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

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Nursing
Montana State University
© Copyright by Cynthia Joy Walton (2002)

Abstract:
Institutionalization of a family member is usually viewed as a last resort. However, family caregiving continues after institutionalization. The purpose of this study was to describe caregiving behaviors of family participants who placed an elderly relative in a nursing home who was near the end-of-life. Bowers’ (1988) theory of family caregiving provided the framework for the study. Bowers identified one predominant type of family caregiving in the institutional setting, which she labeled preservative care. This care is aimed at preserving the elderly relative’s self and preventing or protecting the elderly relative from depression. Preservative caregiving contains four categories: (a) maintaining family connectedness, (b) maintaining the relative’s dignity, (c) maintaining a sense of hope (of recovery) and (d) assisting the relative to maintain control of the environment. Eighteen family members who had cared for fifteen decedents while receiving nursing home care formed the base for this study. Participants were selected from a larger study (N = 43) that examined family members’ perceptions of the end-of-life experience of decedents who died in 1995. The interviewees included six daughters, seven sons, a wife, one stepdaughter and her husband, and a nephew and his wife.

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
ELDERLY RELATIVE IN A NURSING HOME

by

Cynthia Joy Walton

A thesis submitted in partial fulfillment
of the requirements for the degree
of
Master
of
Nursing

MONTANA STATE UNIVERSITY
Bozeman, Montana

September 2002
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.

Helen Lee, PhD
(Signature) May 10, 2002
Date

Approved for the College of Nursing

Lea Acord, Dean
(Signature) 2/8/02
Date

Approved for the College of Graduate Studies

Bruce R. McLeod
(Signature) 9/10/02
Date
STATEMENT OF PERMISSION TO USE

In presenting this thesis in partial fulfillment of the requirements for a master’s degree at Montana State University, I agree that the Library shall make it available to borrowers under rules of the Library.

If I have indicated my intention to copyright this thesis by including a copyright notice page, copying is allowable only for scholarly purposes, consistent with “fair use” as prescribed in the U.S. Copyright Law. Requests for permission for extended quotation from or reproduction of this thesis in whole or in parts may be granted only by the copyright holder.

Signature  

Date  

Cynthia J. Walton  

08-30-2002
# TABLE OF CONTENTS

1. **INTRODUCTION**

   - Purpose of The Study ......................................................... 6
   - Conceptual/Theoretical Framework ........................................ 6
   - Assumptions ............................................................................ 8
   - Definitions ............................................................................. 8

2. **REVIEW OF LITERATURE**

   - Impact of Caregiving .............................................................. 11
   - Demographic Trends .............................................................. 11
   - Trends in Social Institutions
     - Public Policy Trends ............................................................. 13
     - Economic Trends .................................................................. 14
     - Status of Women .................................................................. 18
   - Parent-Caring Roles ................................................................. 21
   - Gender ..................................................................................... 22
   - Institutionalization
     - Role Changes .................................................................. 24
     - Preservative Caregiving ...................................................... 26

3. **METHODS**

   - Population and Sample .......................................................... 35
   - Design ..................................................................................... 36
   - Procedure for Data Collection .................................................. 37
   - Human Rights and Subject Consent ............................................ 37
   - Data Analysis .......................................................................... 38

4. **FINDINGS**

   - Bowers’ Model of Family Caregiving ........................................ 40
     - Family Connectedness .......................................................... 40
     - Preserving Dignity ................................................................. 42
     - Sense of Hope (of Recovery) .................................................. 45
     - Control of Self and Environment ......................................... 46
     - Failure to Provide Preservative Caregiving .......................... 48
   - Additional Analysis for Sense of Hope ....................................... 48
   - Hope fostering categories ...................................................... 49
     - Interconnectedness ............................................................... 49
<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Description of Population</td>
<td>93</td>
</tr>
<tr>
<td>Figure</td>
<td>Description</td>
</tr>
<tr>
<td>--------</td>
<td>------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>1.</td>
<td>Bowers’ Model of Preservative Caregiving in an Institution</td>
</tr>
<tr>
<td>2.</td>
<td>Preservative Family Caregiving of Institutionalized End-Of-Life Care Recipients</td>
</tr>
</tbody>
</table>
Institutionalization of a family member is usually viewed as a last resort. However, family caregiving continues after institutionalization. The purpose of this study was to describe caregiving behaviors of family participants who placed an elderly relative in a nursing home who was near the end-of-life. Bowers' (1988) theory of family caregiving provided the framework for the study. Bowers identified one predominant type of family caregiving in the institutional setting, which she labeled preservative care. This care is aimed at preserving the elderly relative's self and preventing or protecting the elderly relative from depression. Preservative caregiving contains four categories: (a) maintaining family connectedness, (b) maintaining the relative's dignity, (c) maintaining a sense of hope (of recovery) and (d) assisting the relative to maintain control of the environment. Eighteen family members who had cared for fifteen decedents while receiving nursing home care formed the base for this study. Participants were selected from a larger study (N = 43) that examined family members' perceptions of the end-of-life experience of decedents who died in 1995. The interviewees included six daughters, seven sons, a wife, one stepdaughter and her husband, and a nephew and his wife. 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.
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.
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.

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.

Gender

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.

Bowser (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.
Bowers’ theory is conceptualized as follows in Figure 1:

![Bowers' Model of Preservative Caregiving In An Institution](image)

Figure 1

This model illustrates that maintaining family connectedness was identified as the primary responsibility of the family members. The other three types of caregiving required collaboration between staff and family members (see Appendix A for illustration of Figure 1 and descriptions of the types of caregiving).

Bowers (1988) proposed four types of preservative caregiving that were identified by purpose, rather than associated with tasks. The first typology of preservative caregiving is maintaining family connectedness. Family members engaged in strategies to preserve their older relative’s self as connected to the family which they felt was primarily their responsibility. Family connectedness was maintained through activities such as family
visiting, taking the resident on a day trip or placing memorabilia in their room.

The second type of preservative caregiving was engaging in activities aimed at preserving the dignity of the family's older relative through maintaining the relative's sense of competency and personal uniqueness (Bowers, 1988). In her study 57% of the family caregivers described occurrences of undignified or humiliating experiences such as a resident’s messy personal appearance, release of intimate information to outsiders, loss of control of body functions, a sense of being a burden to staff and family, and a lack of respect for individual differences. Most of these situations were related to difficulties with activities of daily living including eating, dressing, and toileting. Families thought that the staff was often insensitive to the impact of these situations on the well-being on residents. These findings are similar to Street and Kissane (2001) in their study of dignity related to palliative end-of-life care. They state that dignity is related to the concept of personhood, or dignity as self-worth. There is always a struggle, even in the stories of good quality care, for the patient always to be regarded respectfully and not as an object of care. They described bladder and bowel incontinence as the most common priority for patients and relatives in terms of dignity. They also reported what they called “heroic attempts to maintain bowel and bladder function, at the expense of comfort, in order to preserve dignity” (p. 97).

The third type of preservative caregiving was maintaining their relative’s hopes of recovery (Bowers, 1988). If rehabilitation were not an option, families would often try to protect their relative from full knowledge about their deficits. Families often felt that a formal rehabilitation program was crucial to maintaining the resident’s hopes. Fifty
percent of the family members whose relative was receiving rehabilitative services viewed a decrease or termination of rehabilitation as a signal that the staff had given up or lost hope for recovery, or that staff thought the resident was not worth the effort. Family members were concerned that their elderly relative would perceive this situation as an indication of hopelessness of their chance of recovery. The most likely causes for decreased or terminated services were related to staffing problems and third party reimbursement but family members reported feelings of betrayal and anger.

Bowers (1988) related the findings of the relationship between rehabilitation and a sense of hope to an uncompleted study that indicated nursing home staff viewed rehabilitation of a resident as encouraging them to be as independent as possible, especially in self-care activities. The staff viewed the families’ behavior as undermining the resident’s rehabilitative process by encouraging dependent behavior. The families thought that other activities such as crafts were more appropriate for rehabilitation than activities of daily living (ADLs). They felt the failure of their elderly relative to perform ADLs was perceived negatively by the resident. Failure or having difficulty in learning a new craft was not perceived as having the same negative message.

The fourth type of preservative caregiving was aimed at increasing their relatives’ control of self and the environment (Bowers, 1988). The families identified important issues such as the nursing home’s schedule regarding when the resident was to get up or go to bed; when the resident was to move from one chair to another; when friends could visit; what to wear and whether the resident could refuse medications. Conflicts arose
between staff and families when the staff schedule or medical orders were different from the family members' preferences.

These four types of preservative caregiving were aimed at preserving the elderly relative's self and preventing or protecting the elderly relative from experiencing depression (Bowers; 1988). Eighty percent of the caregivers identified depression of the elderly relative as the most likely consequence of failure to provide preservative care. Only one type of caregiving, maintaining family connectedness, was identified as the primary responsibility of the family members. The other three types required collaboration between staff and family members. However, the family perceived that the staff often did not provide preservative care. Their descriptions of poor care were generally related to the staff's failure to provide one or more of the types of preservative care. Family members spent a great deal of time engaged in preventing and trying to invalidate any harm (depression) associated with the staff's frequent neglect to provide preservative care.

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 (Bowers, 1988). 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. Findings indicated that family members attributed responsibility for most of the tasks to nursing home staff but considered it was their job to oversee the care.
The simultaneous performance of technical care and preservative care by staff members was an expectation of family members (Bowers, 1988). Families clearly distinguished between expertise required to perform skilled technical care and expertise required to perform preservative care. Technical expertise was needed to provide physical care and medical supervision. This type of expertise was acquired through formal training, prolonged experience in caring for the ill, and through education. Biographical expertise was required to provide preservative care. Biographical expertise required an intimate knowledge about the life of the elderly person and what makes that individual unique. Knowledge about personal preferences of the person may influence their quality of life in the nursing home. For example, knowing that a resident enjoys listening to classical music during meals or sharing that a resident’s greatest fear is losing her memory gives the staff member privileged information and insight into the resident’s needs and vulnerabilities. Biographical expertise is especially important for preserving a sense of the self as unique. Sixty-eight percent of the family members described the lack of biographical expertise of the staff and therefore staff members were consequently unable to provide preservative care.

Many families identified the issue of the lack of technically expert, skilled care (Bowers, 1988). It is interesting to note that 93% of family members thought that the care provided was generally adequate or better than most. However, 71% of families voiced disappointment over the lack of skilled care, which they defined as care provided directly by a nurse, rather than a nurses’ aide. These family members stated that their decision to place their relative in a nursing home was based primarily on the expectations of skilled
care and they were angry about the minimal contact between their relatives and registered
nurses.

Bowers (1988) concluded that in order to provide good quality technical care, the
simultaneous use of both types of expertise is required. Highly skilled technical care must
be performed while utilizing biographical knowledge of the resident. However, the staff
generally lacked the biographical expertise to perform even the most technical procedures
for an individual in an acceptable style. Family members lacked the technical skills and
knowledge to provide safe and therapeutic technical care. Therefore, good quality care
depends on a partnership of shared and collaborative care between family members and
staff. Families and staff should be jointly responsible for care rather than a division of
work between the two groups.

The findings suggested that the ability of families to provide preservative care is
largely dependent upon staff cooperation. Families also perceived that their participation
and input were required in order for the staff to deliver good quality care. The provision
of good quality care is thus perceived to be a collaborative process between family
members and the staff, rather than a division of tasks between them.
CHAPTER THREE

METHODS

This study was conducted using a qualitative research methodology. Qualitative research is an interpretive approach that evolved from the behavioral and social sciences as a method of understanding the unique, dynamic, holistic nature of individuals. The philosophical base of qualitative research is interpretive, humanistic, and naturalistic (Burns & Grove, 2001, p. 28). It is concerned with understanding the meaning of social interaction with people and their environment within their sociohistorical context (Munhall & Boyd, 1999 as cited in Burns & Grove, 2001).

Population and Sample

Sixteen end-of-life situations were selected from a larger study (N = 43) that examined family members’ perceptions of the end-of-life experience of a family member in Missoula County who died in 1995. Interviews with family members from the larger study were selected for analysis if their family member had been placed in a nursing home at some point during their care. Subsequently, one situation was excluded because the decedent was placed in a nursing home only hours before her demise. Therefore, a total of fifteen end-of-life situations with eighteen participants were included in this study. According to Sandelowsky (1995) a sample size of 10 is adequate for homogeneous or critical case samples.
Of the adult children participants, six were daughters and seven were sons. Of the sons and daughters, there were a brother and sister who jointly shared caregiving duties. There was one wife. There were one stepdaughter and her husband and one nephew and his wife (see Table 1 in Appendix B for description of population). The caregivers in this study had exhausted all external resources of providing care in an attempt to keep family members at home in the community setting.

The caregiver participants in this study reported the following serious health problems of their family members: two of the care recipients had Alzheimer’s disease, three had cancer, one had Parkinson’s disease, two had dementia, and three had histories of stroke, with resultant deficiencies. Two had hip fractures from which they never recovered, and two had heart problems.

Many required assistance with toileting, bathing, getting dressed, personal grooming, moving from one position to another; or assistance with eating. During the course of their residency at the nursing homes, the family members also suffered from a multitude of additional health insults such as falls, pneumonia, severe pain, depression, incontinence, impaired communication and memory loss.

**Design**

A secondary analysis design was used for this study. Secondary analysis involves studying data that was previously collected in another study. Data was reexamined and a new dimension of the data was explored using a different analysis from that previously used (Burns & Grove, 2001, p. 277). Szabo and Strang (1997) stated that secondary
analysis is a credible method of generating nursing knowledge. It has the advantage of being cost-effective and convenient. It also allows the researcher to be sensitive to respondent burden. Therefore, it provides the maximum use of data without adding further stress and burden for the participants. Secondary data analysis provides the opportunity to view the data set with a detachment that may be difficult to attain by the original researcher.

Procedure for Data Collection

Participants in the larger study were interviewed face-to-face using a semi-structured interview schedule developed for the project. The interviews were conducted between February and June 1997, with the interval between the family member’s death and the interview ranging from 13 to 38 months. The length of the interviews ranged from 45 minutes to 120 minutes. The interviews were audio-taped and transcribed verbatim. The purpose for transcribing verbatim is to emphasize rigor in the transcription process. Every utterance, pause, laughter, tears or reference to contextual interactions with pets and other people is included to increase the precision of the analysis of the text.

Human Rights and Subject Consent

Human subjects’ approval for this study was received from the Human Subjects Committee at Montana State University - Bozeman College of Nursing. Even though human subjects were not directly involved, the data transcripts were from a study that interviewed human subjects and was therefore acknowledged as sensitive data. The
transcripts from the original interviews of the 18 participants were e-mailed to the researcher. The transcripts of the interviews were password protected on the researcher's computer and the transcripts were also copied to a floppy disk. The disk and hard copies of documentation were stored in a locked filing cabinet in the researcher's office located in the home of the researcher. Working documents were handled in the same confidential manner.

Data Analysis

The method of content analysis was used. Categories had previously been established prior to the analysis based on Bowers' (1988) theory of family caregiving. Therefore a priori coding was used. The unit of analysis was the individual transcripts or texts. The data were read and reread to identify themes, recurring words or language, attitudes, behaviors and patterns of belief that were congruent with the categories established by Bowers' theory of family caregiving. The four categories were (a) family connectedness, (b) maintaining dignity, (c) maintaining a sense of hope (of recovery) and (d) maintaining control of sense of self and the environment. The categories were also viewed in the historical context of social structures. Individual thoughts, attitudes, behaviors, actions and patterns of belief were examined for themes or categories not previously identified by Bowers' framework. The data was coded by hand to increase the insightfulness and meaningfulness of the interpretation of the data set for each participant.

First a chart was developed to record page numbers of each individual transcript to identify the frequency of references that fit each category of caregiving. The more
instances or examples that were identified implied a high degree of confidence that the data was in agreement with Bowers’ (1988) categories. Words or themes were underlined using different colored hi-liters for easy identification. Thoughts, comments, questions or ideas were written in the margins of the transcripts. Additional thoughts or ideas were recorded and stored on a computer disk for quick access. Initially the words or descriptions of the type of care as defined in Bowers’ theory guided the analysis. As the transcripts were reread for accuracy, additional words or themes were identified in common across the data set and were documented for further analysis. Finally, categories from the review of literature were examined to identify common themes.

Validity of the data was confirmed by providing examples of the categories from the original text. Face validity was obtained through agreement of the committee members.
CHAPTER FOUR

FINDINGS

The findings are presented using the four categories of Bowers’ (1988) model of family caregiving - (a) family connectedness, (b) preserving or maintaining dignity, (c) maintaining a sense of hope (of recovery), and (d) maintaining a sense of self and the environment. Since the findings for the third category, hope of recovery, were limited, the analysis was expanded to include Herth’s (1993) categories of hope used by elderly individuals. This chapter is concluded with findings regarding the characteristics of caregivers.

Bowers’ Model of Family Caregiving

Family Connectedness

Family connectedness was described by Bowers (1988) as family visiting, taking a relative on a day trip or putting memorabilia in a relative’s room. The data from interviews were rich with evidence of maintaining family connectedness. Participant 11 provided details of a multitude of ways he maintained connectedness with his mother:

Like on holidays, uhm, Thanksgiving and Christmas a couple of times, I went up and picked her up with a wheelchair, got her in my car, brought her down here, and got her in the house.

In addition he stated

I’d take the mail up to her. She’d get her church bulletins in the mail up there so she could see what was going on in church. And then I, I’d, the phone I got her was a combination phone, radio, clock radio, so I tuned that into the channel so she could
turn it on on Sunday, cause the church that she went to for years, and I still go to, has a radio broadcast of the service on Sunday. She could hear the church service.

Participant 08 reported:

I took him outside a lot in his wheelchair when the weather was nice. Put a cap on him, walk him over to Hospital A and buy him an ice cream bar. Take him in the wheelchair, walk him all over, go a couple of miles.

The use of touch to maintain family connectedness emerged from the data set.

Participant 33’s husband had Alzheimer’s disease. She relayed a story about her husband and touch as follows:

He was very happy when I came and I would sit there, even when he wasn’t talking. Um, I’d sit and hold his hand, this hand. And this one day, ah, well, his room was right across from the nurses’ station, and so, when I come, the nurses come in and talk to me and you know and stuff and and the minute I walk in and he heard my voice, his hand came out from underneath the blanket. And she said, “Did you see that?” so, he knew I was there and that I usually sat and held his hand. So, that was probably the last really noticeable thing.

Participant 39 said this about his mother in relation to touch:

It was the only way I felt I could keep a relationship with her or keep in touch, try to keep in touch with her. And that was, you know, that was relatively easy to do. Ah, you could tell, there is just so much more to me that can be communicated through touch.

Assisting a family member with eating also emerged as a concept related to family connectedness. Participant 11, a male, discussed assisting his mother with eating:

If she would get served a meal while I was there, I would offer to help her and, and the times that I helped her eat would have been shortly after she had the stroke until she kind of regained some of her functions and was able to do that herself.
Participant 24 was caring for his elderly uncle, with whom he reported not having a close relationship. He stated

He got down to like puddings and stuff like that. And he had trouble with some of that and sometimes [I] helped [him] do a little of that. And always, you know, water, you know you always giving him water.

Bringing a favorite food to a relative was also evidence of family connectedness.

Participant 25's mother had a diagnosis of cancer. She described the following scenario:

Well, when she was in the nursing home she wouldn't feed herself. Somebody had to feed her. She really, I don't think, ate very much. I came there one day when there was, I think, a social services person there that I had never met. And [mother] had just, been ill and thrown up a little bit. And I was coming to see her and I brought her a couple of Whopper Juniors [from Burger King]. And she snarfed it right down. I mean, you know, had been sick 10 minutes before and ate the whole burger [and was able to keep it down].

Participants 24 said:

We, ah, you know, brought him a pie for his birthday, we just um, lemon meringue pie and someone who brought him the apple pie. And that was about that was about the last time we had pictures that was about the last time that he really, yeah, we took pictures of him and, you know, and, you know, Julie sitting on the bed with him with the pie between 'em and stuff like that.

Preserving Dignity

Maintaining dignity of the elderly relative was a difficult task. Bowers (1988) stated that the purpose was to maintain the relative's sense of competency and personal uniqueness. Problems that interfered with dignity, according to Bowers, were messy personal appearance, loss of control of bodily functions, sense of being burdensome to staff and family, release of intimate information to outsiders and humiliating circumstances related to eating, dressing, and toileting. Participants reported few instances of maintaining
dignity. A rather humorous account of maintaining dignity was provided by participant 03:

They had her all dressed up. They had a nice nightgown on her. It didn’t happen to be hers but it sure looked pretty on her.

Participant 21 described an account of his mother whereby it was she who was in charge of maintaining her dignity:

The day before she died she couldn’t even get up and walk but she made them carry her to the bathroom. She says, “I’m not going to mess in the bed.” And that’s (laugh) she was so weak and, ah, you know, she was so, I don’t know, self-conscious or just ah, very respectful of herself. That was really the shocking part, you know, couldn’t even hardly move and stuff, but she made them carry her into the bathroom.

Two participants reported that their relative initially did not have problems with incontinence, but it was more convenient for staff to put them in Depends. Participant 06 stated

And I felt that at that nursing home and I felt that they worked very hard. I just felt that they didn’t have enough help to do everything that they needed to do for people. And I know that um, she had never been incontinent. And that was a real issue for them because a lot of times they had to come when she would ring the bell because she couldn’t get out of bed on her own. So soon she was wear[ing] the, I don’t know, I’ve forgotten what they’re called now the - the Depends, yes. Um, and that was a real bother to her. I realize that they couldn’t always answer that bell when she needed to get to the bathroom. So it was more convenient, basically.

Participant 09 related:

No, she seemed to, she usually could go to the bathroom on her own. And even up there at Nursing Home B, she was able to go on her own for a long time. But it was when she fell down a couple of times, that’s when she, she couldn’t go to the bathroom on her own. Yeah, she didn’t really have to be in Depends.
The majority of the elderly residents in this study were incontinent. A son, participant 39, reported the difficulty his mother encountered with having someone attend to intimate body functions:

Uh, it’s something mother was always overly concerned about and became more so as she became more frail and couldn’t help herself so much. You know, being ah, helped to the toilet was, or having somebody stand there was, um, was really, it’s just not done.

Other participants reported the humiliation of the relative being attended by a member of the opposite sex. Participant 08 talked about her elderly father:

And I think, ah, in a man’s case, for a woman to have to be caring for them is, I think it’s very humiliating. It was very hard. He would hold onto his sweats because he didn’t like the girls changing him.

Participants 41 reported a humiliating experience related to neglect of dignity through a messy appearance, loss of bodily control, dressing, and toileting:

I just don’t understand how And we were just, I mean, it was human-just common dignity, I mean-I mean, you’d walk in and he’d be sitting in his chair with his pajamas down around his ankles, you know, and his, and he, when he was up there, he was wearing Attends because he was having bowel or bladder trouble. I mean, we’d walk in and he was just, he would be just a mess. I mean, there would be BM all over. He’d be sitting in the dark. And his light would be on. The call light. His call light would be on. I mean, and it wasn’t like it, I mean it was even dried. You could tell that it was not, you know, it was just ugly. Just ugly. I just hated it. And I hated that he had to be part of it.

One participant, 08, cared for her elderly father in the nursing home as she felt that her mother would have done, had she been alive. The daughter filled in the gaps of care that were not provided by the staff and maintained the dignity of her father exceptionally well:

I did his laundry. I would brush his teeth. I would, he loved hot packs on his face. So I would get nice warm wet towels and put on his face and clean his eyes good, make sure there wasn’t any matter in them. I always kept his fingernails clean and clipped -washed his hands in warm water. Rubbed his feet. Made sure he always looked nice.
He had plenty of clean clothes. He looked the best of anybody down there. And they told me to put him in sweatshirts and I said, absolutely not! Don’t you even.

Participants 41 described an instance of indignity and their failure to wield any power to effect positive change so that the quality of care and therefore, quality of life was better for their institutionalized family member. They reported:

Yeah, in response to one particular time, I found my, I went up to find my dad sitting in a dark room with, all he had on for clothes was a bathrobe, which was on backwards. He did not have his Attends on. There was loose stool all over him, all over the chair, all over the floor. I went to talk to the director of nurses. And she [said], “We don’t do that here.” I said, I just saw it, you know, I was just there, you know. And ah, she later sent the person who had left him, you know, in the bathrobe, down to apologize to me. And this person said, “I know these are difficult times, aren’t they?”

**Sense of Hope (of Recovery)**

Maintaining a sense of hope of recovery, according to Bowers (1988), was accomplished by projecting a competent sense of self into the future, by protecting the relatives’ full knowledge of their deficit, and through rehabilitation, which was perceived by caregivers in her study as being crucial to maintaining the resident’s hope. There were instances in this study that conceptualized hope in this way, such as attempting to protect their relative’s full knowledge of their deficit while handling financial aspects of their family members’ lives. Participants engaged in strategies such as that of participant 08:

Um, I wouldn’t, but I don’t know how much he grasped. In other words, as far as handling his finances and things, I never felt right about some things. So I would go up and I would talk to him. I would say, Daddy, I had to do such and such and I went ahead and I took care of your taxes and I got that all straightened out. And he’d look at me and he’d nod. And I think he understood. So, I would always make sure that I let him know that, what his finances were. And it made me feel better to let him know that it wasn’t like I was just taking it over and you don’t have any more to do with it. Because I don’t feel that’s right.
Participant 01 stated:

At times I was adverse to doing it. I certainly felt awkward. And suddenly to engage in this sort of a thing, sort of a role reversal, taking on some parenting of my parents. I'm grateful that it went on over a period of years. And at least I could have my father's one-sided conversations telling what I was doing with his finances. So I think it eased it for me to at least tell him what I was doing. To report in.

Participants 41 described an element of Bowers' (1988) model of maintaining hope through the use of rehabilitative measures that were perceived as important to caregivers:

No, just that, you know, the system I think, should also, you know, work to maintain people's current status, rather than insist on improvement. Because he could have, I mean, even when he wasn't getting better from the PT, he was maintaining, yeah you know, and he could, he could go for walks, I mean, with his walker. His balance was better, his, you know, all sorts of things, but. But I mean, and once they quit, there was no maintenance of anything, you know. I mean anything. Of course you're going to go down hill. I mean, there was—he didn't walk, I mean, except for bathroom, he would go for a walk. He couldn't. Yeah.

Participant 06 provides an account of loss of hope related to rehabilitation:

Part of the time, she didn't always receive therapy. After she got so bad, there's a limit to the amount of therapy they will do.

Control of Self and Environment

Bowers (1988) stated that maintaining control of self and the environment as perceived by family members were issues regarding decisions such as when to go to bed or get up, when to move from one chair to another, when to visit with friends, whether to refuse medications or what to wear. Conflicts arose when the staff schedule or medical orders conflicted with the resident’s timing of these activities. Conflict also arose when staff tried to convince the resident to take medications that she or he did not want to take.

Participant 01 described his perception of his father's sense of a loss of control which is
congruent with Bowers’ model:

In lots of ways I think he was resisting institutionalization. To a big extent. Um and having to deal with, ah, giving up an independent life and having to submit. And spend a lot of his day submitting. Having other people suggest where he sit and what he do. How long he should wait for dinner and so.

He went on very intuitively to say:

So, that it became almost a defining part of him that was shaping more and more his daily life. And so that was a constant. And it became a bit confused whether it was he was resisting seeing his ability to control and participate in his life falling away from him or whether it was that he was just resisting what was becoming a completely institutionalized life. There wasn’t much definition between the two.

Participant 08 said this about medication:

And yet in the nursing home he gave up everything all at one whack. His choice. And he never touched any medicine again unless I would give it to him.

Participants 41 also described some of the issues identified by Bowers:

I mean, and we went and got, they didn’t even have a decent chair for dad to sit up in, I mean, when he was out of bed. So, finally I talked to one of the nurses, who was nice, and we went and just kind of appropriated a chair out of the dining room, you know, that dad could sit up in, you know, that would have some back support and he could sit back and he could rest his head on the back. But, I mean, they would have just left him in bed, I swear to God, twenty-four hours a day if we hadn’t made a point of saying that, you know, we wanted him out of bed, we wanted him sitting up, we wanted him cleaned up. We wanted the curtains opened. We wanted him to be able not to close the doors so he could see people going up and down the halls, you know. So he could watch his squirrels, watch the birds.

Participant 11 was very cognizant of the importance of a sense of control over the environment. He assisted his mother to maintain control through the following activities:

Well, I got her a TV with a remote so she could, with her good hand, she could change channels and turn it on and turn it off and that whole thing. So that kind of gave her a little bit of control over her life. I took a mirror, had them put a big mirror up on the wall cause the head of her bed faced the hallway and she had this nice window that looked out over the alley. And she faced the wrong way so I put this mirror up on the
wall so she could see the reflection of the window in the mirror, so it was kind of like seeing out. Ah, I had a bird feeder put on her window.

Failure to Provide Preservative Caregiving

Family members spontaneously described instances of failure to provide preservative caregiving as defined by Bowers (1988). Participant 06 described this expertly:

Some of the people at the nursing home, I'm thinking primarily of the nurses' aides or LPNs. I don't know if they do nurses' aides anymore. Just seemed pretty stressed and over worked. I mean, they did the job, they did it well. But it was just like I am when I pour water in the dog's bowl. I mean, it's just a task I am doing. I think that those residents would do better with more caring, perhaps.

Participant 03 stated:

But, the nursing home, there just isn't, there wasn't time to spend with her. They don't, they just rush from patient to patient. They're barely able to feed them all, I think, from what I could see. And it's such hard work, you know, it's emotionally and physically hard. I, I couldn't really complain. On the other hand, it didn't fulfill the needs Mom had. So - and the ones that stayed here, all did their jobs were, um, all did their jobs. But, like I said, some of them were just putting in their time.

Participant 08 also described the work of monitoring the quality of caregiving as described by Bowers (1988):

Yeah, a lot of times I would go in maybe to check to see how he was being cared-in other words, I would just show up at an off-time. Because I feel that the more you're there, the better the care is that they get. If [you] can call it better.

Additional Analysis for Sense of Hope

As dying becomes more of a reality, hope may be expressed in different ways. Feeling uncomfortable with the findings of so few elements of a sense of hope in accordance with
Bowers' (1988) model that were described by the participants in this study, an additional literature search was conducted in an attempt to clarify different aspects of the concept of hope. Herth (1993) conducted a study to explore the meaning of hope in older adults. She identified strategies that were used by elderly individuals to foster hope and factors that impeded hope. She distinguished eight hope-fostering strategies that are unidimensional, but not mutually exclusive.

Hope-fostering Categories

The hope-fostering categories identified by Herth (1993) were (a) interconnectedness with self/others/world (b) purposeful activities, (c) uplifting memories, (d) cognitive strategies, (e) hope objects, (f) refocused time, (g) lightheartedness, and (h) spiritual beliefs/practices. Examples of these categories emerged from the data in this study.

**Interconnectedness.** Interconnectedness was defined as a perceived meaningful link with self and others, (family, friends, professional caregivers, pets) nature, and/or the world (people of other lands) (Herth, 1993, p. 148). Hope fostering strategies identified in this study that were used to maintain interconnectedness included interaction with family members, visits from relatives, friends or church members, visits from a pet, interacting with nursing home staff, receiving cards, letters, and gifts, viewing nature, and staying connected to the larger world through television, newspaper, or radio.

An example of interconnectedness with a family pet was illustrated by Participant 25 who relayed that her mother would not or could not feed herself. However, when the
daughter brought the mother’s dog for a visit the mother was able to perform an activity that the daughter had thought the mother would be incapable of:

I don’t know why she couldn’t feed herself. I’d bring her dog to see her and she picked up the dog.

Participants 41 discussed their father’s desire for nature:

*And he* He liked to watch the squirrels. He liked to have some flowers to look at and preferably something to watch it grow.

The brother and sister went on to describe an incident involving squirrels and their father’s connectedness to a particular staff member:

I’m thinking particularly of Sam, that young attendant, that would, you know, make sure that he got to watch the Braves game, make sure his TV was on and would do little respectful things. Actually, he cut the screen, so that he could try to entice the squirrels to come into the room. *And wouldn’t you know that the one screen that they cut, he cut, was some high tech electronic screen that sent alarms off. And he got in BIG trouble for cutting that screen. And Dad wouldn’t tell.* Yeah, they came down to ask Dad. *They asked Dad who did it.* “I don’t know, maybe I did it.” *He wouldn’t rat (laugh) he wasn’t going to rat on him.*

**Purposeful Activities.** Purposeful activity was described by Herth (1993) as “both passive and active activities that were ‘other focused’ and provided meaning and purpose” (p. 149) or for those that were functionally impaired, this also meant listening to others and sharing inner resources. Participants 06 reported activities that were provided at the nursing home:

I mean they do lots of nice things there, I think. They, oh, there would be a little group to come in and do little dance programs. And then they would have a sing along. And they had somebody who came by and did popcorn every week. And they had an ice cream cart. So, there were lots of things going on.
Participant 08 discussed an activity that her father participated in:

And he liked to play a ball game where they would take one of these big air filled, like a rubber balloon and bat it. And he would bat that around and hit it. He seemed to enjoy doing that. Um, but a lot of times he just sat in his chair in his room, or down by, they have a bird cage down by the Nursing Home D.

She also said:

Plus, they would, ah, a gal would read the newspaper in the mornings or get magazines that were current and talk about [them] and he seemed a few times to enjoy that. One time, she said, he did interact a little bit with a few things, but she said most of the times he didn’t.

Uplifting Memories. Uplifting memories included past memories of positive times (Herth, 1993). This strategy was used by the caregivers as well as the care receivers. In addition, personal reflection on past memories of difficult times and remembering that the person had made it through those times gave them conviction that they could make it through the present difficulties. Uplifting memories were described by participant 20 who said:

Jim would come up and spend quite a bit of time with him just talking over old times and, and kidding with him.

Participant 24 talked about his Uncle:

Long term, ah, he could remember a lot of the things, you know, earlier, you know, and, you know, when he was a kid and growing up and cowboying and stuff like that. He could remember that. And he could remember his sisters, you know, and he would often, you know, tell me stories about them.

Cognitive Strategies. Cognitive strategies were defined as “thought processes used consciously to transform perceptions into a positive frame” (Herth, 1993, p. 149).

Examples included positive self-talk, using comparative optimizing (tomorrow will be
better), and envisioning hopeful images. Cognitive strategies were frequently used by both caregivers and care receivers. The most frequently reported cognitive strategy was maintaining a positive attitude. This was described by participant 03:

I guess, to be as positive as I could. And that got to be kind of hard. But, just be cheerful.

Participant 09 said his strategy was:

Just to be on the happy side, you know, cracking jokes, laughing a lot. Al, he loves to tell jokes, and we always like to laugh at them, you know.

Participant 09 described an instance of his mother’s use of positive self-talk:

I was sitting in back of her bed, and she woke up; she didn’t know I was there, and she was saying, oh, I mustn’t give up, I mustn’t give up. (laugh). That was my mother! She was Irish. She didn’t believe in giving up.

Participant 19 said this about her mother’s positive outlook:

She must have had, I never could figure out what was going on in her head that kept her going so well. I wish I could have dissected her brain or something, you know. I would see the exterior and she never dwelled on the negative, which, bad news, you know, when you hear bad news from the doctor, I’d be driving her home or out to lunch. It was as if it wasn’t touching her. It was, I don’t know what her mental processes were. But I think there must have been something positive there that kept her ... I’m convinced a person’s mind, you know, has a lot to do with attitude.

**Hope Objects.** Hope objects were described as inanimate objects that have a significant positive meaning to a person beyond the concrete (Herth, 1993). Examples included handmade gifts, art work and music. Participant 25 described this concept exceptionally well:

Or let’s see, my grandson, I think he was 17, 16 at the time, 17, um he brought her a stuffed animal that she really liked. And of course, there was, ah, oh I don’t know pictures, or some flowers or just, you know, small things. Something that she didn’t have to do anything with except look at.
Refocused Time. Refocused time was the passage of time linked to anticipated, planned, or completed activities with others. Time was not measured by clock hours, minutes, days, months, or years (Herth, 1993). Examples included a family reunion or seasonal changes in nature. No data emerged from this study that was related to this category.

Spiritual Beliefs and Practices. Another cognitive strategy was facilitating an environment and resources to express spiritual beliefs and practices (Herth, 1993). Examples included reading the bible or inspirational books, praying, listening to spiritual music, or attending church. Participant 08 said:

And they had, they did have, one thing I really appreciated when they did have the one lady working there with activities, is they did have devotions a lot in the mornings. And I also had a Walkman for my dad because he liked to listen to Bible stories. So she would put that on him but then when she quit, because they worked her to death, nobody would do that for him. Um, but they did have devotions a lot of times different mornings of the week so they would make sure, they did make sure Dad would get to those.

She also said

I think the best thing that was said and that really helped me the most was people, especially from the church and my brothers and sisters are all Christians and everything was, we’ll see him again. This is not the end. This is the beginning. We will get to see him again. And that really meant a lot. There’s a hope. It isn’t just—that final you die and that’s it. That isn’t the way it is. To me there’s a hope.

Participant 03 described an event that included connectedness and spiritual beliefs:

Mom prayed all the time. She got the nurses to pray with her, too. There was one nurse that really told me that Mom really changed her life. Mom was ready to go. She knew the Lord and she was really ready. So, I didn’t feel like-I felt it was a great gain for her and I want it to be that way for myself too. And that way I feel real peaceful about that.
Lightheartedness. Lightheartedness was defined as “a sense of delight and playfulness of the inner spirit” (Herth, 1993, p. 150). Strategies included the use of humor.

Participants 41 said:

Dad’s doctor was really good. I mean, he had, he and Dad had a really good relationship. I mean, and Dr. Jones listened to Dad and he talked to him. What was that? What he was asking Dad that he was doing these days, for entertainment. And Dad says, “Oh, just reading magazines and doing crosswords and”- He says, “Well, so Henry, what are you reading, Playboy?” (laugh) and my dad kind of looked at me out of the corner of his eye, got this big grin, said, “No, just the pictures.”

Participant 09 and his brother also used humor during visits to their mother:

And we’d crack jokes and laugh. She liked that, you know. I think we were the hit of the rest home for a while. Al, he loves to tell jokes, and we always like to laugh at them, you know.

Hindrances to Hope

Herth (1993) defined hindrances to hope as “those factors that interfere or inhibit the possibility of attaining or maintaining hope” (p. 146). Hindrances to hope may be more frequent in a nursing home patient population, nearing the end of the life span. She identified four categories of factors that interfere or inhibit attaining hope or maintaining it. The categories were (a) hopelessness in others, (b) depleted energy, (c) uncontrollable pain and suffering in self/others/world, and (d) impaired cognition. Examples of these four categories emerged from the data.

Hopelessness in Others. Hopelessness in others was described as “catching” and included disheartenment and discouragement in others (Herth, 1993, p. 147). Others included loved ones, friends, and health care professionals. Examples included
expressions on health care professionals’ faces or a roommate giving up hope.

Many family members gave an indication of loss of hope upon admitting a relative to a nursing home as this was viewed as a last resort. Participant 33 said this:

I guess I felt that it was a blessing for him [to die] because his quality of life was nothing toward, you know, once they’re institutionalized, what’s there left for them? They’ve lost control of their life, their belongings, everything because he wasn’t able to ever come back. Once he went out of the house, that was the end.

Participant 08 reported a similar attitude expressed through the actions of others:

I don’t know how to put this. I won’t say I’m upset or anything. But I cannot understand, when something like this happens to a person they [friends] act like, well, they’ve lost it all and they’re there, they wouldn’t know who I am anyway and they’re not going to bother with them anymore. And it’s like, when they go into a nursing home, it’s like, for all practical purposes they lose everything, including their friends. I says, that’s a wrong attitude. And it is, it’s a very wrong attitude. Because if you’re their friend, shouldn’t friendship go beyond the door of a nursing home? At least I think it should.

Other caregiver participants described loss of hope when the institutionalized family member was diagnosed with a terminal illness, experienced a deterioration of health in which there were no visible gains, or had suffered a permanent disability. Participant 21 talked about his mother’s cancer:

I had went over to see her and her belly was all bloated. And I asked them over there what was going on and they went and checked her out real good and they said to get her over to the hospital. But a few days later it didn’t get any better. So I requested that she go back to the hospital and have a better look at what was going on and found some liver cancer. And at that time I figured it was, there was really nothing they could do anymore. I mean. They could make her comfortable, but that was it.

Participant 37 had this to say about his mother’s disability:

When she first went after the big stroke, she would come out and know people and then she wouldn’t know ‘em and-I don’t know if she knew me or not. At that point it didn’t matter whether she knew me or not. I’d hardened myself to the fact that-and even so far as to say that I had hopes that she would die if she wasn’t going to be any
better. I knew she wouldn't want to lay around not being able to move or talk or anything else.

**Depleted Energy.** Depleted energy was characterized by a perceived loss of physical vitality and endurance. High fatigue was identified as decreasing hope (Herth, 1993).

Findings by Owen (1989) and Herth (1990) indicate that energy is required in order to hope.

Participant 21 discussed his concerns about his mother's depleted energy level:

[She was] very tired. Very tired. [It was handled] with concern because she was always so energetic and lively and, you know, she always wanted to do things for people and she just was one of those persons that if you walked into the house, you didn’t leave without having a cup of coffee or something, you know.

**Uncontrollable Pain and Suffering.** Pain and suffering occurs in everyone’s life, but when it is unmanageable, despite all interventions, hope is threatened. This concern extends beyond the self to include suffering that has occurred in others and in the world (Herth, 1993).

Participant 19's mother experienced great pain and suffering prior to her death. She said:

At the end she died in great pain. You couldn't touch her anywhere. I couldn't hold her hand even because she was too, her whole body must have been in pain. And if somebody touched her or helped roll her over or something. So she died in great pain. And I couldn't do a darn thing about it. The last night when she died that whole scenario of just there was nobody there to help me. Ya. I'm saying help me. When I finish that statement is help me to help her. I guess I haven't verbalized that but my frustration was to eliminate some of her pain and if we could have, there's nothing wrong to have upped her pain dosage. When somebody is dying they can have more. It's just humane. And that's what I wanted for her is to put her out of her pain and just to give her some pain pills that would cover the pain and let her go peacefully. She was
hurting. And I would have liked to have seen less struggle. And I think it could have been done.

Participant 03 talked about her mother’s pain issue:

She had a lot of back pain before she even had the stroke. And that was way harder for me. Because that was something that was just excruciating and I couldn’t do anything to help it, and nothing, nothing helped it. So, that was worse.

**Impaired Cognition.** An awareness of and overwhelming fear of increasing forgetfulness diminishes hope, although with aging, loss of memory (impaired cognition) is a very real possibility (Herth, 1993). Participant 03 described her mother’s fears perfectly:

And mom’s mind was good, in general. Most of the people there, their minds were, weren’t so good. And mom felt like it was only a matter of time ‘til she’d be like they were. And, I just, I guess I wish that they could really make a point of keeping all the ones whose minds are good, together, instead of mixing them like they do. Because it is so depressing for a person who realizes what’s going on. I think that was the major part of, she felt like we thought that she was like all of the rest of those people.

**Characteristics of the Caregivers**

Prior research on caregiving focused on different factors such as gender, familial relationship to the relative and the relative’s functional status. The majority of caregivers in the United States are women. However the participants in this study appear to be part of the trend of changing roles of males in society that are consistent with the literature findings. There were nine female and nine male caregivers in this study, for a total of eighteen participants. Six female caregivers and six male caregivers reported that they were the only primary caregiver. Three female/male caregiver pairs provided caregiving together (refer to Table 1 in Appendix B).
Stoller (1990) reported that men and women’s roles were based on gender-based division of labor and Miller and Cafasso (1992) found that women provide most of the day-to-day, personal, and hands-on care. In this study, after institutionalization, 67% of the caregivers did not perform personal care tasks. The majority of the caregivers expected the nursing home staff to perform the tasks of providing personal care. This was congruent with Bowers’ findings. Many caregiver participants in this study who did provide personal care tasks did so to cover the gaps in care that the nursing homes did not provide. This was usually associated with a lack of adequate staff. Of those caregivers who did participate with personal care tasks, 44% were female and 22% were male.

In this study gender-based division of labor was compared using three different tasks. The first task was the performance of personal care such as changing clothing, brushing teeth, toileting, changing linens or bringing a change of clothing. Personal care in the nursing home was performed by six of the care providers (33%). The number of females that participated were four out of nine (44%). The number of males were two out of nine (22%). The remaining twelve caregiver participants (67%) did not perform personal care for the care recipient during institutionalization.

The second task was assisting the care recipient with eating. Four of the care recipients did not require assistance with eating. All of the remaining care recipients that needed assistance with eating were helped by family members. All of the female and male caregiver participants performed this task and there was no gender difference related to this task.
The third task was handling the care recipient's finances. Eight out of nine female caregivers participated in handling the finances. Seven out of nine male caregivers were responsible for the care recipient’s finances. Thus, there were no significant gender differences in handling finances.
CHAPTER FIVE

DISCUSSION

This chapter contains a discussion of the findings about Bowers’ family caregiving model and an expansion of that model. Characteristics of caregivers are discussed; the chapter ends with study limitations and nursing implications.

Bowers’ Model of Family Caregiving

The original use of Bowers’ family caregiving model (1988) was to elicit data about how quality of care was perceived and maintained by family caregivers of elderly relatives who were institutionalized. Four categories of preservative caregiving were identified (a) maintaining family connectedness, (b) maintaining the relative’s sense of dignity, (c) maintaining the relative’s sense of hope (of recovery) and maintaining the relative’s sense of self and control of environment. There is evidence from the findings/results of this study that are consistent with findings from Bowers’ family theory of caregiving. The application of this model seemed particularly suited to the population of care recipients in this study who were all toward the end of the life span. Thus, the model may be applicable to other types of residential populations.

New dimensions of the categories were discovered in analyzing the data that add depth to the categories and reveal the complicity of social relationships in the provision of caregiving. A new diagram is envisioned that expands Bowers’ theory. The theory has been renamed to encompass the specific population of end-of-life care recipients. The
The category of family connectedness has been expanded. The category of maintaining sense of hope (of recovery) has been renamed "maintaining sense of hope" and the category has been expanded (see Appendix C for illustration of Figure 2 and descriptions of categories). The new model is conceptualized in Figure 2:

![Diagram](attachment:Figure_2.png)

Figure 2

An important feature of the care recipients in this study is that they were at the end of their life span. This new model is particularly suited to this population thereby providing an expanded model of quality of care.

Additional changes were related to the categories of care. Bowers' category of family connectedness was expanded to include the use of touch, eating, and bringing a favorite
food. The category of maintaining hope was expanded because hope is conceptualized differently when care recipients are at the end of their life span. Herth's (1993) model of hope was incorporated into this category. It includes hope-sustaining strategies and hope-inhibiting factors.

**Family Connectedness**

Evidence of maintaining family connectedness as defined by Bowers was found in all of the transcripts. Bowers' category of connectedness focused on the context of the relationship between the family caregiver and care receiver in the provision of caregiving. Family members engaged in strategies to preserve their older relative's self through connectedness with the family. This was maintained through activities such as family visiting, taking the resident on a day trip or placing memorabilia in their room (Bowers, 1988).

Family connectedness was redefined based on emergent data from this study. The new findings suggest an added depth to the activity of maintaining family connectedness. The addition of two categories of family connectedness expands the original framework.

The use of touch emerged from the data as a new concept related to family connectedness. Chang (2001) stated that Physical touch in caring promotes the exchange of positive affection between the caregiver and the care-recipient. Physical touch functions as a means to convey respect by care-giver to care-recipients, to channel positive feelings between people, and to create the feeling of comfort in interactive situations (p. 821).

Touch therefore also implies reciprocity in the caregiver-care-receiver relationship.
An additional finding that emerged from the results was that assisting a family member with eating was associated with maintenance of family connectedness. Bowers (1988) viewed eating as a process of maintaining dignity. However, in our society, food and eating have an important cultural and social significance. Eleven elderly family members were assisted with eating. The remaining four individuals were reportedly able to feed themselves up until their death, with the exception of one elderly family member who inadvertently received tube feeding at the end of life.

Finally, bringing a family member a special food that they liked also served to maintain family connectedness. According to Farb and Armelagos (1980 in Locher, Burgio, Yoels, & Ritchie, 1997, p. 25) sharing food with others is one of the most often used ways to initiate and develop relationships.

The category of maintaining family connectedness has been expanded to include all of the following: family visiting, taking the resident on a day trip, placing memorabilia in their room, assisting the resident to eat, bringing the resident a special food, and the use of touch.

Preserving Dignity

Maintaining dignity was difficult, with approximately two-thirds of the participants citing examples of indignity related to incontinence. There were more negative instances reported wherein dignity was not maintained than were positive instances. Their stories emphasize a common thread of lack of dignity directly related to lack of care by staff. The data regarding undignified situations was elicited spontaneously throughout the course of
the interviews. Since there were no questions specifically addressing dignity or lack of dignity, it is possible that a bias was introduced regarding the topic of dignity. Participants may have focused on reporting the negative aspects of the consequences of institutionalization in relation to the amount of caregiver role strain experienced. However, their stories revealed an appalling lack of care and supervision that is consistent with reports of poor quality of care received in nursing homes.

Family caregivers appeared powerless in many situations to maintain dignity, through inaction, passivity or factors related to the lack of staff provided by the institution. Some participants appeared to identify with the nurse’s aides because they had experienced the difficulty of performing the tasks of caregiving and felt that the staff members were doing the best that they could. Therefore, they tolerated substandard care for their elderly relative and did not intervene in the situation. Amela (1999, p. 884) discussed the concept of power among nursing assistants in a nursing home. She noted that even though nursing assistants are in a position of the least power in an institution, they have a great deal of power over the residents.

Participants voiced the need for an improvement in caregiving at the nursing home facilities. Some participants even hired private duty nurses to help provide care in the facilities. However, this was not a long-term solution and it was costly. The most common complaints were lack of adequate number of staff and uncaring staff. Concerns about lack of registered nurses and adequate training of nurses’ aides were also voiced.

Some participants felt that their relative may have received substandard care because they were Medicaid recipients. However, they were unable to validate that concern.
Harrington, et al. (2000) conducted a study to identify deficiencies in nursing home care. The data reporting system for all U.S. certified nursing homes was examined. They reported that fewer registered nurse hours and nursing assistant hours per resident per day were associated with total deficiencies and quality of care deficiencies in nursing homes. They also reported that facilities with a higher percentage of Medicaid residents had more deficiencies. Therefore, family participants in this study may not be far off the mark with their observations.

**Sense of Hope**

The findings were consistent with Bowers' (1988) theory of maintaining a sense of hope (of recovery) but were present in few of the interviews. Bowers narrowly defined maintaining a sense of hope (of recovery) in relation to the elderly resident receiving rehabilitation. She reported that families in her study often felt that a formal rehabilitation program was crucial to maintaining the residents' hopes. For institutionalized family members who may be near the end of life, hope may be conceptualized differently.

Additional analysis was conducted using Herth’s (1993) research on hope in elderly persons. It extended the category of maintaining a sense of hope which does not necessarily include a hope for recovery in the population of individuals who are at the end of life. Herth used Brim’s lifespan development to explain how elderly people cope with increasing age, limits on what they can accomplish and multiple losses by altering their expectations in order to maintain a sense of worth and competency, either by their own personal standards or by social standards.
Much of the research prior to Herth’s (1993) study had been based on empirical studies with youth and middle-aged adults. Hope in younger people is characterized by expectation of future achievements, maintaining personal control, and attaining goals (Stanley, 1978; Potish & Axen, 1984; Owen, 1989 as cited in Herth, 1993). Farran, Salloway, and Clark (1990) have suggested that older people may experience an accumulation of losses, multiple health problems, and a decreasing ability to care for themselves. Thus, older people may need to rely on other means of maintaining or regaining hope than younger people. However, Roberts (1976 as cited in Herth, 1993) asserted that maintaining hope is not dependent on the necessity to regain impaired function or to be whole again.

Hope was synthesized in Herth’s (1993) study as “an inner power that facilitates the transcendence of the present situation and enables a reality based expectation of a brighter tomorrow for self and/or others” (p. 146). Hope has also been described in the literature as a “powerful human response that positively influences adaptive coping during times of suffering, loss, and uncertainty” (Hinds & Martin, 1988; McGee, 1984; Rideout & Montemuro, 1986; Stephenson, 1991 as cited in Herth, 1993, p. 139). A loss of hope and narrowing of expectations and goals in life is thought to reduce the quality of life for individuals (Haase, Britt, Coward, Leidy, & Penn, 1992; Stoner & Keampfer, 1985; as cited in Herth, 1993, p. 139).

Herth (1993, p. 141) used the framework of Brim’s lifespan development to study the concept of hope in elderly individuals. Brim posited that human beings’ needs and circumstances vary throughout life and that people have a great capacity to change and
Lifespan development theory tries to predict, explain, and optimize changes in behavioral responses as a consequence of life events as they occur over an extended period of time. Brim proposed that as increasing age limits what people can accomplish and losses multiply, expectations are altered to maintain a sense of worth and competency either by personal or social standards.

The ages of the participants in Hertl’s (1993) study ranged from 60 to 100 years old. Individuals resided in either a private home, senior citizen housing or a long-term care facility. All of the participants, regardless of age, that lived in a long-term care facility who had poor health and moderate to severe impairment in functional ability described their hopes as focused primarily on friends and care providers in the immediate future. Hopes for self often were described as focused on a “life in the hereafter.”

Hertl’s (1993) findings indicated that two variables were found to influence hope (a) place of residence and (b) level of energy. Residents of long-term care facilities and/or those individuals experiencing severe fatigue had significantly lower levels of hope than those people who lived in their own home or in senior citizen housing and/or who had high energy to moderate fatigue levels (1993).

The hope-fostering categories identified by Hertl (1993) were (a) interconnectedness with self/others/world (b) purposeful activities, (c) uplifting memories, (d) cognitive strategies, (e) hope objects, (f) refocused time, (g) lightheartedness, and (h) spiritual beliefs/practices. Examples of these categories emerged from the data in this study. Hope-fostering strategies were characterized as those resources that functioned to instill, maintain, or renew hope by facilitating the process of hope in some way (Hertl, 1990).
In Herth’s (1993) study several hope-fostering strategies were used by each participant, suggesting that hope in older adults is maintained through multiple methods. The most frequent means of maintaining hope in Herth’s study were family, friends, health-care professionals and God or a “higher being.”

Seven of the eight categories of hope-fostering strategies were evident in the conversations of this study’s participants. The most frequently used strategies cited by caregivers were interconnectedness, cognitive strategies, and spiritual beliefs/practices. No instances of refocused time were elicited from the data.

Interconnectedness as a hope-fostering strategy is not associated with Bowers’ category of family connectedness which focused on the relationship between the family caregiver and care receiver in the provision of family caregiving.

Herth (1993) also identified four categories of hope-impeding factors. Hindrances to hope were identified as those factors that interfere or inhibit attaining hope or maintaining it. Herth’s definition of hindrances to hope was “those factors that interfere or inhibit the possibility of attaining or maintaining hope” (p. 146). Four categories of factors that interfere or inhibit attaining hope or maintaining it were identified as follows (a) hopelessness in others, (b) depleted energy, (c) uncontrollable pain and suffering in self/others/world, and (d) impaired cognition. Examples of these four categories emerged from the data. However, Herth’s examples of hopelessness in others (expressions on health care professionals’ faces or a roommate giving up hope) were described differently in this study by the caregivers. The examples of hopelessness emerging from this study did however, meet the criteria of the definition of hindrances to hope. Additional
examples from this study that described hopelessness in others were (a) admitting an elderly relative to a nursing home (viewed as the last resort), (b) dementia such as Alzheimer's, (c) incurable illness, (d) decreased services such as physical therapy or occupational therapy, and (e) powerlessness to improve care in relation to the nursing home organization and staff.

Control of Self and Environment

Maintaining a sense of self and control of the environment was present in few of the interviews in this study. No conflicts or problems related to when the relative was visited at the nursing home were reported. The low incidence of findings in this study may be a result of the lack of questions that focused on obtaining this information in the interviews. The data obtained were spontaneously elicited from the interview participants.

Failure to Provide Preservative Caregiving

The reports in this study about the lack of preservative caregiving may illustrate the lack of communication between caregivers and nursing home staff and administration. Another reason for lack of preservative caregiving may be low job satisfaction for nursing home staff. In addition, professional caregiver burnout is frequent which may also lead to lack of preservative caregiving. High staff turnover and lack of adequate training also may lead to substandard care.

The lack of adequate staffing was a major concern of participants. Participants noted that a lack of staff contributed toward poor quality care. In addition, participant expectations for care were most likely based on the type of care that they had been able to
provide in the community setting and which were unattainable in the nursing home.

**Characteristics of Caregivers**

There were the same number of female and male caregivers in this study, with most of the care recipients being women. This may represent a trend of more participation of males in caregiving. However, it may also be a result of less formalized gender roles as one ages.

Gender did not influence the function of assisting with eating, as this was performed by all caregivers when the care recipient required assistance. Male caregivers assisted male care receivers to eat. This may have been a way for them to show family connectedness within culturally defined values of behavior of males toward another male.

No significant gender differences were found in handling finances. Females and males participated almost equally in this task. Findings from previous research indicate that males are more likely to handle finances than females. However, the findings from this study may be related to the fact that there were equal numbers of male and female caregivers.

**Study Limitations**

The application of secondary analysis has two limitations. First, there was a lack of control in generating the data set for the secondary study. Secondly, there was the inability to follow strictly the guidelines of the chosen data analysis method (Szabo & Strang, 1997). In other words, this study was not conducted to elicit information about preservative caregiving. Rather, data was gathered from unsolicited information that was
gained in the course of the interviews. In addition, the information gathered from the larger study was from caregivers whose relative had been deceased for approximately two years. Therefore, recall bias is a problem as well as the participants' change of attitude or feelings over time. Attitudes are not constant but are fluid and evolving in relation to social and historical contexts. An additional bias may have been introduced due to the fact that the care receivers were already deceased.

The participants represented a homogenous sample of the white population. The results of the data analyses were specific to this study and may not be generalizable. However, data obtained from the 1996 Medical Expenditure Panel Survey (MEPS) (Krauss & Altman, 1996) and the 1997 National Nursing Home Survey (NAC-AARP, 1997) indicated that nursing home residents are predominantly white.

It is possible that the participants may not have represented a typical population. They were extremely vested caregivers who viewed nursing home placement as a last resort. The care recipients in this study were a unique population who were placed in nursing a home with a serious illness. However, Bowers' theory of family caregiving may be generalizable to other nursing home populations.

The over-representation of male caregivers was unexpected and may have affected the results, but gender did not appear to influence involvement in care. It may be speculated that the interaction of male participants with a female interviewer could have produced different interview results than if the interviewer had been a male.
Nursing Implications

Bowers' theory of family caregiving provided a model to explore the change in responsibilities of caregivers once the care receiver is institutionalized. The model was found to be a valid and useful model for family members with institutionalized family members who are near the end of life. However, a comprehensive model of quality care should include the caregiver, the care receiver, the staff providing care as well as the institution itself.

Institutionalization

Institutions have been associated with poor quality of care and have been the focus of public rhetoric for some time. This has served the purpose of maintaining the status quo of men's position in society. The provision of caregiving in the home has been provided by women at low or no financial cost, but the female caregivers often pay a heavy price through loss of health and economic wealth. Americans live in a rapidly changing society. New demographic trends, social and public policies, economics, concern about rising health care costs and the status of women have all contributed to the devaluation of elderly citizens who are considered a burden on society, and are therefore victims of ageism. Institutionalized care is embedded in the concept of ethics. The rights of the elderly who live in an institution have been delegated to those providing informal care and professional care. Residents, especially toward the end of life, may not have a voice in decisions regarding their health and welfare. Therefore, it is the responsibility of the institution and family members to ensure that residents receive quality care and
experience a meaningful quality of life.

Institutional policies and procedures that facilitate communication and expectations between family and staff members may increase the provision of better care. Restructuring the organizational power horizontally and empowering nurses' aides may increase job satisfaction and in turn result in better care. However, the general working conditions and compensation are inadequate, revealing the low value placed on elder care and women in society. The care of nursing home residents is labor-intensive. There is a high risk for physical injury when lifting, changing, turning, or assisting a resident with mobility. In addition, staff may be exposed to communicable diseases such as tuberculosis. There is also the possibility of injury from patients with cognitive deficits. Much of the physical care related to lifting, turning, transferring and bathing is more suitable to men, who are larger and stronger than women. However, few male aides are found in nursing home facilities.

The working hours and shifts of professional caregivers may vary, which create an additional burden, especially for women who are single parents with children. Members of the staff are required to work evening, night and weekend shifts to provide care to residents.

Nurses' aides, who provide most of the care in a nursing home, have limited opportunities for advancement. The 1999 Occupational Employment Statistics report issued by the Montana Department of Labor and Industry revealed a mean wage of $7.75 per hour for nurses' aides, as apposed to a mean wage of $8.59 per hour for the United States. The minimum wage of $8.20 per hour meets the federal poverty level. The
Northwest Job Gap Study (Northwest Policy Center, Northwest Federation of Community Organizations, and Montana's People's Action; 2001) reported statistics for living-wage jobs in Montana. A living wage is a wage that allows families to meet their basic needs without using public assistance. In addition, there must be some ability to deal with emergencies and plan ahead. The minimum living wage for a single person living in Montana in 2000 was reported to be $9.90 per hour. For a single person with two children the minimum living wage was $16.24.

The consequences for residents living in nursing homes can be high. The lack of adequate staffing leads to neglect, incontinence, falls, pressure sores, inadequate nutritional intake and abuse of elderly residents. Caregivers do not have time to develop a personal relationship with care recipients or family members when they are rushing from patient to patient. This leads to strained relationships between families, the staff providing care, and the organizations' administrative staffs.

**Implications for Long Term Care.** Several trends are occurring in long-term care. First, more federal funding is being funneled toward nursing home care than in the past. Secondly, many institutions are practicing a business concept directed toward consumer-directed and consumer-centered care. Kane (2001) cited a report by the Institute of Medicine issued in 2001 on long-term care quality (Wunderlich & Kohler, 2001) that stated that a consumer-centered approach would

necessitate a fundamental shift in the approach to determining and evaluating the quality [including] going beyond health and safety outcomes to include outcomes such as quality of life and autonomy (p. 31).
A separate statement issued by seven of the 17 committee members stated that “quality of life, as perceived by the long-term care consumer (or, when appropriate, his or her agent) is an essential part of the quality of long term care” (Kane, 2001 p. 299).

Kane (2001) stated that consumer-centered care was considered a controversial approach by the medical community. She emphasized that this is an illustration of the extent to which paternalism governs long-term care policies and practices for the elderly population (p. 300).

As the population of the United States ages, fewer workers will be available to care for the elderly. At the same time, there will be an increased demand for long term care, increasing the challenge to provide quality care. The short term concern of many, including policy makers is the shortage of workers. Some of the ideas to create an increased work force of nurse’s aides include (a) offering certified nurse’s aide certification courses in high school and (b) encouraging or requiring baccalaureate nursing students in their junior year of college to work at nursing home facilities as nurses’ aides. However, these measures are temporary and will not increase the quality of care alone. Kane (2001) states that the problems of long term care are lack of quality, access to care, and high cost. She recommended other solutions to resolve the issue of quality of care. They included experimenting with new ways to organize care and services and the creation of rewarding jobs (p. 297).

Nurse practitioners can help bridge the gap in care through providing high-quality, cost-effective care. Nursing homes can be improved through the inclusion of nurse practitioners on their staff. Nurse practitioners provide holistic, patient-centered
innovative care that is responsive to individual, organizational and community needs. Nurse-managed long term care has been successful since the late 1980's. Academic nurse-managed long term care facilities provide opportunities for faculty research and practice, and clinical sites for student nurse education. However, rules and regulations related to the scope of practice may be a barrier for nurse practitioners in some states, thereby decreasing the potential contribution of care by nurse practitioners.

Implications for Policy Considerations. Public and social policies should be examined that affect the quality of caregiving. Health care policies are a reflection of societal values. Some issues that need to be addressed include (a) the devaluation of women and the elderly (ageism and sexism); (b) inequitable distribution of medical and health care resources (ageism), (c) lack of receiving a living wage, (d) lower retirement benefits because of interruptions in employment due to reproduction (child rearing) and elder caregiving and (e) women being paid lower wages than men, even to perform the same work.

Health care providers such nurse practitioners are in a prominent position to lead the way for policy change. Nurse practitioners typically assume a peripheral role in social, economic, and political affairs. As a group, nurse practitioners should work toward forming alliances with consumer groups such as those that represent women and the elderly and address their concerns through social and political action. Individual contact with local and state politicians to educate them about the issues and gain their support is one way of being politically active. Another example is becoming a member of a
professional organization such as the American Nurse’s Association involved and active in health care issues. Nurse practitioners should participate in local or state politics to address concerns such as sanitation, air and water pollution, or toxic materials in the environment, thereby improving the health of the community and in turn, the world.

The act of caregiving and who is responsible for the provision of caregiving is an especially salient issue for public and social policy in the face of an unprecedented aging population. Of particular importance in the quest for quality care is the low societal value placed on caregiving. Nurse practitioners are in a unique position to provide education and consultation, conduct research, and become active in groups to facilitate health care reform for long term care.

Chopoornian (1986) identified societal structures and institutions as the focus for nursing practitioners to bring about change or adaptation rather than focus on the individual patient. By identifying and acting upon the social, political, and economic conditions in society that produce the patient’s situation, nursing practitioners can assume an activist role in changing the conditions that cause or lead to health problems, such as heart disease, alcoholism, violence against women and elders, among others.

Conclusions

Bowers’ (1988) model of family caregiving was successfully applied in this study to a different care recipient population. This model for institutional caregiving does lend itself toward the end stage of life and appears to be more applicable to institutional residents at the end of their life. Future research should be directed toward using the expanded
renamed model to develop an instrument that is intended to measure quality of care at the end of life.

Quality of care in this model is closely tied to quality of life indicators identified by Kane (2001). She distinguished 11 domains of quality of life. They are (a) sense of safety, security and order, (b) physical comfort, (c) enjoyment, (d) meaningful activity, (e) relationships, (f) functional competence, (g) dignity, (h) privacy, (i) individuality, (j) autonomy/choice, and (k) spiritual well-being (pp. 297-299). She stated that there is enough evidence that the behavior of caregivers and the environment in which caregiving is delivered can influence the quality of life, either for the good or the worse.

Caregiving is a complex phenomenon which must be examined at different points in time and from different standpoints and methodologies to create a new vision for quality caregiving in an institutional setting. Future research on caregiving should focus on different cultural groups to increase nursing knowledge and understanding of the diverse nature of caregiving from the perspective of different racial or ethnic backgrounds. In addition, the provision of caregiving may be different in rural areas than urban areas. Caregiving provided by lesbian and gay couples and caregiving for specific patient populations such as those with AIDS should be included in research and added to the body of nursing knowledge.

Diversity exists within and among families. Each family has different resources and challenges to which they must respond (Coontz, 1997, p. 8). Examining the context of social, economic and political forces over time may assist families to depersonalize and defuse family conflicts. It may encourage constructive solutions for families at both the
social, personal, and political level. It may help families learn how to minimize their distinctive variabilities and build on their special strengths (Coontz, 1997, p. 9)
References Cited


Coontz, S. (1997). Getting past the sound bites: How history and sociology can help today’s families. The way we really are (pp. 11-32). New York: Basic.


APPENDICES
APPENDIX A

BOWERS' MODEL OF PRESERVATIVE CAREGIVING IN AN INSTITUTION
Bowers' Model of Preservative Caregiving In An Institution

There are four types of preservative caregiving aimed at maintaining the older person's self and preventing depression. The model illustrates that maintaining family connectedness is the primary responsibility of the family members. The other three types of caregiving require collaboration between nursing home staff and family members.

**Maintaining Family Connectedness**
Family members engage in strategies to preserve their older relative's self as connected to the family. This is their primary responsibility. Family connectedness is maintained through activities such as family visiting, taking the resident on a day trip or putting memorabilia in a resident’s room.

**Maintaining Dignity**
This caregiving refers to engaging in activities aimed at preserving the relative's sense of competency and personal uniqueness. It involves avoiding or preventing undignified or humiliating experiences, usually associated with a relative's messy personal appearance, release of intimate information to outsiders, loss of control of body function, a sense of being a burden to staff and family, and a lack of respect for individual differences.

**Maintaining Sense of Hope of Recovery**
Families feel that a formal rehabilitation program is crucial to maintaining the resident's hope. If rehabilitation is not an option, families try to protect their relative from full knowledge of their deficits.

**Maintaining Sense of Control of Self/Environment**
Strategies are aimed at increasing their relatives' control of self and the environment. Important issues identified include the nursing home’s schedule regarding when the resident is to get up or go to bed, when to move from one chair to another, when friends can visit, what to wear, and whether medications can be refused.
APPENDIX B

DESCRIPTION OF POPULATION
Table 1.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Relationship(s) to Family Member</th>
<th>Gender</th>
</tr>
</thead>
<tbody>
<tr>
<td>01</td>
<td>son</td>
<td>male</td>
</tr>
<tr>
<td>03</td>
<td>daughter</td>
<td>female</td>
</tr>
<tr>
<td>06</td>
<td>daughter</td>
<td>female</td>
</tr>
<tr>
<td>08</td>
<td>daughter</td>
<td>female</td>
</tr>
<tr>
<td>09</td>
<td>son</td>
<td>male</td>
</tr>
<tr>
<td>11</td>
<td>son</td>
<td>male</td>
</tr>
<tr>
<td>19</td>
<td>daughter</td>
<td>female</td>
</tr>
<tr>
<td>20</td>
<td>a. step-daughter</td>
<td>female</td>
</tr>
<tr>
<td></td>
<td>b. step-daughter’s husband</td>
<td>male</td>
</tr>
<tr>
<td>21</td>
<td>son</td>
<td>male</td>
</tr>
<tr>
<td>24</td>
<td>a. nephew</td>
<td>male</td>
</tr>
<tr>
<td></td>
<td>b. nephew’s wife</td>
<td>female</td>
</tr>
<tr>
<td>25</td>
<td>daughter</td>
<td>female</td>
</tr>
<tr>
<td>33</td>
<td>wife</td>
<td>female</td>
</tr>
<tr>
<td>37</td>
<td>son</td>
<td>male</td>
</tr>
<tr>
<td>39</td>
<td>son</td>
<td>male</td>
</tr>
<tr>
<td>41</td>
<td>a. daughter</td>
<td>female</td>
</tr>
<tr>
<td></td>
<td>b. son</td>
<td>male</td>
</tr>
</tbody>
</table>
APPENDIX C

PRESERVATIVE FAMILY CAREGIVING OF INSTITUTIONALIZED END-OF-LIFE CARE RECIPIENTS
Preservative Family Caregiving Of Institutionalized End-Of-Life Care Recipients

There are four types of preservative caregiving aimed at maintaining the older person's self and preventing depression. The model illustrates that maintaining family connectedness is the primary responsibility of the family members. The other three types of caregiving require collaboration between nursing home staff and family members.

Maintaining Family Connectedness
Family members engage in strategies to preserve their older relative's self as connected to the family. This is their primary responsibility. Family connectedness is maintained through activities such as family visiting, taking the resident on a day trip, putting memorabilia in a resident's room, the use of touch, bringing a favorite food, and assisting the relative with eating.

Maintaining Dignity
This caregiving refers to engaging in activities aimed at preserving the relative's sense of competency and personal uniqueness. It involves avoiding or preventing undignified or humiliating experiences, usually associated with a relative's messy personal appearance, release of intimate information to outsiders, loss of control of body function, a sense of being a burden to staff and family, and a lack of respect for individual differences.

Maintaining Sense of Hope
Families engage in strategies aimed at protecting the relative from full knowledge of their deficits; rehabilitative services (PT, OT) are used to increase or maintain functioning. Families and care recipients engage in hope fostering activities: maintaining perceived interconnectedness with self and others (family, friends, professional caregivers, pets), nature, and/or the world (people of other lands). Activities include interaction with family members, visits from relatives, friends or church members, visits from a pet, interacting with nursing home staff, receiving cards, letters and gifts, viewing nature, and staying connected to the larger world through television, newspaper or radio; engaging in purposeful activities, either passive or active, that are "other focused" and provide meaning and purpose. In the functionally impaired, this includes listening to others and sharing inner resources; using uplifting memories that include past memories of positive times and reflecting on past memories of difficult times which give the conviction that the person can make it through present difficulties; using cognitive strategies to promote a positive attitude such as positive self-talk, comparative optimizing (tomorrow will be better), and envisioning hopeful images; the use of hope objects, that have a significant positive meaning to a person beyond the concrete, such as hand-made gifts, art work, and music; engaging in the use of refocused time - the passage of time linked to anticipated, planned or completed activities with others, rather than measured by hours, minutes, days, months, or years; facilitating an environment and resources in which to express spiritual beliefs and practices such as reading the bible or inspirational books, praying, listening to spiritual music, or attending church; engaging in lightheartedness, including the use of humor.

Maintaining Sense of Control of Self/Environment
Strategies are aimed at increasing their relatives' control of self and the environment. Important issues identified include the nursing home's schedule regarding when the resident is to get up or go to bed; when to move from one chair to another; when friends can visit; what to wear; and whether medications can be refused.