynthia J. Walton

This thesis has been read by each member of the thesis committee and has been found

to be satisfactory regarding content, English usage, format, citations, bibliographic style,

and consistency, and is ready for submission to the College of Graduate Studies.

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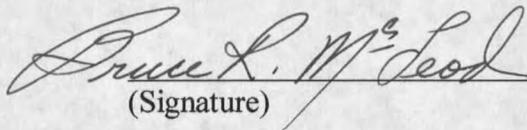
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ABSTRACT

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CHAPTER ONE

INTRODUCTION

The task of providing caregiving is both a historical and a contemporary issue in many cultures (Sodei, 1995 as cited in Hashizume, 2000). The concept of family caregiving was recorded as far back as the Bible. In his New Testament letter to Timothy, 5:4, Paul counseled his followers to care for their aging parents (Robinson, 1997, p. 1). Throughout history the roles of the family in providing caregiving have changed. The shifting and diverse nature of families represents a challenge to understanding the family in various contexts of change through different points in historical time (Hareven, 1991, p. 95).

Institutionalization of a family member is usually viewed as a last resort. This attitude supports the belief that nursing homes provide a poor quality of care (Smith & Bengtson, 1979). Nursing home placement is often preceded by a deterioration of health of an elderly person who exceeds the resources of the family for providing care. Family caregiving continues after institutionalization with differing levels of involvement. The consequences of caregiving continue to be felt by the primary caregiver as well as the effects of institutionalization of the family member. The stress of caregiving is not necessarily diminished by nursing home placement but may be traded for another set of stressors (Stull, Cosbey, Bowman & McNutt, 1997, p. 1-2).

The difficulties that families experience in replacing caregiving and a sense of role loss have been described in the literature (Zarit & Whitlatch, 1992; Robinson & Thorne, 1984; Dellasega & Mastrian, 1995). Dellasega and Mastrian indicated that role redefinition was

crucial for caregivers after placement of a relative in a nursing home.

Family involvement may influence the quality of life for the relative in the nursing home (Ekman & Norberg, 1988) and the quality of family member visits for the relative (Hertzberg & Ekman, 1996 as cited in Ekman & Norberg, 1988). The nature of the involvement family members have with their elderly relative prior to placement in a nursing home is likely to influence their relationship with the elderly relative while they reside in the nursing home. Smith and Bengtson (1979) concluded that institutionalization does not reflect a breakdown in family solidarity. The data from their study suggested that family relations may actually be enhanced, especially when family ties were strained to meet the needs of the older relative. The six consequences of institutionalization of a parent by an adult child identified by Smith and Bengtson were (a) renewed closeness and strengthening of family ties, (b) discovery of new love and affection, (c) continuation of closeness, (d) continuation of separateness, (e) quantity without quality interaction and abdication, and (f) institutions as a dumping ground. They concluded that these six types of consequences reflect improvement, continuation, or deterioration of family relationships after institutionalization.

Families and nursing home staff frequently find themselves in adversarial positions regarding the care of an elderly family member (Bowers, 1988; Duncan & Morgan, 1994). In addition, institutional policies and practices may hinder families and staff from working well together to provide caregiving. Litwak (1985 as cited in Pillemer, Hegeman, Albright & Henderson, 1998) noted fundamental differences between formal organizations and informal primary groups such as families. His theoretical work on the

relationship between families and nursing homes indicated the existence of structural

barriers to cooperation between the two groups. Formal organizations are characterized

by bureaucratic structure, formal rules for behavior, and impersonal ties. Families are

characterized by their ties of birth, love, lengthy or lifelong period of contact, and a

concern for special characteristics of individuals. Problems arise when there is a

mismatch between the structure of formal organizations and the types of tasks it seeks to

take over from family caregivers. The potential for conflict is exacerbated because long-

term care facilities take over the tasks that have been performed by the informal family

groups. The work of caregiving is then performed within the structure of a bureaucratic,

routinized, organizational framework (Litwak, Jessop, & Moulton, 1994 as cited in

Pillemer et al.). Duncan and Morgan (1994, p. 235) found that due to the basic structure

of primary groups such as the family, they are best able to manage unpredictable events

and nonuniform tasks with many contingencies. Formal organizations, in contrast, are

better equipped to manage uniform or technical tasks that require technical expertise and

knowledge.

Research on the division of caregiving tasks between families and staff has revealed

that technical tasks involving physical or material care needs are performed primarily by

the staff of nursing homes. Nontechnical tasks such as providing emotional or

psychosocial care are more likely to be provided by family members (Lieberman, 1969).

Rubin and Shuttlesworth (1983) found that involving families in the process of providing

caregiving in the nursing home may be hindered by the ambiguous subdivision of

caregiving tasks between staff and families. In their study, not only were there differences

of opinion between the nursing home administrators and relatives about task provision but in fact there were discrepancies among responses in each group. Other studies reported that families consistently designated more overall responsibility to themselves for providing care tasks than the staff attributed to family members (Shuttlesworth, Rubin & Duffy, 1982; Rubin & Shuttlesworth, 1983).

Duncan and Morgan's (1994, p. 242) findings indicate that this ambiguity in the provision of tasks can lead to conflict. In their study family members often felt that staff did not recognize their expertise in the provision of caregiving. Family members felt "ignored and invalidated." In addition, family members resisted a division of labor in which staff focused only on the provision of technical care. Family members expected staff to share responsibility in the provision of social and emotional tasks as well.

Bowers (1988), a well-renowned geriatric nurse researcher and educator, questioned the usefulness of a task-based conceptualization of family caregiving. Her study revealed that family caregivers distinguished the type of caregiving by purpose, rather than by task. Findings indicated that family members attributed responsibility for most of the tasks to nursing home staff. However, family members maintained responsibility for monitoring and evaluating the effectiveness and quality of caregiving tasks, both technical and nontechnical that were performed by the staff. Bowers reported that family members accomplished this goal through teaching the staff how to deliver high quality care, filling in the gaps where they thought that staff had failed, and providing direct care themselves that was aimed to preserve the elderly family member's sense of self.

Family involvement in caregiving in the nursing home functions to individualize care and provide a link to the elderly family member's biographical history and personal preferences (Robinson, 1994). Family members have identified the importance of staff viewing the elderly relative as a unique human being as an important factor in the provision of quality care (Bowers, 1988; Duncan & Morgan, 1994; Looman, Noelker, Schur, Whitlatch & Ejaz, 1997; Hertzberg & Ekman, 2000).

The care of older adults is a central feminist issue. Not only does this work remain largely unpaid and unrecognized, but the majority of the caregivers and recipients of caregiving are overwhelmingly women. (Hooyman & Gonyea, 1999, p. 150). Gender-based inequities in care responsibilities have limited women's economic independence and personal rights. These responsibilities are increasing as a result of changes in the family, the growth of the aging population, increased movement of women into the labor force, public policies, privatization of care and the increased pressure for families to provide care (Hooyman & Gonyea, 1999, p. 153-154).

The nature of caregiving is dynamic, shifting and fluctuating in relation to contextual factors (Anehensel, Pearly, Mullan, Zarit & Whitlatch, 1995 as cited in Dellasega & Nolan, 1997, p. 443). The caregiving role and experience of family involvement in an institutional setting during the residence of an elderly family member are not well understood. Little research in nursing has addressed the attitudes and behaviors of caregivers who are involved in providing care for a family member in a nursing home.

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Purpose of the Study

The purpose of this study was to explore the attitudes and behaviors of caregivers who had an elderly family member in a nursing home. The goal was to understand the role of family members who provide caregiving in the institutional setting and to describe the nursing home experience from their perspective. Nurses and other health care professionals may lack a sufficient understanding of the family caregiving experience. To provide quality care for a nursing home resident, the institution, families and staff must address issues that stand in the way of cooperatively working together.

Another purpose for this study was to test Bowers' theory of family caregiving in an institutional setting. Potentially, the findings of this study could contribute to the development of theory about family caregiving in an institutional setting.

Conceptual/Theoretical Framework

Family caregiver attitudes and behaviors were explored using the framework of Bowers' theory of family caregiving (1988). This theory evolved from Bowers' (1987) previous study of intergenerational caregiving, in which she identified five conceptually distinct but overlapping categories of family caregiving in the home. Family caregivers conceptualized their caregiving work by purpose, rather than by task. The categories of care included (a) anticipatory (anticipating and preparing for what may happen to the elderly parent), (b) supervisory (coordinating and supervising care provided by others),

(c) instrumental (performing physical care tasks), (d) preventive (prevention of physical harm to parent), and (e) protective care (protecting the parent's self-concept of self and the parent-child relationship). Only instrumental care is considered task-oriented or hands-on caregiving behavior. The other four types of caregiving (anticipatory, supervisory, preventive and protective) are not observable behaviors but are processes that are essential to intergenerational caregiving and contribute toward understanding the experience of intergenerational caregiving.

Protective care is considered the most important and difficult type of care to provide because the purpose is to protect the elderly parent from potential consequences that were perceived by the adult children caregivers as threats to the parent's self-image (Bowers, 1988). Even though the caregivers could not prevent cognitive decline, the caregivers believed that they could prevent the parent from experiencing an altered self-image or depression resulting from knowledge of the cognitive decline. An important aspect of protective caregiving is the caregiver's attempts to prevent the elderly parent from awareness that they are being taken care of. A great deal of effort is devoted to protecting the parent's identity and maintaining the parent-child relationship resulting in caregiver stress.

Bowers further developed her theory in 1988 and expanded it to include family caregiving of an institutionalized elderly family member. Protective care was relabeled as preservative care although it is the same type of caregiving work. Bowers identified three core categories of preservative caregiving. The first category included the work in which family members engage to insure quality care for their older family member. The second

category involved the types of expertise required to administer quality care and the third category was the families' perceptions of quality care. Dimensional analysis revealed two subdimensions of quality care which included instrumental (technical care), and preservative (emotional/psychosocial) care. Family members expected both types of care to be employed in all tasks, even those tasks that were considered technical, although each type of care is based on a different type of expertise.

Assumptions

Since this study was conducted using a portion of a previously collected data set, it was assumed that the interviews reflected what family members were able to verbalize about their situations at the time of the interview. It was also assumed, due to the fact that nationally the majority of caregivers are women, there would be a larger number of family members who were female caregivers. A third assumption was that the majority of the caregiver recipients would be females with limited financial resources.

Definitions

Caregiving

Family caregiving can be conceptualized as the process of taking responsibility for and providing for the needs of another individual. This includes physical, emotional, social, and physical needs. Maintaining the environment of the care receiver is also important. Actions, thoughts and feelings of the caregiver are also considered to be part of

caregiving. Because each individual is unique, the response to the caregiving experience may be considered burdensome for the carer and/or the care receiver, leading to strained relations between them. It can also be emotionally satisfying and rewarding at times. (Orem, 1991 as cited in Bunting, 1992, p. 55).

Bowers (1989) defined caregiving by "the meaning or purpose a caregiver attributes to a behavior rather than by the nature or demands of a behavior itself. Any process engaged in for the purpose of caregiving is therefore included" (p. 284). Bowers stated that this method of defining caregiving has important implications. First of all, in this definition observable behaviors and mental activities are included. Plans and decisions made by caregivers are not observable tasks but may have important consequences. Secondly, it is not required for the caregiver and the parent to have consensus and shared understanding about the meaning of an activity for it to be considered caregiving. Finally, a behavior may serve more than one purpose at the same time. In Bowers' study, when caregivers were forced to label a particular behavior as either caregiving or something else, caregivers made arbitrary distinctions. For example, preparing a meal may be viewed as a gesture of caring, a technical task or both at once. A single activity such as preparing a meal can be used to communicate very different messages. The message intended by the caregiver frequently is not the message received by the parent, or care receiver. Because caregiving is an interpretation of a situation rather than an observable event, situations are open to multiple, conflicting understandings.

Family

Hanson (2001) defines the family as "Two or more individuals who depend on one another for emotional, physical, and economical support. The members of the family are self-defined" (p. 6). Ransom's (1984) definition of family (as cited in Robinson, 1995) further expands on the reciprocity of family relationships.

> Thus it is not that a family is more than the sum of its [members], but that the [family members] are redefined and recreated in the process of their interaction. This re-creation, in turn, restructures the family, which creates new conditions engendering further recursive cycles of this kind (p. 117).

Furthermore, each person in the family has a historical perspective that can clash with the present and produce a stressor. According to Robinson (1995) "individuals/family members cannot be separated from families and families cannot be separated from individuals/family members" (p. 120).

Institutionalization

In this study institutionalization refers to placement in a nursing home. Individuals may be placed in a nursing home for the purpose of receiving skilled nursing and/or rehabilitation services after a qualifying hospital stay. Other applicants must need supervision and assistance with at least one activity of daily living such as bathing, dressing, transfers, toileting, ambulating or eating (Swagerty & Rigler, 2000, p. 3, 6). In order to be accepted for residence in a nursing home, patients must meet preestablished admission guidelines. The applicant's functional, psychological, and medical status are assessed to determine whether they are in need of nursing home care.

CHAPTER TWO

REVIEW OF LITERATURE

The literature on research relative to caregiving is rich with data. The focus of this review of literature was to examine factors that affect the caregiving experience. The factors of caregiving under investigation in this study are the impact of caregiving on the elderly population and on caregivers and characteristics of the caregivers and the content of caregiving.

Impact of Caregiving

Demographic Trends

The responsibilities facing caregivers are intensifying due to several trends. First, the demography of the United States is rapidly changing due to the "graying of America." The oldest-old are the fastest growing segment of the population within the aging population and the overall population in the United States. Second, life expectancy has dramatically increased. The result is that middle-aged and young-old adults will share thirty or more years with their aging parents (Hooyman & Gonyea, 1999, p. 155).

Women are the predominant group in the aging population. The number of women aged 75 and older outnumber men by two to one. Women have a greater tendency for chronic illness and require more assistance with activities of daily living. By age 85, including women living in nursing homes, the need for personal assistance increases to 45% (Camacho, Strawbridge, Cohen & Kaplan, 1993; Bould, Longino & Worley, 1997).

A third trend is the decreasing size of the family. The average number of children per family is 2.2 in the United States and the number of one-child families is increasing (U.S. Bureau of Census, 1997). The trend toward smaller families effectively limits the number of children available to help older parents. This also decreases the probability that the available children will be female (Horowitz, 1985, p. 612). Another change in the American family is an increase in the number of single-parent households which may affect the ability to provide caregiving for an aging parent. In the 1990s, a single parent, most likely a mother, maintained almost one-third of all households with children under the age of 18. For African-Americans, this is now the most common family structure (Hooyman & Gonyea, 1999, p. 155). Another significant demographic trend is the increased number of women in the labor market (Horowitz, 1985, p. 612). Women account for 46.2% of the workforce in the United States (U.S. Bureau of the Census, 1997). The most dramatic increase in the female labor force has been among married women. Fifty-nine percent of married women work outside the home (U.S. Bureau of the Census, 1993). Currently 60.5% of women caregivers are employed (National Alliance for Caregiving-American Association of Retired Persons [NAC-AARP], 1997, p. 11). The typical caregiver is a married woman in her mid-forties who works full-time. She has a high school education and a combined annual income of $35,000 (NAC-AARP, 1997, p. 8).

Trends in Social Institutions

Concurrent with changes in demography are significant changes in social institutions that may affect the availability of adult children for caregiving. Women are attaining higher levels of education, delaying marriage until they are older, and the divorce rate has increased (Harris Braudy & Long, 1999, p. 244). In addition to delaying marriage, women are also delaying childbearing until they are older. This has increased the number of women who are "sandwiched" between two generations that need care and support (Hooyman & Gonyea, 1999, p. 155). Pavalko and Artis (1997) estimate that the average American female can expect to spend 18 years caring for an older family member compared to 17 years spent caring for her own children.

Montgomery and Datwyler (1990, p. 34) stated that the caregiving role as it exists today in the United States can be attributed directly to the unprecedented increase in the elderly population. Caring for elders creates a hardship primarily for women who traditionally have been the main providers of caregiving. They stated that this conclusion does not take into account modern society's view of the provision of medical care and the value that is placed on different types of care for the elderly population. Public policies have shifted the burden of care to families in the context of incongruent societal values based on gender inequities, demographic changes and myths of the family's role in caregiving in past society. Institutionalized medical care is aimed at 'cure' rather than 'care.' Colliere (in Robinson, 1997, p. 3), a French nurse, theorizes that as "cure" became a valued activity in the domain of men, "care" became the activity undertaken by women, remaining undervalued, uncompensated and invisible. Montgomery and Datwyler (1990)

observed that the patriarchal medical model relegates unskilled care that is necessary for comfort and survival and place little value on custodial care. This responsibility is transferred to individuals who are paid low wages or to family members or friends who are unpaid workers. These values are represented in public policies and practice. The mechanisms leading to the emergence of the caregiving role today include the rapid rise of health care expenditures, lack of adequate coverage through welfare programs and the low value placed on custodial care that ought to be a basic human right of the elderly population (p. 34).

Public Policy Trends

Public policies affect the type of care and choices available to caregivers and recipients of care. Family caregiving patterns are a reflection of current long-term care policies in the United States resulting from historical, economic and ideological constituents (Montgomery, 1999, p. 393). The assumption and expectation that caregiving provided by women in the home is free underlies much of the public policy and research on caregiving (Ward, 1990). Typically, social policies and practice interventions have defined the problems of caregiving faced by women as personal or private concerns (Hooyman & Gonyea, 1999, p. 151). It may not be readily apparent that policy makers and legislators promote home family caregiving because it represents an untapped resource for cost savings by those concerned with rising social and health care costs (Horowitz, 1985; Bunting, 1992; Robinson, 1997). What is actually being advocated is

that the private sector (women in the home) take over a responsibility that belongs to the larger society (Brody, 1981).

There is a social and cultural expectation that women are caregivers. Public policies have reinforced this ideology with little concern for the psychological, physical, or financial effects on women's lives (Hooyman & Gonyea, 1999). Without women who are willing to put aside their own life goals and potentially jeopardize their own futures to provide care, the number of elders in institutions would be tripled (Brody, 1981). Those who take on the role of caregiver should have choices and options for caregiving. They should not have to impoverish their present and future lives by surrendering their social contacts, their professional promotions, and their own self-care (Bunting, 1992, p. 64). Existing structural arrangements create women's dependency and limit their choices in old age (Hooyman & Gonyea, 1999, p. 151). Finch and Groves (1982) stated

> If policy makers were under a legal requirement to ensure that their community care strategies were completely non-discriminatory as between the sexes, they might well rapidly lose interest in the whole notion of community care since it would stop looking like the cheap alternative which currently makes it look so attractive to cost-conscious decision makers (p. 434).

In the United States decentralization of long-term care programs has transferred management responsibilities to state and local government. In addition, there has also been a move toward privatization of long-term care (Harrington & Pollock, 1998). Underlying the concept of privatization is the assumption that caring is a private duty, not a societal responsibility. This assumption has caused a reduction of services that are available to lower-income individuals traditionally served by public agencies, most of whom are women and minorities (Hooyman & Gonyea, 1999).

Economic Trends

The aim of these policy changes is to shift responsibility for funding from society to the individual. Long-term care includes formal services such as nursing home care, residential home-care services as well as community and home-based health care and social services. In the United States long-term care is a personal responsibility but the burden of cost is commonly paid by two public funding programs. The federally funded Medicare program was created in 1965 as an indemnity health insurance plan aimed at primarily covering the costs of acute medical care for the elderly and disabled. The program does not cover long term care beyond 100 days which is more frequently needed by individuals and is provided by nursing home facilities (Harrington & Pollock, 1998; Bierman & Clancy, 2000).

Many older individuals pay for their own long-term care until they are eligible for Medicaid coverage. The inception of Medicaid was in 1965. The program is designed for the poor, and it is the major payer for long term care services in the United States. The Medicaid program is funded by federal and state governments, but is administered by each state. Medicaid provides long-term care coverage that is based on financial need. Therefore a resident (of a nursing home) must exhaust all of their financial resources prior to eligibility (Harrington & Pollock, 1998).

The 1993 Family and Medical Leave Act was created for employees that are caring for a frail parent, ill child or and/or a disabled spouse. The law mandates that employers with 50 or more employees must grant up to 12 weeks of job-protected unpaid leave. One problem is that this creates a disadvantage for employees who work at a small business

and are not guaranteed this opportunity. Another disadvantage is that the leave is unpaid.

Therefore, caregivers who receive low wages are least able to benefit from the policy

(Lechner & Sasaki, 1995, p. 105).

Workplace initiatives have gained popularity in the face of an aging workforce, a

decreasing supply of workers and an increased dependence on working women (Hudson

Institute, 1987 in Lechner & Sasaki, 1995, p. 105). Benefits and services have been

targeted to working caregivers by providing educational seminars on work and family

issues, resource and referral services, dependent care assistance plans for dependent care

expenses, and flexible working schedules. However, only large companies or unions have

implemented these practices and only their employees benefit from access to these

services (Lechner & Sasaki, 1995, p. 106).

The economic consequences of decreased Social Security benefits for workers who

retire to provide caregiving are tied directly to public policy. Kingson and O'Grady-

LeShane (1993) identified the need for policy reform but stated there is a lack of

consensus about how it should be done. In their opinion a policy reform will require, in

part, political consensus on the value to society of the care provided by women and the

fairness of the current distribution of the cost for providing such care. They stated

> Barring dramatic changes in gender roles, the question of the recognition of the value
> to society of the care provided by women and the cost to the individual
> woman of providing such care will likely remain on the public agenda (p. 238).

Status of Women

Many feminists (Chow & Berheide, 1988; Hare-Mustin, 1988; Hooyman, 1990) have conceptualized the present caregiving situation as being tied to the status of women's work within the private sphere of the home. In preindustrial society the family served as the primary unit of production for food, clothing, medicines and household goods. The contributions of women were recognized, though less valued in many societies. However, there was not a distinction between work that was associated with family maintenance from work that was associated with the production of other goods (Bunting, 1992).

The family in modern society does not serve as the primary unit of production. Family welfare is governed by a wage economy. The result is a separation of household production from paid work. The labor that women provide in the home is not compensated by wages. Therefore services and products produced by women for the family do not have a recognized market value (Hare-Mustin, 1988; Bunting, 1992). Bunting argues that this situation has added to the devalued status of women in the home and in society due to the fact that in the present socioeconomic situation, an individual is valued according to what they are paid or for their capacity to generate income.

In the late nineteenth and early twentieth century there was an emphasis placed on the separation of the public sphere of the work place and the private sphere of the home. The separation of the public sphere and the private sphere was perpetuated by legislation, unions and company policies that banned nepotism and the participation of women in the work force. During this time the home became idealized as a haven for the breadwinner

husband and the stay-at-home wife (Bunting, 1992, p. 59). This created the myth of the housewife with leisure time to perform other tasks.

Poor women have always had to work for pay outside of the home. However, the twentieth century brought about a dramatic increase in the paid work force by middle-class women (Bunting, 1992, p. 59). Women continued to perform their home responsibilities with the added burden of paid work. Ward (1990) and Colliere (1986) identified caregiving as "invisible" work, devalued because it is performed by women in the private sphere of the home where it is viewed as a labor of love or duty. Arno, Levine and Memmott (1999) stated that informal caregiving lies outside of the market economy and is socially and politically invisible. Therefore, the economic value of home care is not generally acknowledged. They estimated that the national economic value of informal caregiving in 1997 was $196 billion compared with $32 billion spent on formal home health care and $83 billion spent on nursing home care. The economic value of informal caregiving is equivalent to approximately 18% of total national health care spending, which is $1,092 billion. Informal caregiving is not included as part of national health care spending but if it were, the trillion-dollar figure would rise by nearly $200 billion.

Women are more likely than men to move in and out of the workforce across the life span in order to assume care responsibilities. Female caregivers are more likely than males to give up employment, change their work schedules, or pass up promotions or career development opportunities to accommodate care responsibility (Neal, Ingersoll-Dayton & Starrels, 1997; Pavalko & Artis, 1997). Not only does this effect women in terms of lost income but it also lowers Social Security and pension benefits at retirement.

The Metlife Juggling Act Study (1999) estimated an average loss of $25, 494 in Social Security wealth for caregivers.

More women than men retire to provide caregiving and often retire involuntarily, against their wishes (Richardson, 1999, p. 57). Women who have delayed or interrupted work force participation are therefore penalized (Emlet, 1998, p. 106, 108). Thus, the Social Security system effectively works to discriminate against women. Individuals who retire early receive a permanently reduced social security benefit amount. Kingson and O'Grady-LeShane (1993) conducted a study using data from the Social Security Administration's 1982 New Beneficiary Survey to examine the effect of caregiving late in life on women's Social Security benefits. Their findings indicated that poor and moderate-income women who retired to provide caregiving were economically disadvantaged but higher income women were not significantly affected. They estimated that the Social Security benefits for low income women in 1983 who left work to provide care to others was $59 less than women who left employment for voluntary reasons. For moderate income women, there was a $58 reduction and for high earners there was only a $14 reduction in benefits (p. 237). Women represent almost half the workforce but experience double the rate of poverty in old age, 16% compared with 8% of men (Hobbs & Damon, 1996; Hooyman & Gonyea, 1999).

Donelan, Falik and DesRoches (2001) state that two-thirds of caregivers who are employed outside the home report monetary losses for unpaid leave and career sacrifices, including foregone promotions, smaller pay raises, and fewer training and advancement opportunities. For example, the Metlife Juggling Act study (1999) reported an estimated

cost to caregivers of $659,000 for lifetime lost wages, social security, and/or pension contributions.

Parent-Caring Roles.

Several researchers (Lang & Brody, 1983; Brody & Schoonover, 1986) reported that employment and higher income decreased the amount of time women spent in providing direct personal care to frail older relatives. Archbold (1983) conducted a qualitative study of 30 female caregivers and care recipients. She identified two types of parent-caring roles. The first role was the care-provider whose duties included identification and performance of services that the parent needed. The second role identified was the care-manager who identified the services needed and managed the provision of the services by others. Findings indicated that socioeconomic status was the major factor influencing a woman's choice of the type of caregiving role. Care managers had full time jobs in socially valued career positions and came from higher socioeconomic backgrounds. Career commitment was identified as a salient competing role to caregiving. Archbold noted that the importance of the individual's occupational role enabled care managers to delegate caregiving activities with little internal conflict. Income was the primary determinant of whether and how many services could be purchased. In general, caregivers with higher incomes had more options and flexibility in obtaining services. However, personal services were costly and only a few care managers were able to purchase services for long periods of time.

In contrast, care providers who were employed were not career oriented (Archbold, 1983). Their occupational roles were less valued by society than those of the care managers. In addition, the income of care providers from their employment was not enough to purchase needed services. Care providers also experienced internal conflict between their paid employment and their obligation to their parent, causing some to quit their jobs and assume full-time caregiving activities.

<div align="center">Gender</div>

Gender roles and differences were used by many researchers to provide an explanation for the type and amount of care assistance provided by women and men to older family members. Other research examined the caregiver's experience of placing a relative in a long term care institution. Women make up the largest group of caregivers but the participation of men is increasing and should not be overlooked (Brody, 1981; Stone, Cafferata & Sangle, 1987; Stoller, 1994; Hibbard, Neufeld & Harrison, 1996; Wagner, 1997; Harris Broudy, 1998). Lee, Dwyer and Coward (1993 as cited in Stoller, 1994) identified a demographic perspective to explain the large numbers of women caregivers by looking at the structural features of the older population. The fact that wives outnumber husbands as spousal caregivers was explained in demographic terms. The combination of women's tendency to marry older men and women's 7-year advantage in life expectancy translates into younger wives with the ability and availability to care for their husbands. They extended this demographic argument to explain the larger number of adult daughters caring for elderly parents. They found that even though daughters were

more likely than sons to care for elderly parents, the predominance of daughters was less pronounced when the care recipient was an older father. Their conclusion was that the predominance of daughters reflected in part the predominance of older widows among elders that needed care from their adult children.

Results from prior research suggest that the caregiving role and experience may be different depending on factors such as the caregiver's gender, familial relationship to the relative, and the relative's functional status. Some researchers have reported differences in the type of assistance offered by men and women. Stoller (1990) found that men and women give different patterns of assistance according to gender-based division of labor. The studies conducted by Horowitz (1985) and Miller and Cafasso (1992) revealed that most of the day-to-day, personal, and hands-on care is provided by women. According to Finley (1989) and Chang and White-Means (1991) men are more likely to arrange for services or provide care management. However, Neal, Ingersoll-Dayton, and Starrels (1997) found no gender differences in the provision of caregiving tasks but noted that women devoted more of their time to the caregiving role. Their findings were also consistent with previous research regarding the effect of the caregiver's relationship to the care receiver on the type and amount of care given (Young & Kahana, 1989).

Stoller (1983) reported gender differences in the level of parental caregiving related to employment. Being employed decreased the average level of assistance by 20 hours a month for sons. However, employment was not a significant predictor of caregiver hours among daughters (Stone, Cafferata & Sangle, 1987, p. 617).

Horowitz (1985) examined gender differences of adult children who were primary caregivers to an elderly parent in a community setting. There was a total of 32 sons in a population of 131 adult children. Eighty-eight percent of the sons were either only children, children from an all-male sibling network, or the only child available geographically. Therefore, Horowitz concluded that they were caregivers by default. She found that sons did not significantly differ from daughters in their level of involvement as caregivers. No gender difference was found in providing emotional support to parents. However, daughters were more likely to assist their parent with transportation, household chores, meal preparation and personal care. Sons provided more financial management, financial assistance and dealing with bureaucratic organizations, tasks which may appear more male-oriented or less gender specific. Sons spent considerably less time than daughters in the provision of caregiving. Sons were also more likely to involve their spouses in caregiving and to depend on them. Daughters were more likely to experience considerable strain in the caregiver role, even when they provided similar levels of care.

Gender roles and expectations are also slowly changing. This is exemplified by women's occupation selection. The proportion of women who are professional workers has risen from 40% in 1950 to 52% in 1990 (U.S. Bureau of Census, 1993). Men are also becoming increasingly responsible for sole custody of their children and becoming the primary caregiver to a parent (Harris Braudy & Long, 1999, p. 244). In 1997 a comparative analysis of family caregiving revealed that 28% of caregivers to the elderly were men, an increase from 25% in 1987 (Wagner, 1997).

Institutionalization

The caregiver role changes and the experiences of caregivers following institutionalization of an elderly family member have been described extensively in the literature (Bowers, 1988; Matthiesen, 1989; Johnson, 1990; Mathew, Mattocks & Slatt, 1990; Dellasega, 1991; King, Collins, Given & Vredevoogd, 1991; Pruchno & Kleban 1992; Zarit & Whitlatch, 1992; Ade-Ridder & Kaplan, 1993; Duncan & Morgan, 1994; Dellasega & Mastrien, 1995; MacDonald, Higgs, MacDonald, Godfrey, & Ward, 1996; Dellasega & Nolan, 1997; Penrod & Dellasega, 1998). Each of these studies emphasizes that caregiving does not end with nursing home placement or institutionalization of an elderly family member. Rather there is a shift of caregiving responsibilities after placement (Penrod & Dellasega).

Some research has found that caregivers experience considerable emotional distress and subjective burden even after placement of a relative in a nursing home (Colerick & George, 1986; Zarit, Todd & Zarit, 1986; Zarit & Whitlatch, 1992). A common response reported by caregivers is feeling guilty about placement (Johnson & Werner, 1982; Dellasega & Mastrian, 1995; Nay, 1997). Caregivers experience a range of ambivalent emotional reactions about admitting a relative to a nursing home (Ade-Ridder & Kaplan, 1993; Dellasega & Mastrian, 1995; Dellasega & Nolan, 1997; Nolan & Dellasega, 1999; Nolan & Dellasega, 2000; Ryan & Scullion, 2000). The typical feelings experienced are relief accompanied by guilt, shame, sadness and a sense of failure (Ade-Ridder & Kaplan, 1993; Dellasega & Mastrian, 1995; McAuley, Travis, & Safewright, 1997; Penrod &

Dellasega, 1998; Nolan & Dellasega, 2000). The difficulties that caregivers and their relatives experience are exacerbated by the negative attitude of institutional-based care portrayed by policy makers, academics and the general public (MacDonald et al., 1996; Nolan & Dellasega, 2000).

Role Changes

Some researchers have examined how family members define their roles in a long-term care setting (Bowers, 1987, 1988; Duncan & Morgan, 1994; Dupuis & Smale, 2000). Their findings indicate that family members think of their roles in terms of the meaning or purpose they attribute to their role, rather than thinking about the tasks that they perform. Bowers' (1989, p. 284) analysis revealed that the process of caregiving was more complex than a task-based definition of the role. She concluded that much of the stress associated with the provision of caregiving was unrelated to the performance of tasks and therefore distinguishing among tasks was not relevant to understanding the experience of family caregiving.

An example of the familial caregiving role employed by family members is the preservation of the older relative's dignity and sense of self. Bowers (1987) conducted a qualitative study of 33 middle-age female adult children caregivers of mildly cognitively impaired aging parents in the community. She found that the adult children frequently viewed the performance of physical care tasks, identified as instrumental or technical care, as a threat to their more important preservative, or protective care. Protective caregiving, as she labeled it, is related to emotional well-being and protection of the

parents' identity. It was reported by caregivers as the most difficult and important type of care provided. This type of caregiving work is largely invisible. The purpose of protective caregiving is to protect the parent from the consequences of things that were not or could not be prevented. These potential consequences were perceived by primary caregivers as threats to their parent's self-image. An important aspect of protective care is the caregiver's attempts frequently to protect their parent from awareness that they are being taken care of. This was verbalized as role reversal but adult children also described the efforts they took to prevent the parent from sharing this reversed role perception. Adult children described the importance of protecting both their parents' identity as well as the parent-child relationship. An enormous amount of protective caregiving work was aimed toward this goal and created a great deal of caregiver stress. This type of preservation care was central for primary caregivers and also accounted for most of the reported conflict among family members and between caregivers and health care professionals.

Bowers (1988) conducted another study of 28 family caregivers who had an institutionalized elderly parent. One of the purposes of this study was to contribute to the development of theory about family caregiving in an institutional setting. The focus of the study was to discover what families do and how they perceive the care provided by themselves and by the staff. Another purpose for the study was to test the usefulness of the family caregiving typology in an institutional setting. The findings indicated that family members expected nursing home staff to be responsible for the performance of most tasks, but family members held themselves accountable for monitoring and

evaluating the effectiveness and quality of technical and nontechnical caregiving tasks performed by the staff. The strategies identified by family members to increase the quality of care included teaching the staff how to deliver high quality care, filling in the gaps of care that were perceived by family members as failure of the staff to provide care, and providing direct care themselves. Family members reported that they actually taught staff how to perform a variety of technical tasks but they spent most of their time helping the staff acquire biographical expertise. They described continual efforts to personalize the care provided by the staff because they believed that the staff viewed old people as "pretty much alike." Family members perceived this viewpoint as insulting and demeaning, thereby minimizing the uniqueness of their elderly family relative. Bowers stated that preservative care can be provided without technical expertise, but technical expertise must be provided with preservative care to provide good quality care.

Preservative Caregiving

The predominant type of family caregiving in the institutional setting was preservative care, similar to the protective care described in Bowers' (1987) earlier study. Bowers (1988) stated the purpose of this type of caregiving was to "maintain the older person's self, or more accurately, the adult offspring's perceptions of that self" (p. 24). Bowers stated that this concept corresponded more accurately with the purpose of preservative caregiving work.