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Daughters' decision-making about the nature and level of their participation in the long-term care of their dependent elderly parents: A qualitative study

McGrew, Kathryn B., Ph.D.
The Ohio State University, 1990
DAUGHTERS' DECISION MAKING ABOUT THE NATURE AND LEVEL OF THEIR PARTICIPATION IN THE LONG-TERM CARE OF THEIR DEPENDENT ELDERLY PARENTS: A QUALITATIVE STUDY

DISSertation

Presented in Partial Fulfillment of the Requirements for the Degree Doctor of Philosophy in the Graduate School of The Ohio State University

By

Kathryn B. McGrew, B.A., M.S.W.

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To my parents
Phyllis and John Blocher
ACKNOWLEDGMENTS

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VITA

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CHAPTER I
INTRODUCTION

Family decisions about the long-term care of the dependent elderly are made in a context of societal ambiguity about filial obligation toward dependent parents, reflected in tentative policies for the long-term care of older citizens. Family long-term care decisions are also made in a context of changing role expectations for women. Daughters of the elderly are often called "women in the middle" to reflect the conflicting obligations they confront: to self, to spouse and/or children, to work or other activities, and to parents. (Brody, 1981)

Recent policy initiatives in long-term care suggest an attempt to promote, through a system of incentives, in-home family care for the dependent elderly. (Doty 1986; Frankfather, 1981; Schorr, 1980) Related research indicates that such initiatives have developed out of a "myth of abandonment" or a sense that families don't care for their dependent elderly as they did in previous generations. (Brody, 1985; Shanas, 1979) A converse policy issue is the reluctance of government to channel Medicaid dollars to in-home care programs for fear that families already providing care without formal assistance or support will come "out of the woodwork" to seek compensation, thereby creating an overwhelming demand on public resources. Both perspectives appear based on undemonstrated assumptions about the dynamics of family decisions about care.
At the direct service level, gerontological social workers are confronted with the challenge of understanding and assisting in the decision-making process of women about the long-term care of their dependent parents. Gerontological and social work literature is filled with studies of daughters as caregivers, and numerous studies have contributed to our understanding of both the attitudes of daughters about caregiving and of their actual caregiving behaviors. Little is known, however, about the relation between attitudes and behaviors as it is manifested in the decision-making process.

As Elaine Brody wrote in 1985, "Some aspects of parent care are not well understood as yet... the inner processes of individuals and families when parent care becomes necessary, and the interaction of values with personal, situational and environmental factors in determining filial behavior." (p.22) "[V]irtually nothing is known about the processes by which different options are selected--processes which have profound implications for clinical approaches and social policy." (p.26) How do women decide the nature and level of their participation in parent care? It is the purpose of this study to explore this process.

DEFINITION OF TERMS

Dependent elderly

This project has as its focus decisions about the care of the functionally dependent elderly, defined by the Institute of Medicine (1977) as "those individuals over 65 whose illnesses, impairments, or social problems have become disabling, reducing their ability to carry out independently the customary activities of daily life." (p.1)
Long-term care

A distinction is made between care that is provided in the episodic case of acute illness or other short-term problem, and care that extends, or is expected to extend, over a period of time (six month minimum for this study) due to the chronicity of illness, impairment or social problem. While the definition of long-term care has historically implied institutional care, the meaning has broadened to include the "long-term management of illness and disability." (Atchley, 1988)

Caregiving/Caregiver

Cicirelli (1981) has identified sixteen types of services children may provide their parents: homemaking, housing (providing living quarters), home and yard maintenance, income, personal care (bathing, dressing, "moving about"), home health care (medical or health treatments or nursing care), transportation, social and recreational activities, psychological support, employment ("finding a job or a market for goods and services"), spiritual, bureaucratic mediation, reading materials, career education, enrichment (learning new hobbies, etc.), and protection ("guarding against crime or danger, checks on daily health and security"). (p.66)

From the broadest perspective, caregiving has been defined as the provision of any of these services at any level. From the narrowest (and more conventional) perspective, caregiving has been defined as the provision of the more intimate of these services, especially personal and home health care. Stephens and Christianson (1986) define the informal caregiver as one who assists with one or more of the following tasks:

1. Medical care:
   Physical, occupational or speech therapy
   Other medical treatments

2. Personal care:
   Eating
   Getting out of bed or a chair
Dressing  
Bathing  
Getting to or using the toilet  
Cleaning up after bowel or bladder accidents

3. Instrumental Activities of Daily Living (IADLs)  
Giving medicines or injections  
Meal preparation  
Housework, laundry, or shopping  
Chores (heavy housework or minor repairs)  
Transportation or escort  
Managing financial affairs

4. Supervision for personal safety (staying with the elderly person because he or she could not be left alone)

5. Arranging for benefits or services and dealing with providers

6. Minor errands  
(Stephens and Christianson, 1986, p. 35)

Caregiving is defined for this study as assisting with the performance of these tasks identified by Stephens and Christianson, and caregiver as one who gives this assistance.

Caregiver types

It is important to distinguish between both formal and informal caregivers and primary and secondary caregivers. This study has as its focus informal caregivers (individuals in an informal support system such as family) as opposed to formal caregivers (institutions, agencies, and/or professionals such as nursing homes, home health care agencies, meal and transportation services, private nurses). The 1982 National Long Term Care Survey/Informal Caregivers Survey divided informal caregivers into four types: 1) primary caregiver only, 2) primary caregiver with informal help, 3) primary caregiver with informal and formal help, and 4) secondary caregiver. This typology is used for this study.
Decision

Decision is broadly defined as a process or act of choosing between or among alternate courses of action. Further definition is made through the discussion of decision theory in the literature review.
CHAPTER II

REVIEW OF LITERATURE

Introduction

Daughters make decisions about both the nature and level of caregiving they will provide. Daughters decide not only whether they will provide care, but also what type of assistance they will provide, and the extent to which it will be provided. As levels of dependency increase, many daughters increase their level of participation in parent care. Indeed, some women have ultimately provided all types of care through every identified level.

This review of literature begins with a descriptive statistical profile of daughters as caregivers, followed by an exploration of the context of decision making from three perspectives: context as culture, context as demographic and social trends, and context as a field of alternatives. It then moves to a discussion of daughters' attitudes toward, and experiences with, caregiving. The review will conclude with an overview of decision theory, an argument for exploring daughters' caregiving decisions through a conflict model of decision making, and the proposal of a moral dimension to that conflict.

PROFILE

Much of the literature about caregiving suggests that parent care has become a normative family experience. Significant demographic and social changes have contributed to this phenomenon, particularly: 1) the dramatic increase in the very old
population, and 2) an increase in chronicity, or long-term illnesses. "[F]ew people reach the end of life without experiencing some period of dependency." (Brody, E. 1985:21) Data from the 1982 National Long-Term Care Survey were compiled to provide a profile of care recipients and caregivers. Estimates from these data support previous research findings that the majority of caregivers are female. This study determined that 72% are women, with adult daughters comprising 29%, and wives 23% of all caregivers. (Other female caregivers include daughters-in-law, sisters, granddaughters, other female relatives, and nonrelatives.)

A statistical breakdown provides a detailed profile of caregiving daughters. Of all daughters in this national survey (n=637,000), 23% were primary caregivers only, 36% were primary caregivers with informal help, 11% were primary caregivers with both formal and informal help and 30% were secondary caregivers. One fourth of these daughters were between the ages of 14 and 44, 63% between the ages of 45 and 64, 13% between 65 and 74, and one-half percent aged 75 or over. Seventy-eight percent of caregiving daughters were white and the remaining 22% were of other racial backgrounds.

The survey also determined that 61% of primary caregiving daughters lived with the disabled parent, while the remainder did not. Slightly more than one quarter of the caregiving daughters were identified as poor or near-poor, 57% low or middle income, and 4% as high income. Over half of the daughters were married, while 14% were widowed, 16% divorced or separated and 13% had never married. Finally, of all caregiving daughters, 24% were described as having excellent health, 44% with good health, and the remaining 32% having fair or poor health.

This survey also provides a helpful profile of competing demands among caregiving daughters. Seventy-six percent of caregiving daughters had no children

\[1\]All figures are rounded to the nearest one percent.
under age eighteen living in their households. Eleven percent had one child, 9% had two, and 4% had three or more children living in their households. Regarding employment status, the survey found that 44% of caregiving daughters were working, 12% had quit work to assume caregiving responsibilities, and 44% were not working for other reasons. Caregivers were reported as "conflicted caregivers" if they reported one or more of the following: worked fewer hours, rearranged schedule, took time off without pay. By this standard, 29% of daughters were identified as conflicted and 71% as non-conflicted. Among employed caregiving daughters, 23% worked fewer hours, 35% rearranged work schedules, and 25% took time off without pay in order to perform caregiving tasks.

Another study, an evaluation of the National Long-Term Care Demonstration\(^2\), provides a helpful profile of the types of care provided by primary caregiving daughters. Twenty-eight percent of primary caregiving daughters in this survey provided medical care, 80% provided personal care, virtually all assisted with Instrumental Activities of Daily Living (IADLs), and nearly half provided supervision for personal safety. In addition, nearly 60% of daughters provided transportation and approximately 70% assisted in the arranging of services for the dependent parent.

**CONTEXT OF CHOICE**

**Context as culture**

All decision makers do their deciding in a context of culture. Anthropologists have made important contributions to our understanding of culture as a control

mechanism for governing behavior in a society. What aspects of culture create a context for decision making in long-term care?

Shweder (1980) identified five types of cultural control mechanisms: 1) regulations (or laws) validated by relevant authority, 2) conventions (or customs) validated by consensus, 3) morals (or ethics), intrinsically validated 4) truths (or beliefs), empirically validated by consensus of experts and 5) instructions (techniques, recipes, or "know-how, also empirically validated by consensus of experts." (p.84) It is the role of society to organize itself within the expectations of culture, and the role of individuals to conduct themselves (and make decisions) within the expectations of both culture and society. Individuals fulfill these expectations by assuming identities, fulfilling roles, following laws, and contributing to cultural preservation by reinforcing expectations through interactions with others.

What is the source of these control mechanisms? Turiel (1978) asserts that it is a set of universal moral rules, e.g. the value of life, physical and psychological security, retribution, and the sharing of goods, that determines culture as reflected in all societies. It may be argued that the authority and maintenance of these rules is achieved through power. Berrien (1968) credits French and Raven with distinguishing between six forms of power:

1) coercive power, which results from the belief that another has the capability to inflict punishment and harm;
2) reward power, based on the perception that another person may mediate rewards, benefits, or desirable returns;
[Powers 1 and 2 may be exercised by a single agent]
3) legitimate power, based on broad general norms about the beliefs, opinions and attitudes of what influences are appropriate and proper;
4) informational power, based on the cognitive elements in a communication which to a greater or lesser degree influence the subsequent behavior of the recipient of that information;
5) expert power, additive to informational power for the reason that the source of information is perceived as a person of special knowledge; and 6) reference power, which stems from the reference group with which the individual identifies himself (Berrien, 1968:194)
The question of autonomy and free will is intrinsic to any discussion of power. Given the moral universals that are expressed through culture as a control mechanism, by the authority of multiple sources of power, it would seem that pure autonomy and free will are not infinitely exercisable. From this perspective, we must assume that culture does indeed influence both decision making and decision outcome. It is from this assumption that Shweder’s five control mechanisms are now addressed.

Regulations/laws

Regulations are first established by a set of taboos and cherished values, and are made specific by law and related policy. That the laws and policies in this society have been determinist in constraining the choices of women is a fundamental premise of this study that will not be argued here. Suffice it to say that the alternatives of women in virtually any significant decision context have been circumscribed by a history of regulations and laws which have subjugated women’s social and economic power. It can be broadly stated that, as a group, women make decisions from a position of relative (to men) vulnerability to all forms of power.

Specific regulations and laws in the context of both long-term care and related family policy set parameters within which daughters may choose from the alternatives available to them and to their parents. Some laws struggle to define the nature of obligation of child to parent. At present, twenty-six states have statutes that can require children to provide financial support for parents. (Callahan, D., 1985) As another example, most states have statutes allowing an adult child to petition for legal guardianship of a dependent parent, a status which affords the child considerable discretion in determining the care and affairs of the dependent parent. Medicaid, which is the major source of public financial assistance for long-term care, has state-developed and administered policies which delimit alternatives of care. (Atchley, 1988)
The above examples are but a sample of the specific rules and regulations that derive from cultural values of life, security, and the sharing of goods. As law, they set boundaries beyond which decisions are made in a condition of discretion.\(^3\) That is, women make caregiving decisions by choosing from all alternatives left to them after the dictates of society are defined and expressed by law and social policy.

**Conventions/customs**

That it is customary for women to serve as caregivers in this society is common knowledge. The adaptation of behaviors and activities related to mothering and nurturing is a validation-by-consensus of the role of woman as caregiver. Elaine Brody (1985) offers interesting insight into the contemporary myth that women don't provide the level of care for their parents that was customary in the "good old days." Brody claims that evidence refutes this myth, that on the contrary, more women are caring for parents for longer periods of time than their "foremothers" did. The guilt and/or negative social sanctions that appear to ensue from the irreconcilability of myth and reality would seem to have an impact on the perception of caregiving alternatives.

**Morality/ethics\(^4\)**

Closely tied to custom, and a moral issue of our time, is the standard of reciprocity that shapes the decision dilemma. Daughters making caregiving decisions have been lifelong recipients of caregiving from the parents who are now dependent. Clear behavioral norms are absent in this issue (Brody, 1985). Ambiguity about the

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\(^4\)Although the terms morals and ethics are often used interchangeably, ethics are actually a system of moral principles which suggest or prescribe behaviors, (duty) based on the moral judgments of "goodness" or "rightness" (Lewis, 1984).
moral idea of reciprocating care and its associated norms produces a context of unclear precepts and conflicting role expectations.

That women define themselves as moral persons by some standard of responsibility and caring in relationships is a theory proposed by Carol Gilligan (1982). Though not without its challenges (largely methodological), Gilligan's theory is regarded as a resonant attempt to explain the "different voice" of women's moral development. This voice is assumed to have been culturally influenced. As women assess the self- and social-approval values of the decision alternatives, the moral standard of care and responsibility is likely to receive serious consideration. The question becomes whether women are especially vulnerable to deciding from a single moral precept, e.g. obligation to reciprocate care.

Truths/beliefs

The system of truths and beliefs in our society has its source in collective logic or reason, based on experience and observation. Truths are validated empirically by a consensus of experts. (Shweder, 1980) Examples of truths range from the elementary to the complex: "Humans age" "Old people may become dependent." "Differentiation must be made between the effect of age upon convolutional size in the 'control' where only a moderate degree of atrophy is noted and the severe atrophy seen in Alzheimer's disease and some cases of senile dementia." (Brody, H. and Vijayashankar, 1980:242) Obviously, the level of access to truths will dictate, to some extent, the level of effect on behaviors. The decision maker's perception of alternatives and capacity to evaluate them effectively will influence the decision process and outcome.

Metaphysical truths or beliefs, e.g. "God will provide." "Love conquers all." "What goes around, comes around," have their source in religion and custom, and are also significant inputs into the decision process. Decision makers who "put the
decision into the hands" of a superior or supreme power, e.g. "let God decide," or who make decisions from a position of resignation to some predestined fate, give evidence to cultural influences.

**Instructions/techniques/recipes/know-how**

Studies of strain among caregivers indicate that caregivers are confronted with a variety of issues requiring instruction, including personal care practices, legal and financial considerations, time management, resource utilization, and family adjustment. These issues are among the factors evaluated in decisions about caregiving. (Cantor, 1983; Lund, *et al.*, 1987; Moore, 1987; Soldo and Myllyluoma, 1983)

As mechanisms of control, instructions and techniques are evident in childrearing practices, for example, but vague or absent in parent-caregiving practices. There may be a relationship between the absence of behavioral norms in this area, and the culturally and societally defined recipes for approaching the experience. Level of access to know-how, as well as level of access to truths, would seem to shape the decision maker's perception of alternatives.

**Context as demographic and social trends**

Three important demographic and social trends in the population of daughters of the elderly help us to frame the decision-making context. First, due to a declining birth rate, daughters have fewer siblings than did past generations on whom to rely for sharing in parent care. (Shanas, 1979; Troll, 1971) Indeed, a full 15% of caregivers in one study had no living siblings, and 30% had only one living sibling with whom caregiving tasks could potentially be shared. (Cicirelli, 1981)

Second, caregiving daughters are more likely to be working than not. As stated earlier, 63% of all caregiving daughters are between the ages of 45 and 64. At the same time, "69% of all women between the ages of 35 and 44 are in the work force as
are 62% of those between the ages of 45 and 54, and 42% of those in the 55 to 64 age group." (Brody, 1985, p. 24) Indeed, the fastest rate of entrance into the workforce is among 40-59 year olds. (Hendricks and Hendricks, 1981)

Third, as people are living longer and thereby experiencing more chronic illnesses or disabilities, not only does the number of people requiring long-term care increase, but so also does the length of their care. Furthermore, because ten percent of all people 65 years or older have a child over age 65 (NRTA-AARP, 1981), an important risk exists: that some caregivers of the "old old" will be confronting their own increasing dependency as they also confront the tasks of parent care. (Robinson and Thurnher, 1979)

**Context as a field of alternatives**

Decisions about long-term care are logically influenced by the number and kinds of options both known and accessible to the decision maker. From what alternatives does a daughter decide the nature and level of her participation in parent care? The mixed bag of service options in U.S. communities reflects a generalized ambiguity about both filial obligation and public responsibility. It is no secret that the U.S. has demonstrated an "institutional bias" (Frankfather, et al, 1981) in its policy and programs. It is estimated that "90 percent of all public support for the chronically disabled goes for the purchase of institutional care." (Frankfather, et al, 1981:2)

In addition, it is estimated that $10 billion in expenditures are saved annually through the uncompensated services of informal caregivers. (Paringer, 1983) Brody and Lang (1982) claim that adult children provide 80-90% of the health and social services required by the dependent elderly. As a function of the investment in institutional care and the savings represented in informal care, it is not surprising that public policy makers actively seek to promote family care for the elderly at home.
Inherent in these incentives is both a public norm of filial obligation (the belief that children owe parents support in their later years) and a myth of alienation or abandonment (the unsupported conclusion that this obligation is not being met to the degree it was in earlier generations). Among proposals considered at the Congressional level are:

1) tax incentives for family members who bring impaired relatives into their homes
2) public funding for "respite" and other supportive services
3) cash grants to low-income families to care for elderly relatives
4) changes in Supplemental Security Income and food stamp rules such that benefits are not decreased when an elderly person moves in with a family, and
5) permitting family members to work as paid helpers under public programs.

(Doty, 1986, p. 34)

Critical resistance to these initiatives is partly grounded in a fear of the "woodwork effect." The argument is that families already providing care for their elderly relatives with minimal or no public assistance would come out of the woodwork to demand their share of those resources designed as incentives to promote at-home family care in families not previously inclined to do so. The center of this argument is that such a demand would impose an unmanageable burden on public resources. So, it would seem, the government has itself in a bind. How does it promote at-home family care in reluctant families without obligating itself to families already providing it? More importantly, are such utilitarian considerations likely to alter decision outcomes? Or are there other, equally compelling considerations operant in the decision process?

According to Health Care Financing Administration researcher Pamela Doty (1986), nearly one quarter of U.S. citizens over age 65 are functionally disabled, yet only one in five of those disabled are cared for in nursing homes. Nearly three-quarters of the remaining disabled elderly (or 60% of the total number) rely totally
on family and friends for assistance. Of this noninstitutionalized care only twenty-six percent is government financed. Families, therefore, appear in another sort of bind, that is that all alternatives are not equal.

Is the institutionalization alternative a financial incentive? Two arguments can be made that it is not. The first argument is that if there is an incentive it is not necessarily financial. Institutionalization does, in fact, involve a forfeiture of expected family inheritances as the elderly are required to spend their income and savings on institutional care, at an estimated yearly average of $26,000. Moreover, in many cases individuals “spend down” their resources to a level of poverty at which they become eligible for Medicaid assistance.

The second argument is that if there is a financial advantage to institutionalization, it is not necessarily an incentive. Even among the families of those already eligible for Medicaid (and full support of nursing home costs) there exists a resistance, not an inclination, toward institutionalization. To most families, institutionalization remains an unsatisfactory alternative, considered only as a last resort. (Schorr, 1980, Smallegan, 1985)

Most studies indicate that the preferred alternatives for support are for direct in-home services, e.g. home health care services and respite care services, as opposed to direct financial supports. Indeed, when asked to identify the greatest source of caregiving-related stress, most caregivers cite emotional strain and impositions on recreational and personal time, and seldom cite financial strain as a caregiving burden. (Cantor, 1983; George and Gwyther, 1986; Horowitz and Dobrof, 1982) In a study by Horowitz and Shindelman (1983), eighty percent of informal caregivers asked to rank
preferences for various services and economic support programs preferred direct homemaker and medical services to receiving any kind of financial compensation. 5

Alvin Schorr, for the U.S. Department of Health and Human Services (1980), argues that community services provided to the aged do not "come to the heart of functional dependency." He cites a 1978 Cleveland, Ohio study (U.S. General Accounting Office, 1978) which lists information and referral as the most commonly offered community service and identifies in declining frequency transportation, recreation, outreach, and education as other prevalent services. Far lower on the list are personal care, meal preparation, and homemaker services. In addition to limited resources, Schorr identifies three problems which limit the alternatives of the decision maker.

First, Schorr argues, health and social welfare professionals operate along "parallel lines" while the medicalization of services functions to maintain the schism. Second, community social welfare services are "seriously disorganized" creating delays and carelessness which may result in a rationing of services. Finally, Schorr argues that overlapping services, particularly aging, mental health, and disability services compete for control rather than negotiating compromise in order to expand services. Certainly these problems function to constrain the alternatives of decision makers.

Another influence in the decision making context is the preference that the elderly themselves have for family care vs. formal care. (Troll, et al, 1979) Cicirelli cites a number of reasons for this attitude:

5Harkins (1985) found that even though direct services from formal support systems are preferred to financial supports, for nearly two-thirds of caregivers even the provision of those direct services would not necessarily prevent or postpone an institutionalization decision. Institutionalization occurs most frequently when 24-hour supervision or care is needed, reducing the feasibility of home care in most cases, even where there is an abundance of community services. (Smallegan, 1985, p. 364)
...[The use of formal supports] is embarrassing to them as they associate such services with being on welfare...they do not like the feeling of being dependent on someone else, especially some impersonal organization outside the family.....there may be the problem of dealing with a tremendous amount of "red tape" to determine eligibility and arrange for services. (Cicirelli, 1981:13)

From the contexts of culture, demographic and social trends, and a field of alternatives, women develop attitudes toward caregiving. These attitudes have been the focus of a number of studies. It is to some of these studies that this review now turns.

ATTITUDES OF FILIAL OBLIGATION

Considerable attention has been given in the literature to attitudes of filial obligation toward parents. (Berman, 1987; Brody, 1981; Daniels, N. 1988; Finley et al, 1988; Johnson and Werner, 1982; Robinson and Thurnher, 1979.) As stated earlier, Berman (1987) suggests that there exists a "norm of reciprocity" which renders parent caregiving an obligation. Parents are the initial caregivers in the parent-child relationship. This care, according to Berman, is not able to be fully reciprocated by the adult child in later years; hence Berman argues that there exists for adult children a sense, not only of obligation, but of irredeemable obligation toward parents. Brody (1981) found that the "vast majority" of three generations (grandmothers, daughters, and young adult granddaughters) in a study conducted by the Philadelphia Geriatric Center, "resoundingly endorsed the traditional value of filial responsibility to the aged." (Brody, 1981, p.475)

Cicirelli, on the other hand, identified what he describes as only a moderate sense of responsibility toward elderly parents, based on the results of a Filial Expectancy Scale administered to a sample of 53 "middle-aged" children (both males and females). (Cicirelli, 1981) One explanation for this discrepancy may lie in differences between male and female attitudes toward filial obligation. Horowitz
(1985) found in a study of gender differences in caregiving that caregiving sons tended to become caregivers only when no female sibling was available to provide care, tended to rely on the caregiving support of their wives, and provided less overall assistance to their parents, particularly in the area of personal care.

Finley et al (1988) studied differences in attitudes of filial obligation between gender and parent type (mother, father, in-law) from the predictor variables of role conflict, affection, and education. They concluded that there exists for females a qualitative difference in the development of filial obligation, characterized by an emotional component and a correlation with affection for parents not paralleled by males. Finally, they warn that a male's perception of role conflict (between caregiving and other obligations such as work) may not diminish a sense of obligation to parents but may in fact diminish actual caregiving. While eleven percent of primary caregivers in the Stephens and Christianson study cited earlier were sons, four and one half percent were daughters-in-law, and one-half of one percent were sons-in-law. The significant role of wives providing caregiving for husbands' elderly parents is also illustrated in studies by Shanas (1979) and Brody (1981). Finley, et al argue that when a daughter-in-law acts as caregiver, the son's "sense of obligation may be satisfied with little investment of his actual time." (Finley, et al, 1988, p. 77)

The study by the research group of the Philadelphia Geriatric Center (Brody, 1981) drew interesting conclusions about women's attitudes about gender-appropriate roles in the caregiving context. These attitudes were increasingly liberalized from one generation to the next in this three-generation study, but even across generations the majority of women endorsed attitudes of male-and-female-equal responsibility toward aging parents. But as Brody writes, "women,...with deeply internalized social strictures and ingrained behaviors, do not always demand that men share." (1981: 476)
Attitudes of filial obligation appear, in general, to translate into the assumption of caregiving responsibilities. (Brody, 1981; Doty, 1986; Frankfather, et al, 1981; Schorr, 1980; Shanas, 1979) That attitudes of male-and-female-equal obligation are not translated into equal behaviors raises an important question in the exploration of the caregiving decision process. Just as important is the question of how far filial obligation extends. Is there a limit to obligation? How much care is enough? How much care is too much?

In an extensive discussion of the concept of filial obligation, philosopher Norman Daniels (Am I My Parents' Keeper?, 1988) argues that "we live in a society in which there are diverse beliefs about family responsibility, and we have neither a homogeneous tradition nor a compelling philosophical account that can overcome this diversity." He further argues that there exists a "mismatch between past and present social patterns" which makes it impossible to provide the care traditionally required of children. (p.24) He writes:

Even if there is validity to such moral notions as filial obligations, we cannot simply abstract past patterns of family responsibility from the economic and political context in which they functioned and then insist that these patterns "ought" to apply within our vastly different institutions and social practices. (p. 27)

THE CAREGIVING EXPERIENCE

Brody wrote in 1981 that attitudes are only "somewhat predictive of behavior", (p. 476) and in 1985 that "attitudes and opinions are not always reflected in behavior." Women are subject to changes in social patterns or pressures as well as to changes in the conditions or circumstances of the dependent parent. Obviously caregiving is not a static experience; it follows that response to the experience will also change. For example, in a study of nursing home admissions following in-home informal care, it was found that placement decisions were not made casually, but at a
"breaking point" at which the level of caregiver stress overcame the level of caregiver tolerance for the circumstances of caregiving. (Smallegan, 1985)

Stages of caregiving

Jane Lewis and Barbara Meredith, in a British study titled Daughters Who Care (1988), offer helpful language for articulating the stages through which the caregiving experience may pass. They found that caregiving "was not a single process, or phase, but a collection of relationships and inputs which varied as caring progressed to its conclusion...." (p. 181) First, although not all caregiving experiences move through every stage, all caregiving begins with a trigger, or an event or change such as the development of dependency in the parent, the loss of resources for caregiving, the loss or absence of sibling support, etc., which produces a need for caregiving. New triggers occur to move the caregiving experience through its stages.

Stages include semi-care, part-time full care, and full care. Semi-care may last over a period of years, and is characterized by vague caregiving tasks and gestures not necessarily warranted by the physical or mental condition of the parent. During the semi-care stage, the caregiver's primary devotion of time and energy is to her own family and needs. Part-time full care is a time in which caring for parents and caring for families is "held in rough balance." Increased energies are expended on behalf of the dependent parent in this stage. Finally, full care represents a "tipping of the balance" of care in favor of the dependent parent. Each of these stages represents qualitatively different experiences.

Just as caregiving is not a "single process, or phase", it may be argued that neither is decision making a single process or phase. Lewis and Meredith also identified three processes by which carers "opted into care": natural, drift, and conscious decision. Natural carers are those who found it difficult to answer questions about the reasons for their caregiving and how it came to be. Generally, co-residency
daughter and parent[s] sharing living quarters) was more readily explained as natural, while caregiving itself was regarded more a matter of "drift" or "conscious decision." Drifting into caregiving is described as a gradual, timeless process not characterized by a decision moment. As parents became increasingly dependent, daughters drifted into increasingly higher levels of caregiving. Conscious decisions in the Lewis-Meredith study appeared more conflictual in nature, and included resistant and reluctant decisions as well as "happily" made decisions. Lewis and Meredith identified only one fourth of their sample of forty-one caregiving daughters as having made a conscious choice to provide care. All others were identified as having come to the decision "naturally" or by having drifted into it. This dynamic process of decision making receives further attention in a later body of this literature review.

Caregiver strain and the response to burdens of care

Although an increasing number of studies are being written about the concepts of caregiver burden, stress, and strain, researchers have consistently found that less stress exists than has been hypothesized. (Cicirelli, 1981; Stone, et al, 1987; Zarit, et al, 1980) By far, the most pervasive consequence of caregiving and its inherent burdens is emotional strain. Springer and Brubaker (1984) cite a number of important emotional consequences of caregiving, among them, the fear of the unknown, loss of freedom, isolation, guilt, and grief. Brody (1985) cites depression, anxiety, frustration, helplessness, a lowered morale and emotional exhaustion as potential consequences of care.

Johnson and Catalano (1983) found in a longitudinal study of family caregivers that, with prolonged dependency, caregivers develop adaptive mechanisms to the burdens of care. These include distancing techniques, and enmeshing techniques which are in direct contrast to distancing techniques. Distancing responses to caregiving burdens include establishing greater psychological and/or physical distances between
the caregiver and the dependent elderly. The process of enmeshing involves the intensifying of the caregiving relationship to the exclusion of other relationships. This may include role entrenchment, or a process in which caregiving is "accepted as a permanent, full-time role that takes precedence over other social roles."

Springer and Brubaker (1984) distinguish between stressful emotional situations and stressful structural situations within the caregiving family. Stressful structural situations include role conflict, effects on caregiver health, financial strain, changes in family routine, and, clearly germane to this study, the decision process itself. It can be argued that these stressful structural and emotional situations are a product of conflict in the caregiving experience.

Conflict

Elaine Brody's 1985 study identified a number of issues related to parent caregiving that illuminate the conflictual nature of the caregiving experience. Brody studied 172 "conflicted" women providing care to their mothers. First, she identified as a central issue the dialectical tension of dependence/independence in the caregiving situation: "the inevitable shift in the delicate balance of dependence/independence of the elderly parent and adult child reactivates that child's unresolved conflicts about dependency." (p. 23) Second, she asserted that the needs and demands of spouse and/or children compete with the needs and demands of the dependent parent. Third, Brody found that women frequently give up their recreational and socialization activities in the interest of parent care. Fourth, she found that 28% of a sample of nonworking women had quit their jobs because of elderly parents' needs for care, and a similar proportion of the working women were considering quitting their jobs for the

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6 A brief profile of the caregiver sample is provided here: mean age=49.1, 80% married, 84% with one or more child living at home, 20% with the dependent parent living in caregiver's home.
same reason. And finally, of all women studied three-fifths of caregiving daughters indicated feeling guilty about not doing enough for their parents.

Most research lends support to categorizing competing demands into two major types: competing familial obligations and work conflicts. (Soldo and Myllyluoma, 1983; Stone, et al, 1987) It has already been established that a significant portion of caregiving daughters are married (56%) and/or have children under age eighteen living in their homes (24%). It has also been established that 44% of caregiving daughters are working, and that for most of these women work-related sacrifices had to be made to perform caregiving tasks. Indeed 12% had quit work to pursue caregiving. All of the literature addressing the issue of competing demands conclude that these conflicts exacerbate the stress of caregiving. (Brody, 1981; Brody, 1985; Lang and Brody, 1983; Soldo and Myllyluoma, 1983; Robinson and Thurnher, 1979; Stone, et al, 1987; Zarit, et al, 1980)

The central assumption of this study is that the conflictual nature of the caregiving experience renders the decision process conflictual as well. Decision makers choose among competing needs and demands. As has already been established, the caregiving experience is a dynamic one, evoking different responses in different stages. It is assumed that these stages all may be characterized by conflicting alternatives.

DECISION THEORY

As stated earlier, decision may be defined as a process or act of choosing between or among alternate courses of action. Classical decision theory has two basic components: 1) value (objective or subjective), or the desirability (utility) of an outcome, and 2) probability (objective or subjective), or the likelihood that the
outcome will occur. (Leigh, 1983) Decisions may be made under conditions of certainty (risklessness) or uncertainty (risk).

The large body of literature characterized by the label "decision theory" comes from many disciplines, including economics, mathematics, statistics, psychology, and business administration. Most theory in these fields has been developed out of experimental research in which effects of the environment on decision processes and outcomes have been tested. Decision theory is generally divided into two primary categories: 1) normative theory, which generates hypotheses about how people ought to choose in given situations and environments, and 2) descriptive theory, which is constructed to explain the way people actually do make decisions not predicted by the assumptions of normative theory. A third category, developed by Baron (1985) and unique to him, distinguishes between normative and prescriptive theory. Baron suggests that normative theory is concerned with outcomes and prescriptive theory with process that ought to be achieved in the decision experience. Before turning to a discussion of the major decision theories, it is necessary to elaborate on the following concepts: utility, probability, certainty/uncertainty, rationality, and concatenation.

**Utility and Probability**

The decision maker's cognitive task is to aggregate and evaluate the utility and probability of all alternatives in order to achieve a conclusion of "best choice." The concept of utility is abstract. For our purposes, utility is best described as the subjective valuing of decision outcome. Discussions of utility in decision making may focus on material or moral consequences. Decisions are conducted and evaluated according to a principle of worth or desirability ascribed to each alternative by the decision maker.

**Probability** may be defined as the subjective or objective likelihood that a desired outcome may be achieved through the chosen alternative. Statistical tests are
the best examples of objective probability measures, while individual assessments and judgments (e.g. guesses, conjecture, even naive belief) are examples of subjective probability measures. Decision theory literature is rife with mathematical theories of probability, and a growing body of literature also contributes to our knowledge of subjective probability.

**Certainty/uncertainty**

Decision may be said to be riskless or certain when the relationship between action and consequence is determinate. In decisions under *certainty*, each choice can lead to only one future state, knowable to the decision maker. The decision maker in a condition of certainty has only to consider the predictable consequence of each choice, and act on the choice of most desirable consequence. This is a condition of risklessness. In contrast, a condition of *uncertainty* exists when the relationship between choice and consequence is not clear or not knowable. Risk is inherent in the decision process. It may be said that there exists a certainty/uncertainty continuum, but that most decisions take place under conditions of uncertainty or risk, due in part to the limited predictive and evaluative capacities of the decision maker.

Ward Edwards (1967), a major contributor to decision theory, suggested that it is an "Economic Man [sic]" who makes decisions under certainty. Edwards maintained that the Economic Man has three properties of *unlimited* capacity: "a) He is completely informed. b) He is infinitely sensitive. c) He is rational." (p.13) A decision maker who is completely informed has total knowledge of the different consequences achievable through appropriate action. To be infinitely sensitive, the Economic Man must have perfect powers of perception and cognition. Finally, if he is to be rational, (that, is controlled by reason rather than impulse), the Economic Man is capable of "maximizing utility" (Fjellman, 1976), or "choosing the course of action which results in the best possible future state." (Fjellman, p.84) That humans
are not all-knowing or infinitely sensitive, and not always rational is a fundamental assumption of this study.

Rationality

The terms "rational" and "rationality" pervade decision theory literature. Baron (1985) calls rationality a "property of the thinking" that is part of the decision making process. (Processes, not products, may be said to be rational or irrational.) A rational decision, then, is one in which a thoughtful process of weighing alternatives has been carried out. Baron argues that rational thinking is thinking that follows a prescriptive model of decision making, and is founded in utility theory.

The theory of rational choice is hierarchical. At the top of the hierarchy is a rational life plan: long-term personal and moral interests. The choice of the plan is made without consideration of utility. The next level of rational choice is the decision maker's personal "policies," which do include utility and relative weights. These policies in turn guide the making of individual rational decisions in particular circumstances. (Baron, 1985)

Rational decision making requires three fundamental conditions. Level of rationality in a particular decision is directly related to the knowledge, capacities, and unmodifiable emotion of the particular decision maker. Rational choices are made on the basis of knowledge and beliefs, as utility and probability are weighed according to accessible and acquired knowledge and beliefs. Capacities are the "ability parameters" that affect the success of the decision, such as intellectual capacity to perceive choice and evaluate alternatives. Adherents of a pure rationalist perspective of decision making argue that emotion sabotages rational decision making. Emotional control in the decision process is vital to the rational process.
Concatenation

Discussion to this point has assumed a consciousness of a decision moment in the decision process. Decision theory research and literature appear to disconsider in decision making what the philosopher Husserl (1948) wrote is a fluid process of questioning and answering, not reducible to a single decision moment. Each decision is in fact part of a larger series of decisions, and the outcome of each decision serves as a criterion for all others. Does all choice represent discrete decision moments? Sokolowski (1985) calls our decisions "an assembly of choices," arguing that they are concatenated, or linked together in the pursuit of a goal.

DECISION MODELS: Toward a conflict model of decision making

Subjective expected utility (SEU) theory

SEU, the brainchild of Ward Edwards (1967), is often simply called "decision theory", reflecting its central role in the construction of all other decision theories. It is the subjective derivative of expected utility theory (constructed by economists and mathematicians7) and is the major theory of decision making under uncertainty. SEU is a normative theory in which expected utility is considered the primary criterion of rational choice. Expected utility is the product of the individual decision maker's judgment of probability and utility (where utility is weighted by probability) for each alternative. Subjective expected utility theory is founded on a set of four axioms:

1. Decidability. The decision maker should be able to say whether or not outcome A or B is preferred, or whether or not there is no difference.

2. Transitivity. If A is preferred to B, and B is preferred to C, then A should be preferred to C. This allows the ordering of preferences.

3. Dominance. If an alternative (A) produces consequences equal to other alternatives in most cases, but superior consequences in at least one case, alternative A should be chosen.

4. Sure-thing principle. When in the process of deciding between possible alternatives, outcomes not related to the choice should not influence the decision.

The key issue in subjective expected utility theory is the requirement that the decision maker subscribe to and fulfill the four axioms.

Satisficing

Satisficing, a descriptive theory of decision making, is decision behavior only remotely related to the normative expected utility theory. Herbert Simon (1976) claims that decision makers don't always maximize, but rather satisfice, or look for alternatives that are "good enough" or minimally acceptable. Satisficing in decision making essentially eliminates the often complex cognitive process of weighing values and probabilities required for maximized or optimized decision outcomes. According to Janis and Mann (1977), the satisficer 1) considers only a few requirements for decision outcome, 2) generates only a few alternatives, 3) haphazardly orders alternatives, and 4) sets a minimal cutoff point which is standard for each requirement.

Incrementalism is the product of a series of satisficing decisions; each small change is seen as "good enough" because it is an improvement over the last small change, now represented by the status quo. Often associated with policy making, this decision theory also has application to intrapersonal decisions.

Quasi-satisficing: Moral decision making and elimination-by-aspects

Several approaches to decision making closely related to satisficing, but more thoughtful or reflective, have been posited in the last two decades. Schwartz (1970),
is one theorist who, in a study of altruism, described the process of making decisions based on moral precepts or imperatives, rather than utilitarian considerations. As opposed to the satisficer who makes a "good enough" decision, thereby discarding all other alternatives, the moral decision maker makes the best (most moral) decision, disregarding the consequences of all others. **Moral decision making** will receive fuller attention in a later body of this review.

*Elimination by aspects* is the use of a series or combination of simple decision rules, in which decisions are dependent upon the most salient of alternatives which also meets some minimal requirement. This is essentially a "narrowing-down" process: starting with the most valued requirement (aspect), all salient alternatives are tested against that aspect. Those alternatives that do not meet the requirement or aspect are eliminated; new salient aspects are identified with each comparison, and finally, one alternative "wins." The linearity of this process reduces its maximizing potential.

**Conflict theory**

Generally, conflict models of choice are based on three notions. The first is that people make choices in an attempt to satisfy needs. Second, conflict is inherent in choice, due to the incompatibility of needs or alternatives. And third, conflicts are resolved by balancing the costs and benefits of alternatives. (Hogarth, 1987:67)

The most cited reference in current social work and other literature related to decision making is the Janis and Mann (1977) conflict model of gains and losses. Janis and Mann describe "decisional conflicts" as the "simultaneously opposing tendencies within the individual to accept and reject a course of action." (p.46) This normative model suggests four primary considerations which should be balanced in the decision-making process: 1) utilitarian gains and losses for self, 2) utilitarian gains and losses for others, 3) self approval or disapproval, and 4) approval or disapproval from
others. It should be noted that in this model, "utility" in the classic sense is divided into two categories: utilitarian (material or instrumental) consequences and approval (moral and/or esteem) consequences.

Although the above model derives from normative theory, Janis and Mann propose another, descriptive model of decision making. According to this theory, decision making begins with antecedent conditions such as communication variables, information, personal dispositions or "other situational factors" which affect the mediating (decision) process at each of five stages. Each of the stages is characterized by a weighing of risks. These risks are not to be confused with the earlier discussion about probability. Janis and Mann give little consideration to issues of probability. The risks instead are measures of gains vs. losses.

Such decisions require a level of rationality. Is it possible to "accurately" perceive choices, identify their inherent conflict, predict the costs and benefits of alternatives, evaluate their utility, and resolve the conflict rationally? A common criticism of both Janis and Mann models, the normative and the descriptive, is that they are irrelevant to "life-historical and social contexts" of individuals, and require a logical-rationalistic approach impeded by human limitations. (Sloan, 1987)

As stated earlier, this study is grounded in a premise that caregiving decisions are inherently conflictual. It is not presumed, however, that decision makers conform to the Janis and Mann descriptive model of decision making. It is presumed that, unless decisions are made from a moral imperative where all other alternatives are disregarded, or made from either a condition of coercion or a perception of "no choice", decision makers, at some level, sense and consider a range of conflicting alternatives and attempt to measure the gains and losses they represent. It is also assumed that this attempt is constrained by limited rationality.
LIMITED RATIONALITY

A woman's decision-making experience is determined not only by context (culture, trends, alternatives) but also by her own knowledge, capacities, and emotion, as well as by the interpersonal relationships for whom the decision has meaning. The experience is culturally and socially bound by normative roles and constraints, and by the socio-historical context of the decision. The decision experience is also influenced by the particular personality and needs of the decision maker. Finally, there exists for the woman a range of value and ethical considerations in any significant decision. If knowledge/beliefs, capacities, and unmodified emotions are the givens of rational choice, then it follows that human limitations in these areas limit rationality.

This discussion first identifies limitations in cognition and affect. It then moves to a consideration of other intrapersonally derived influences on rationality: ambiguity tolerance, lifestage development, gender differences, and conscious and unconscious states. It concludes with a brief discussion of family influences.

Cognition

Herbert Simon (1976) developed the concept of limited rationality, sometimes called bounded rationality, to explain the difference between the described (actual) behaviors of decision makers, and the normative, rational models proposed by economists and pure rationalists. Simon argued that reasonable, as opposed to rational, behavior is an appropriate standard given the limited capacities of human cognition. People do not possess either the perceptual ability, the intuitive calculators, (Fjellman, 1976) or the memory capacity required to make pure rational decisions. It has already been determined that most decisions are made under conditions of risk or uncertainty. The decision maker cannot be the "Economic Man" because first, s/he is neither all-knowing nor infinitely sensitive.
Affect

Baron (1985) claims (in defending arguments that rational choice is coldly calculating) that "sentiment" may enhance rationality by "giving us any reason to think at all." (p.239) "Moral sentiments, sentiments of personal loyalty and attachment, desires for a better life, and sentiments favoring rationality itself" (p.239) all encourage rational thinking. On the other hand, strong emotion may impede rational thinking. Decisions, particularly those of the nature we are considering, are often made under stress and high emotion which either preclude rational or reflective thinking, or distort it. Abelson (1963) calls thinking in affect-laden situations "hot cognitions," in contrast to the cold cognitions which are part of routine problem-solving.

Janis and Mann offer five propositions about the relationship between stress and decisional conflict:

1. The degree of stress generated by any decisional conflict is a direct function of the goal strivings that the decision maker expects to remain unsatisfied: the more goals expected to be unfulfilled and the more important the needs to which those goals correspond, the greater the stress.

2. When a person encounters new threats or opportunities that motivate him [sic] to consider a new course of action, the degree of decisional stress is a function of the degree to which he is committed to adhere to his present course of action.

3. When decisional conflict is severe because each alternative poses a threat of serious risks, loss of hope about finding a better solution than the least objectionable one will lead to defensive avoidance of threat cues.

4. In a severe decisional conflict, when threat cues are salient and the decision maker anticipates having insufficient time to find an adequate means of escaping serious losses, his level of stress remains extremely high and the likelihood increases that his dominant pattern of response will be hypervigilance [panic, in its most extreme form].

5. A moderate degree of stress in response to a challenging threat induces a vigilant effort to scrutinize the alternative courses of action carefully and to work out a good solution, provided the decision maker
expects to find a satisfactory way to resolve the decisional dilemma. (1977:50-51)

Janis and Mann conclude that an intermediate level of stress produces the best-quality decisions.

Ambiguity tolerance

As a personality characteristic, ambiguity tolerance has obvious implications for the decision experience. Frenkel-Bruswik (1948) introduced ambiguity tolerance as a cognitive and personality variable, and observed that persons who exhibited intolerance were "disinclined to think in terms of probability." (p.268). Individuals with low levels of ambiguity tolerance tend to see problems in black/white answers, and are likely to underutilize the amount of information available from the environment.

Lifestage development

Cognitive and affective states have different functions according to the stage of development of the decision maker. In the case of daughters making caregiving decisions, it must be noted that parent care is not a developmental stage (Brody, 1985). Developmental stages are aged-linked periods of time; parent-caring may be experienced as young as age 14 and as old as 75 and over. Developmental tasks vary significantly in this broad age span. Erikson's (1963) theory of psychosocial lifestage development suggests a variety of tasks and required adaptive strengths represented in this age range, from identity confusion vs. role cohesion (fidelity), to intimacy vs. isolation (love), to generativity vs. stagnation (care), to integrity vs. despair (wisdom). Developmental readiness, as well as maldevelopments and "malignancies" would seem to influence decision making behaviors. While each of Erikson's stages is characterized by behavioral norms, there is an absence of behavioral norms for the life crisis of parent dependency. (Brody, 1985)
Gender differences in cognition, affect, and decision making

A number of human behavior and personality theorists have "observed" general gender differences in development and behaviors, among them Freud⁸, Piaget⁹, Chodorow,¹⁰ and Margaret Mead¹¹. Much theory has been extrapolated from predominantly male-subject studies (e.g. Freud, Piaget, Kohlberg) and has concluded that women are somehow cognitively inferior to a male standard of development. For example, in one of Piaget's earlier works (1932), "girls" were represented in a mere four entries in the index, while "boys" did not appear at all. They were subsumed, rather, under the "the child", which "boys" were assumed to represent. (Gilligan, 1982) As Belenky, et al write, "Developmental theory has established men's experience and competence as a baseline against which both men's and women's development is then judged, often to the detriment or misreading of women." (1986: 7)

Belenky, et al studied Women's Ways of Knowing (1986), identified five different epistemological perspective categories, characterizing different women:

1. **Silence**: a position in which women experience themselves as mindless and voiceless and subject to the whims of authority.
2. **Received knowledge**: a perspective from which women conceive of themselves as capable of receiving, even reproducing, knowledge from all-knowing external authorities, but not capable of creating knowledge on their own.
3. **Subjective knowledge**: a perspective from which truth and knowledge are conceived of as personal, private, and subjectively known or intuited.

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4. **Procedural knowledge**: a position in which women are invested in learning and applying objective procedures for obtaining and communicating knowledge.

5. **Constructed knowledge**: a position from which women view all knowledge as contextual, experience themselves as creators of knowledge, and value both subjective and objective strategies for knowing. (p.15)

The varied responses among women to information and knowledge would suggest varied responses to the decision experience, a relationship which merits study. The Belenky, *et al.* study raises important ideas about women's thinking, but does not pretend to compare women's with men's ways of knowing. Likewise, this study is less concerned with the possibilities of gender difference in cognition, and their consequent biological determinist conclusions, than it is concerned with the external forces which influence males and females differently, for example, culture, society and family.

**Moral development**

It may be argued that the conflicting obligations of daughters of dependent parents represent moral choices. Carol Gilligan (1982), in response to Kohlberg's male-dominated work, argues that, for women, moral dilemmas are created out of a conflict between responsibility to self and others. Using her argument, we would anticipate that caregiving decisions indeed represent moral choice. On the other hand, it may also be argued that, for some women, the decisions are strictly instrumental ones, without a perceived moral dimension. Therefore, while it is fair to assume that these significant decisions may be moral ones, and require our understanding of moral development, it is important not to assume the presence of a *perceived* moral dilemma in individual decisions.

**Altruism** and **guilt** are two issues related to moral development that bear mention here, due to their relevance to caregiving decisions.\(^1\) Altruism is a concept

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\(^1\) Discussions of guilt and obligation pervade the caregiving literature. See, for example, Johnson, M.A. and C. Werner, "'We had no choice': A study in familial guilt feelings surrounding nursing home care," *Journal of Gerontological Nursing*. 8(11) 1982,641-654; Berman, H.J. "Adult children and their parents: Irredeemable
complicated by questions of motivation. Three categories of motivation suggested by Morgan and Green (1980) are 1) no conscious intent, 2) conscious intent to help, and 3) disguised selfishness. The third category suggests, for example, that decisions to help are motivated by an interest in the reciprocal help of others (Trivers, 1971).

Freud (1927) conceived of the superego as a component of personality consisting of conscience and ego ideal. Mosher (1980) writes that the concept of guilt "is used to designate both a personality disposition, motive, or trait and an episodic emotion or state." As a personality disposition it is an affective-cognitive structure, developed from past guilt-related experiences. As a motive, guilt is used to explain self-punishment and the avoidance of immoral situations. Guilt as emotion refers to the affective experience that accompanies regret, remorse, and self-punishment. Guilt, then, may be seen as a motivator to approach an alternative in decision making, or also as an incentive to avoid others. In either case, it is clear that guilt may inhibit rational decision making.

Conscious and unconscious states

Most of the preceding discussion has assumed in the individual a consciousness of motivations, alternatives (including their values and probabilities), and forces (both internal and external) impacting the decision. From a psychoanalytic perspective, we may presume that there exist conflicting motivations, alternatives, and forces of which the decision maker is not conscious. Defense mechanisms of repression protect the individual from consciousness of incompatible wishes or drives. Freud, who largely ignored decision making in his theoretical work, proposed his own "normative theory" of decision making in a letter to his friend Theodor Reik:

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When making a decision of minor importance, I have always found it advantageous to consider all the pros and cons. In vital matters, however, such as the choice of a mate or a profession, the decision should come from the unconscious, from somewhere within ourselves. In the important decisions of our personal life, we should be governed, I think, by the deep inner needs of our nature. (Freud, in Clark, 1980:50-1, as quoted in Sloan, 1987:62)

Experimental research sheds little light on the role of the unconscious in decision making, as its very nature eludes observation and measurement. Our understanding of the unconscious is derived from psychoanalytic case studies, not the experimental laboratories which gave birth to most other theories of human behavior.

The family

Having identified individual limitations to rational decision making, we now turn to a brief consideration of family as both a primary agent of socialization to cultural rules and a facilitator of psychological and emotional development. In the case of decisions about caregiving, family patterns and relationships not only influence the individual decision maker's perceptions of alternatives and capacity to decide among them, but family members are also likely to be active participants in the actual decision experience. This study is bounded by a focus on individual rather than family decision making. It assumes however, that due to the decision impact on family members that decision making may become, in many cases, a "family affair." The family as a system is often bounded by the nucleus of parent(s) and child(ren). For the purposes of this discussion, the family boundary is extended to multiple generations. This boundary extension speaks to a central issue in the caregiving decision: that is, the blurring or shifting of family roles that accompanies parent dependency. Three theories which contribute to our understanding of family influence on decision making are offered here.

Exchange theory is founded on the principle that interaction between individuals or social groups can be characterized as seeking to maximize material and
non-material rewards and minimize both material and non-material costs. (Dowd, 1975) An assumption of exchange theory is that individuals are capable of rational decision making as described earlier. A principle of reciprocity takes precedence over a principle of profitability, however, and cooperative exchanges among individuals take place. (Zimmerman, 1988) Among the consequences of the alternatives considered by the decision maker, from this theoretical perspective, is the effect of the decision on the system of exchange.

Conflict theory, in contrast to the cooperation dynamic of exchange theory, has as its core concept the struggle over outcomes in a zero-sum structure (Janis and Mann, 1977). Family conflict in decision making occurs when different and conflicting alternatives are sought by members. This situation requires negotiation and bargaining, and is characterized by power struggles. Decision making under a condition of conflict has significant implications for both the process and product.

Family stress theory was constructed around the concept of a "stressor event" (Zimmerman, 1988:96) which involves changes in family interaction, goals, boundaries, or demands that the family is required to meet. Bengston and Kuypers (1985) suggest that perceptual distortion is a product of stress in the aging family. Reality is distorted in a cycle of family breakdown where a self-fulfilling prophecy of problem-solving incompetence is generated. The power of family crisis to distort the rational decision process suggests further evidence of family influence in decision making.

We have thus far reviewed decision theory and models with a focus on conflict and limited rationality. Discussion to this point has alluded to, but not fully considered, the moral dimension in the decision conflict. That full consideration is now given.
THE MORAL DIMENSION

Conflicting obligations, conflicting choices, and the idea of moral choice

We have established that: 1) there exists for most adult children an attitude of filial obligation to assist with long-term care\textsuperscript{13}, and 2) caregiving is often provided in the face of conflicting obligations and competing needs.\textsuperscript{14} It appears that women are especially conflicted. We are reminded that women "resoundingly endorse the traditional value of filial responsibility to the aged" (Brody, 1981), that women do most of the caregiving, and that as reflected in some very significant demographic and social trends, women experience increasingly conflicting obligations and role expectations. It may be argued that this configuration of conditions adds a moral dimension to our consideration of caregiving decisions.

To make this argument, we must first define two concepts: choice and moral action. The work of Robert Sokolowski (\textit{Moral Action}, 1985) provides the conceptual framework for this discussion, and is applied to the caregiving experience. Sokolowski differentiates the chosen from the compelled, the automatic, and the accidental, and also from what he calls the simply voluntary. Women who act as caregivers are likely to do so not out of compulsion, habit, or accident. Neither are they likely to act out of simply wanting or willing to give care for the process itself (the simply voluntary, where the performance is an exercise of desire). Rather, they are likely to act in view of something else, or for the sake of something else (the chosen). For example, they are likely to act in view of the need for care, or for the sake of the parent.

\begin{itemize}
\item \textsuperscript{13}(Brody, 1981; Brody, 1985; Berman, 1987; Cicirelli, 1981; Finley, et al, 1988; Horowitz, 1985; Schorr, 1980; Shanas, 1979)
\item \textsuperscript{14}(Brody, 1981; Brody, 1985; Brody and Lang, 1982; Cantor, 1983; Christianson and Stephens, 1984; Cicirelli; George and Gwyther; Horowitz and Shindelman; Robinson and Thurnher, 1979; Smallegan, 1985; Soldo and Myllyluoma, 1983)
\end{itemize}
Choice may be defined simply as preference between two wanted alternatives, for example, between caregiving and working. Choice may also be defined as the more deliberative and strategic form: that which is made in view of something, or that which has ends in mind, for example the preference made for working because it is financially rewarding.

How are choice and the chosen related to moral action? Sokolowski asserts that moral action must be distinguished from material performance. The act of caregiving is a material performance. It becomes a moral action when the performance is 1) owned by the caregiver and 2) recognized or identified as being good (or bad) toward the parent for whom caregiving is being performed. Therefore, a daughter who chooses to provide care in view of the good it represents for the parent has made a moral choice.

Moral problems

Moral action becomes problematized in two ways: First, moral action becomes a moral problem when the actor does what she does not want to do, for example, acts out of fear (including coercion), acts out of moral weakness, or acts out of obedience (under orders). Second, moral action becomes a moral problem when the actor believes she ought to do two things (or more), but cannot do both. We will deal with the former problem first.

Performing acts that are not wanted

Berman (1987) argues that a caregiving decision is often "not a free choice situation, but rather a situation in which people are compelled to do something to avoid a less desirable alternative."(p. 23) Gonyea (1987) suggests that caregivers often "choose" institutionalization after they have reached "the end of their rope".

15Harold Lewis, (1984) provides this partial list of "goods" to which "all people in all societies aspire": knowledge, security, justice, well-being, salvation, aesthetic satisfaction.
There exist for the caregiver at this time no perceived alternatives. Johnson and Werner ("We had no choice": A study in familial guilt feelings surrounding nursing home care,"), and Smallegan ("There was nothing else to do: needs for care before nursing home admission," 1985) both problematize the concept of choice.

**Acting out of fear**

Action out of fear is performed not for itself but as against an alternative. A daughter who brings her mother to live with her may not want to do so, but may be afraid of the alternative: e.g. her mother's rage at being "sent" to a nursing home, or the financial risk nursing home care represents to the family. (The parent may also coerce the daughter by introducing fear into the situation: e.g. by threatening to "die before going into a nursing home."

**Acting out of weakness, virtue, self-control, and vice**

Doing what one does not want to do is expressed in four forms of human character: weakness, virtue, self-control, and vice. Acting out of moral weakness implies doing what one wants but wishing it were not wanted. Perhaps the daughter believes that she should bring her mother to live with her in view of the good (e.g. family attention, better care) it will mean for her mother. What the daughter wants to do is arrange for private formal care for her mother. Acting out of moral weakness, she does what she wants to do, wishing she didn't want it, and wishing instead that she wanted to do the thing that is good for her mother.

There are other responses to this scenario. Believing that home care is best for her mother, the daughter may act out of moral virtuosity, and bring the mother home. A virtuous actor would not even consider another alternative. The daughter may act out of self-control. The self-controlled actor considers other alternatives but, with self-control, denies her wants and chooses according to the good that has been defined.
Finally, a *vicious* actor, certainly the rarest and also the most complex, is the opposite of the virtuous actor. The vicious actor holds what is bad as good. Vice is more than a weakness in self-control. For the vicious there is no conflict between what is thought and what is wanted. Acting out of vice, a daughter may do what she wants to do, for example, physically abuse and neglect her mother, or institutionalize her father as punishment, but she will have to retreat into deception. Vice, according to Sokolowski, is "trapped by authentic reason and by the natures of things that reason discloses." (p.129) The vicious has to publicly act according to reason, and deny, by deception, her own behaviors.

*Acting out of obedience*

The actor who does what she does not want to do may do so out of obedience. Against her will or judgment, she obeys the will or judgment of another. This implies that, for the actor, there is an authority to whom she is accountable. A woman for whom medical doctors represent authority may choose a course of care for a parent in order to obey "doctor's orders." A woman may "choose" to quit working, or to seek caregiving assistance, or to send a parent to a nursing home when the parent becomes demented, all out of obedience to her husband. Finally, a woman may act in obedience to the very parents for whom care is being considered.

*Moral dilemma*

Our second problem of moral choice is the moral dilemma or moral conflict: that condition which exists when one *ought* to choose two or more competing, and mutually exclusive goods or rights. We have already discussed choices made in view of goods. When a daughter ought to protect her mother's physical security and ought also to protect her mother's financial security, she may find that one alternative excludes the other, as in the case of a need for institutionalization at $26,000 a year.
Rights are grounded in goods. They are moral claims to goods: e.g. a right to justice, a right to security, a right to well-being. A daughter making a long-term care decision may weigh the right to security of her parent, against the right to security of her children, against her husband's right to well-being, and may find that, no matter what action she chooses, all rights cannot be met. She must then evaluate the dilemma, and act accordingly. The outcome, or moral action, will reflect this process.

Duties are grounded in rights and are the actions to which we are obligated. A daughter who believes she is obligated to provide long-term care to her parent, obligated to provide nurture and guidance to her children, and obligated to fulfill her responsibilities at work, may learn that she cannot fulfill all obligations. Again, she must evaluate the dilemma, and act accordingly.

Certainly at issue may be the competing choices of daughters and dependent parents, of daughters and well spouses of dependent parents, of daughters and siblings, and of daughters and spouses and/or children. Central to the decision experience may be an autonomy/paternalism dilemma rendering choice problematic. (Kleinig, 1983) Whose choice is this? is an important moral question.

The process of evaluating a dilemma may be defined in two categories: 1) the formalist, or deontological, and 2) the utilitarian, or teleological. Dilemmas evaluated and resolved using a formalist approach base moral judgments on moral imperatives which subsume all alternatives. According to Kant, a deontologist, moral imperatives are "commands or prohibitions" (Kant, 1948, translated 1971, p.38) which come from moral principles, e.g. "Honor thy father and thy mother," It is wrong to lie, It is good to care. The moral imperative to reciprocate care may subsume for a daughter all other alternatives presented in the decision dilemma. Evaluating from formalist perspective, she would disregard the consequences of all alternatives not consistent
with her obligation to reciprocate care. (This is the form of quasi-satisficing discussed earlier.)

Dilemmas evaluated and resolved using a utilitarian approach base moral judgments on the consequences of each proposed act. John Stuart Mill, a teleologist, argued that, "[t]here is no ethical creed which does not temper the rigidity of laws by giving a certain latitude, under the moral responsibility of the [actor] for accommodation to peculiarities of circumstances..." (Mill, 1961) Using a utilitarian approach, a daughter confronting conflicting rights or goods (for example, her mother's right to a healthy environment, vs. her own need to work, vs. her obligations to her children and/or husband) will evaluate the dilemma through a process of predicting the consequences and weighing their utility, each against the other. (Subjective expected utility theory, satisficing, and the conflict model of choice, discussed earlier, are all descriptive of the utilitarian approach to moral dilemma or conflict.)

The construction of moral problems

Given the earlier configuration [that women "resoundingly endorse the traditional value of filial responsibility to the aged" (Brody, 1981), that women do most of the caregiving, and that women experience increasingly conflicting obligations and role expectations], we may now presume that, for many daughters confronting long-term care decisions, there exist inherent moral conflicts. Recent studies by Carol Gilligan lend support to the idea that women are especially vulnerable to moral conflict when issues of care are being considered.

Gilligan (1982) categorizes moral thinking in two perspectives: justice (the male "voice") vs. care (the female "voice"). The perspectives are further dichotomized: law and logic vs. relationship and communication; categorical vs. contextual thinking; rights vs. responsibility; simplicity vs. complexity of choice. She
argues that: 1) Women define themselves as moral persons on the basis of their relationships to others. 2) "[W]omen not only define themselves in a context of human relationship but also judge themselves in terms of their ability to care." (p. 17) 3) Women construct moral problems differently based on this different perspective.

The moral ideal of care, according to Gilligan, is an "activity of relationship, of seeing and responding to need, taking care of the world by sustaining the web of connection so that no one is left alone." (p. 62) Moral dilemmas for women are represented in conflicting responsibilities to care. The central moral problem for women then is the conflict between self and other, and morality becomes defined as the responsibility to care for others. This conception of morality lends support to the idea of a moral dimension in caregiving decisions.

Summary

Clearly, decisions about the nature and level of participation in parent care involve multiple issues with far-reaching implications. This literature review has provided a profile of daughters as caregivers, explored the contexts of the decision experience, examined both caregiving attitudes and caregiving experiences, reviewed the decision theory literature, established an argument for the pursuit of inquiry from the perspective of conflict and limited rationality, and proposed a moral dimension of choice in the decision experience. Fundamental questions about the caregiving decision process remain. These include:

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16 Gilligan argues that her conclusions are not strictly gender-divided, that her work is a focus on the difference between the two moral orientations (justice and care): "The title of my book was deliberate; it reads, "in a different voice," not "in a woman's voice." (Gilligan, in Kerber, et al, p.327) However, she consistently assigns the moral orientation (or "different voice") to women and the justice orientation to men. I have preserved this assignment in the argument, because the argument is not dependent on the exclusion of men from the orientation. For further discussion, see Kerber, L.K. et al, "On In a Different Voice: An interdisciplinary forum," Signs, Vol.11:2, 1986, pp.304-327.
What caregiving behaviors are recognized as products of decision, and what are not?

How do decisions about care transpire? (What are the triggers, what is the time frame, who are the actors?)

How do individual decisions interface with interpersonal decisions (e.g. daughter and family, dependent parent, professionals)?

To what resources do decision makers turn in the decision process?

What alternatives are considered in the decision process?

What consequences to alternatives are considered in the decision process?

What factors limit rationality?

What is the role of values in the decision process?

What are the effects of the decision experience for all actors?

It is with great caution that this literature review has been conducted. An attempt was made to identify the salient features of the decision experience without consequently constraining the research process with premature focus. The inquiry begins, therefore with one central question:

_How do daughters decide the nature and level of their participation in the long-term care of their dependent parents?_ Or, reframed: _How are caregiving behaviors and attitudes linked in the decision process?_
CHAPTER III
METHODOLOGY

Introduction

Inquiry into the decision process of women regarding the nature and level of their participation in parent care must be undertaken with respect for the complexity of the decision experience. Differences in the life stories of individual women in their particular contexts must be assumed, and their dynamic nature anticipated. The purpose of this study is exploratory and descriptive. Qualitative methods are used to respond more sensitively to the multiple and distinct (less generalizable) realities of research participants.

This study utilizes the "stories" of daughters' caregiving decisions as the primary data for analysis, relying partly on the memory of their decision experiences. It is valuable, for purposes of analysis, to consider whether memory is reproductive or reconstructive. That is, do stories represent the way things "really" were, or do they represent the attribution of new meaning to the way things were?

Reconstructions

Kurt Lewin, who first proposed an analysis of decision making as psychological conflict, raised important issues about social pressures and other sources of "defective" decision making. He contributed important work about the psychological consequences of social commitment to a decision. In 1957, as an outgrowth of Lewin's work, Leon Festinger introduced a theory of cognitive dissonance. This theory holds that a re-evaluation of attitudes occurs after a decision in order to make relevant
cognitions consistent with choice behavior, i.e. to reduce cognitive dissonance. (Festinger, 1957) This phenomenon is called cognitive bolstering: magnifying the attractiveness of the chosen alternative, and minimizing the attractiveness of rejected alternatives.

Stover, Belenky and Gilligan (1982) argue that memory is reconstructive rather than reproductive but that it is possible to reconstruct events in the same terms as the original construction. The question remains: what is the effect of bolstering on memory? Is a decision made rational through reconstruction in order to reduce dissonance? Is a decision justified on grounds other than its original motives? Does it matter? Attribution researchers argue that accuracy of perceptions doesn't matter. What matters is that stories do indicate some relationship between response to the decision outcome and the memories of the decision circumstances. (Johnson and Werner, 1982; Nisbett and Valins, 1971) What can we know about decisions shared from memory, even recent memory? This question informs the research methodology in this study.

What we are able to know from women's stories is the constructions of their particular realities and the meaning that is derived from them. What is "true" or "real" is what they construct to be true or real. Truths cannot be established a priori, imposed and tested by research design. The only truth claims we can make are to the shared interpretations of the researcher and the participants as they emerge in the research process. This is achieved through a qualitative approach.
DESIGN

This design is characterized by the following principles and methods as identified by Lincoln and Guba (1985):

*The use of the human instrument and interactive interviews*

The researcher is the primary data-gathering instrument, utilizing interactive interviews in the methodology. Utilization of *tacit* (intuitive) *knowledge* in addition to propositional (expressed through language) knowledge is a product of the interactive interview process. Unstructured interactive interviews allow for the immediate responsiveness of the researcher to the data as they emerge. As data emerge, they inform further inquiry. Inquiry therefore is based not on *a priori* assumptions as the research begins but on the developing focus suggested in the data as the inquiry evolves. By beginning with unstructured inquiry, the researcher puts the participants at the center of the inquiry. The participants name what is important to the study by the issues and experiences they identify as meaningful. This especially allows for the attention to particulars of individual stories and the individual meaning they have to each participant. In this study, the individual and group interviews are the dominant strategy for intervention. Through an interactive process of mutual interpretation, the researcher and participants collaborate to develop theory.

*Inductive analysis, emergent focus, grounded theory and emergent design.*

Categories of meaning are allowed to emerge from the data through the use of inductive data analysis. This approach is theory generating. Theory emerges, or is grounded in, the data. (Strauss, 1987) Lincoln and Guba argue that no *a priori* theory could encompass the multiple realities likely to be present. The interpretation of data is therefore *idiographic* in nature, that is, conclusions are drawn in terms of the particulars of the cases studied, rather than in terms of lawlike generalizations. This approach implies *tentative application* of findings and *special criteria for
trustworthiness (or what is conventionally called validity and reliability), to be discussed later in this chapter.

Purposive sampling

Purposive sampling is used to achieve as full a range of "realities" as possible. In this study, maximum variation sampling is used to cover as broad a range of decision experiences/outcomes as possible. This approach allows for both the shared and idiosyncratic characteristics of the stories to be analyzed.

Triangulation

The qualitative design of this study requires the triangulation of data, procedures implemented to validate one group of data with another. Methods of triangulation include the use of multiple sources, methods, or researchers. In this study two data gathering methods, individual interviews and focus group interviews, were used to enhance the trustworthiness of the data. In addition, outcomes or findings were negotiated through a process called member-checking in which the researcher shared and verified information and interpretations with research participants.

FOCUS

The problem for research is the decision process of daughters about the nature and level of their participation in the care of their dependent elderly (over age 65) parents. In one case, the mother was 64 years old, but her level of dependency, the critical criterion, so high that the daughter was included in the study. Participants represent varied decision experiences, represent a moderate age range (ages 43-60), and are residents of Southwestern Ohio.
SITE OF STUDY

Individual interviews were conducted at multiple sites. In order to ensure maximum comfort and convenience for the participants, time and location of the interviews were left completely to the discretion of the individual participants. In one case, interviews were conducted in the chapel of the nursing home in which the participant's mother resided. In three of the cases, interviews were held in the participants' homes. In the fifth case, the interviews were held late in the evenings at a restaurant near the home of the participant. Although the researcher had concerns about both the privacy and distractibility issues such a site raises, the participant chose this site because it is where she does her "best talking". The restaurant had come to be a place of escape for her, and her judgment was followed in using this site.

The focus group interviews were conducted in a comfortable video recording studio at Miami University, Oxford, Ohio.

SAMPLE

The sample used in this study was limited and purposive, to cover five different decision experiences/outcomes:

1) direct placement in formal caregiving facility
2) placement followed by home care (co-residency)
3) home care (co-residency) followed by placement
4) all home care (co-residency)
5) out of home care (separate residences, parent in own home)

Ten women were selected to cover the five decision areas: five participants for individual interviews (who covered items 1 through 4, above) and five participants for focus group interviews (who covered items 2 through 5, above). The sample was limited to daughters only.¹ Participants whose dependent parent/s is/are still living,

¹It is assumed that the dynamics of the relationships of daughters-in-law and parents-in-law are qualitatively different from those of daughter-parent relationships. A study of daughters-in-law would be an important follow-up study.
and for whom at least some of the decisions about care were immediate or recent, i.e. within a three month period, were selected.

All of the women in the sample cared for dependent mothers. Therefore the study developed an early focus on mother-daughter caregiving, even though two women were also giving care to fathers. All of the women in the study were white and ranged from working class to upper middle class socio-economic status. This range of socio-economic status was inferred by occupations, and secondarily by indicators of economic background in their stories. No effort was made to establish more than this inferred range of socio-economic status. All of the women in the sample are married, and all have children. Four out of the ten work outside the home. A brief biography of each participant is presented here.

**Individual interview participants:**

**Diane**, age 51, married with two grown children. Diane works four days a week as an office manager in a professional office. Her husband is in middle management and is also a part-time farmer. Diane's mother, age 85, is physically well but is dependent by nature of her dementia, and needs constant supervision. Diane's mother lives with her and goes to day care at a nursing home four days a week.

**Carol**, age 47, married with two grown daughters. Carol did not work at the time of the first interview, but was working full time by the time of the second interview. Carol's mother, age 74, has circulation problems and has lost one leg as a consequence. Carol's mother lived with Carol's family for five years, and eventually moved to a retirement center upon Carol's request.

**Helen**, age 55, married with one grown daughter. Her husband is an insurance agent. Helen does not work outside the home. Her mother, age 85, has multiple diagnoses, including cancer and neurological problems, and has been living in a nursing home since her hospitalization.

**Linda**, age 57, married with two grown children. Linda does not work outside the home. Her husband is a factory worker. Linda's mother, age 88, also has multiple diagnoses, including diabetes and heart disease, and at the time of the first two interviews was non-ambulatory. Linda also cares for her developmentally disabled
sister, three years her senior. Linda's mother and sister have lived with her for eleven years. Linda's mother was placed in a nursing home after the second interview.2

Susan, age 43, married with two grown children and one four-year-old daughter. Susan does not work and her husband is in middle management. Susan's mother, who died after the second interview at age 64, had Parkinson's disease and was bedridden. Susan's mother had been in a nursing home at one time, and had been receiving full-time care from Susan's sister at the time Susan assumed caregiving. Susan's mother lived with Susan in her home until her death.3

Focus group participants:

Janet, age 52, married with three grown children. Janet does not work outside the home. Her husband is a professional. Janet's parents are both living. Janet's parents are dependent by nature of their frailty, by the father's alcoholism, and by their mismanagement of their affairs. Janet's parents live in their own residence, where they moved from out of state to be near their daughter.

Eve, age 49, married with three grown or college-aged children, some of whom live with Eve and her husband off and on, and one teenager, still at home. Eve works part-time as a secretary. Her mother, age 86, is grossly dependent by nature of her severe dementia. After living for three months in Eve's home, she was placed in a nursing facility.

Marian, age 60, married with two grown children. Marian does not work outside the home. Her husband is a professional. Marian's mother, age 88, is minimally dependent by nature of her frailty and poor judgement about diet, etc. She has lived with Marian and Marian's husband for one year.

Nan, age 49, married with one grown son. Nan works full time, and her husband is a professional. Nan's mother, age 87, has severe dementia and heart disease. After living with Nan for over ten years, she was placed in a nursing facility.

Kay, age 53, married with three grown children, one of whom has a chronic illness and lives at this time with Kay and her husband. Kay works part-time in her husband's professional office. Her parents, both living, ages 86 and 84, live four hours from Kay's home. Kay makes an average of two four-day caregiving trips per month to her parents home where she manages their household affairs, and prepares and freezes meals for the period of her absence.

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2 In Chapters IV and V of the analysis, this case is presented from the perspective of the first and second interviews, before nursing home placement. The impact of nursing home placement on Linda and her mother is discussed in Chapter VI.

3 In Chapters IV and V of the analysis, this case is presented from the perspective of the first and second interviews, when the mother was still living. In Chapter VI, the fact of the mother's death and its impact on Susan are discussed.
Recruitment of participants

For the individual interview sample, social workers at nursing homes, hospitals, and social service agencies in Butler and Hamilton counties were contacted, informed of the study and its purpose, and were asked to solicit permission of potential participants to be contacted by the researcher. Once permission to be contacted was obtained, basic identifying information, including the status of parent care, were then given by the social workers to the researcher. The researcher categorized the list of potential participants according to the five decision experiences identified above.

Letters of introduction and information were then mailed to prospective participants and each letter was followed by a telephone call as had been indicated in the letter. (Appendix A) This telephone contact served to answer questions about the study and to establish an initial agreement and interview appointment with interested participants. In three cases, the mothers of the participants died or were hospitalized, and the prospective participants withdrew before an interview could be scheduled.

In securing the focus group participants, the researcher used a combination of purposive and snowball sampling. Following Phase One of the data collection (individual group interviews) it was determined that the approach to covering the five decision areas was effective and still desirable. A particular effort was made to recruit at least one participant who was giving out-of-home care (separate residences, parent in own home), an area uncovered in the individual interview sample.

Two recruitment obstacles arose in securing the focus group sample. First, due to the requirement that the participants come together in the video recording studio, it was determined that recruitment of participants living nearby was necessary. Second, participants were asked to commit to two common dates, one week apart. Those obstacles were overcome by using a snowball sample.
The director of the area senior citizens' center provided the researcher with a list of eight names of potential participants. Of those eight, only two could participate, but they were able to identify others in the community who would fit the purposes of the sampling design. The researcher telephoned these prospects directly, naming the source of the referral and explaining the study. Twelve prospective participants were called before two common dates could be identified for five participants. As it happened, although all five came to the first group interview, two were prevented by unforeseeable circumstances from returning the next week.

As might be inferred from the use of a snowball sample, all of the participants were acquainted with at least one other participant in the group. They were also acquainted with the researcher, who lives in the same area as the group participants. Subgrouping, one of the risks of such an arrangement, was not apparent. As a matter of fact, it was the subjective impression of both the researcher and the participants that being acquainted with at least one other member in the group enabled the group to "skip over" superficial issues and introductions, and achieve an earlier focus than might have been possible otherwise. In addition, the group participants pointed to immediate trust and comfort with the researcher, something that took longer to establish in the individual interviews.

DATA COLLECTION PROCEDURES AND INSTRUMENTATION
To achieve triangulation of data in this study, two methods of inquiry were utilized: 1) individual interviews, and 2) focus group interviews. In addition, a member-checking procedure (Lincoln and Guba, 1985), returning to the participants with a preliminary analysis through which interpretations were discussed and negotiated, was utilized as a triangulation device. The two identified data collection methods will now be discussed in greater depth.
Phase One: Individual interviews

Five women were interviewed individually, face-to-face, for two one-and-one-half to two-hour sessions. Participants were fully informed as to the nature of the study, the use of the data, and the requirements of the participants. Informed consent to participate was granted through a written contract. (Appendix B) Each interview was audio-recorded for later transcription, as agreed to by participants prior to the signing of consent forms. In addition, notes were taken by the researcher during the interview. An unstructured interview initiated the study. The initial question was:

_Could you please describe the status of your parent's (s') care, how it came to be, and how you were or are involved in this process?_

This open question allowed each participant to identify salient issues from which the interviewer was able to derive further, more focused, questions. Some questions (semi-structured), derived from the literature review, were held in reserve and available at the discretion of the interviewer. (Appendix C) Some of these questions were indeed used, but only at the cueing of the participants' stories.

All five individuals were interviewed at the first phase before going back for Phase One second-level data collection. For this reason, the interviews were scheduled as closely together as possible (within a one-month period) to minimize lag time between first and second level interviews.

As described earlier, the interviews were minimally structured from the central research question. Consistent with the concept of emergent focus and design, more specific questions developed as the data were gathered. Each interview, and each level of interviews, provided a ground from which a higher order of inquiry was pursued.
Second-level interviews began within one month after first-level interviews were completed. This level served as a time for further exploration of earlier issues raised as well as for member-checking.

**Phase Two: Focus group interviews**

Focus groups rely for data collection less on the interaction of researcher and participants than on the interaction of participants within a group setting. The hallmark of focus groups is "the explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group." (Morgan, 1988:12) Different data emerge through the interaction and mutual stimulation of participants who share common issues. (Wells, 1979) The process of mutual shaping and construction of realities generates perspectives different from those gained in the individual interviews. A further advantage of the group interview is the de-emphasis of the researcher's perspective as members' perspectives are reinforced by peer feedback and support. (Morgan, 1988)

The group met for two two-hour sessions. The first group interview of five new participants represented the second phase of data collection. As with the individual interviews, informed consent for participation was also obtained (Appendix B). In the case of the focus groups, videotaping was used in order to identify the voices of individual participants for transcription. Notes were taken by the researcher during the groups.

The central research question, in its broadest form, served as the foundation of the group interviews as a means of preserving the triangulation power of the group approach. However, additional, more structured research questions in the focus groups were grounded in interpretations of Phase One data. (Appendix D)
A second-level group interview was held one week following the first group interview. The purpose of the second session was to further explore content and to member-check interpretations of both the earlier meeting and this particular session. **Phase Three: Member-Checking Interviews**

Although member-checking is an on-going process, a distinct phase of the design included the sharing of data analysis with each of the participants following the conclusion of data collection interviews. Telephone interviews were conducted in which the researcher 1) shared the core categories of analysis, as well as a summary of interpretations. Telephone interviews were not tape-recorded. Instead, the researcher took notes during the interviews.

These member-checking interviews represented attempts at pulling together the salient features of the decision process for verification of the participants. The interviews were not designed to elicit generalizations, but allowed for identification of both shared and disparate features of the decision process, allowing particulars to be preserved. In addition, the researcher identified for the participants how their stories and quotes from their stories were to be used in the analysis and its presentation. Feedback of the participants was sought, using the following question: *Do you feel your experience [your story] [your voice] is represented in this analysis? How is it, or how is it not?*

Responses from the member check were supportive of the analysis as it had developed. The participants used expressions such as "I think that's exactly right" to "You have worded it beautifully" to "I think so, yes." (Is your voice represented?) Participants also added ideas to the analysis at this time. One important dimension added to the analysis from the member check was the function of time in achieving a balancing point of care.
The member-checking interviews served their intended purpose and also functioned to update the researcher on the caregiving activities of the participants. In two cases, significant changes had occurred, and in one case a caregiving shift appeared to be imminent. Those three cases are presented with two others in Chapter VI and are presented in two parts, the analysis from the first two interviews and a "postscript" from the third.

DATA ANALYSIS

Consistent with the idea of grounded theory and emergent focus and design, data analysis is an on-going process. Data were analyzed as they were discovered, using a "constant comparative method" (Strauss, 1987), the comparing of new data to concepts generated by the inquiry. Constantly reshaped and reframed, on-going analysis elicited ideas with which the focus was narrowed and interpretation refined. The center of data analysis in this project is text, or the words and expressions that form the stories of the participants. Text was transcribed verbatim from the tape recordings of the interviews. A professional typist transcribed the individual interviews from the audio recordings, and, to assure confidentiality, the researcher transcribed the group interviews from the video recordings.

Text was analyzed through a process of coding, or conceptualizing data. The following procedures of analysis developed by Anselm Strauss (1987) were utilized:

1. Data collection is included in analytic procedures because the gathering of data and the analysis of data are mutually shaped. Data analysis begins very early in the data gathering process. In the case of this project, data analysis began with the first interview. The early, provisional analysis shaped and informed subsequent data.

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4An illustration of coding, from a page of interview transcript, is presented in Appendix E.
collection. That is, data collection was directed not only by data gathered within each interview, but by data gathered from interview to interview, level to level, and phase to phase in the study.

2. Concept-indicator model which directs the coding. Text was examined for observed or described actions, ideas or events which when integrated with a constant comparison method indicate a concept. An example of a concept used in the study was "shift in caregiving".

3. Coding is the general term for naming and conceptualizing data. Coding is derived from identifying the conditions, interaction, strategies/tactics, and consequences of an observed or described action, idea, or event. Coding begins with an open coding method, identifying provisional indicators, and ultimately becomes more focused and selective as the analysis develops. Codes may be: 1) in vivo codes, terms used by the participants in the study. An example of an in vivo code in the study is "caregiving as reflex". 2) researcher-constructed codes, codes formulated by the researcher using social science knowledge. An example of a researcher-constructed code in the study is "dependency".

4. Categories are groups of concepts, linked and distinct by their relationship with each other. An example of a category is "filial obligation".

5. Core categories are those categories of concepts from which theory is generated. Strauss identified several criteria for the determination of a core category. It must be central (related to many other categories), appear frequently, relate easily to other categories, have clear implications for a more general theory, and allow for maximum variance in the analysis. An example of a core category in this study is "moral ideas".

6. Integration is the center of evolving theory. Integration is a process whereby the researcher/analyst determines the salience of identified dimensions and categories,
pulling them together to build theory. An example of theory developed out of the integration of categories is "impulse to care".

7. **Theoretical sampling** is a process by which the researcher decides what data to collect next and for what theoretical purpose. This analytic method clearly shapes the emergent research design. In this project, theoretical sampling was used to select the participants for the focus group after Phase One of data collection.

**Coding, editing, and organizing data**

Data were coded by hand on the interview transcripts. (Appendix E) The text was computer-edited, i.e. cut-and-pasted, from hand-noted categories for each interview. For example, all quotes expressing "filial obligation" ideas were hand-noted as such, and were cut by computer from the interview text and pasted together under categories (e.g. "filial obligation"), in sequence. This editing was done with both interviews for each participant. One product was one book of categorized and core-categorized quotes for each of the ten participants. A second product was three books of categorized and core-categorized quotes for all of the participants, subdivided for the integrated areas of Impulse to Care, Decision Process, and Balancing Point (subsequently Chapters IV, V, and VI). At one point in the analysis a fourth book, Paternalism and "Mothering", existed but was integrated with both Impulse to Care and Decision Process.

Editing of quotes, that is, extracting them from context, risked not only the disintegration of the stories, but also the distortion of meaning. An attempt was made to minimize these risks by frequent cross-reference with both the individuals' books of edited text, and the individual and group unedited transcripts.
PLAN FOR TRUSTWORTHINESS

Trustworthiness is a concept in qualitative inquiry substituted for the conventional concepts of validity and reliability. Lincoln and Guba (1985) have provided important guidelines for the development of trustworthiness. The central question of trustworthiness is "How can the research findings be demonstrated as worth taking account of?" Procedural criteria are built in to promote credibility, applicability (or transferability), and consistency of findings without constricting the variation of the findings, and without pretending to generalizations and predictability.

Credibility is achieved through what Lincoln and Guba call the test of isomorphism, that is, the researcher must demonstrate that she has adequately represented, through the data and interpretations, the multiple constructions of reality inherent in a subject of human variation. The interpretations made from the inquiry process and analysis must be credible to the participants of the study, the original constructors of the realities being studied. This was achieved in this study through processes built into the research design: prolonged engagement and triangulation of method.

Prolonged engagement is the extensive investment of time of contact with the research participants. The use of multiple interviews with each participant in the research design allowed the researcher to build trust, test for misinformation, and allow for in-depth examination and mutual interpretation of stories.

Triangulation methods in this design are 1) the use of multiple sources: individual interviews and focus group interviews; and 2) member-checking. Multiple sources allow for a high level of variation from which an organization and integration of concepts, and more credible theory, may be generated. Multiple interviews serve as a member-check mechanism, a means for sharing interpretations of ideas and checking the interpretations against the perceived realities of the research participants.
Confirmability is a measure of the accuracy of the data, and is achieved primarily through an audit trail. The audit trail is the compilation and organization of the raw data (e.g. tape recordings, transcripts), data reduction and analysis products, (e.g. interview notes, all coding notes and diagrams), and all instrument development information. The audit trail was made available to an auditor, in this case the Dissertation Committee, in order to attest to the confirmability of the research.

Another method used to enhance the trustworthiness of this research project was the self-reflexive journal, recommended by Lincoln and Guba. The purpose of the journal is to provide an account of the daily schedule and logistics of the study, a personal diary for reflection upon both subject matter and the research experience, and a methodological log which provides a record and rationale for emergent methodological choices. Although not kept daily by the researcher, this method served to keep the project focused and organized. However, the self-reflexive journal was secondary in usefulness to another Lincoln and Guba method: peer debriefing.

Peer debriefing is a procedure in which the researcher shares the research progress and developing analysis with a "disinterested peer". Its purpose is to expand the boundaries of thought, allow for new perspectives, and provide for an exercise in conceptualizing data and building theory. The researcher's biases are probed and interpretations challenged. Ten peer debriefing sessions were held between the researcher and one "peer", a fellow researcher. The peer debriefing sessions lasted from one-half hour to two hours.

PILOTS

Two pilot interviews were conducted by this researcher. The first was with a woman who had cared for her stroke-disabled father in her own home for twelve years before he went to a nursing home two weeks before his death. The second was with a
woman who provided "long-distance" caregiving to her mother and ultimately assisted her with nursing home placement. Both interviews were rich with data. Both were also emotional experiences for the participants.

Most significantly, the two interviews reflected both different and shared experiences and ideas, suggesting with just two interviews the potential for rich variation and, provisionally, the development of meaningful concepts. In spite of the provisional identification of concepts from the pilot interviews, the first level of interviews in Phase One was kept very open and unstructured. That is, no conscious effort was made to analyze the data until Phase One began.

PROTECTION OF PARTICIPANTS

All tapes, transcripts, and notes were kept in a locked file. No taping took place without the consent of participants. Although transcripts will be preserved after the publication of the research project, tapes will be destroyed at that time. Confidentiality has been protected through the obscuring of identifying information in both the discussion and the writing of this research.

Participants were at risk of becoming emotionally uncomfortable by the exploration of caregiving issues, and indeed, particularly the individual interviews were emotional ones. The researcher, a Licensed Independent Social Worker and Qualified Mental Health Professional, is skilled to handle immediate needs and to make appropriate referrals when indicated. Grief counseling was recommended in one case.

EXPECTED IMPLICATIONS

It was expected that new knowledge about long-term-care decisions would unfold in this study. The study is descriptive and exploratory, and does not seek to make generalizations about the decision processes of all daughters of the dependent elderly.
Instead it seeks to build a theory of decision making from the in-depth study of a small sample. Knowledge about how daughters decide and the meaning they ascribe to their decisions have both policy and clinical applications. Policy-makers can begin to base their policy and program initiatives on clearer assumptions about the relationship between caregiving attitudes and caregiving behaviors. Gerontological and other social workers who assist daughters with decision, or with its effects, can do so with an enhanced understanding of the dynamics of the decision experience.

**LIMITATIONS**

Although this study does not make generalizations about the population of daughters of dependent elderly, a number of sampling issues limit the transferability power of the findings. First, sample recruitment led the researcher only to women who were involved with their mothers' care at some level. Nursing homes, hospitals, and social service agencies made referrals from their client populations---those already connected with services. The sample does not account for those women who have declined or are unable to participate significantly in their parents' care.

Second, the sample is limited by a certain degree of homogeneity. All of the women are white, married, with children. None of them are poor. This essentially middle-class sample enjoys a higher economic standing and hence a higher resource threshold than their less advantaged peers.

Clearly, the voices of minorities, single women and poor women are not represented in this study. Attempts were made to secure a more heterogeneous sample in sampling recruitment; such women were in the pool of prospective participants but declined or were unable to participate in the study. The recruitment process tended to eliminate women for whom participation in a study was regarded as an extra burden on an already-burdened caregiver. Daughters who were "home-bound" by their
caregiving more easily participated in the individual interviews, adaptable to location and time. Requirements of focus group participation excluded women who could not easily leave their homes for the group interviews.

Another sampling limitation is the cohort issue raised by the age range of the daughters in the study. Not represented are those daughters over sixty, who are a generation older than the youngest participant in the study. The population of caregivers over age 60 confronts added issues in caregiving decisions not the least of which is the regard for their own health and physical capacity to give care. The findings of this study must also be cautiously transferred to the cohort group under age forty which is characterized by a high percentage of working women and by a generation of women for whom decisions about caregiving may be objectively different from their elders'. In the Philadelphia Geriatric Center caregiving study, Elaine Brody (1985) and others found “value continuity” in three generations of women with regard to attitudes of filial obligation. We will not know, however, how attitudes of the younger age cohort are translated into behaviors until they are confronted with the real dependencies of parents and the necessity to make caregiving decisions.

A final sampling issue is the limitation this sample places on our understanding of daughters’ caregiving decisions on behalf of dependent fathers. Great caution should be exercised in transferring findings about mother-daughter caregiving decisions to father-daughter decisions. Likewise, caution should be exercised in transferring findings about daughters’ decision making to that of daughters-in-law, wives, sisters, etc. of the dependent elderly. It should be clear that this is a study limited to daughters’ decision making about the nature and level of their participation in the long-term care of dependent elderly parents, most particularly dependent mothers.

A limitation arguable in the data collection phase of the research is the effect of mutual acquaintanceship on the focus group. It has already been argued that the trade-
off for relative anonymity was a level of comfort which allowed the group to move beyond otherwise necessary superficialities in the early phase of what Spradley (1979) calls "grand tour" and Lincoln and Guba (1985) call "warm up" questions. The question remains, however, how acquaintanceship might have limited self-disclosure in the group. It is informative to note that the group interviews were less emotional than the individual interviews. In the individual interviews, each of the women wept during some part of telling her story. The group interviews elicited no such tears; rather, the group was characterized by an upbeat, mutually supportive and reinforcing spirit, and by what appeared to be a mutual bolstering of decisions made.

A limitation of the research design in terms of analysis is the use of a single coder, the researcher. The research findings are inevitably bound by the perspectives of the researcher, her world view, and her way of knowing. Multiple coders may have produced a quite different analysis.

Finally, as alluded to earlier, the process of editing text, that is, removing it from its context, risks the distortion or misinterpretation of meaning, and jeopardizes the coherence of the women's stories. This limitation was addressed in a number of ways. First, the procedure of keeping multiple books, including transcripts of unedited text for frequent cross-reference served to keep the researcher in touch with each story as a whole. Second, the ongoing member-checking and collaborative nature of the study minimized distortion and misinterpretation of meaning. Mutual interpretation included a mutual verification process. Third, five cases are used in Chapter VI in a case presentation format, allowing each of the five women's stories to remain intact.
Summary

This qualitative inquiry project produced rich data from which theory about caregiving decisions emerged. It allowed for the multiple realities of the individual participants to be heard. Repeatedly the researcher encountered information and perspectives in the interviews not able to be anticipated and not achievable in a quantitative project. In retrospect, the researcher believes a quantitative project developed from her literature review would have asked strikingly different questions, and consequently produced strikingly different information. By putting the participants at the center of the research project, that is by allowing each to define meaning in her own decision experiences, the research design produced meaningful theory about daughters' caregiving decision processes.
CHAPTER IV
THE IMPULSE TO CARE

Introduction

The ten women in this study represent not only a broad range of caregiving circumstances but also a richly varied response to the needs of their dependent parents. Common among all of them, however, is the impulse to care, the struggle to balance self vs. others in their decision experiences, and the movement of this struggle toward a balancing point of care which each has defined, in quite individual ways, as "enough". This analysis begins with an exploration of the impulse to care and its impact on caregiving decisions. It then turns, in Chapter V, to an examination of the decision experiences of these women and a discussion of the relationship of these experiences to decision theory. In Chapter VI, the analysis concludes with the development of the concept of a balancing point as it is interpreted to influence patterns and shifts in caregiving behaviors.

THE IMPULSE TO CARE

The idea of an impulse to care is the outcome of a struggle to conceptualize a human response to human need that defies human explanation. Indeed, to reduce the impulse to care to a singularly determined human condition is to under-regard the multiple dimensions and dynamic nature of human development and social relationships.
Words considered and discarded in the effort to conceptualize the response to a parent's need for care as the research evolved were compulsion, instinct, injunction, and imperative. *Compulsion* was rejected by the women in the study as suggesting something out of their control and was also negatively associated with disease or personality disorder. *Instinct*, though used by two of the women in associating caregiving with mothering, was dismissed as unsupported by other information, and as representing an unfounded leap to biologically-determined conclusions. *Injunction*, used frequently in caregiving literature, and *imperative*, used frequently in moral theory literature, both were rejected by the researcher as representing social forces or ideas which shape the human response to need, but do not name it. Rather, the women in this study, describing their response, use words such as "natural", "automatic", "reflex", "obvious", "need to", "want to", "have to", and "impossible to do otherwise". *Impulse*, therefore, emerged as the best word to name the response to need in a way that 1) adequately reflects the inextricability of the self from the situation (of parent dependency), as expressed by these women, 2) clearly represents the first inclination to care evident in their stories and 3) allows for all the possibilities of predisposition to care, *including* compulsion, instinct, injunction, and imperative. *Impulse* describes, without pretending to explain, the first response of the women in this study to the long-term-care needs of their dependent mothers.

In an outburst of reaction to the question "Why do you give care?" the women in the focus group demonstrate multiple dimensions of the impulse to care in attempts to explain it. All of the following dialogue is in a tone of "Preposterous! What a ridiculous question!":

**Kay:** Well, I wouldn't have it any other way, and I don't think they would either! They would help me! They would do everything they could....

**Janet:** You love 'em!
Nan: And they've done for us. They have done for us, and what we're doing is returning that affection and doing what we need to do to show them that, you know, we're appreciating what they've done for us.

Marian: We care!

Nan: I just wouldn't think about it any other way!

Kay: Well how would they get along?

Janet: It's just because they are ours that you do it without question, when you know that they really need it.

Eve: You do it because you have to. Because it needs to be done. And also because we're here!

Inextricability

What are the implications of the idea of impulse for the decision experience of daughters of dependent mothers? The first consideration must be to the inextricability of the self from the situation. Daughters express intense feelings of attachment, love, and identification with the mother which contribute to this sense of inextricability. Feelings of attachment pervade their stories, and often are related directly to the absence of all but the most superficial consideration of alternatives to parent care in the early stages of parent dependency. These feelings of attachment are expressed in strong metaphorical imagery.

Helen: You feel like there is no decision or you can't make decisions. It's almost just a reflex. You just feel a responsibility to your mother......it's like the umbilical cord was never cut.

Kay: I think blood runs deep here. I'm not saying that I could do a better job, but I have more of a feeling of what's going on by being the family, than a person outside the family.

Susan: It would be like if your hand was deformed, you'd hate it, but would you cut it off? Even though they're your parents, it's just like a responsibility of family too.
When asked about alternatives to caregiving, some express a sense of impossibility, attributing it to love for the mother.

**Diane:** I really couldn't do that...I just couldn't. I couldn't have left her. Deep down it is love. If you didn't get hurt about it, you wouldn't care.

**Susan:** I couldn't abandon something I love. It would be hard to abandon somethin' I didn't love, the stray dog come to the door...I couldn't just say ---- Git! So to turn away from somebody you truly love, you know, it's an impossibility...It's just so overwhelming... I couldn't do it. It would break my heart. Because here with me...I love her, you know. Somebody else is not gonna love her....if you could take part of that away and carry part of her burden yourself, you would do it.

Feelings of identification with the dependent mother and her suffering or disability intensify the impulse to care.

**Nan:** I feel as much pain (points to heart) I'm sure as my mother does when she has her angina attacks, because this is such an intense, horrible thing and her face just distorts...and I just say I want to make it better, Mom, I just want it to be O.K., I want it to go away. I don't ever want it to happen again.

**Susan:** I think being so totally dependent on somebody that you can't even scratch your own nose. You can't, you can't even take a sip of water, or put a bite of food in your mouth or shift your body when you're uncomfortable. To be that dependent on somebody....At one time I thought----well, anybody that'd be in that situation, you know, everybody would surely flock [to help]....that's not reality......people turn their back.....It just feels like you're ripped apart, you know? And at times, it can be so intense that I don't know if you've ever been so hurt, physically hurt, that you black out. It's like that.......I'd identify so much, and it's almost like I'm putting myself in [her] place and then trying to make it like I'd like it to be.......It was like everybody's were filling up in me. And I couldn't feel free.

Finally, a sense of being the "only one" to give care, for practical or theoretical reasons, pervade the daughters' stories, and contribute to a sense of inextricability.

**Helen:** I guess it's because I know the kind of life she's had, I figure if I write her off, there's nobody.
......Any way I look at it, I'm gonna be a big part of this picture. Any solution, because I'm the only one., I'm gonna be in this picture. This is gonna be a big part of my life at least right now.

**Susan:** You feel like it's real important to be the one in charge and you don't trust those other people. Somebody has to, and there's no one else.
It's more like I have to do this job because no one else will do this job.

**Eve:** I'm the one that's here and if [my sister] were the one that were here it would be the other way around.

**Nan:** Well who knows my mother better than I do? I mean she and I, I mean I grew up with her and I understand her, she understands me and...it's kind of like soul sisters or whatever. I understand her and I know her and know what she's all about and I don't think there's anybody else who could handle it better than I can! I really don't!

*First inclination*

The second feature of the impulse to care which has an impact on caregiving decisions is the first inclination of the daughters to act as caregivers. For some, the inclination to care is so immediate that it *precludes decision*, consistent with what Lewis and Meredith call natural (as opposed to drift or conscious) caregiving.

**Linda:** At the time you don't think about anything like that, whether you want to do it or not. I just did it automatically, you know. I never even give it a second thought.......it's just family. I've always helped take care of my family and I, I really have not thought anything about what I do.......I just automatically took it on me.

**Janet:** I think part of it is very unselfish. It's just because they are ours that you do it without question, when you know that they really need it.

**Diane:** ...it's like well something has to be done, what do we do? And it wasn't exactly a conflict, ....I guess I didn't really think. It was just something that had to be done.

**Carol:**...it wasn't a practical decision to make. It was just heart over mind. And you didn't listen to your mind, you listened to your heart because if you'd have thought about it more you'd probably have said---forget this! .......The biggest thing is you don't ask questions. You don't go to the people that you need to because you don't know, you just have to, you go by what your parents did for their parents when they got old.

*Predisposition*

The third feature of the impulse to care is the multiply determined predisposition to care. Among predisposers identified by the daughters, are need, socialization (including roles as women and the family history of caregiving), and moral ideas about caregiving. These predisposers are mutually shaped and form a complicated web of issues that are best described as an intertwining of *having* -to and
wanting -to give care. The daughters struggle to separate or distinguish, for example, the sense of duty (having) to care from the sense of being drawn (wanting) to care.

Nan: I'm doing this because I want to...it's something that I have to do, but I want to do it. I enjoy, doing it, it's something that I want to do, I have to do, I mean nobody else is going to do it, but I want to do it more than anything.

.........Some days it's one and some days it's another. If there's a problem at the nursing home, for example, and I know they're going to be short-staffed, I have to do it, because well, because I want to do it. I have to do it because I want her to feel good and I want me to feel good, so I guess they're intertwined, I don't know, I don't know....

.......................I have to do it for the intangible as well as for the manifested, physical help that I am giving. I don't know that I can separate that.

Eve: Kind of indistinguishable almost.

It may be argued that the having-to becomes the wanting-to and the wanting-to becomes the having-to. This intertwining or indistinguishability of having to and wanting to give care problematizes the attempt to explore predisposers concept by concept. It will be evident that need is related to socialization, socialization to moral ideas, and so on. For some of the women, one predisposer appears or feels more dominant than another, but all of the daughters identify multiple issues in exploring their predisposition to give care.

Furthermore, the women's attributions often appear contradictory, for example by first attributing caregiving to the need for approval from others, and later attributing it to a utilitarian concern for the mother's security, or by first attributing caregiving to love for the mother and later attributing it to fear of future guilt. Clearly, these factors are not contradictory, but surface alternately as salient to the part of the story they are telling. Moreover, they are intricately bound to each other and often surface together, in tension with each other:

Carol: I wanted to be a good daughter, and I wanted to get, I guess down deep, a recognition from her that, yes, you're a good daughter.

or in compatibility with each other:
Helen: It's my own feeling that I want to be there because she enjoys it when I'm here, I think I can get her to eat a little more, and the other thing is I don't trust these places (nursing homes).

Suffice it to say that multiple, intertwined predisposers to caregiving contribute to an impulse to care. Having acknowledged their interrelatedness, this analysis now moves to an exploration of the predisposers: need, socialization, and moral ideas.

Need

Need is offered by most of the women in the study as a simple yet unexplainable, and vague but powerful factor in deciding to care. Need may be said to be both a predisposer and a manifestation of impulse.

Helen: I guess I just feel a need to do it. I need to be here with her and for her, that's about all I can say.

Eve: It's a very, very self-centered type of thing, because now she doesn't need me to be over there (nursing home). I'm not even sure she knows who I am. But it's a need that I have of doing the most I can.

Nan: I do think that there is a compulsion there of some sort....I do feel compelled to help because there is no one else that would do it....but more than that, I mean it's that plus a lot of other things.

For Susan, her need to feel comfortable with the decision overrides the losses to her personal freedom that caregiving represents.

Susan: I just don't feel, I feel like it's something I really have to do. I couldn't be comfortable with, I didn't want to do it, but I couldn't be comfortable any other way....as much as I hated to have to forego all my freedom, I just felt like the only thing I could....I felt like I had no choice.

Susan, who took over full-time caregiving from her sister, also attributes her decision to a need to control the caregiving situation.

Susan: If I didn't go (to sister's house to help with caregiving there) I felt guilty I didn't go. And if I did go I felt miserable. It was like you really couldn't call your days your days. .....I thought if I say I'm gonna take Mom full time and I set up the schedule, I can make it work and feel like I can have control that way. It was like everything was topsy-turvy all the time, and I have to have some kind of order in my life. I have to know where I stand.......It's better just to bring my problem, put it there at home.
Explaining further, Susan describes the emotional consequence of not controlling the caregiving.

Susan: I think I would have this real dread, that panicky feeling too, like feel anxious all the time. I'd just be so uncomfortable with myself that it wouldn't be worth it, you know.

Carol believes that at the time she brought her mother into her home, she was subconsciously looking to fulfill a need for affection and bonding with her mother, which Carol expected to be expressed in some form of gratitude for the care she was giving.

Carol: There's always been a kind of feeling that I was just out there! I wasn't part of her I guess is what...I never got the feeling that the closeness that you think you should have with your mother, like I feel I have with my girls. I never felt that feeling was there between my mother and I. A closeness that I missed and that I needed.

Closely related to need is the idea of reward, or the emotional benefits to the daughters that result from the caregiving relationship.

Nan: I was thinking, you know, people automatically assume that what you're giving or whatever is in some way a negative thing on your life. It is, in some respect, in that we have this other person or other persons to think about....to our husband or husband and children or other family members, but basically, it's not all negative. It's really, we are really, I mean I feel that I am reaping a lot more....I mean I feel good. When my mother sees me, when I walk into that room, and her face lights up and she says, "Oh, you're here!" it gives me ten thousand percent. I mean I can't give her as much as she gives me! Honestly!

Socialization

The socialization of women as nurturers and caregivers is intrinsic to our culture and the sources of female socialization are many. Other, less gender-specific but related socializers may also contribute to the development of an impulse to give care. How is it that these daughters have developed the impulse to care as is manifested in their decisions? The women are able to point to varying aspects of their socialization as clues.
Linda, who grew up with the severely disabled sister for whom she now also cares, attributes her impulse to care to caregiving learned as a helpful sibling in her childhood. Linda describes caregiving as "instilled" in her through these early experiences.

Linda: With my sister, we was always taught, well she can't do this and she can't do that, so we just helped with her. You know, it wasn't that we was ever jealous of anything that she got or had, we was just there because we knew that she couldn't do for herself....and we always was taught well, when, you know, when someone needs it, you help....We knew she couldn't do for herself so we just automatically whatever she wanted, we got it for her. Or did for her. So I guess that was just instilled through me all my life, you know, that I had to do it.

Susan identifies early caregiving behaviors of a different sort. The daughter of an alcoholic father, it was Susan's "role" to comfort and care for her mother in times of crisis.

Susan: My dad would be out in cafes a lot and my mom, she would more or less cry on my shoulder. And I just felt for her so much it was like I wanted to be the one to take care of her, to make her feel better.

Rewarded for the compensating Susan did for her father's drinking, she learned to rescue the family, and calls this a "blueprint" for caregiving.

Susan: I was the good one: "Oh, I don't know what I'd do without her!" And it made me feel good to hear that. And when you're programmed a lot, when somebody says, Oh I don't know what I'd do without you, and you're a child, you know, it's like a blueprint. That's the way I got my affection, O.K? And from that, I think it just escalated.

For Diane, her role as the oldest child explains much of her impulse to care.

Diane: I guess I just feel a sense of responsibility. I don't know, I guess maybe being the oldest child does that. Because when I was about eleven I guess mother did go out in the evenings and babysit through a babysitting service before my sister was born. So I was at home with my brothers. And you know I guess there's times you are just expected to assume responsibilities or you just do. It's like you're the oldest...you just do.

Being the oldest of her siblings not only contributes to Diane's "sense of responsibility" but is also related to the expectations of her siblings that she will provide the care needed by their mother. Diane's identification of this relationship
between birth order and responsibility is consistent with research which demonstrates that a correlation indeed exists. Older daughters are "more likely to share households with their mothers and to provide more hours of help." (Brody, 1990, p. 61)

_Diane_: Sometimes when you're the oldest it seems like things are kind of, I don't know, maybe it isn't always the case, but it seems like [the oldest] is expected to do certain things sometimes. You know, when I was younger I had to watch my brothers and all that sort of thing so I think maybe this is the same thing.

Generally, attribution of the impulse to care to gender-related issues is not made explicit in the early telling of these stories. Rather, the synonymy of woman and caregiver seems to hang like a giant assumption throughout. To illustrate:

_Researcher_: Where are the......Why are you [caring] and not the brothers?

_Marian_: I think daughters-in-law are perhaps not as close.

_Researcher_: OK. Now, set me straight...but the implication there would be that it would be logically the woman....

_Marian_: Yeah.

_Researcher_: Is that right? That when I suggest sons, that to you means that the wife will be doing a lot of....

_Marian_: Yes, of the care.

This assumption is so enmeshed in the women's world views that, when probed for, it takes the women by surprise. Diane, for example, struggles with the question (What do you think being a woman might have to do with this?):

_Diane_: Uh, maybe.... Like, well, the mothering instinct you mean?

_Researcher_: I don't know. I'm wondering if you think that explains any of your decisions or your situation.

_Diane_: Maybe it does. I don't know. I really....Just because I'm a woman, I don't know if it would be, I don't know if it would have been any different....I really can't say. I think a daughter probably feels more obligation to care than maybe a son I would say.
Carol, too, claims that she never thought about what being a woman had to do with her caregiving choices. Seeking to explain this, she ultimately associates her caregiving impulse with her role as mother.

Carol: I never thought about it! I guess I just always figured that you're the mother, you're supposed to take care of everybody. I guess it's just the mother in me. It just, it's something I guess I've felt I've always had. 'Cause I can never remember even as a child wanting to do anything else but be a mother.

.........I think being a woman is something that you figure, you're like me, I'm a mother and I'm supposed to take care of people. And that may have been there, that I am supposed to take care of someone just because I am a woman. 'Cause our, we still live in this, this is a woman's thing to do, this is a man's thing to do.

Associating caregiving with traditional and customary women's roles, Helen both laments its absence in men but defends its place for women. Describing a wife who visits her husband daily in the nursing home as dedicated, she equates women with caring.

Helen: This is a woman's, this is caring. I don't see men getting involved in this....it's wives, and it's daughters, and you know. Now there are some good men who come in here, I've seen a few, but...I know that it's the women that are gonna do the caring.....That's all right with me, because I feel it's kind of a role, I'm not a women's libber. I don't like a lot of things quite frankly that I see. If I were to have a baby today, I'd never go off and leave it.

Susan explores the possibility of "chemistry" in the discussion of women and the caregiving impulse, calling it a "nesting instinct".

Susan: I think a lot of it is female. I read one, somewhere, that they found like women that just could not nurture their children...That they were actually missing a chemical in their brain and maybe a lot of it is chemistry! You know, you have more something that makes you more nurturing.

Rethinking this later, Susan concludes that environment must also play a part.

Susan: I think it probably meshes together with the chemistry and your, you know, your environment, the way you were raised.

In a discussion about their brothers' responses to the needs of their mothers, the focus group daughters share a consensus that not only is caregiving traditionally a
woman's role, but it remains an expectation and a reality that women will give care in most contexts.

**Janet:** I think traditionally it's the woman....

**Kay:** Yeah, I agree with her.

**Nan:** I still agree that it would have been [my brother's] wife, had he taken Mom on, it would have been his wife who would have been involved in probably seventy-five percent of the care! (All agree.)

**Mothering**

Discussion of the socialization of these daughters as caregivers must include the experiences they have had as mothers and the implications of mothering for the response to parent dependency. It may be recalled that Carol attributed her caregiving impulse to "the mother in me". The daughters in this study respond to parent dependency in a way that feels like, or is akin to, the response to the dependency of their children. In Chapter V we will discuss the implications of this response for the decision process, particularly as it affects the paternalistic nature of some caregiving decisions. For now, however, the discussion is contained to mothering as learned caregiving and its impact on socialization and the impulse to give care.

The translations these daughters make from mothering to parent-caring are dominated by the impulse to protect the parent from his or her own dependency. Reference is made to the similarity between protecting a child and protecting a parent.

**Susan:** The main thing is, it's almost like a helpless child. To look down at her and say well, you can't stay here? I mean it's not like she can say, Well, O.K., I'll find.....She is totally dependent. I just couldn't do that.

**Helen:** Mother, she's like the child now. Sometimes when I go to feed her, she's like a little bird, ...and I'll have the food on the fork and something will distract me and she'll say, Feed me! Feed me! You know. Like a little kid, or like a bird. So they really, they just become childlike. This is not like the lady six months ago....

**Eve:** It's like caring for a child. It's caring for a loved one that needs your care.
Marian: [At night you listen for them] with one ear! Just the way you would with a child.

Nan: Uhm, I'm there (at the nursing home) every day, twice a day lots of times, and I think....I do it because my mother likes it, she enjoys my company, and she's kind of like my good buddy, you know, and I just....if I had a child in an institution I would feel no different, I mean...I want to be sure she's well taken care of. It's your child! It's my mother!

Janet: We've all been mothers, so this mothering just continues.

Nan: I do say things to my mother like, "Do you have to go to the potty?" and I find myself thinking, Oh, why did I say that? But I do, I mean, I do. There are times when you really, really do look at this individual in a, as if she were a child, and you know I think Why did I say that? Why did I put it that way? But you know, it sort of just pops out of your mouth. It's like when I would have said to [my son] when he was a kid you know: "Do you have to go to the potty before we go out for a ride?" You know, I do say that!

Much has been written in recent literature about both the fallacy and hazards of the concept of "role reversal", the idea that the child becomes parent to the parent, and the parent becomes child to the child. Seltzer argues that not only is the concept inadequate to describe the dynamics of parent care but also that it is "conceptually, ideologically, and therapeutically limiting" (1990:5). Brody (1990) frames the issue of increasing parent dependency as a dialectic of dependency and independence in parent and child, arguing that the phenomenon in question is a shift in roles, not a reversal of them.

Regardless of its conceptualization, the daughters in this study perceive an association, however imperfect, between their roles as mothers and their roles as parent caregivers, and name it as influencing their impulse to care. Although parent caring has become a "normative" family experience (Brody, 1985), it is without clear behavioral norms. Socialized to give care through their experiences as mothers, these daughters respond to parental dependency with an impulse to protect and nurture. Role reversal appears to be a metaphor for an experience which is as yet underdefined. In the absence of behavioral norms for parent caregiving, these daughters have borrowed
from their roles as mothers to respond to the dependency of their parents. Role 
borrowing may better describe the phenomenon as it exists in the impulse to care.

**Family caregiving history**

As these daughters confront the needs of their dependent parents they also 
borrow from their family history of caregiving. Though less impelling than their 
personal development as women, daughters, mothers, etc., past family patterns 
function not only as a context for learned caregiving, but also as a standard or 
precedent against which to measure caregiving choices and behaviors.

This sample of daughters presents a mixed bag of family caregiving histories. 
Susan and Kay lived, as children, with both their parents and their grandparents and 
participated in the caregiving of grandmothers. As a matter of fact, Kay's house as a 
child was filled with people, and she describes the "unselfish" way in which her 
parents cared for others, including her maternal grandmother.

**Kay:** My mother and father never had an empty nest either, and I was an only 
child. They always had people around. Always. And they even had like single 
teachers live in our house. We had a very large house. Daddy was so wonderful 
about letting Mother's mother live with them from married life, right almost 
from the beginning on......

Susan was a "participant observer" of caregiving at a young age, and uses the 
pronoun "we" when describing the caregiving that took place on behalf of her 
grandmother. Susan is conscious of the length of the caregiving experience in both her 
great-grandmother and in her present context and feels as though she "measures up" to that 
standard of care by going beyond the time period of caregiving required of her mother.

**Susan:** I was extremely close to my grandmother. It was like another mother, 
because we always lived in the same house.....
When it got real bad I think Grandma lived for several months....and I helped 
with Grandma then...we took care of her at home....., but it didn't go on for 
years, like in my situation with [Mom].
Helen sees a "repeat pattern" in assuming filial responsibility as modeled in her family caregiving history, but she believes her mother, who is in a nursing facility, is angry at a betrayal of family "ways".

Helen: I think it was probably a good deal of anger on her part. Because she took care of her mother in her home. And because at 85 we're used to the old ways. When my mother was a girl, they were poor, and my grandmother was dependent on her because she was the only girl.... and there, again, the women do it. The four brothers did their thing, played ball and baseball, they were still home, but mother was the one that did the grocery shopping and all those things. And I see a kind of repeat pattern here. You know with me.

Family caregiving history even remotely related to the present context can influence the socialization of these daughters to care. For Diane, her decision to bring her mother into her home as opposed to nursing facility placement was made against a standard of care her aunt had received from the aunt's children. Because the aunt's level of dependency was greater than Diane's mother's, and because the cousins had cared for their mother at home, Diane felt nursing home placement would not measure up to the standard they had set. For Diane, the precedent became a standard and the standard became an expectation.

It can be seen by these examples that the socialization experiences identified by the daughters as salient to their present caregiving situations contribute to the impulse to care. The variability of the experiences and backgrounds may contribute to differences in the nature and level of participation of mother caregiving, but all of the daughters agree that their development as women, mothers, daughters, granddaughters and sisters predisposed them to give care.

MORAL IDEAS

Prior to the interviews, as discussed in Chapter Two, a cautious assumption developed from the literature review that, for many daughters confronting the long-term-care needs of their parents, there exist inherent moral conflicts in the face of
conflicting obligations and competing needs. It was argued that conflicting obligations of
daughters of dependent parents represent moral choices. For women whose conception
of morality is developed around issues of care and responsibility in a context of their
relationships to others (Gilligan, 1982), these choices are especially conflictual.
Identifying and exploring the moral ideas of these daughters regarding their response
to the needs of their mothers is essential to understanding the impulse to care, the
struggle to balance self vs. others in the caregiving relationship, and the development
of a personal balancing point of care, the central focus of this analysis.

What are the moral ideas that predispose daughters to give care and ultimately
render caregiving conflictual? Language such as "debt", "duty", "responsibility", and
"good" are woven throughout the stories of these women. "Guilt" is also a recurring
theme and functions both as a motivator to approach caregiving decisions in a manner
consistent with moral standards of care and responsibility, and as an affective
experience that accompanies regret, remorse, and self-punishment. (Mosher, 1980)

Central to the discussion of moral ideas is the dance between self and other
represented in each concept. Gilligan (1982) argues that the central moral problem
for women is the conflict between self and other, a "continuing opposition of
selfishness and responsibility." (p.136) Moral ideas, then, are principles of
selfishness and responsibility, and guilt the moral control mechanism regulating their
opposition. These ideas will now be explored in depth.

The norm of reciprocity

Images and ideas of debt appear in the stories of these daughters, and support to
some extent the concept of a norm of reciprocity (Berman, 1987). The idea that
parent-to-child caregiving must now be reciprocated as a debt owed the mother is
evident, but not dominant. Rather, debt may be regarded as a secondary thought, as yet
another principle with which to bolster the choice to care. Perhaps it is the sense of
irredeemable obligation (Berman, 1987) associated with the norm of reciprocity that renders ideas of fulfilling debts secondary to other principles.

**Linda:** I just feel like she took care of me for many a year when I needed it, so.....even when I was an adult. Any time I was sick or anything she was there for my children.....I don't try to pay back. I just do what I wanna do, what I can do!

----------You have to really love 'em, love your parents and things and feel like your givin'.....not that I feel like I have, that I owe them anything, but I've just, I thank God I've been able to do what I've been able to do and help my mother....So it's just, I just consider it an everyday thing....something that I have to do.

With some of the daughters, references to reciprocity have to do with what the mother *would* do for the daughter if the daughter were now in the same state of dependency, rather than what the mother has done for the daughter in the past. The reciprocation is in the *principle*, not necessarily the *history* of caring, that is, "I *will* do for you what you *would* do for me."

**Kay:** Well. I wouldn't have it any other way, and I don't think they would either. They would help me! They would do everything they could....

**Susan:** They raised me with this feeling, like when I grew up that if anything went wrong, Mom and Dad would take care of me. You have this feeling that Mom and Dad they're always gonna take care of you.

----------I figure, you know, here your parents would have done that for you. So what do you do?

Carol questions the norm of reciprocity, unsure that she owed her mother care.

**Carol:** It was just as though she felt that I have this problem now so people have to wait on me. And, maybe she felt we owed her something. I don't know, I can't say how she felt. But sometimes I get the feeling that it was, we owed her to wait on her because she did for us.

Helen felt manipulated by her mother, as though her mother sought a repayment to compensate for vague sacrifices or losses in her life.

**Helen:** She does her manipulating thing. I feel bad that she didn't get to do more in her life but we make our own way in this world, we make our own decisions or we don't decide and she made hers long ago. Then you can't become in your 80s and suddenly hope for a new lifestyle 'cause it's not gonna happen!
Filial obligation

Related to the principle of reciprocity is the idea of obligation, expressed in a language of "duty", e.g. "It was just a duty," "It's kind of my duty and my obligation to see this through with her." Filial obligation is a cultural expectation of children to care for their parents, and attitudes of filial obligation are implicit in these daughters' stories. Although "having to" and "wanting to" give care may be indistinguishable, the having-to which appears so often in their narratives may speak, in part, to this sense of obligation, e.g., "We just do what we have to do, as we can do," "You do it because you have to."¹

Again, asked to define "having to", the women struggle, yet it is clear that obligation to parents is manifested in the impulse to care. Carol is the only daughter who explicitly scrutinizes her own attitude of obligation and it's source.

Carol: Well, your parents, when you're little your parents are first. It all goes back to my feelings that I'm not supposed to hurt my parents. Honor your father and your mother. It all goes back to that. If you look back in time, all the way back to the Bible, it goes all the way back. You take care of your parents.

The norm of reciprocity and the attitude of filial obligation take an interesting twist when daughters discuss what they expect of their own children as the family ages, adding another dimension to the concept of "women in the middle". Essentially, these daughters are saying, "I may owe this to my mother but my children do not necessarily owe this to me."

Diane: Certainly there probably comes a time when they have to take over some obligations, but as far as total care, I don't expect that, but if a situation were similar to mother's I would hope that somebody would pitch in and take some sort of care of you. I would hope that somebody would do that for me if it were necessary.

¹*The Oxford American Dictionary* (1980) defines have as "to be under the obligation of."
Diane continues by asserting that she does not expect care to be limitless, saying that it would "all depend on her (daughter's) circumstances. Very much depend on her circumstances."

Carol expresses ambivalence on the matter, but generally believes that her children don't owe her what she did for her mother.

**Carol:** Just when I get to the point I can't take care of me, fine. You put me somewhere where I'm not going to interfere with your life. And I, **now** I say I won't be upset with 'em. But you never know what you're gonna do and how your feelings are gonna change, but as long as your children know that you love 'em, and uh, I have no doubts that I would probably resent it for a while, until I stopped to think about what I had been through and I do not want to put them through.

Linda is less ambivalent.

**Linda:** I really don't expect her to take care of me. I wouldn't want to put her in that position. Which my mother really didn't put me in that position....once she got older, I just chose to take care of her. But I wouldn't put that on my daughter either. If she wanted to take care of me, fine, if not, I wouldn't have hard feelings if I had to go to a nursing home.

Susan is even less ambivalent about her expectations of her own children in terms of caregiving, hoping she would never put them in that position.

**Susan:** I definitely don't want her to go through with me what I'm goin' through with my mom....I think if I knew that I was gonna be dependent, I would take it out of everybody's hands. I think everybody, you know, it's like if you're trapped you'll scratch [to get out] until you bleed...it's a matter of you want to survive. I don't know how I'd be as far as desperate, if the time would come, thinking now with what I'm doing. I would hope they would never have to do it, I don't know how else to say it. I don't really want 'em to do it.

Saying she would "let them off the hook", the hook appears to be for Susan what she hopes is a "compassionate, caring" nature in her children, and an attachment with her that would predispose them to care.

**Susan:** It would be in their soul what is right, I'm not gonna judge 'em, it would be what they feel right inside. I think they're compassionate, caring human beings. And I hope there's enough of a bond there, of love, that....I don't want to wreck their households. So I would definitely let them off the hook and say I don't want you, in fact, I tell 'em now, I don't expect you ever, I don't want you to have to go through this with me if something would happen. And I think if...
they hear that, then if the time ever comes, then they'll feel what they individually can do. And you just have to go from there.

Responsibility

Although the idea of responsibility is often linked by these women to the attitude of filial obligation it is addressed here as a separate concept because it is a more generalized moral ideal and because ideas of responsibility are applied not only to relationships with the mothers but also to husbands, children, and others. Gilligan identifies responsibility to care as a central feature in women's definition of morality, and the women in this study attribute their impulse to care to both a sense of responsibility and a definition of themselves as responsible persons. Diane attributes the fact that she, and not her brothers or sister, is doing the caregiving partially to her greater sense of responsibility.

**Diane:** I don't think my responsibility should be any greater than theirs. But it seems to be that it is. Obviously it is or she wouldn't be here. She'd be there, somewhere else.

Helen's account of why she participates so heavily in the care of her mother in the nursing home has to do with her identity as a "responsible person."

**Helen:** I guess I feel like I'm a responsible person, because even though I've had to place her in a nursing home and felt like I had to and did it, I'm gonna be with her.

Feelings of responsibility to others clearly render the caregiving experience conflictual in the cases of these "women in the middle" and the women struggle to order those responsibilities in a way in which they are all met. Yet, while they feel responsible to husband and children as well as to mother, their impulse is to address the responsibility to the person whose need they identify as the greatest at the time of crisis, most often the mother.

**Susan:** To me it's just, it would be like practical. It'd be like if you had so many children and one of 'em needed shoes and the rest didn't. You'd get the shoes for the ones that needed them. It's just something you just do. It may be that one kid needs more hugs than the rest of the kids. You just do it.
In the focus group, Kay discusses the responsibility she feels to make frequent caregiving trips to her mother's home several hours away, in spite of the responsibilities she has at home.

Kay: If they (husband and children) don't understand, I'm sorry, but that's the way it is. I belong entirely to that trip up there and taking care of them (parents).

Nan responds, and illustrates the possibilities of ordering responsibilities based on need.

Nan: But there's a difference because you know your husband, if he were not well, it would be a different story, but at this point if your husband is well and everything is going along in the house and at work and every place else, and everything's going along, then you know, it's easy to choose. It's easy to say that this other thing, your mom or whatever is the priority, because that's what needs the attention at the time.

It is a statement of these women's moral identities that they do not rue the impulse to care as it is manifested in their decisions. Rather, responsibility to others is regarded as a cherished principle that they believe should be universalized.

Diane: I don't think I'm a special person to take care of my mother. I guess I hope we're all special.

Linda: I've always lived like that (that others come before you) [Are you unusual that way?] No. I hope not, I hope a lot of people consider, you know, the other person.

Susan: If you were walking along and somebody handed you a rope and then they jumped off a cliff, and you're standing there and you're holding that rope, and they holler up and they say—Don't let go now! You know. Is it your obligation to always stand there and hold that rope? Because when you think if you let go, that person's gone, you know. And maybe they could come to terms with like—That wasn't my responsibility, because you're the one that handed me the rope. But where is the caring? Everybody can't just step aside and say—Oh, somebody will take care of 'em, you know. 

..........Could you imagine if, in this world, everybody tried to take care of one or two people? To make their life, let's say, if you could be somebody else's guardian angel and just every now and then just do something to make them feel special, loved, and yet that was a universal thing....The difference in the quality of everybody's life...Of course, that's silliness, but it would be neat, you know.

Nan: Is it not, I think this is what's wrong with society, the apathy of society is so appalling to me, you know if we would just simply do those things that I would call natural things to do, you know, society would be better off!
Goodness

Caregiving behaviors motivated by ideas of reciprocity, obligation, and responsibility are tied to a definition of goodness that emerges as critical to the decision to give care. If there indeed exists a "continuing opposition between selfishness and responsibility", then "goodness" is the signification of the victory of responsibility over selfishness. When considering their personal strivings or the caregiving behaviors of others, good is equated with "unselfish" and "involved", for example in Helen's discussion of the "few good men" who visit relatives in the nursing home.

Helen: You can kind of tell that they're pretty good people. There's something that kind of comes through. I just think if you're a selfish individual, if you're selfish and you could care less about your folks, I think that kind of person's not gonna be involved.

For Carol good is associated with "doing the right thing."

Carol: I wanted to do the right thing, I wanted to be a good daughter. I wanted to do the right thing..

And for Susan goodness is putting others before oneself.

Susan: I think a good person can put another person ahead now and then, especially when the need is there. That you, it's a person that's not totally self-centered. And there's varying degrees of goodness.

Describing a daughter who is not a "good person", Susan also equates goodness with compassion and caring, and relates this to unselfishness.

Susan: When it comes to compassion and caring, I think she's very deficient. I think she's a person who puts [herself] first all the time.....You have to step back sometimes and put somebody else first.

Among the most intriguing issues to surface in the stories of these daughters is the differentiation they make between others' and their own caregiving choices and behaviors in assessing or defining "goodness". If reciprocity, obligation and responsibility are moral principles or ideals, it would seem to follow that those who
reciprocate, oblige, and are responsible to their parents are deemed "good". Indeed, these women often assign such labels (as well as the converse label of "bad") to others related to their caregiving activity. However, they resist defining themselves as "good" daughters. For that matter, they express discomfort with the idea, suggesting that without pure altruistic motivation to care (without total wanting to), and without absolute subjugation of their own wishes and needs to the higher wishes and needs of their parents, they cannot call themselves "good". Though they strive to be good, and though this striving is part of the impulse to care, the goodness in caregiving is rendered impure by the daughters' own selfish thoughts and feelings of discouragement or anger.

In regarding their expectation of themselves, goodness is equated with what Sokolowski (Chapter II) calls virtue, where the impulse to care is uncorrupted by other (selfish) impulses. That the daughters use what Sokolowski calls the moral action of self-control to master impulses counter to the perceived need to give care, is not considered "good", or at least not "good enough". Furthermore, even in the absence of selfish thoughts or emotions, even in a condition of pure "wanting to", these daughters deny that it is a mark of goodness for them to do something that is only "natural" and appropriate to do. Virtuosity becomes diminished by its own expectedness.

Linda: I never even think [of myself as a good person.] No I don't. I don't give myself any praise because I feel like I've always loved my family and I just do what I can for 'em. I know I get hateful sometimes, because you know, I just get tired and I'll answer sometimes too harsh and then I'll tell 'em I'm sorry. ............As far as being special, I don't consider myself one bit special, because I think it's just my way of life because I've had to do it because that was my choice, you know....

Susan: I don't think I am a good person. I think I'm a good person but I'm hard, I'm very critical of myself. I don't feel like I'm always, I don't feel like I'm internally a good person, do you know what I mean? Because I've got very nasty thoughts....
If people come up and they'll say, "Oh, it's so nice what you're doing for your mom..." Well, what's nice about it? I'm doing what I feel I'm supposed to do. This is what I should do. I don't enjoy doing it, so therefore I can't say--Oh, I'm just this wonderful person.

**Marian:** My mother-in-law used to grab my hand and say, "Oh, you're so good to me" and I would always feel guilty, because I didn't feel like I was, because every once in a while there would be those feelings that would go through my head, like, "Oh, I wish I were off doing something else!" And then I'd feel guilty that she was giving me all this credit.

**Eve:** (To the focus group) I don't know if the rest of you...I'm sure that we've all been told, "Oh, you're so good. You are so good to be doing this. (All agree) It almost gives you delusions of grandeur! And it's hard because......(Kay: You get tired of hearing it) You do because you have this problem with yourself saying "No, no, no, (slaps own cheek) I musn't believe that because that's not true! Because this is something that's a natural thing that I need to be doing for my mother.

**Nan:** I'm sick and tired of people saying to me, "Oh, you're so wonderful. Why are you doing this?".... Well...."Why are you asking me? Why are you asking me this? Hey, cut it, you know? Cut it!"

The following dialogue from the focus group serves as a final illustration of the minimization of goodness that operates in these discussions.

**Researcher:** So what does it mean when someone says, "How do you do it? You're such a good daughter"?

**Nan:** You just say, "Well, it's no big deal. I just do it!"

**Eve:** They've not been through it. They would understand.

**Janet:** And they would do it, too.

**Eve:** Sure they would.

**Guilt**

Although these women respond with self-deprecation to discussions of goodness, they still strive to be and feel like good daughters, consistent with social and personal expectations of themselves. Marian, who felt guilty being given credit for undeserved "goodness" (above), illustrates a function of guilt in both monitoring and measuring this striving. As stated earlier, guilt functions both as a motivator to approach
caregiving decisions in a manner consistent with moral standards of care and responsibility and as an affective experience that accompanies regret, remorse, and self-punishment. (Mosher, 1980) Guilt functions in these stories as a decision control mechanism and, to some degree, as the emotional residue of decisions made.

It has already been established that these daughters have moral ideals that impel them to give care, and that they act on that impulse. It is also clear that these women are vulnerable to regret, remorse, and self-punishment. Aside from seeing that their mothers' needs are met, it is the objective of these daughters to make decisions that they can live with, decisions that will protect them from future regret, remorse and self-punishment.

Carol: A lot of it has to do with—Can you live with yourself? Could I have lived with myself if I hadn't taken her in and something had happened? The answer to that was No! It would be easier to live with her than to live with the guilt.

...........To be truthful, I think it was more protection for me. I needed to know that I had done everything possible. It would be the constant—What could I have done to stop this? Oh, how can I say it, just when you know, when something happens and you think—Well I could have prevented it. And to know that you didn't do all that you possibly could to prevent it. You keep this guilt inside and it just eats at you. You just think, well did I do wrong again? And you constantly tear yourself down. And that's what I would have done. It's not an easy thing to describe, because you're not sure exactly what the feelings are. You just know that you wouldn't have felt that you did the right thing. And if I'd ever gone in there and found her hurt or something like that—knowing my temperament—I would have said that a breakdown is very possible.....It would have taken a lot of professional help for me to get over it.

Helen: There is no way I could have her in a nursing home without being there a lot. I just could not live with myself. And a lot of that is because I don't have peace of mind when I'm not around.....

Susan: [Guilt] is like a nagging, uncomfortable.....and I don't feel like a good person. To abandon and just go on like nothing happened... I can't put, I can't, that would be like turning off your feelings. It would just haunt me to the point that I would just feel so sad for 'em.

Janet: You want to be sure that later on you would never feel any regret. I don't ever want to be able to, or have to look back, and think---Why didn't I do this? you know, and feel remorse for the rest of my life.
Eve: For me, I think the whole basic thing of it was so that some day when she's gone I won't have any regrets.

**Summary**

It has been argued that these daughters respond to parent dependency with an impulse to give care from which they approach decisions about the nature and level of their participation in the long-term care of their mothers. Central to these decisions is that opposition between selfishness and responsibility: *balancing selfish motivations with responsible-"enough" decisions to arrive at a tolerable choice.* Complicating those choices is the balancing point sought not only between self and responsibility to the mother, but also between self, responsibility to the mother, and responsibility to children, husband, work, etc. We now turn to the decision experiences of these daughters.
CHAPTER V
THE DECISION PROCESS

Introduction

That these daughters respond to the situation of parent dependency with the impulse to care does not assume that caregiving behaviors are the product of conscious, deliberate, and certainly not rational, or economic decisions. Indeed, it is clear from their stories that a range of decision experiences occurs: from the unconscious (what Lewis and Meredith call "natural"), to the barely thoughtful, often incremental, concatenated, (what Lewis and Meredith call "drift"), to the conflictual, to the dilemmatic. Furthermore, the decision processes are inevitably limited. Outcomes are not always consistent with expectations, or more to the point, outcomes are not expectable. And, finally caregiving decisions require interpersonal decision making which often renders the search for a balancing point conflictual.

This chapter begins with a brief discussion of the perception of choice and decision in the situation of parent dependency, and moves to an examination of the relationship between the decision stories to decision theory, and particularly to the Janis and Mann conflict model of decision theory. Finally, the role of mother, husband, siblings, children and professionals in the decision process and the implications of interpersonal decision making in the pursuit of a balancing point will be explored.

It is important to consider that the stories of these women are stories of multiple decisions: from decisions to bring a mother into one's home, to decisions to make frequent long-distance caregiving trips, to decisions to "place" a mother in a
nursing facility, to decisions to assist in the care for a mother in a nursing facility, to
decisions to ask a mother to move out of one's home, to decisions to share care with a
sibling or a professional. The daughters make a distinction between what one of them
calls "Big Ds" (Decisions) and "little ds". Generally speaking, it is the Big Ds (e.g.
placement decisions, a mother moving from her home to her daughter's home) that are
the focus of this analysis. It is clear, however, that the little ds are strongly enmeshed
in the Big Ds, and vice versa. The objectives of this discussion of decision experiences
are 1) to understand how the pursuit of a balancing point is reflected in shifts in the
nature and level of caregiving: the assumption of care, the sharing of care, and the
relinquishing of care, and 2) to understand the impediments to achieving this balancing
point in the decision process.

PERCEPTION OF DECISION

The analysis of decision experiences is problematized by issues of perception or
consciousness of choice and decision. Decision was defined in Chapter II as a process or
act of choosing between or among alternate courses of action. It may be argued that
decision requires perception or consciousness; conversely it may be argued that
unperceived selection and changes of behaviors are products of unconscious choice or
decision. It may be said that the impulse to care is strong enough in the earliest stages
of parent dependency that alternatives to giving care are not perceived and certainly
not sought. The daughters "automatically"-"naturally"-by-"reflex" provide the care
needed by the mother as it arises. It has been illustrated that caregiving can be
initiated and shifts in caregiving can occur without much thought.

Not until the daughter is made conscious of a constellation of alternatives or of
competing needs or demands does decision become conscious. A constellation of
alternatives may include multiple resources on which the parent may rely, for
example other children, a neighbor, a friend, a service agency or professional. The decision is a process of selection among alternatives. For some of the daughters, competing needs (their own, their mothers', their families', their jobs') surface, or are made conscious, in the earliest stages of dependency. For others, with the exception of the "little ds", competing needs or demands are not perceived, and therefore the need to decide not perceived, until much later in the caregiving experience.

Even when made conscious, some decisions are not identified as such by daughters, because: 1) they are "easy" choices ("It was easy. There was no decision necessary.") or 2) they are intractable ("There was nothing else to do", "There was no choice."). In the first case, decision is not named because alternatives (choices) are perceived and one or all are clearly desirable. In the second case, decision is not named because no alternatives (choices) are perceived, and the act is experienced as compelled or coerced, not decided. The daughters are able to name the experience a decision experience when they are conscious of competing courses of action over which they have some control.

Perception of control

These daughters often use the language "falling", "fallen", "fell on me", "fell into it", reflecting at times an absence of a sense of control of outcome. If decision is not decision until it is owned by the decision maker, ideas of "falling into" caregiving or having parent care "fall onto" the caregivers suggest another problem with our understanding of perception of decision.

Carol: It was like a trap and I fell right into it. I just can't say there was any one specific thing.

Diane: [This] really has kind of fallen on my shoulders...I don't know, it just has.....It's just kind of fallen that way.....I guess it probably falls on the one that's, everyone thought was the most stable to take care of her. I don't know.
Nan: In terms of having her go into the nursing home, I mean it just falls into place, I don't think I thought about long term at all.

Perception of conflict

The perception of struggle in decision experiences ("Lots of thought. Lots of sleepless nights", "I've struggled with this...."), contributes to the facility with which some decisions are identified by these daughters as they tell their stories. The greater the struggle, the more readily it is called "decision", up to the point of intractability.

Carol: It was a choice of two evils. Leave her by herself or bring her with me...I'd never say it was a simple decision.

On the other hand, decisions made without struggle are harder to identify and scrutinize.

Nan: You know, if we're talking about decision making, I never really, I mean I don't consider that part of what I'm doing a decision. I mean, I just, I just do it, and I, I don't think I have ever really delved deeply within me to say, "OK, now what's this all about?" It's something that just sort of...happens.....How did it really happen? And it just, I mean, I couldn't answer that. It just really does happen!

Marian: I never looked forward to it or was afraid of it. I mean I really didn't give it much thought at all.

Kay: Don't you think it's just a process which we go through and it's inevitable that it's going to come?....It flows.

Perception of a decision moment

A final issue in the discussion of perception of decision is the perception of a decision moment, or the capacity to sort out and separate these concatenated decisions. Because many of the decisions made are incremental ones which are represented by a series of blurred and overlapping choices and behaviors (in what Husserl called a fluid process of questioning and answering, and Sokolowski calls an "assembly of choices"), it is difficult to isolate discrete decisions for analysis.

Carol: I mean it's just one thing led to another, led to another, led to another.

Helen: Well, I didn't choose it (amount of visiting). It just kind of worked out that way.
Linda: I had not considered [relinquishing care]. I just do each day what has to be done. I have just taken one day at a time. I don't, I've just never really thought any other way....

Eve: There were decisions made every day. Basically the daily decision was what do I do next...am I doing the right thing. Every day it was a daily assessment.

Nan: It evolved for us. As things went along over the years, I really did take over.

To summarize, decision perception, or the absence of it, has two functions. First, perceived and identified decisions may be readily analyzed, while unperceived and unidentified decisions elude us. The first issue then is a methodological one, and could be considered a limitation of the analysis. However, the absence or presence of perception and identification of decision tells us something in and of itself. This is the second function. When shifts in the nature and level of participation in parent care take place in the absence of perceived and identified decision, that is they are not called products of decision, the changes are products of forces outside the rational process. It is argued that most important among these forces are the impulse to care and the will of others. In pursuing a balancing point of care then, these daughters contend with three things: their own impulse to care, the will of others, and the choices which present themselves. It is the act of deciding among these choices to which we now turn.

DECISION PROCESS: THEORY vs. PRACTICE

Two major decision theories were presented in Chapter II: subjective expected utility theory, and the Janis and Mann conflict model of gains and losses. These theories are explored here, juxtaposed to the decision realities in the stories the daughters are telling. The objectives of the discussion are: 1) to identify the impediments to effective decision making as illustrated by their stories, and 2) to understand how decision limitations leave the daughters vulnerable to their own impulse to care and the will of others.
As defined in Chapter II, subjective expected utility theory is the derivative of the mathematical expected utility theory, but allows for the subjective nature of evaluating the utility and probability of alternatives. Effective decisions may be said to be those in which the utility and probability may be evaluated, under certainty, and with a rational weighing of alternatives. Utility, probability, certainty/uncertainty, and rationality of these daughters' decisions are examined in this analysis of the decision process. Before beginning that discussion, however, it is important to consider the potential of the effect of time on the decision process, and also the influence of prior planning or discussion on caregiving decisions.

**Time**

Decisions made hastily or under time pressure, regardless of the potential for meeting the criteria of effective decisions, are at-risk decisions. Pursuit of a balancing point is sabotaged by time-forced decisions made without adequate evaluation of utility or probability of alternatives. Time pressures, such as DRG-related swift hospital discharges, render decisions uncertain and irrational.

**Diane:** I guess it came about very suddenly. I received a telephone call from the hospital...It was so sudden, and I had to take, I said, Well, can I wait til tomorrow to come and get her? I mean I couldn't drop..my husband..nobody was at home....

**Helen:** The decision was really made for me. The decision to put her in a nursing facility had to be made while she was still in the hospital.... I got a call from the administrator saying, Well, her pneumonia is gone, you have to get her out, you have to get her to a nursing home. Well, I was just flabbergasted, you know. Possibly, I guess I was thinking she was going to be in the hospital longer. So I hadn't at that point really---I didn't think too much about, Can I care for her here? The hospital thing had to flow right into the nursing home thing because we were pushed and we had two days. Going back to that, we didn't talk about it, we had two days....

**Eve:** It happened so fast that I didn't have time to catch up with it.
Prior discussion or plan

Time pressures create a decision crisis that is exacerbated by lack of planning or plannability. Diane illustrates how lack of planning or prior thought produces a situation in which her impulse to care dominates her response in a context of unconsidered contingencies.

**Diane:** I had made no contingency plans whatsoever because mother was very out and about. She was going to live by herself and she'd done very well doing that until this happened....It would be difficult to say when this happens I'm going to do this because you don't know when it's going to happen or what the conditions are going to be when it happens, what your situation's going to be and how you respond. Because the first thing when somebody's sick or in the hospital, you want to help them of course or do the best you can.

**Helen:** A lot of this is because, well, none of us ever expected her to lose the use of her legs. We just weren't ready for this.

Discussion of contingencies prior to the "onset" of dependency leads to a sense of contract with which the daughters enter decisions, making compliance easy, and non-compliance difficult. This sense of contract may be vague and inferred:

**Susan:** [My mother] has said, I always took care of my mother, you know. O.K. So you know how that reads.

or explicit:

**Eve:** We had talked about this a long time ago...She had said, "Please, promise that you'll put me in a rest home if this kind of thing ever happens."

On the other hand, lack of prior discussion leaves the daughter without basis for decision other than her impulse to care and the currently expressed or inferred will of others. Kay talks about the difficulty she has discussing plans with her parents.

**Kay:** I am more of an open-type of person than my parents are, uh, they still cling to the old-fashioned way: "Well, let's not talk about it until the time comes." And I want to get it out, lay it on the line.... Talking like that and getting things like that out in the open is not easy. It's very, very difficult.

Finally, attitudes and circumstances change, and in times of crisis, "contracts" may be rendered null and void, leading to confusion, and sometimes a sense of betrayal.
Even so, Eve relied upon memory of that earlier "contract" (above) to reconcile feelings about the decision to place her mother in a nursing facility.

*Eve:* Somehow she was able to recall that (contract), although after she got [to the nursing home] she thought it was a conspiracy..... But, um [remembering the contract] made it easier for me.

**Utility, probability, certainty/uncertainty, and rationality.**

It is clear from their stories that these daughters resort to "deciding" on imagined or unimaginable outcomes. The incapacity to predict a future state of affairs is a product of the unpredictable nature of aging, illness, renewed intimate mother-daughter relationships, response of others, etc. This serves to prohibit or distort the evaluation of utility and probability, increase the risk or uncertainty of consequences, and impede rational decision making. These daughters make decisions that are not only time-pressured and without planning, but also are, in spite of their best efforts, information-poor, alternative-poor, and prediction-poor. Furthermore, the impulse to care, while it may function to involve the daughters in the first place, also limits rationality. These issues will now be examined.

**Information- and alternative-poor decisions**

Some of the daughters describe a combination of information- and alternative-poor decisions that are a consequence of either their failure to ask questions, their ignorance about resources for answers, or the obstacles they confront when seeking information. Other daughters are more effective, or at least "luckier", in their attempts to inform themselves or identify alternatives. Either way, it can be argued that the amount and accuracy of information these daughters have about the nature of their mothers' disabilities, the caregiving experiences of others, and available caregiving alternatives impacts the effectiveness of the decision process in matching outcome with objective.
Carol describes not knowing what questions to ask and its impact on her decision experience.

Carol: If I had it to do over again, I would ask questions, more questions than I did then. And you don’t know what kinds of questions to ask before you have a parent move in with you, or who to ask. .... What is she capable of doing? What is she not capable of doing? We don’t ask, we never asked questions. Had we had someplace to go to be able to ask questions, or to know who to ask, then we’d have been better off. If we had known who to ask and what to ask she’d have never moved in with us....we would have seen the pitfalls.

The daughters' stories are laced with the failures of professionals and service providers to communicate information and alternatives. Occasionally, this is due to inability or refusal to release and discuss information.

Diane: My sister and I went down a couple of times and tried to talk to the doctor, went to his office and practically camped out in his waiting room and he refused to talk to us. I had said, couldn’t the doctor please call me and explain what’s been going on and he would not even call! If I leave her there and I’m not getting any feedback from him, you know, I just wasn’t, I just didn’t feel comfortable.

Carol: I can’t ask the doctor, because he wouldn’t talk to me. At the time, my mother was taking an awful lot of pain killers and I didn’t understand why and I needed to talk to him. He flat out told his nurse to tell me—Your mother has all her faculties and I will not talk to you. It was her business, it was none of mine, and he just, that was it.

Other stories are told of vague or insubstantial help from professionals and agencies.

Diane: I talked to a social worker [at the hospital] on the telephone, and asked her what options were available, if there was any way that they had any service or anything that could be done on that end, and she said, well that’s something you have to look into yourself. They didn’t provide any service or any real help except, you know, you have to see if you could get somebody to come in several times a day or maybe the Meals on Wheels type of thing, I presume they have something like that.

Helen: Sometimes you get very vague answers from the medical profession.....

The daughters tell of gathering or stumbling across information, by design or by accident.

Diane: At the doctor’s office they weren’t aware of [the day care center]. I was just real glad when the girl I work with had been to one of her church circles
and the program had been about the day care at the Y. So if it hadn't been for that, I don't know what I would have done. It was a blessing.

**Kay:** I had been helping my parents sort out their finances. I was sitting in the hospital lobby waiting for my father's tests to come back and I saw a sign: Golden Hearts. And I thought, What in the world is Golden Hearts? So I walked in, and this was in a small, little hospital and they said, We'll take care of the whole thing! Agh!! I felt as though I had a hundred pounds lifted off of my shoulders. I couldn't believe it!

**Nan:** You know, something that just occurred to me...I didn't even remember that I had done this, but, before Mom was really ill I went to the senior citizens' center....I don't know who sponsored it even, but they would have seminars in the mornings several weeks in a row, and it dealt with aging and illness, and I did attend those, and it was kind of helpful to have that background information before I needed it. So I felt that I was somewhat, not knowledgeable, but I had an introduction to certain kinds of things that I would eventually need to think about.

**Diane:** (Later, about day care) I guess I probably did read something about that in the paper at some time or other. But if you don't read the right column you don't have—unless it was a feature article. I think they do have a column now about elderly care or something...Well, maybe it's because I am in that situation. If I weren't in that situation, I wouldn't be as apt to look at anything. You know in the newspaper or anywhere else.

**Linda:** I don't, I don't know many agencies....I tried to get the senior citizens' bus. They came one time and said we really wasn't allowed to do that, so here in [our small town] we really don't have anybody that will come to your home to do that.

Janet describes her use of friends in town to gather information.

**Janet:** I did look, before they came, into what was available in this community, as far as house help and home nursing care. So I had made a lot of phone calls, I had talked to a lot of people... [A friend] that took care of her husband for so long at home you know, and she had lots of, lists of phone numbers for me and uhm, I talked to people who had cared for an elderly parent.

Finally, Carol expresses the irony she sees in her readiness to seek help and information with an earlier family crisis but failing to consider the possibilities for help and information as she decided about her mother's care.

**Carol:** Now when we had trouble with our oldest daughter, and [my husband] came very close to hitting her one night...We knew then that we needed help, we knew where to go. (Names the agency) We called 'em up and told 'em the problem and they said Come! If we'd have thought about that with mother, I'd probably have done the same thing, called them and said Do you know somebody I can talk to? But we didn't think about there being anybody out there for that kind of a problem.
Prediction

Awareness of information and alternatives enhance the evaluation of probability and utility. Less readily knowable even when sought are other, more dynamic, factors such as the change or unpredictability of the mother's illness and/or disabilities, the effect of the shift in caregiving on the relationship, and the response of others to caregiving decisions. "Unpredictables", therefore, have a profound impact on the decision process and outcome.

Diane: There was really evidently nothing other than a nursing home, and I didn't even think about it at the time, because first of all, we, I thought, well we'll bring her here and, you know, let things settle down. And in fact, we didn't even give up her apartment right away. I just really didn't know...It was just like an unknown. You just open the door and...I had no idea what it was going to be like....We just had to go on faith that things would work out. It might have been different if we were to plan ahead of time. But a lot of things like that cannot be planned ahead of time.

Carol: It's like, uh, almost like getting married. You're not really sure how this is gonna work. And if your personalities are totally different there's this conflict that you're gonna have...Are you gonna be able to work that out, to keep the "marriage" going?

These stories strongly suggest that unpredictability reduces long-term care solutions to short-term decisions. The incremental nature of the decision process is a product of those imagined or unimaginable outcomes.

Nan: First of all, I didn't expect, and neither did the doctors, that she would live this long because she was very bad, but I, any decisions or any thoughts that I had along the way were just assessing the situation at the time and dealing with that and moving along, and I didn't know where we were moving or how far we were moving or what, but it's just sort of something that you worked on at the time, it fell into place and then you went on to the next thing.

Eve: I never thought in terms of long-range things. It was just what had to be done at the moment. One day at a time. I can't thing of any time when I was thinking of long-term effects or consequences or anything like that.

Susan: I knew it would be hard on us, but you figure, you know, if you play this game like you can do anything if it's only one week...Well....maybe you can do anything if it's only two weeks, and so on... And I thought we'd get through it some way....Sometimes I look at her and I think, there's no way you can keep goin' on and other times I look at her and I think five years from now I'm gonna still be standing here feeding you broccoli.
Rationality

The requirements for rational decision making, as outlined in Chapter II, are the capacity to perceive and weigh alternatives, predict their costs and benefits, evaluate their utility, and approach the decision with a moderate level of emotion and or/stress. The difficulties with information-, alternative- and prediction-poor decisions have been established. It is argued here that the impulse to care, as it is experienced emotionally, may function either to enhance or impede rational decision making. We are reminded that Baron (1985) writes that "sentiment" may enhance rationality by "giving us any reason to think at all." The impulse to care, for these daughters, becomes the impulse to give thought to, examine and weigh alternatives for care. Conversely, and at the extreme, an unchecked impulse to care may impede rationality by obscuring alternatives.

Carol, who talks about her decision to bring her mother into her home as a decision of "heart over mind" (emotion over reason) believes that if she had listened to her mind, she probably would have said "Forget this!" Reason now tells her that she made the "wrong" decision, that even her mother would have been better off in another arrangement, but that the decision was the "only one [she] could live with at the time."

Susan describes herself as "too vulnerable" to the impulse to care:

Susan: You want to rescue everything and you want to protect everything and you use yourself up.

Herbert Simon (1972) suggests that satisficing, or making the "good-enough" or "acceptable" decision, is a product of limited rationality. In the stories of these daughters, rationality is preempted by the pursuit of the decision that can be lived with, the decision that balances the impulse to care with the needs of the mother, the needs of oneself, and the needs of others for whom the decision has meaning, particularly husband and/or children. Janis and Mann (1977), arguing for a conflict
model of decision making, suggest that this process implies a balancing of gains and losses for self and others (Chapter II). We now turn to a look at the utilitarian and approval considerations made by these daughters as they confront parent dependency.

THE JANIS AND MANN MODEL OF GAINS AND LOSSES

To review, Janis and Mann posit that four major considerations should be made and weighed in decisional conflicts: 1) utilitarian gains and losses for self; 2) utilitarian gains and losses for others; 3) self-approval or -disapproval; and 4) approval or disapproval of others. It is evident from the stories of these women that, at the "time" of decision, no conscious, organized efforts are made to map out or quantify alternatives and their consequences, (no "pros" and "cons" lists are made, no *quid pro quo* equations are calculated). It is also evident that they are able to identify, in retrospect, considerations made in all four areas. They are also able to identify which considerations "tip the balance", causing shifts in caregiving behaviors. Before moving on to this model, it is important to consider the effects of attribution on their stories.

Attribution: Contradiction and bolstering

An attribution issue in the accounts of weighing gains and losses is the contradiction the daughters seem to make in naming "reasons" for their decisions, alternately naming utilitarian and approval consequences for example, as reasons for their caregiving decisions. Rather than contradiction, this suggests a number of things: 1) Caregiving decisions are multiply determined. Decisions are products of multiple motives and circumstances. 2) Decisions are products of a dynamic process of balancing alternatives. The balance may tip in multiple directions, many times. 3) Reconstructed decisions rely on memory which is not always accurate. 4) Reconstructed decisions may reflect simple afterthought, that is, what surfaces as
important now vs. what was "really" considered then. 5) Decisions require bolstering when they are in conflict with real or anticipated standards of behavior, or when they are in conflict with other choices.

The illustrations of this process are presented with a respect for the possibilities of decision bolstering in these daughters' accounts. Bolstering, or the reconstruction of decisions in order to play up the positive features of alternatives chosen and the negative features of alternatives not chosen, may indeed be operating in these women's stories, consciously or subconsciously. It is maintained here, however, that what matters about the attributions and reconstructions of these daughters is the meaning they have for what is at stake in their decisions. Their stories tell us that what is at stake is tolerable decision: the resolution of the opposition between self and others as it is born from an impulse to care. In a dynamic context of difficult choices, bolstering is a requisite for keeping decisions "tolerable".

As an example, when Helen was asked what she considered when thinking about bringing her mother in to live with her and her husband, Helen bolsters her decision to place her mother in a nursing home with awareness she now has about the strains which her frequent visiting there place on her marriage.

Helen: Probably a divorce. I think it would have been hard on my relationship with my husband. It is right now. This whole situation has put a strain on us.

Utilitarian gains and losses for self

In the earliest stages of parent dependency, considerations of utilitarian gains and losses for one's self are clearly overpowered by the impulse to care and by the more dominant considerations of utilitarian consequences for others and approval issues. Utilitarian consequences for the self become increasingly part of the balancing equation as caregiving continues, however. Although this balancing equation or balancing point is explored in depth in Chapter VI, Linda's story serves here as a brief
illustration of this process. After caring for her mother and disabled sister for eleven years, Linda begins to seriously weigh the consequences to herself, and is considering a shift in caregiving: relinquishing primary care to a nursing home.

**Linda:** The only thing is it would give me more time to do the things that I need to do. I don't have a minute to myself to do what I even need to do here at home. You know what I mean? There is constantly something that needs to be done, it seems like for her. You know, it seems like every time I start to do something, she needs a drink of water, she needs the bathroom. Of course, that's all in taking care of her, and I understand that, but it's just that I don't have any time to myself.

Carol's utilitarian considerations for herself, when deciding to bring her mother to live with her and her family, were not negative ones. For Carol, approval issues weighed much heavier in the decisional balance, as well as a positive utilitarian consequence for herself.

**Carol:** I don't think that I ever thought of anything negative in the way of consequences for myself in bringing her in. I don't think that ever showed up. ....I was cleaning her house once a week, but that wasn't good enough so I was going over and cleaning [more frequently]. [My husband] would have to take care of the yard...and if you're gonna do that...I might as well have her here...Because then I would have just one to do and not two. It would be much easier to move her in as to run back and forth.

Before her mother was hospitalized, Helen had been managing her mother's affairs and making frequent visits to her home each week to help with groceries and housework. By the time of the health crisis, Helen was beginning to regard utilitarian consequences for herself more seriously.

**Helen:** I think I did think [bringing her into my home to give care] would be unlivable. I just didn't see, you know, picture things...I guess I'm thinking she's going to have me up and down all night and my husband said she'll have you up and down.

When utilitarian gains and losses for self are identified, they include such issues as time and freedom. Diane's discussion of these issues demonstrates the effect that current awareness of consequences has on reconstructing past decisions.

**Diane:** Oh, I'm sure I knew that there would be more responsibility on me...That my days wouldn't be as, you know...We have a lot to consider as far as you just
can't get up and say o.k. let's go to the ballgame tonight, you know. The lack of freedom is taken away, and you just have to do more planning, more planning.

Kay, when asked to name utilitarian consequences for herself she might have considered in her decisions to make caregiving trips, first mentions the interruption of her caregiving role to others, an issue shared by all of the daughters in the study. Secondarily, Kay mentions concerns about her own health, but only as they impede her capacity to give care.

Kay: [The consequences to myself are] that my husband can't even push a microwave button! And so, I feel very bad about leaving him. And so...it was very hard, but thank heavens the rest of the family picked themselves up and helped out. And of course taking care of my husband was my major concern. Now I have some concern about myself, too, because, I could feel that I had to do something to help myself out. You do think about the toll that it's taking on yourself, and I've had some health repercussions that I thought I'd never have. I thought no, I'd be indispensible that way......

Utilitarian gains and losses for others

In describing their earliest responses to parent dependency, the dominant utilitarian issues are those for their mothers. In explaining her choice to care for her mother at home as opposed to placement in a nursing facility, Susan assigns heavy weight to the better care her mother could receive at home.

Susan: I think [placement] would have been easier if she wouldn't be in the condition she is in, but like I said, not being able to ring for help and not being able to call out and even the simplest thing of wanting to express herself, you have to work to get it across....I know they just don't have the time. On the plus side of taking care of her [myself]----I know she's well taken care of.

Nan's decision to participate in daily care of her mother in the nursing facility also has to do with improving her care.

Nan: For the kind of care I want her to have I'm there most mornings at 6:30 in the morning. I'm there before I go to work and I'm there several evenings a week.

Diane's utilitarian concern for her parents was a financial one. She describes her decision to move her parents near her from another state as one of "financial desparation", and Nan's early decisions with her mother were similar.
Diane: I just feel there would have been total financial ruin for them, and then they would have probably had to come live with us within our home, that kind of thing, with us supporting them. Because there was such lack of control [of finances] this decision allowed them to remain independent for a while longer.

Nan: I was really concerned that she was just going to really diminish, diminish her funds as well as diminish herself, if she were to be out there alone.

Kay's decision not to move her parents nearer to her but instead to make frequent long-distance caregiving visits is attributed to her concern for what such a move would do to their health and to her parents' social life.

Kay: I think the consequences if they came down here and were completely unhappy, the health just goes right down the tubes. And I guess another consequence I felt might be a big problem was that they have lost a lot of their friends, and moving [would mean losing more].

Although utilitarian consequences for the mothers dominate the utilitarian considerations of these daughters, particularly in early stages, consequences for others to whom the daughters give care are also considered. The ability of these daughters to rank order the needs of those for whom they are responsible was discussed in Chapter IV. It may be seen in their stories how the balance tips toward utilitarian considerations for husbands and children as caregiving of the mother is prolonged. Just as utilitarian consequences for the self increasingly enter the balance equation, so do utilitarian consequences for others. "As long as things are going along" (Nan's words), that is, as long as the utilitarian sacrifices and demands of one's self, husband and children are not too great, balance is achieved and the decision is tolerable.

As will be discussed, the husbands in this study (by their wives' reports) are generally passive, if not generous in their early support of their wives' caregiving decisions. The women describe this support as important, if not essential, to their decisions.

Diane: If he would have said, No, we're not gonna bring her here, I wouldn't have done it. Because that would have been a conflict. If he didn't support it at all I think, oh, it would be difficult. You would have, you'd be pulled all different directions.
Linda: The only thing I considered was my husband, whether he would want me to do it or not. Had he said, uh, We're gonna have to do something [else], I think I would have tried to do it because it's my marriage, you know. I wouldn't, I love my family and we have a good marriage, so it would be a hard decision.

Ultimately, Linda's concern for her husband accompanies her regard for herself as it "creeps" into the caregiving equation: "I would have time for myself and my husband, I mean we just don't get to do anything rarely."

For Susan, however, her mother's needs are so dominant, that they overwhelm utilitarian considerations for others.

Susan: In effect, with my husband and my kids, like I said my mom's needs was greater. So I felt like she had to have it, but yet on the other hand, my family's important, and to get them, it was like I would almost try to manipulate them into getting them to [support my decision]. I mean I'd do whatever it takes, and I have at times you know...I told him, I won't do it if you say, if you don't want me to do it. But if you say No, I don't want you to do it, I feel like my heart's torn in half because I feel like it's the right thing to do.

Self-approval or -disapproval

Much of the discussion of self-approval and -disapproval considerations has already taken place in Chapter III, under the impulse to care. These daughters are predisposed to give care by very strong standards of responsibility to others and by an attitude of filial obligation. Their expressions of guilt and guilt avoidance are expressions of self-measuring and self-monitoring against those standards of responsibility and obligation. Seeking decisions they can live with means seeking self approval, the ultimate gauge of a balancing point.

Carol: In the long run maybe it was just something that needed to be done. Just to show me that I did care for her and that I did help her.

Linda: When it comes down to the personal part of it, you know, you still think---Should I or shouldn't I?

...........When I think about puttin' her away (nursing home placement), I just feel like I'm bein' too harsh or I'm bein' cruel. (Why would that be cruel?) Well, in my mind, to me. I think maybe I'm bein' cruel and mean, and then I think, well you know. I have to think about myself a little bit and I don't want to be cruel, I don't want to be mean with doin' it, so.... I keep tellin' myself I'm not cruel.
I wouldn't want to feel guilty. I wouldn't want to feel like that. I want to feel like I've done the best I can, or doin' the best I can. That's what I want to feel like I was doin'. I wouldn't want to place guilt on myself.

Susan: I would feel like I was such a rotten person that you know....I could put, if I put Mom in a nursing home, I'm the one that has to live with that.... even though I hate my situation, I detest my situation, to the point that I want Mom to die.

Others' approval or disapproval

It must be argued that the approval of others is linked, though secondary, to self-approval in these stories. Often, the approval of others is anticipated or sought against the daughters' own standards. For Carol, the approval of others is very important and is named as one reason for her decision to bring her mother into her home.

Carol: My more conscious realization was so that the family, aunts, uncles, my brother, wouldn't talk about me as not caring about her....I just didn't want anyone to be able to say that I didn't take care of her...."She didn't take care of her mother"......Nobody can ever come back and say we didn't try.... ..No one ever expressed anything. This was all anticipation. It's that need to have people feel you're doin' right. I think that's the insecurity...An insecure person always wants someone else to tell them that they're doin' good.

For Helen, the opinions of others (with the exception of her husband) have no direct bearing on her actual decisions, but do serve to make her angry.

Helen: I feel like I'm doing what I feel is best, and if people don't like it or that, you know. [They say], "Oh, I wouldn't do that with a family person", and I slough it off...I figure, well here's another one of them. [They] don't know the total situation. ...Any body who would say that to you is not a friend. It just makes me mad. As soon as I hear that come out of their mouth, I just get very angry because they don't know the situation. They don't, and then to be that thoughtless.

Helen suggests that if anybody could make her feel guilty about her decisions it would be her mother, but that her mother has withheld disapproval.

Helen: She could do a better job than the outside folks. But she hasn't really, I haven't felt that from her....She's never said, You should feel guilty for doin' this to me. But then, she's smart enough to know that I'm the last resort! I'm all there is!
Linda is especially sensitive to the approval of her mother as Linda looks toward nursing home placement.

Linda: I worry about my mother thinkin' I don't want her. That's the worst part of it, of her thinkin' that I'm just tryin' to get rid of her, that I don't want to take care of her or somethin'....Cause each time she'll say---Well, go ahead and put me there. And I'll say, Mom you'll feel hard on me. That part I consider more than anything, is what she thinks.

The decisional balance

The support of husbands has been alluded to, and it is clear that the approval or "permission" of husbands is critical to the decisions these daughters make. Approval of children and friends also appears in the stories as important. In general, however, the approval of mother, husband, children, friends and professionals serves to make the caregiving experience, once decided upon, less stressful, but is weighed secondarily in the decisional balance. The moral imperative to care and the mother's well-being are at the center of the impulse to care and disallow or out-weigh other considerations. It will become clear that moral self-approval and the definition of a balancing point is so personal and insulated that it withstands the approval and disapproval of others.

NEGOTIATING WITH OTHERS

Although a balancing point is pursued and owned by the decision maker, that is she defines what she can live with, achieving a balancing point of caregiving activity is a matter of negotiation. As they enter negotiations with their mothers, husbands, siblings, children and professionals, these daughters take with them both the impulse to care and their need for a balancing point. These become part armor and part vulnerability in interpersonal decision making. Negotiations with important others are now examined.
The mother

These daughters describe varying levels of mothers' involvement in caregiving decisions. Logically, when the mother's wish and will are compatible with those of the daughter, decision is easier, less conflictual; when wishes and wills are incompatible, the decisions are difficult.

Linda: Well, she is the one that told me to [arrange nursing home placement] to start with. I know, she'll say I don't want to go, but you need a rest. I think she really understands how hard it is with the two of 'em, you know. No, she definitely won't want to go, I know. I don't know what to do. It's very difficult....I said, Mom, I told her several times, I just don't know the answer. I don't know what to do. I said Mom, I know you don't want to go into a nursing home. She said, No Linda, I don't, but she said, It's too hard on you now. It's to the point I can't do anything. It's too much on you, so you hunt me a place to go.

In Nan's case, where there is a high level of trust established between mother and daughter, decisions are easier.

Nan: In many respects I've had it easy in terms of making decisions for my mother, because you know, she just trusts me to do the right thing, and so I've never had a problem. We discussed power of attorney and I said Mom, you know, I explained to her what it was about and all that, and she said...whatever you think....

Marian and her husband built a room onto their house for Marian's mother, before they invited her to move in with them. Marian describes how her mother worked to "own" the decision to make the move.

Marian: She kept saying, "Don't call it my room. Don't call it my room. Oh, don't call it my...." and I would consult her about a color or something for your ro...."Don't call it my room!" And so, uh, she was retaining I guess her independence until the last. It was totally mother's decision to come. ...We kept telling her that we weren't gonna make the decision for her because I didn't want her to say afterward, "You made me come here and it's awful and I hate it!"

The concept of dependency takes on new meaning as we look at the involvement of the mothers in caregiving decisions. Not only are the mothers dependent on others for instrumental help but so also are they dependent upon others' decisions to proffer that help. This vulnerability adds another dimension to their dependency. Issues of autonomy and paternalism arise out of the shifting dependency/independence
relationship, and create some of the most conflictual decisions these daughters confront. *Whose decision is this?* When daughters decide about the nature and level of their participation in the long-term care of their dependent parents, they inevitably risk exploiting that dependency.

To the extent that they feel able, the daughters work to preserve the independence (freedom from the *need* for others) and the autonomy (freedom from the *will* of others) of their mothers.

*Janet:* As long as those things are going well, then I'm not going to interfere. If they can do it, I'll let them. Until the point becomes impossible, and when I see that it isn't working then I'll just suggest something else for them.

In all of their cases, however, some level of decisions are made without involvement of the mother, from decisions about medications, to decisions to sell a home, to decisions to place in a nursing home. Some mothers, though involved in the decision process, are coaxed, others are persuaded, and others are manipulated.

*Helen:* She was very open to, as long as I coax her along, since we've had this long relationship, as long as I tell her this change'll be O.K., she'll go along with me. But when you get right down to it, what choice does she really have? Somebody has to make the decisions.

*Susan:* I'd make up all these stories, just like you would for a kid you know. Just always trying to come up with different things to kinda like shove it under the rug.

*Janet:* We bought a condominium that was available, and they said Yes, they gave the consent to...Yes, move to Ohio. Although when I look back on it I realize that I caught them at a weak moment. ....I went through a lot of agonizing guilt ridden days when my parents first arrived here. It was January! To Ohio from Florida! And they were freezing cold and it was an awful adjustment for them....you know, these guilt feelings that I made them come back here in the winter! You now, I didn't make them, but I did say, Yes, this is what I think you should do.

In other cases, mothers are excluded from the decision process completely, by the daughter's design, or by the mother's passivity.

*Helen:* It's just as well she's not asking. Um, she has never asked me what it costs to stay here (in the nursing home). Now, for a woman that's of sound mind you think she would. I don't know if she thinks it's gonna upset me if she asks,
or if she doesn't want to know. I think maybe about [what happened to] the house, she doesn't want to know.

Kay: You say, O.K., you do it, fine. But they don't do it so you have to do the decision making for them in that particular case.

Carol's communication with her mother is impaired, and this functions to limit the involvement of her mother in decisions.

Carol: Had I had better communications with my mother, it might have worked out easier, we could have talked before we finally made the decision. But mother and I have never been able to talk.

Finally, for some of the daughters, the mother's diminished physical and/or mental capacity to participate in negotiations requires otherwise unwarranted paternalism.

Diane: I don't recall asking, Mother, what do you want to do? I don't recall if we ever said. At this point she was still pretty confused. I don't think she knew what was going on still. As far as having any input, well she clearly told me many times she didn't want to be here (daughter's home). She just isn't want to be on this earth: I wish I was dead type thing...Why didn't they just let me die.

Linda: You weigh one thing against another trying to...I try to figure out what I think is best for her because I know that she is not capable of really making a decision now. My mother's not, she doesn't understand.

In every case, the daughters express an an intent to protect the best interests of their mothers and though the decisions are conflictual, the daughters believe them to be justified. Furthermore, the daughters cite protecting the mothers from the decision experience itself as sometimes in the mother's best interests.

Helen: I just think the more she knows about the fact that everything is being sort of taken away from her and all that's left is just, here she is, in this [nursing home]. I don't even know if she figures she's gonna stay here 'til she dies, which could be a long time or it could be tomorrow. I don't know what she thinks. And those are things you don't talk about. Why would you? You know?...So, anything I can do to not put more stress on her......I think she would be stressed out even more than ever.

It has already been argued that these daughters respond to their mothers' dependency with behaviors borrowed from their roles as mothers. Nowhere is this felt more profoundly than in the power/dependency issues at work in these decisions.
References to making decisions as one would for a child, and to "taking charge" of their parents, surface in their stories, and the daughters express the dilemma this presents.

**Eve:** I think when you feel like you are shredding them of their independence...you're causing them to become more infantile. [When I took my mother's car away from her] she'd say, "Well, you won't let me have my car." It was like a little child saying Well, you won't let me have my toy. And I felt, oh, my goodness, this was like her last link with real independence!

**Kay:** Taking over as far as being power of attorney was one of the most difficult times.....It made me feel as though (slams fist on table) I've got power over them. I can do anything I want to and that is not the way it should be....When times got tough there I knew I was gonna have to have power of attorney. I didn't like it. That's awfully hard to do. Awfully hard.

**Nan:** I make all her decisions. I take care of her. It's kind of like she's my kid except that you know as you have your children, your children start growing and maturing----My mother is regressing you know. It gets worse and worse every day...So you sort of feel that same kind of thing, where you're making more and more and more decisions about everything....Eventually, when she got really ill, I absolutely, absolutely took over. I just said, O.K. Mom, I'm in charge of you.

Some of the daughters express a concern for the risk of unnecessarily creating dependency when they assume care for their mothers. Janet remarks on the increasing willingness of her parents to subject themselves to their daughter's decisions.

**Janet:** You know, they become like your kids after while and after while they let you become their parent. They allow you to make the decisions for them. It's no longer a struggle.

----------The more assistance I give to Mother and Dad, the more they are going to let me do for them. It's one of those things that you kind of hold back a little. Uh, you don't want to give it all....I know that sounds sort of crass, but..... doing all these things that would take me from my own life.

Carol also found that if she gave care prematurely, her mother became dependent prematurely, "laying the groundwork for this total dependence."

**Carol:** She was getting to a point where she was letting everyone do everything for her. Even to a point where some decisions, she didn't want to make them. I was beginning to treat her like a child. And when you think about it, your children you raise for them to leave you, and I was more or less doing the opposite with mother---pulling her towards me, and taking away her independence and taking away my independence.
Carol's story demonstrates, in the extreme, how the impulse to care and the vulnerability of the parent may combine to impede the independence and autonomy of both parent and daughter, in spite of the best intentions of the daughters. Generally, however, each of these daughters works to consider the wishes and will of her mother as they negotiate toward a balancing point of care.

Husbands

As mentioned earlier, for the most part the husbands in this study are reported by their wives to be supportive, even generously so, of the caregiving decisions made by these daughters. The women report a variety of styles and levels of involvement of their husbands in the decision to give care. Two extremes of husband involvement are presented here.

Although Marian had been making frequent and lengthy long-distance caregiving trips to her mother's home, Marian's husband initiated the idea of bringing Marian's mother to live with them.

Marian: It was my husband's insistence. My husband was the one that pushed, and urged us to go ahead and build the room without Mother saying that she would come. His encouragement, very much...he's always been very close with her and very fond of her...and he said, "Let's go ahead and build it, because if wait until she says Yes or until she has to come, it might be too late."

Susan, it will be remembered, tells of manipulating her husband into complying with her decision to bring her mother into their home. Although she describes her husband as "one in a million" and "very supportive", she describes coming to a conviction that she should bring her mother home, and "negotiating" with him in a way to secure that outcome. Early on, this meant that Susan had to bolster her decision in front of her husband and children.

Susan: And then, because I felt like they were having to give up stuff, then it's like you put in even more effort to please them, too. And I think one of the biggest strains and minuses of all this is when things would get rough, where I'd feel like I had to blow off steam and I'd complain about my mom in any way, and
my husband says, Well it's just too much and I don't want you watching her....So I could never complain.

In between these extremes the daughters tell stories of talks, not negotiations, with their husbands during the decision process. Ultimately the husbands test the balancing points of their wives by suggesting shifts in caregiving: sharing or relinquishing care.

Diane: So he said, "Well, you know, we'll just have to get her and bring her here. There's nothing we can do but to bring her here." But he said this is your decision, I'll support you in whatever you decide.

(Two years later)
He's not been real verbal, but he has in some ways because there'll be times he'll say maybe it's time to look for something else. When I've had a frustrating time or something like that. He hasn't said, By such and such I want her out of here. He's never said that. But he knows there's times, and he says at times. maybe you should look into something else. It's just like, Well, one of these days, you're gonna have to make a decision to place her in a nursing home or that type of care. And I think in a way, just the remarks he makes now, it's like sometimes I think it's time for me to find other care for her.

Carol: My husband and I talked it over for a long time and decided the best thing to do was to move her in with us.

(Five years later)
He was never against it. In fact he has been a rock throughout this whole thing. Uh, no matter what I wanted to do, it was fine with him. He's never said anything against it until he and I started fighting. The decision for her to move in would be both of us. And the decision for her to move out would be both of us. He didn't want to come to me and say—You have to tell your mother she has to leave right now...We have always made our major decisions together.

Helen: My husband wouldn't have said a word if I had said, I can't put mother in a nursing home, we have to bring her home. [After deciding I couldn't bring her home] I sort of said, well maybe I should see if he agrees. He'd be the one I would talk to first.

(One year later)
This is his usual pattern through this: "Don't get so upset over this." And then I'll say "But I do!" When I was coming home so upset, and I'd go through the whole tirade...I was beginning to worry about myself, you know. And he said, You know, you just got to quit this. It hasn't changed [my number of visits] but it might make me look at myself and how the whole thing's affecting me and see if I can't deal with it in a better way.

Linda: The only thing I considered was my husband, whether he would want me to do it or not and with him sayin' he didn't care, why that just solved the problem and we went on from there.

(Eleven years later)
He knows that I get mentally depressed and wore out. You get mentally depressed and wore out, and he can see that side and that's why he tells me----
Maybe you should go ahead and do it (nursing home placement). You will get over the worst part of it. And he knows it will be hard to start with. He don't tell me to do it, but he said it's just that he knows how tired I get. He tells me...really, it's your decision, but maybe you should do it for your own self, and he realizes that we need time together, but he don't make an issue of it. He has never complained one day. He's a very loving and caring person or he would never, he would never have put up with this.

_Siblings_

With the exception of Kay and Helen who are only children, each of the daughters has important stories to tell about negotiations with siblings about the care of their mothers. These stories, like all the others, represent a broad range of experiences. Though four of the daughters have only a brother and no sister, two have both brothers and sisters, and two have sisters only. Diane's story about a family meeting she had with her siblings regarding the fate of her mother's care following hospitalization serves as an informative introduction to the issues of negotiations with siblings. Diane outlines in this story the _process of elimination_ that led to her assumption of her mother's care. At the time of the meeting, Diane, with a two-month-old "empty nest", had brought her mother home to live with her "temporarily".

_Diane_: I asked my brothers to come down and my sister and we all got together and decided. I said, I don't feel like I should make this decision alone, but I want you to know what's been going on. I just felt that everybody should be in on the decision. I just thought it was only right. And it was certainly a lot easier than talking over the phone.....We really didn't talk about it very long. As I remember we had dinner and a visit and so forth but when it came down to the nitty-gritties....It was like, you know, everybody said, Well I can't....My sister-in-law, the one who had a son die a year before, said I can't deal with this right now. And my brother said, I got three still at home. And my sister, with her four, she just didn't have the room.....I guess I just felt it would turn out exactly the way it did turn out. I could sort of predict what everybody, what was gonna happen. I mean I just felt like I could predict that and that's exactly what happened. Maybe I shouldn't have predicted what would happen. But, I still thought it was a good idea to have the meeting. Because then, nobody could say, Well, you made this decision without telling us. If I have to put her in a home, I probably would go through the same procedure. If there would be a choice involved, I probably would involve them.

Diane demonstrates how her impulse to care fills up the hole in caregiving left by the other siblings, but maintains that she could have allowed her sister or brothers
to be the primary caregivers had they had the space and/or inclination. Even Susan, who describes herself as a rescuer and protector, does not pursue caregiving for the act itself, and insists that if she felt her mother could receive comparable care from her sister, Susan would be comfortable with relinquishing care to (or sharing more care with) her sister. All of the daughters are inclined to share care with their siblings whenever possible and would welcome more participation from their siblings. However, the process of elimination that led to the caregiving holes is generally legitimized by the daughters' sense of logic. They understand the process, even when they regret or resent it, and they demand little help from their siblings.

**Diane:** (About her sister) Now she's been willing to help, you know, like she takes her on one day and...It was like here's the situation, and this is the best way to resolve it.

**Susan:** I felt like in fairness, we should all take part in her care. With four children, it could have gone a lot nicer, but with four different personalities coming in there, plus their spouses, it ended up that it divided my sister and I against my brother and other sister. And so it worked out to be what seemed to be a fair situation between my sister and me.

**Nan:** I do have a brother in New Jersey, he is sixty-seven years old, and has had quadruple by-pass surgery. I do talk to him on the phone occasionally, but he doesn't make any decisions. I just inform him about what's going on. [When we first brought Mother to live with us] I think my brother would have done it, but I still agree that it would have been his wife....had he taken Mom on, it would have been his wife involved...in the care.

**Janet:** My brother wasn't concerned, or didn't appear to be as concerned about my parents' situation as my husband and I were. Uh, I think he was willing to let it proceed with whatever direction. Although it was driving him quite mad too, but he didn't take the action that we did. I think so long as I'll do it, he'll let me do it.

**Marian:** My brother's a federal judge so he's very busy...... I'm sure that it's easier on them. They miss her, but they would take their precious weekends and go down to see her as often as they could.

**Eve:** My sister is married to a minister, and they have a very busy life.....She would help if she could...She can only visit once a year.
Among the most difficult of negotiations with siblings is the negotiation to share care. As the siblings are generally not inclined to offer assistance, the daughters are put in a position to ask. For many reasons, they are uncomfortable doing this.

**Carol:** (Calling her brother on the eve of her vacation) The doctor said he wanted mother in the hospital, and I called my brother, extremely upset, crying. And I said, I need help. He says "What do you want me to do? Come out there?" Well, I said, Yeah! He said, "Kiss my ass!" and hung up. Granted it was an unreasonable expectation....I was so desperate. All I needed was for him to say---You know I can't do that right now. If you can give me a couple of days, or somethin', I can work something out...But just to say "Kiss my ass" and hang up. He has never apologized for being so nasty.

............I think what I wanted from him was a little moral support. You know. That you're doin' a good job, I really appreciate what you're doing.

**Diane:** You always get the sense that, Oh, I'm glad it's you, that you're doing it. Instead of me, you know, sometimes you get that feeling: I'm glad you're doing that.

-------- [My brother] would be the one that would not want to put [mother in a nursing home]....and I thought, you don't even come down to see her, you don't talk to her, you don't write her, you don't call her...anything. And here you're high and mighty, worried about how long she's gonna last in a nursing home.

**Susan:** (describing going out on Tuesday nights when her brother stays with their mother) I know he's waiting on me. And he's not one to say--Now, don't worry when you come back. Instead, it's like, Can you tell me when you're coming home? And for that couple of hours, I think---Gee, he's been there so long, I gotta go home. I get sick to my stomach.

*Children*

The women share stories and feelings about the involvement of their children in the care, and decisions about care, of their grandmothers. Carol's daughters were not included in the decision to bring Carol's mother into their home, even though one of the daughters was still living at home.

**Carol:** We didn't talk to them at all. When it came to family decisions like that, moving, things like that, the poor girls were left out. These were decisions mom and dad made. We are moving, if you don't like it I'm sorry........ ..........A decision like that should not be an isolated thing. We should have gone even if just to talk to the girls and we didn't. It was something that my husband and I made on our own with really no help from anybody else.

........But the girls never asked anything. You know, they were never belligerent about that or anything. They were very supportive when we decided what we were gonna do.
Helen talks about her daughter's "place" in the decision making.

**Helen:** My daughter's very supportive, you know. She hasn't been down since Christmas, but they were down twice, and we talk on the phone....I tell her how Mother is doing and she's never once questioned it. "Do you think you should have done this?"...she's never done that. And also the fact, she's never had any care of her, so it is really not her place to say, Well I don't think you should do that, Mother. Because I'd probably say, "Do you want to come home and share in this?"

Susan expresses resentment of her daughter's failure to offer help, but Susan doesn't ask for it, wishing that her daughter could see the need and offer help before it is sought.

**Susan:** As much as I love my daughter, I think she's a really sweet girl and she's got her head on pretty straight...I resent it over the fact that she could call the house and [my four-year old] is sick and I'm havin' a hard time with Grandma and she don't say----Mom, would you like me to come over and give you a break? She don't. I resent her for not seeing and caring, showing that she cares. If I ask [for help] she'll say Yeah, Mom, I'll definitely try. And she will try. But not that....To me it's like you see somebody drop something, you go pick it up. It just comes natural. And I kind of expect that to be in her. That she'd be there when things are rough, and she isn't.

Kay, whose long-distance caregiving trips, are out of the sight of her husband and children, believes that having her grown daughter along to help on one of the visits sensitized her to the situation.

**Kay:** I think during the time that I have struggled with this commuting and the phone calls almost every other day, uhm, everyone sort of thought: Mom is sort of overexaggerating. Mom is highlighting this whole thing. Well---My daughter came back [from the caregiving visit] and she said to my husband, "Mom could not have done it. It's right, Mom could not have done it."

**Professionals**

Problems with obtaining information and resources from professionals have been identified earlier. Other than those experiences, the daughters tell few stories about working or negotiating with professionals as they made their caregiving decisions. Nan explains.

**Nan:** I had thought at one point of talking to someone about decision making, but I never did do that, because I never quite felt that anyone would understand. I just never quite felt that my laying X,Y,Z out on the table was the same as my
feelings about X, Y, and Z, and I just didn't really trust anybody else to know the situation!

Nan, like all the other daughters, has defined her own balancing point of care. The balancing points of these daughters "look" different from each other as they are manifested in a variety of caregiving behaviors. It may be argued that the balancing point as an ideal exists, as a sense of what is "enough", prior to the situation of parent dependency and is discovered through caregiving decisions. From that ideal balancing point a balancing point of caregiving activity is uniquely achieved through negotiations with others, and in the choices they confront. This analysis now turns to the balancing point of care.
CHAPTER VI
THE BALANCING POINT OF CARE

Introduction

A balancing point of care, though the underpinning of all caregiving decisions, is especially evident in the major caregiving shifts: assumption, sharing, and relinquishing of care. How do we explain the variety in levels, lengths and forms of parent care: why some daughters "hang in there" longer than others, and why some daughters give certain forms of care and other daughters don't? Circumstances (the nature of parent dependency, the will of others and the choices which present themselves) do not define this balancing point; otherwise, caregiving shifts would be predictable and standard by those circumstances. We can only explain these shifts by the unique and multiply-determined definition of "enough" that each daughter has decided for herself.

BALANCING POINT vs. "BREAKING POINT"

Frequent references are made in the caregiving literature to reaching the "end of one's rope" (Gonyea, 1987), "burnout" (Doty, 1986) or a "breaking point" (Smallegan, 1985), suggesting that caregiving shifts take place in a context of exhaustion and breakdown. Indeed, for the daughters in this study, the caregiving shift of relinquishing care may be experienced as crisis and a breakdown in capacity to give care, but is one expression of a balancing point. This balancing point is defined as a "threshold of support" (Frankfather, et al, 1981) beyond which each cannot sustain
care, but also as a minimum of support below which the impulse to care cannot tolerate. "Breaking point", as a descriptor of the phenomenon, explains only half the dynamic of caregiving decisions (the threshold of support), and indeed speaks only to sharing and relinquishing, not assumption, of care.

Helen's balancing point is evident in her decision not to bring her mother into her home and again in her decision to provide extensive daily care for her mother in the nursing home. Susan's balancing point is evident in her decision to take over full-time care from her sister and her determination to see caregiving through until her mother's death, "like a tour of duty." Diane's balancing point is evident in her decision to bring her mother into her home, but to continue working, while sharing the care of her mother with a day care center. Eve's balancing point is evident in her decision to place her mother in a nursing facility when the costs to her family and herself become too great.

The balancing point then, is an equation of impulse to care and the limits of caregiving, and includes the opposition of self and others. It will be determined that these daughters are not a "bottomless pit", bound to their impulse to care (for parents, husbands, children) by a limitless denial of self. Rather, they work to establish a place for themselves in the equation, tolerable within both their impulse to care and their own limits. Guilt functions to control, flawed decisions function to distort and/or sabotage, and the will of others functions to test, push, threaten, or reinforce that balance. Furthermore, the balancing point is fragile, labile, and elusive. In working toward decisions they can live with, in a dynamic and uncertain context, these daughters struggle to both protect and care for their mothers and families and to protect and care for themselves.
THE MORAL DIMENSION

Carol Gilligan writes, "Opposition between selfishness and responsibility complicates for women the issue of choice, leaving them suspended between an ideal of selflessness and the truth of their own agency and needs."(1982: 138) Such is the struggle of these daughters. Calling this opposition "self-blinding", Gilligan argues that, for women, the "moral ideal is not cooperation or interdependence but rather the fulfillment of an obligation, the repayment of a debt, by giving to others without taking anything for themselves." (p.139) Only by expanding and reframing the idea of morality to integrate or reconcile the needs of self and others can women avoid risking what feels selfish and "morally dangerous".

The ideas of morality and goodness, founded on principles of responsibility and "others before self", operate at the center of the impulse to care and create for these daughters choices that strike at the heart of their moral identities. In their caregiving decisions, particularly in the major caregiving shifts, the daughters confront and challenge their moral selves. Guilt, the watchdog of morality, intensifies their moral consciousness, reinforces moral principles, and "hangs around" to punish when moral principles are disobeyed.

Relatively guilt-free shifts in caregiving may occur when decisions are not owned, but instead are coerced or compelled. Examples are those shifts in caregiving which occur when the daughter lacks the skills or finances to care for her mother or when the mother or her guardian assert legal rights to alternatives to care. However, for these daughters, owned, guilt-free decisions are possible in only two ways: 1) by deciding on the side of responsibility to others and abnegation of one's self or 2) by reframing the moral principle of care and responsibility to include both others and self.
How is it that these daughters are not bottomless pits of self-denial? Each daughter confronts and comes to terms with her threshold of support, and reconciling it with her impulse to care, achieves an ideal balancing point of care for self and others. When the ideal balancing point and the level and nature of caregiving activity are well-matched, she has made a decision she can live with. When they are not well-matched, she struggles with regret, remorse, and self-punishment.

Clearly choice is also complicated when the daughter is impelled to give care to more than one person: the mother, father, husband, and children for example. Competing dependencies add layers to the conception of "others" in the opposition of self and "others". Within that layering, each daughter struggles to weigh the needs of, and her obligation to, those for whom she cares. Even while a daughter is finding a place for herself in her decision to care for her mother, she is facing parallel and inevitably linked struggles in her decisions about care for other family members. Not only must she find the balancing point in her caregiving decisions about her mother, but she must find a *balancing point of balancing points* to account for all for whom she feels responsible. It is argued that this process ultimately requires a moral maturity and a transformation of the regard for the self in caregiving decisions.

**Moral maturity**

Daughters may work to avoid regret, remorse or self-punishment when disobeying the moral precept to care for others by: 1) assigning priority to utilitarian consequences, subsuming the moral imperative; 2) reducing the expectations inherent in the decision; and 3) bolstering the chosen alternative. According to Janis and Mann (1977), the less a person takes responsibility for another, the less she is likely to use a moral precept as her decision rule. That is, she attributes her decision to utilitarian considerations and does not follow a moral imperative. ("I wanted to take care of her and I would if I could, but it's not possible for me to quit my job." or "She is
too ill to care for at home anymore.")  And Festinger (1964), in his theory of cognitive dissonance, argues that when expectations are perceived as unfulfillable, they are adjusted to individuals' perceptions of what is possible. ("I can't be expected to work and care for mother at the same time." or "Mother would get better care in a nursing home than I can give her here.") It is possible that reconfiguring the moral imperative to care and the consequent inclusion of self in the caregiving equation are products of decision bolstering. Indeed, as argued earlier, some bolstering is necessary to produce and sustain decisions that can be lived with.

It is also possible that reconfiguring the moral imperative and its consequent inclusion of the self are products, not of self-deception, but of moral maturing. Eve, who says she "didn't have time to catch up" with her decision to relinquish primary care of her rapidly deteriorating mother and is ridden with guilt about her choice, may not have had time to mature in this struggle between self and other, to establish a place for her own "agency and needs" in her response to the dependency of her mother. And Helen describes feeling more comfortable with her decisions "as time goes on." Through the passing of time and hard mental work, Helen has come to terms with the tension between self and others in her caregiving decisions. Her balancing point can be likened to a pendulum which at first swings widely, and gradually, over time, comes to rest, only to be disturbed again by new choices.

To illustrate the emergence of a balancing point in the struggle between self and others, five cases are used. The shared and idiosyncratic characteristics of their stories are evident. Because of significant changes in caregiving circumstances in three cases, each of those three cases are presented in two parts: Part 1, the analysis following the first two interviews, and Part 2, the postscript following the third interview.
CASE ILLUSTRATIONS

Diane

Part 1

As will be recalled from Chapter IV, Diane's impulse to care is attributed to her love for her mother: "I couldn't have left her, Deep down it is love," and to a strong sense of responsibility attributed by Diane to her position as the oldest child in the family. It is hard for Diane to identify what being a woman might have to do with the impulse to care, and when pressed, suggests it perhaps might have something to do with a "mothering instinct", although she is not convinced of this. Instead, she believes that her role as a daughter and particularly the oldest child is one deciding factor in her impulse to care. Diane's mother, whose primary limitation is a rapid-onset dementia, had been well until the time of hospitalization and Diane had made "no contingency plans" for the possibility of illness. Diane was unable to get helpful information about her mother's illness or alternatives. Her mother was discharged from the hospital before Diane had time to make arrangements other than to bring her to her own home. She held a family meeting at which time her siblings declined to participate in the care of their mother, and the care "fell" (her word) on Diane.

For Diane, her impulse to care, especially the sense of responsibility to her mother, was stronger than any competing demands, and she acquiesced to this process of elimination. Tipping the balance toward assumption of caregiving, then, in this context of minimal information and alternatives, was her sense of responsibility and her love for her mother, rendering all other needs and demands secondary to her mother's crisis.

Diane, who works, shares the care of her mother with a day care center and with her sister who cares for the mother one day a week. Diane wants to hold on to caregiving as long as possible because of a "guilt feeling" which keeps her sensitive to
her "responsibility". Although she is unable to predict with certainty what her support threshold will be, it appears that for Diane, a worsening physical condition of her mother would incline her toward a decision to relinquish primary care of her mother.

My hope is that we are able to keep her here as long as her condition is as stable as it is now. If things change radically....Some days you just take it a day at a time. I think if something would happen that she would, say if she had a stroke or something, or if she would go into the hospital or become impaired....You know, if she could not climb up and down the steps, then we would have no choice. There would be no choice that that's what we'd have to do.

Right now we're kind of maintaining things as they are, and as long as she's able to care for her personal needs, and is able to get around the house....unless something drastic changes.

Diane, though having a strong sense of responsibility to her mother, has a sense of her caregiving limits as they relate to her work and her "space". Threats to her work and space, e.g. the loss of day care, would tip the balance of care toward nursing home placement. Diane, then, has a fairly clear understanding of what her threshold of support is in terms of her losses to her self. At this time the balance is not threatened because her mother is able to qualify for day care, and is physically well enough not to require twenty-four hour care from Diane. Even so, Diane has an understanding of how her balancing point of caregiving activity might be disturbed.

I try to do what's best for her. but then you also have to think of what's best for you.

If I hadn't found the day care I would have had to either quit my job or had to put her in a nursing home permanently....I think the decision would have been to put her in the nursing home. I really do like the job and I think if I, I think just as she needs her space, so do we. If I had to be with her day and night, it would be more frustrating to both of us.

Though fairly clear about her threshold of support, the fragility of the balancing point is evident in Diane's occasional wavering.

There are times when I think I should look at nursing homes again, or closer, but right now I haven't made a firm ....when things get a little frustrating for her and with work.....then things will pass as they always do. But then there might be a time when they don't pass and then......
Perhaps sensing its fragility, and not ready for a shift in caregiving, Diane defends her balancing point against the suggestions from her husband that alternative arrangements should be considered.

I mean if we had to put her in a nursing home, I mean if he'd say No, I would say I'm sorry! You know. And there are times my husband says I think you'd better look into it, maybe you should look into something else....because you know the frustration comes at times....

Finally, in confronting decisions to relinquish care, Diane's impulse to care approaches appeasability, though not satiability, by Diane's internal sense of how much care is "enough".

I think it would be easier for me to give up now knowing that I helped in this transition. But in the beginning it was like she needed, she had to have this care. Somehow this had to be provided and we had, you know, something had to be done and I just did it. [I could let go of it] probably better than I could have then....If she had to be cared for more, you know, if something happened and she had to be cared for, I'd know that I did what I could do and I guess I wouldn't have to ask: Could I have done more? Could I have helped her? Did I fail to help in what I could have done?....I mean I'm sure there would be some difficulty, but I don't think near the difficulty because you've done what you could do.

This sense of fulfilling some level of obligation seems to be measured against what Diane's siblings have or have not done to contribute to the care of their mother, suggesting that some satisfaction of the impulse to care can come from having done one's part, or one's fair share, however that is defined.

I suppose that I feel like I've done my part certainly, and if the others haven't done as much then that's the way it is. Not everybody does the same thing or feels the same obligation....And I guess I feel like I've done a lot for mother, certainly more than any of the rest of them. Maybe all the rest of them put together, and I wouldn't feel really bad about having to put her in, now that I've done all I feel I could do. And if the others feel like they should do it, they will, if they don't feel that same obligation, they won't.

To summarize, Diane is giving care at a point above the minimum which her impulse to care can tolerate, naming guilt as the regulator of that, and below the threshold of support she imagines for herself. Although Diane is not able to predict how long she could sustain care, or the precise range of forms of care she would be willing
to give, she does have some sense of what she would and would not be willing to give up.
Diane projects that, should nursing home care become necessary, the decision would be
made easier (with less regret, remorse, and self punishment) by having already
fulfilled her responsibility to an acceptable degree, especially by comparison to her
siblings. This sense of enough is somehow definable and applicable to the equation of a
balancing point of care.

Part 2: Following a three week vacation taken by Diane and her husband.

Although her mother's condition has not changed perceptibly since the second
interview, Diane has started to look at contingency plans for nursing home placement.
The vacation taken with her husband was disturbing to Diane's balancing point. Not only
did her husband increase his urgings that she seek alternative care for her mother, but
Diane experienced an appreciation for her independence from caregiving. As she
regarded her situation, she began to assert herself into the equation, and is especially
sensitive to the failures of her siblings to share in the burden of care. She wonders
what they might have done had she not been willing or able to fill the holes in
caregiving, but she does not ask them. At the time of the third interview, Diane was
starting to explore nursing home options, "just in case".

Carol

In hindsight, Carol believes that she brought her mother in to her home
prematurely, that is before her mother was "dependent enough" to need such care.
Carol's mother has circulation problems and has lost one leg as a consequence. She has
trouble wearing a prosthesis, so ambulation is difficult, but possible. Carol was
impelled to invite her mother to live with the family by the quite conscious concern
that her mother would come to some harm living alone, and by the very strong need to
avoid guilt and blame should this happen. Carol was raised with a clear message that
"you take care of your parents."
Describing her decision as "heart over mind", her powerful impulse to care obscured alternative arrangements for securing the safety of her mother. Alternately professing love and dislike for her mother, Carol also believes she had a preconscious wish to achieve an attachment or bond with her, by giving her the care that she had failed to give Carol. Carol describes lacking adequate information about her mother's disability, lacking information about resources and alternatives, and most important, lacking communication with her mother. Carol's mother lived with the family for five years when Carol and her husband found a retirement center for her, and asked her to move out.

When you feel as though your house is not your own, and that your life is no longer your own, something has to change......[My husband and I] said, This has got to stop. Now. Before we both lose our sanity. Or before there's a fight and words are said that we can't take back.

The decision to ask her to move out was one to keep myself together and to keep my marriage on an even keel. We could see the difference between he and I. We picked at each other.....You can't keep your marriage working when there's a third party in there....... Clearly the utilitarian losses to Carol's self and to her marriage caused her to reframe the impulse to care and the sense of duty to her mother. In fact, Carol's interpretation of the moral precept: "Take care of your parents", informing her impulse to care, was ultimately re-interpreted.

Well, as you're brought up in the church, you always hear: Honor your father and your mother. You take care of your parents. And that's all you ever hear. It isn't um, how would you say...Take care of your parents to the best of your ability, to where you can still keep your life. It's always as if you're told, your life has no meaning, take care of your parents no matter what.

Carol's new interpretation of the obligation to her mother now includes a regard for the needs and the rights of her self. As the opposition between self and responsibility to her mother was confronted at the first indication of dependency, Carol's response, and a premature one, was to give care. The balancing point was tipped toward responsibility to the mother and less toward the needs of the self.
Like Diane, but more distinctly, Carol has defined a point at which, in her words, "enough is enough". "I did what I could do. I gave what I could give. I can't give any more." This has involved a real struggle to find a place for herself and her husband in the caregiving equation. Ultimately, when Carol regards the consequences for herself, the balance is toppled, toward what Carol calls a "self-preservation". Aside from reinterpreting the idea of filial obligation, this also means "maturing quite a bit" and finding a way to define herself as separate from her mother, as an individual with her own rights.

You're a person. I'm not just my mother's daughter. I am a person and I do have some rights also. It was like you felt you gave up your rights as an independent person when you parent moves in with you. And I needed to get back to where I was an independent person again. I had rights.

You can live your own life and still love your parents and see that they're taken care of, but you don't have to take them in.

Carol's earlier need for the approval of others, including her mother, became a diminishing issue as caregiving was prolonged. In the five-year period of caregiving, Carol "came to terms with a lot of things".

I found out that I was a person and that I don't need her approval. I still want it, but I don't need it!.....I am to a point that I don't care anymore [what others think]. I did what I thought was best for me and my family. And I can't do any more. And if people don't like it, there's the door. They can just walk out.

Approval of herself, which also weighed heavily in the early decision to bring her mother in, remains important to Carol. Just as the balancing point five years ago was a product of her need for self-approval, this need is also evident in her very hard work to come to terms with her decision to ask her mother to move out.

At the time [of her moving in], it was the only thing I could live with. And I guess maybe, in the long run, maybe it was just something that needed to be done. Just to show me that I did care for her and that I did help her....I know in my mind that I cared for my mother. I may not like her real well, but I do care for her. And I didn't want anything to happen to her. So I know in my mind that I did what I thought I could do.
Carol demonstrates the concept of a very personal ownership of the balancing point when she comes to weigh self-approval more heavily than the approval of others.

I felt that I had done what I could possibly do. And that I could do no more...And that in my own mind I had fulfilled my own obligations.

I don't need my husband to stand there and tell me this is what you should do. Now granted, he and I did talk it over, but I had to say this is it!

[I got support] from myself. I made the decision.

Although Carol argues that the approval of others is no longer an issue and that she "just feels comfortable with the whole situation", Carol testifies to the fragility of the balancing point on a number of occasions.

I went through: Are you really gonna be able to do this? You know it has to be done. Have you got the guts to do it? And uh, it was a very difficult decision to make.

I thought for a while that I might feel guilty and the whole works, and I did some, but that's gone, knowing that I did what I could do....And it just, it's like any injury, I guess, it takes time to heal.

It's kind of like you feel you've failed, but you don't really want to say you've failed because you did try, it just wasn't working....And to tell yourself that it wasn't a failure, it just was not working. It doesn't necessarily mean you failed. Now I know it was not a failure. I am not a failure. I tried and found out it did not work.

From this fragile balancing point, Carol struggles with what she is inclined to experience as a "failure" to fulfill the obligation to her mother (once interpreted as implying absolute self-sacrifice). This obligation was not fulfillable and required reinterpretation. Moreover, the bond sought with her mother was not achievable and had to be rejected as unnecessary to her survival. Both adjustments shifted the balancing point of care and the result was the relinquishing of care: Carol's mother moved to a retirement center.
In the following quote, Carol summarizes the principles of owning the balancing point, having a sense of what is "enough" and reasonable, and of preserving the self in the opposition between self and others.

You just have to be able to say, I've done everything I can do, I can't do any more. And I need to be me again.

**Helen**

Helen shares in her stories an impulse to care that feels like "reflex"....."like there is no decision or you can't make decisions....like the umbilical cord was never cut." In addition to this strong feeling of attachment, Helen is an only child and believes she is "the only one" who can give her mother care. To decline to give care would be to "write her off". Helen sees caring as a woman's responsibility and the essence of her goodness.

Prior to her mother's hospitalization and subsequent nursing home placement, Helen had been providing near-daily, non-intimate, care in her mother's own home, doing errands and shopping and managing her mother's household. This caregiving had been stressful for a number of reasons, two of which stand out. First, Helen describes her mother as "manipulating" and "demanding"; Helen was often told that she "did too much" for her mother. Second, her mother was not always "cooperative" with care, a source of frustration for Helen. Helen's balancing point of care at that time, however, was relatively stable; her impulse to care was strong enough and her threshold of support high enough that the aggravations of caregiving were tolerable. From Helen's self-defined balancing point, the level of care at that time was not "too much". The comments from others which functioned to test the balancing point did not function to de-stabilize it.
Helen's mother was discharged from the hospital so quickly that Helen had not been able to identify alternatives other than nursing home care or care in Helen's home. The prospect of bringing her mother home was beyond Helen's threshold of support, a threshold which now became apparent to her as she weighed her impulse to care against her own needs. As a matter of fact, Helen describes herself as almost to that threshold just prior to the hospitalization of her mother.

I guess the reason [nursing home placement] was easier, was I just reached a place where I just can't do this anymore. I'm just worn out from it. [I had been] thinking, I better work out something else with her. These trips are wearing me out. And then I'm faced with not only are these trips wearing you out, but now she's going to be in your house wearing you out.....When it came to thinking about bringing her to my home I guess there was just a little bit of, well, first her being as strongwilled as she was in expressing herself, uh, I just don't think after all I've done for this woman and after all the things that she had not cooperated with, uh, I just don't know if I can deal with it.....When she got sick, I was almost to the point of being stressed out just from all this back and forth and groceries.....I guess I would have to admit when I do think about it now, I was really afraid to have her in my house.

Helen was conscious of the very real losses to her time and freedom and the very real stresses living with her mother might produce, and determined these to be beyond her threshold of support. She therefore relinquished primary care of her mother to a nursing facility, a decision tolerable to her impulse to care.

It is critical to note that relinquishing primary care did not mean for Helen, and does not mean for the other daughters, relinquishing absolute care. Rather, Helen now has a new balancing point. Helen now struggles with decisions about the nature and level of her participation in the care of her mother in the nursing home. It is striking that this work to achieve a balancing point is no less difficult for Helen than her earlier work to find balance between care for herself and care for her mother.

The shift in balancing point implies a shift in caregiving, and the shift in caregiving implies a shift in balancing point. Helen now reassesses her identity as a "responsible person" and her impulse to be responsible is manifested in the caregiving
visits she makes to her mother in the nursing home. She is actually spending more caregiving time in the nursing home than she spent while her mother was living at home. Helen's guilt functions to measure and monitor "responsible enough" caregiving in the context of the nursing home.

I don't think I could have a mother or father, you know, I couldn't have somebody in a nursing home and just leave them. I would feel guilty then! Now that's where I would feel guilty. If I wasn't there a lot I would feel guilty because there was nobody else to do it....

There is no way I could have her in the nursing home and not be around a lot. I just could not live with myself....I don't have peace of mind when I'm not around.

Helen's attitude of obligation to her mother and her sense of being the only one to care for her, that is her impulse to care, is alive and well in this new caregiving activity. What is different in this caregiving behavior is the ratio of tolerability: what her threshold of support can tolerate vs. what her impulse to care can tolerate. While Helen cannot tolerate bringing her mother home, neither can she tolerate relinquishing total care to someone else. To arrive at that equation, Helen has asserted her responsibility to care for herself ("You've got your own life and your own mental state") in the definition of a balancing point. She is able to define for herself what level of caregiving is "too much" and has also decided what is "enough".

It must again be made clear that this definition of a balancing point is fragile, labile, and elusive.

If this went on and on for years and years and years, I don't know, I might change. I might decide I won't be able to stand it...Right now I know how I feel, but if this went on for years, I don't know.

Helen's husband and daughter test the balancing point with their urging to let go of some of the care.

I think [my husband] now figures let the nursing home take care of this lady. She's difficult. Helen doesn't need her to drive her crazy.

My daughter's always felt like I did too much for mother. You know, "You do too much for her" and I have other people tell me that too.
At other times, Helen's husband reinforces her balancing point.

When I'm with my husband he says If [your visits] give you an added peace of mind, if you don't have enough confidence that [the nursing home] will take care of her, or if you just want her to have company, go ahead and do it if it makes you feel better.

Also a threat to Helen's balancing point are the negative comments she gets from others, sometimes strangers, about her decision to place her mother in the nursing home. Helen is well guarded against a need for approval from others, however, and because she owns the balancing point as well as the choices, she is relatively comfortable with her decision. Helen has made what Gilligan calls the "distinction between helping and pleasing" which "frees the activity of care from the wish for approval from others."

Seeking decisions she can live with, and sensitive to the fragility of her own balancing point, Helen believes she has been generally successful in finding this balancing point in her current caregiving choices.

I'm not down about it like I was early on. I would go home and I was really....but I understand from other people this is just a phase that you have to work through to some point where you just don't get so crazy with it.

I know myself. I know the things that upset me. And so I, try as I will, although I'm finding it's, it's a little easier as time goes on. I guess it must be this way with all the things that people go through with children that are ill, or somebody that is home ill....You've got to kind of make it almost normal after a while.

Now I don't know if things go in cycles...They say they do.....They say it takes a long time to adjust, or adapt or something....Perhaps after a year...we don't know how she's going to be, we could live through the four seasons, I will take a different approach, I won't see her as much. I don't know.

Letting go of some of the care is an expression of Helen's balancing point, and again, she describes this as hard work.

[When I'm not at the nursing home] I try deliberately to busy myself, whether it's grocery shopping, or....because I am prone to thinking about her, so if you're busy and don't have time to think about it....I've gotten better at that. If I did the thinking early on it would be to wonder what time is it and what's going on there. I have really gotten better at it. I really think I'm better at it.
In summary, Helen has worked to maintain a balancing point through all of her caregiving choices. The success she has had in matching her current choices with her impulse to care and her threshold of support is expressed in her idea that it is a personal balancing point she can live with for a while.

I still think some people may think that I do spend too much time, but I see others that are [at the nursing home] just as much as I am. And I think, it just depends on you as a person. I feel like I'll do this as long as she's alive.

Linda

Linda's mother and developmentally and physically disabled sister have been living with Linda's family for eleven years, since Linda was forty-six. Although the mother was not herself dependent at that time, she was sufficiently physically limited to be unable to continue caring for her disabled daughter. Linda's care for her mother therefore began by assisting her with care of Linda's sister when Linda brought them both into her home. Linda performed nearly all of the physical care of her sister, i.e. lifting, bathing, grooming. Gradually Linda's mother became disabled as well. She is not able to walk, and unable to use the toilet or feed herself without assistance.

Essentially then, Linda is caring for two dependent family members, although the assumption of caregiving activity on behalf of her mother was gradual and incremental. Linda's family room is filled with two hospital beds and an assortment of hospital paraphernalia.

Linda expresses her impulse to care with frequent use of the word "automatic", e.g. "I just did it automatically". It may be argued that Linda is so socialized to give care by the lifelong history of caring for her disabled sister that her impulse to care indeed is automatic, that is without thought, deliberation or premeditation. Linda also has a strong attitude of obligation to her mother, and although not sure she can reciprocate
caregiving, she "wants to do" what she "can do". Linda does not regard her caregiving as a sign of goodness, but rather as a simple expression of her "way of life".

For Linda, caregiving has been the product of satisficing, or making the good-enough decision, and until recently, alternatives were neither imagined nor sought. Challenges to her impulse to care surfaced gradually, and a threshold of support began to be perceived.

Challenges to Linda's impulse to care and a perception of a threshold of care have come in the form of her own aging and failing health, in the increasing dependency and demands of her mother and sister, and in an increasing sense of the lack of freedom and pleasure in her life measured against the time she and her husband have left to enjoy themselves. She repeatedly describes herself as "worn out", and claims that the past year has been especially difficult. Institutional care is being sought for both her mother and her sister, but placement for her sister is expected to take a matter of years. Linda's story, therefore, focuses mostly on her decision to relinquish primary care of her mother.

This past year we have, uh, it's terrible to say but I feel like I have lost a whole year of my life because I have been totally tied down for almost a year now.

Linda expresses a regard for her husband and her sister in defining a threshold of care. The utilitarian consequences to herself, now entering the equation, are important and so also are the consequences to the others for whom she cares.

I feel like I've aged, I couldn't say, you know. I'm just worn out....As of now it's gettin' to the point I really don't have much choice. Not only am I worn out, she's, she wears us all out.

It's not fair to my husband to never be able to...he and I hardly ever get to go out. You know, and he's not complained, he doesn't complain! But we're not gettin' any younger and we need to, as I said, we need a little bit of time to ourselves. All these years that we've been married and never been by ourselves.

I'd like to be able to get out and do things, 'cause for 11 years....... [Relinquishing care] would mean that I could go and do things that I want to do
and not say—Hey, could you sit or could you come over and stay? I've had this for eleven years now.

Linda is beginning to develop a sense of what is reasonable and enough care. Up until this time, when caregiving was on "automatic", Linda perceived minimal negative consequences to herself and as a matter of fact regarded caregiving as a natural expression of her way of life. Although outsiders might regard Linda as having made an unusual sacrifice, Linda never identified her behaviors as sacrificial—they were consistent with her impulse to care and her threshold of support. Had she been making choices counter to her balancing point at that time, then her identity as a caregiver, part of her impulse to care, would have been sacrificed.

Now, Linda's balancing point has shifted. She has confronted a threshold of care presenting itself as exhaustion and a ticking clock. Linda begins to see her caregiving as bounded, not limitless.

I feel like I've done all that I can do. I mean I've always been willing [to do] anything I could do. Anything I could do, I have done. But I feel like I've done these years everything. That possibly could do for them and still doin'.

It's not that I don't care to take care of my mother...Lord knows I do all I can for her and my sister both, but it's really gettin' to the point, it's gettin' me down in body and in your mind....You just get so worn out stayin' in, lookin' at the house day in and day out.

I'm glad I've been able to do what I've done. You know, that I have been able to take care of them as long as I have, and to have had them with me. But, uh, my husband and I have been married twenty-three years and we have never been alone. We have never lived alone.

Linda says, "I think I've done everything humanly possible that I can do," and in her saying that echoes the other daughters: "I did what I could do", "I gave what I could give". For each of these daughters, that threshold of care, the shifting of the balancing point, and the consequent shift in caregiving activity is personally, individually defined and owned. Linda's impulse to care lives in tension with her threshold of care and support as she confronts the conflict between responsibility and selfishness. That
conflict is reconciled in her personal equation as manifested in her caregiving choices.

As with the other daughters, the equation is self-constructed.

I feel like I'm the one doin' the job. It's my decision really. And it's not one easily made, and not one that I wanna say, Yes I am gonna do it.

Well, if I really wanted to keep her and stay in and I, I could, it's not that I am forced to do it, but on the other hand, I'm not gettin' any younger.....

Also like the others, Linda finds the reconciliation or balance fragile, labile and elusive.

When it comes down to the personal part of it you think: Should I or shouldn't I?

It's just hard to try and put into words what you really feel because one day you feel one way and the next day you think—well I've got to change my mind.

It doesn't make it any easier even though you say I'm gonna do it. You still got mixed, I still have mixed emotions......Some people might not have, but I still do I guess and until I get it done, I will have.

I just kinda keep puttin' it off, you know. It's just something that you just don't want to do so you just keep draggin' it out......Something has to happen whether you want it to or not. You don't always have the control to say, well I'll just forget about it.

I tell myself I'm not doin' wrong. It makes you feel in a way like you're bein' cruel. You know, that you're pushin' 'em out or something....And then I try to tell myself, well, I've done as much as I possibly can do, I've done my best. you know. So you fight yourself back and forth.

Though a struggle, Linda's balancing point is attainable and experienced as comfortable, that is with minimal regret, remorse and self-punishment. Her impulse to care is somehow appeaseable even as she relinquishes care of her mother.

To some point I guess you would think you would feel guilty. But I keep tellin' myself as I said, that I've done all that I can do. I really don't have any parts that I feel like I've been guilty of not trying to do to help and take care of 'em. Had I not done my best, then I think I would feel guilty. But I feel like I have done everything that I can do, so I don't think I would have to feel guilty about what I would do.

Finally, it is important to Linda to preserve the "wanting-to" so enmeshed in the "having-to" of the impulse to care. To preserve the wanting to is to legitimize and value the impulse. Sharing and relinquishing care are not repudiations of the impulse.
The impulse lives and breathes in these decisions, in both tension and compromise with the threshold of support. Fighting images of her decision as a "cruel" one, and facing the controlling influence of guilt, Linda seeks that compromise.

What I'm referring to as cruelty is puttin' 'em somewhere. I just....that comes back to me, like you don't want 'em. But I do want 'em...it's just that I can't handle the situation. I feel like I have down to the last minute, I have just done all I could do for takin' care of 'em, so.... That I don't think would bother me now, I mean you know, that I had to look back and say----Hey, I should have done this or I should have done that. 'Cause I feel like I 've done it.

Linda's impulse to care also has life in the new balancing point she projects for herself once her mother is in the nursing home.

In a way you look forward to it, that you could just come and go, and walk in and out the door, and not to have to answer..... Of course, as long as I'm alive I feel like I have to go to the nursing home, every day probably.

Part 2: Two months following her mother's placement in a nursing facility.

By the time of the third interview, Linda has placed her mother in a nursing facility. Linda shows an energy and peace of mind not evident in the earlier interviews. Her mother is doing very well in the nursing home. As a matter of fact, having received physical therapy five days each week, her mother, confined to a wheelchair for over a year, has begun to use a walker with assistance. Linda regrets not placing her mother sooner. Although placement was delayed by the process of having to "spend down" her assets to be eligible for Medicaid, Linda's own reluctance to relinquish primary care, a product of her impulse to care, also delayed this shift in caregiving. Linda is operationalizing the new balancing point she had imagined for herself by making daily caregiving visits to the nursing home.

Susan

Part 1:

Susan's mother, who has Parkinson's Disease, is the most physically dependent of all the mothers in the study. She is mentally alert but unable to speak and uses a
message board to communicate with what little movement there is left in one arm. Susan takes care of all of her mother's personal needs including feeding, which can take up to two hours per meal. Susan has been the primary caregiver of her mother for over a year. Prior to that time, Susan's sister took full-time care of her mother and Susan brought her mother to her home on weekends. Ultimately, Susan sought full-time care of their mother.

Susan's choice to assume the caregiving of her mother is striking because an alternative was already in place: the full-time care being provided by her sister. Susan's choice, then, was between preserving the status quo or assuming a higher level of care. Susan describes her impulse to assume the care of her mother as a combination of her strong identification with her mother's suffering, her feeling of responsibility to her mother ("It is the moral thing to do. You take care of one another"), and a need to control her mother's caregiving. The level of caregiving Susan had been providing was below the level her impulse to care could tolerate. Achieving a balancing point of caregiving activity meant, for Susan, assuming full-time care.

Always a "rescuer" and "protector" Susan was rewarded for her early protecting and nurturing behaviors, even as a child. Susan strongly identifies with the dependency she confronts in others and experiences their pain very personally. She believes that if perhaps her mother were less dependent it might be easier to relinquish or share care. The greater her mother's dependency, the more powerful is Susan's impulse to care.

Sometimes I think, well if she could talk to people, it'd be different. Maybe then I could put her in a nursing home, I don't know. I don't know. It's like when you're a little kid and you'd lay there at night and you think, if both your parents were drowning, which one would you jump in for? It's like you couldn't choose, you just rather go yourself. It's just too big of a decision.

For Susan nursing home care represents "abandonment" not unlike abandoning drowning parents ("It's out of the question") and the alternative to this is to "go
herself". Unlike Linda, whose caregiving did not feel like sacrifice for many years, Susan is very aware of the personal sacrifice she is making for herself and for her family ("I detest my situation"). Yet for Susan, the only escape from personal sacrifice is her mother's eventual death.

There is a turmoil of I wish she'd die. You know, I look at her and think, I really wish she'd die so I could live.

I want my mom, I guess I want to make things beautiful for her. And I want her to go to sleep and die. That's what I want.

Seeing caregiving as a "tour of duty", the only other possible escape, fantasied but quickly rejected by Susan, is suicide. Susan's impulse to care is so strong that it can only be reconciled with a threshold of support by literally removing herself from the situation of dependency. Even so, she regards herself as indispensable to her mother and, obligated first to her, rejects thoughts about her own death.

I have been so down that if they weren't depending on me I wouldn't be here! 'Cause I'd be driving up the road and I'd think, boy, it'd be just a good feeling to ram into a tree, you know. But I think, but they really need me.....It's not like you can just stop. I might be driving home feeling that way, but when I get home, I still have to give her her medicine, I still have to feed her. You know, you just feel like back and forth, a machine, you just carry on.

The opposition between responsibility and selfishness is not reconciled, that is there is no intergration of Susan's needs with her feelings of obligation to her mother. Susan believes that her impulse to care in any case of suffering has left her "too vulnerable" and she describes "using herself up".

....to the point where it hurts, and to protect myself, you know, I try and turn away as much as I can because it's always like an open wound.

I've come to realize that I've got to quit pickin' up broken wings. And that's what I've always done.

Feeling depended upon, however, she develops what Johnson and Catalano (1983) call an enmeshing technique, entrenched in her role as caregiver to her
mother, secondarily to her four-year old daughter and husband, and to the exclusion of other relationships.

I just emotionally right now cannot get involved in anything other than my mom. I'm trying to survive, just take care of mom. Still trying to be a decent wife and mother, you know. So I just feel like, I, just right now in my life I could not take on one more thing.

Susan protects herself from her impulse to care and maintains her capacity for caregiving by what she calls "putting blinders on" to the needs of others around her, and she makes additional references to depersonalizing herself, to behaving like a machine.

Now, it's overwhelming to take in one more thing, and the only thing to do is just to try and block it out and not think, you know. And I think that's the way the majority of people go about. Maybe that's why things don't hurt so much for them. But I guess if you don't, it hurts too much.

I think I go around sometimes trying to really keep everything, like in a bottle. You know? And if you get talking about it, it starts leaking out.

Sometimes I feel like I'm just a machine, you know. And really, most days, if I can think on those terms, I function better 'cause it's not good to think too much, you know.

Susan further protects her balancing point by conceptualizing caregiving as a tour of duty, and "playing a mind game" on herself.

Well, I was thinking, [my son] signed up for the service and you know, he can't just go and do whatever he wants for the next so many years....In a way it's like I signed up to say, O.K. I'm committing my life to this for just so many years. The only thing is I don't know how long.....O.K., I'm committing, it's not forever, and so it's just a mind game I play on myself.

In order to attain that balancing point Susan "manipulated" her husband into allowing her to bring her mother home, and believes that to protect her balancing point of caregiving activity she has to bolster her decision to her husband and others. Even when her husband pushes the balancing point with suggestions for alternatives, Susan resists, seeking instead his support.

'Cause I still can't live with, Well now we're gonna put her in a nursing home, but sometimes I feel like I'm gonna die. It's like being in a room and somebody's
sucking the air out. You know, (crying) and when I have those feelings, that the air's getting sucked out, you know, it's almost like you gotta cut loose and say how much you hate it. Um, and I need him to tell me-----Hey it's gonna be all right. This isn't gonna be this way forever. And it's almost like a part I expect him to play just to let me get through that.

Susan gets respite from the stresses of caregiving by sharing occasional care with her brother and sister, four hours a week from a respite care agency, and periodic help from a friend or neighbor when she needs to run and errand, for example. Asking for help is difficult for two reasons. First "I feel like I'm putting somebody out....I hate to bother people and I hate to feel, look like I'm needy. I guess there's a pride there or something." And second, it is difficult for her to entrust her mother's care to others and to put her mother through the stress of transferring care.

My mom's been able to go to my sister's every third weekend. I don't think it's absolutely great for her to go in one sense, but I need the break.....Now she hasn't been able to go this last month because of an infection. Now she seems stable, and, Oh!, I need her to go to my sister's so bad. And yet, at the same time, I'm worried sick about her going. I feel like it's almost cruel. I mean she's just so pathetically frail and to put her in the car. But I'm gonna have to do that, you know.

Finally, Susan's impulse to care does not take a respite, even when she does.

I'm not at ease. Like when [the respite care agency] comes to the house, and I go anywhere, there's always this feeling, somebody's waitin' on me. Always!

To summarize, Susan works hard at being true to the "moral thing to do" in her impulse to care by expanding her threshold of support with whatever mechanisms she can devise. Because her impulse to care is intolerant of anything less than full-time caregiving, and because the experience is so stressful to Susan, she looks to her mother's death and to fantasies about her own death as the only tolerable alternative to ending her tour of duty. For now her balancing point of care is expressed in decisions she can live with.

Over a period of time it's just a self....you stroke yourself. Now I can feel good about myself because I feel like I am doin' the right thing.
Part 2: One month following her mother's death.

Susan's mother died in her sleep at Susan's home. ("It was the way I wanted it.") Since that time she has been on an "emotional roller coaster". Aside from the expected grieving over the loss of her mother, foremost among Susan's feelings is the guilt she has about being free to get on with her life.

I used to imagine how good it would feel to be able to come and go. It doesn't feel good at all. To get out and run around now isn't fun. The only reason I get to go out is because she's not here. In order for me to be free, she had to die.

So complete was Susan's exclusion of herself from the caregiving equation, and so nearly absolute was the opposition between self and other, that her reliance on her mother's death as the only way to extricate herself from caregiving became her own no-win proposition. The balancing point that Susan could live with was dependent upon her mother living. Still bound by a precept of responsibility to her mother before self, the death of her mother renders that precept corrupted. Comfortable with her caregiving equation while her mother was living, the equation doesn't work for Susan in her death. Susan carries the abnegation of self with her into mourning both her mother's death and her own freedom.
CHAPTER VII
SUMMARY AND CONCLUSIONS

Through their stories and "voices" the ten daughters in this study have expressed both rich variation and deep commonality in their response to the needs of their dependent mothers. Each daughter's reality is different from the others' yet each shares a fundamental struggle in caregiving decisions that is somehow like the others'. What is it they share? It has been argued that all of these daughters respond to the dependency of their mothers with an impulse to care, that they make decisions in a process that is inevitably limited and irrational, and that they struggle in these decisions to achieve a balancing point of care. This balancing point is an ideal of caregiving which satisfies the impulse to care but does not go beyond the threshold of support.

The balancing point is especially evident in the major caregiving shifts: assumption, sharing, and relinquishing of care. When the balancing point is actualized in caregiving activity, the decision can be lived with, without regret, remorse or self-punishment. When the level of caregiving betrays the impulse to care, giving "too little", the consequence is guilt. When the level of caregiving goes beyond the threshold of support, giving "too much", the consequence is stress.

At the center of this decision struggle is the opposition between selfishness and responsibility and the search for a definition of "enough". Caregiving choices become moral crises when a threshold is confronted (at any caregiving shift). As the daughters strive to reconcile their own needs with the needs of their mothers, unless they are
able to reframe the moral ideal of care by asserting themselves in the caregiving equation, at-threshold decisions are reduced to a choice between guilt and stress. It may be argued that the impulse to care is dominated by a moral imperative to care for the mother, and the threshold of support is dominated by utilitarian concerns for the self and/or family. The balancing point of care, therefore, may be conceptualized not only as a balance of impulse and threshold, but also as a balance of other and self and a balance of moral and utilitarian considerations.

Given this deep commonality, how do these daughters differ in their response to parent dependency? The variation in balancing points is reflected in the variation of the stories. Each caregiving story looks different from the others. Caregiving varies in length, form, and sequence. Characteristics of the impulse to care varies. Decision experiences vary. And thresholds of support vary.

Although all of the daughters respond to parent dependency from an impulse to care, each daughter's impulse is characterized differently. For some daughters attachment and affection for the mother is stronger. For at least one daughter, lack of attachment is part of her impulse to care. For some daughters, identification with the mother and her suffering is dominant. For some daughters, the sense of debt, or a norm of reciprocity is stronger. For others, responsibility or filial obligation is stronger. Some daughters describe strong socialization to act as caregivers; other daughters don't. Some feel a stronger sense of being the "only one" to give care than do other daughters.

Wide variation in the decision experiences of these daughters was also discovered. From her individually developed impulse to care, each daughter weighed approval and utilitarian gains and losses differently in the decision process, that is, when conscious weighing of alternatives took place at all. Some of the women faced time pressures in making their decisions. Others made major decisions incrementally.
Daughters varied in their access to information and alternatives. Levels of predictability of outcome varied in all of the cases. Interpersonal decision-making experiences were strikingly different. Level of the mothers' involvement in the decision varied widely, as did levels of husbands' and children's involvement. The experiences with siblings (two were only children) ranged from limited or no interaction to moderate interaction.

Finally, for these daughters, there was variation in thresholds of support. The daughters assumed different levels and forms of care, shared care differently, and relinquished primary care under different circumstances. Each had identified her own threshold of support. Each had different competing needs and demands, each had a level of tolerance different from the others, and the mother-daughter relationships varied qualitatively.

In summary, it has been argued that though all of the daughters share in their pursuit of what is "enough", given the impulse to care and the threshold of support each comes to a different definition of enough through the decision experience. This individual definition is the daughter's balancing point of care. It is not a breaking point, but an equation of impulse and threshold, others and self, and moral and utilitarian considerations. Though fragile, labile, and elusive, the ideal balancing point, the sense of what is enough, is personally constructed. Fluid and dynamic, yet self-stabilizing, it becomes the touchstone for all caregiving decisions.

The theory of caregiving decisions which has emerged from this study has important implications for long-term care policy, clinical intervention, and research. Foremost among the implications is the respect that must be given to the multiple definitions of impulse and threshold inherent in the population of daughters of dependent elderly, and to the widely varied decision conditions they confront. At the heart of this theory is the appreciation for variation, and secondarily a regard for the
common experience. Approaches to policy, clinical practice, and research which seek sameness in the caregiving decision experience fail in an important sensitivity to what is different. Even so, approaches to understanding and enabling caregiving decisions are unifiable by what we know to be shared by these women.

**IMPLICATIONS FOR LONG-TERM CARE POLICY**

*Policy and the impulse to care*

It should be obvious that the impulse to care is exploitable at many levels. In their impulse to care these daughters are vulnerable to the dictates of their socialization as nurturers and protectors, to the moral rules of responsibility that have become their standard of goodness, and to the guilt which so unrelentingly monitors and punishes for betrayal of their moral selves. As caregiving holes are left by family members, policy failures, and service gaps, these daughters are vulnerable to filling them in spite of the holes they leave elsewhere in the process.

When policy makers in long-term care take the caregiving of daughters for granted, they not only limit the service options of these women, but they also reinforce the rule that daughters give care. Policy becomes a public statement of social and moral expectation. And, from an impulse to care, as daughters move to fill those gaps by giving care, their own caregiving decisions also become a public statement of social and moral expectation. Brothers are off the moral hook. Service providers are off the moral hook. Daughters look around and see other daughters giving care; they own the hook. When the hook is all "having-to" and not much "wanting-to", policy has failed.

Elaine Brody writes that "women in the middle" suffer unrelenting guilt in their caregiving relationships, partly because of the myth that children don't care for their parents like they did in the "good old days". She also claims that such guilt perpetuates the myth. "Not only does the myth persist because the guilt persists, but
the guilt persists because the myth persists."(1985: p.26) Likewise, it may be said
that, not only does the policy persist because the impulse persists, but the impulse
persists because the policy persists.

It must be emphasized that these daughters do not feel victims of their impulse
to care. We are reminded that none of these daughters rue their own impulse, but
rather regard caregiving as an expression of compassion and caring that should be
universalized. Daughters are victims, however, of policies that exploit their impulse,
impede their decision making, and restrict their threshold of support by failure to
provide services.

Creating long-term-care policy that does not exploit daughters of the dependent
elderly can only happen when three requirements are met. The first requirement is a
respect for the impact of policy and service holes on women impelled to fill them. The
second requirement is a sensitivity to the norm-reinforcing power of the messages
inherent in the policy itself. And the third requirement, dependent on the other two, is
the development of policy that sends a counter-message: "The obligation to give care is
not solely yours."

What would such policy look like? Broad social policy is required to achieve
flexibility and support, for example in the work place, for all caregivers, men and
women. In addition policy with a counter-message includes outreach to sons, in the
form of consciousness-raising, caregiving instruction and resource information, and
development of a system of support. A counter-message is also delivered in any
expansion of caregiving alternatives: elder home-sharing, foster care, and day care,
for example. In addition, public education is required to remove the stigma and shame
some associate with nursing home placement. At the same time, nursing homes must
find a way to put daughters (and sons) on the caregiving "team", reducing the sense of
abandonment that placement represents.
Policy and the decision experience

There are several policy implications in what we know from these daughters about the decision conditions they confront. It is clear that many decisions are made with insufficient time, information, and alternatives. Very clearly, policy that promotes early planning and contingency development will have a profound impact on the dependency crises these daughters face. Getting to parents and children before the crisis occurs, educating them about resources, and implementing shared planning would reduce decision strain and enhance the chances for satisfactory decision outcome.

The impact of time-pressured decisions has been discussed. As we confront shorter hospital stays, it is even more critical that discharge planners implement the earliest identification and intervention procedures with patients and families facing long-term care after discharge.

Among the most disturbing of the findings is the difficulty these daughters have in securing information from professionals. Doctors, social workers and administrators must make a priority of the education of patients and their families about the nature of illnesses, impact of chronic disability, and available resources and caregiving alternatives. Information and referral services must not only be developed, but must "go looking" for caregivers and their parents. This is a public relations and public profile issue. Finally, programs specifically designed to assist with caregiving decisions, e.g. decision counseling or mediation services, serve to heighten consciousness of decision making and enhance decision effectiveness.

Obviously, decisions are limited by the alternatives available. Communities poor in resources and alternatives clearly restrict the choices of caregivers. The expansion of caregiving alternatives not only sends a liberating message to daughters, it also allows them to make choices, from a broad range of options, closely matched to their balancing points of care. What policy makers need not fear is a rush to relinquish
care when services are expanded. Indeed, the impulse to care prohibits such behavior. We have seen that, even when alternatives are in place, these daughters do not use them until they have come to their own personal definition of "enough".

Policy and the threshold of support

Daughters with an impulse to care for their dependent parents can be helped to expand their thresholds of support by the introduction of programs that 1) compensate them for caregiving activity, 2) provide support services, such as respite care and day care, and 3) provide education and outreach to husbands, children, and siblings to entice and instruct them in the sharing of care.

It should be the objective of long-term care policy to promote and enable healthy balancing points for the daughters of the dependent elderly. By becoming sensitive to the exploitability of these daughters, and by valuing their caregiving activity, policy makers can more effectively develop policy and programs responsive to the time, information, alternative, and support requirements of daughters confronting caregiving decisions.

CLINICAL IMPLICATIONS

It should be the task of clinical intervention with a daughter of a dependent parent to help her 1) understand her impulse to care, how it has developed, how it is characterized, and how it is manifested in caregiving behavior; 2) identify the function and sources of guilt as a behavior control mechanism; 3) identify decision impediments and requirements; and 4) identify, and come to terms with, her threshold of support. At the center of any clinical intervention should be work toward a healthy balancing point based on these insights.

Family intervention is also indicated by these findings. In these daughters' stories we witnessed the power of the impulse to care to obscure or distort
alternatives, as well as to risk unnecessary dependency and loss of autonomy in the mothers. By empowering the mother (or father) with maximum involvement in the decision process, it should be possible to secure maximum independence and interdependence of both parent and daughter. In addition, husbands, children, and siblings can benefit from intervention intended to facilitate communication and support in caregiving decisions.

Just as these daughters represent distinct and varied responses to parent dependency, the therapeutic possibilities are also varied. Each daughter's balancing point can be said to be a manifestation of her past and present relationships, her moral and psychological development, her personality, her learned coping behaviors, her social environment, and the circumstances of parent dependency. Each of these factors raises possibilities for intervention, and for each daughter, the intervention of choice may be different. As examples, two possibilities for therapeutic intervention are briefly discussed here: separation-individuation therapy and feminist therapy.

Separation-individuation

The shift in dependency which characterizes the caregiving relationship has interesting implications for issues of mother-child attachment and separation. Joyce Edward (1976, 1981) applies the psychoanalytic developmental theory of Margaret Mahler to adult therapeutic intervention. Separation, the "movement from fusion with the mother", and individuation, the development of a person's individual characteristics and self, are on-going, open ended processes, which when optimized lead to healthy social and psychological functioning. The role of the mother is critical to this process. The "good enough mother" (Winnicott, 1953, Blanck and Blanck, 1974) provides just enough (but not too much) nurturing to allow the child to separate and individuate. According to Edward, adults deprived as children of the necessary stages of separation and individuation benefit from psychotherapeutic intervention which
facilitates insight about the dynamic and provides a substitute for the developmental stages in the client-therapist relationship.

What are the implications for separation and individuation in a parent-child relationship now characterized by the parent's dependency on the child? Carol's story of the relationship with her mother, edited below, suggests unresolved or interrupted separation-individuation issues. It will be remembered that Carol asked her mother to move in with her "prematurely" and then asked her to leave five years later, when the attachment she had sought with her mother did not materialize. Ultimately, Carol's decision was a product of her discovery that "You're a person. I'm not just my mother's daughter." ...."I found out that I was a person and that I don't need her approval. I still want it, but I don't need it." In these statements and in the story below, we see Carol at work on on-going separation-individuation issues.

**Carol:** As a child I can remember learning how to get things if I wanted 'em. Well if my brother wanted it, he'd get it! And I can remember little things mom would say---uh, Mom had allergy problems, not real bad but a few health problems and uh, she said a couple of different times, Well I didn't have any of these problems until you were born..... You just crawl back in your hole. Just crawl back in your hole, and hope some day, somebody says---hey you're doin' a good job! And when you didn't, you went and cried somewhere. And I did a lot of that! I still do! It's a terrible hurt to think that somebody you care for so much doesn't return it....Um, Mother has never once, that I can remember said I love you. And it hurts....I could never go to Mother with a problem. If I got bad grades in school----you're not studying enough! So when I did study enough, it didn't seem like that was good enough yet. And it just was something that's always been there....I think a lot of it comes from my father not being around. And you want a parent that you feel that you're really close, like if you have a problem, you could go to them and say---I have this problem, I need help. When I needed Mother, she was not available. There's a lot of anger.....Now [that she has moved out] I don't see her a whole lot. Uh, she doesn't really call...We took her out for Mother's Day and we've been over a couple of different times. She's not a visitor, I'm not a real visitor.

It is possible that Carol, in trying to be the "good enough daughter" is struggling with unresolved attachment and separation issues intensified and manifested in the caregiving relationship. Clinical intervention around these issues has the potential to enhance the relationship and the caregiving decisions for both mother and daughter.
Feminist therapy

The objectives of feminist therapy are to foster self-determination, autonomy (or more appropriately, interdependence) and awareness of life options. (Cammaert and Larsen, 1988) Feminist therapeutic intervention in the caregiving decisions of a daughter would have as its objectives 1) empowering her with understanding of the social construction of her impulse to care; 2) helping her to identify the full scope of options available to her as she confronts parent dependency, and; 3) building in her the ownership of her own behaviors and freedom of choice as she negotiates with her parent, husband, etc. in the decision process. Feminist clinical intervention with caregiving daughters is not designed to liberate these daughters from the care of their parents, but rather to liberate them from choicelessness. Certainly, caregiving chosen consciously and freely is healthier for both parent and daughter.

Other theories for clinical intervention

Approaching caregiving decisions and caregiving relationships from the two theories discussed above merely scratches the surface of possibility. Theories of learned helplessness, co-dependency, exchange, family systems, and crisis intervention all have potential application to intervention with caregivers, their parents and their families. Again, it is the variation in these daughters' stories that calls for multiple theories and interventions.

RESEARCH IMPLICATIONS

This study of ten women has produced new ideas and perspectives, and new theory of caregiving decisions with implications for further research. It has also raised many questions. The questions suggest areas ripe for study and rich in possibilities. Four questions in particular are addressed here.
How do mothers decide about the nature and level of their daughters' participation in their long-term care? This study was designed at the risk of appearing to claim parent dependency primarily a daughter's problem. The problem of dependency belongs first and foremost to the parent, and secondarily to the children. Most of the mothers in this study would have been unable to participate in extended interviews, for various reasons. Stories of their decision response to their own dependency would enhance our understanding of the entire decision and negotiation process.

What parallels and/or differences exist between sons and daughters in response to parent dependency, and how do we account for these? As emphasized in the discussion of limitations in Chapter III, this is a study of daughters. It does not make claims about daughters as they are different from sons, and it does not make claims about sons. In their stories, these daughters told different tales about their brothers' responses to the dependency of their parents. As they describe their own responses and the responses of their brothers, it is clear that these women believe there are important differences between them. Some of this is expressed in bitterness, some in resignation, some in respect. Regardless of the daughters experiences and impressions, the voices of their brothers are not heard. Applying this methodology to sons of the dependent elderly would surely shed light on these questions.

What is the experience of daughters who decline or are unable to participate in the long-term care of their parents? Do they have an impulse to care? What is their threshold of support? How are these characterized? In the course of recruiting participants for this study the researcher encountered a few stories of daughters who had declined to participate at all in parent care, and many more stories of daughters who were unable to assume any level of caregiving. These voices need to be heard in order to expand our theory of daughters' decision making.
Are there parallels and/or differences in daughters' responses to the long-term care needs of their fathers, and how do we account for these? Elaine Brody has made a preliminary foray into father-daughter caregiving decisions, suggesting that a daughter cares for a mother in the way that the mother cared for her, but that a daughter cares for a father in the way that the mother cared for him. (Brody, 1990) Other differences are relatively unexplored, however, and call for further study.

IMPLICATIONS FOR OTHER THEORY

Aside from raising questions, this study has implications for related theory development, four of which are briefly mentioned here. First, the findings in this study support the theory of a "different voice" of moral development developed by Carol Gilligan. Gilligan writes: "Additional longitudinal studies of women's moral judgments are needed in order to refine and validate the sequence (of moral development) described. Studies of people's thinking about other real dilemmas are needed...."(1982: 126) The objective of this study was not to explain women's moral development but to explore, describe, and develop theory about daughters' caregiving decisions. It is clear, however, that the "real dilemma" of parent dependency is especially suited to expanding our understanding about the moral voice of women.

Second, theory developed from this study has implications for our understanding about role "reversal" as a limited and damaging concept. In their impulse to care these daughters borrow from their roles as mothers, and lacking clear behavioral norms for more appropriate responses, they approach parent dependency in a way that feels like mothering. Lucy Rose Fischer (1985), in a study done about the transition into caregiving, made a striking finding about "reversal". Studying both dependent parents and their caregiving children, Fischer learned that, though the sons and daughters identified "role reversal" in the caregiving relationship, none of the
parents identified this same dynamic. It is worth exploring whether or not the impulse to care contributes to daughters' perceptions of role reversal.

A final and related area for further study are the issues of power and dependency, autonomy and paternalism raised in the concept of a balancing point of care. It is important to ask how a daughter's pursuit of balance might impede the mother's own pursuit of balance and hence her autonomy. Insight into the impulse to care and the pursuit of a balancing point may contribute to study of autonomy-paternalism issues in long-term care.

CONCLUSION

It has been the purpose of this study to explore how daughters decide the nature and level of their participation in the long-term care of their dependent parents. Knowledge about caregiving decisions contributes to responsive policy, meaningful clinical intervention, and enlightened research. In the stories of ten daughters we have seen how varied these decision experiences are. We have also identified a common thread weaving its way through the complex tapestry of a rapidly aging society, changing role expectations for women, and emerging norms of caregiving behavior. This thread is the pursuit of a fragile, labile, and elusive balancing point of care. It represents the opposition between impulse and threshold, others and self, and moral and utilitarian considerations inherent in each caregiving decision. It must be the objective of policy, practice, and research to contribute to the reconciliation of that struggle on behalf of both daughters and their dependent parents.
APPENDIX A

LETTER OF INTRODUCTION TO PROSPECTIVE PARTICIPANTS
Dear (insert name)

I am a Ph.D. candidate in the College of Social Work at The Ohio State University. For my dissertation, I am conducting a study, under the direction of Virginia Richardson, Ph. D., of the decisions of daughters about the nature and level of their participation in the long-term care of their dependent elderly parents. I am interviewing five to ten daughters in individual interviews and six other daughters in group interviews.

My objective is to interpret your story and the stories of other women to begin to develop a theory about caregiving decisions. Parts of the finished product are likely to be published in professional journals, presented at professional conferences, shared with the popular media, and/or be published as a book. Confidentiality of all participants is protected.

(Person) of (agency), has already spoken with you. I will follow up with a phone call to see if you are interested in participating in my study, to discuss this further, and to make necessary arrangements.

I hope you will want to participate in this very exciting study. It is my expectation that it will take approximately six to ten hours of your time. (Interviews can be held in your home, if desired.) I believe that you will find it time well spent.

Thank you for your consideration. I'll talk to you soon.

Sincerely,

Kathryn McGrew
922 Silvoor Lane
Oxford, Ohio
45056
APPENDIX B

CONSENT FORM
THE OHIO STATE UNIVERSITY

CONSENT FOR PARTICIPATION IN
SOCIAL AND BEHAVIORAL RESEARCH

I consent to participating in (or my child's participation in) research entitled:

**Daughters' Decision Making About the Nature and Level of Their Participation in the Long-term Care of Their Dependent Elderly Parents**

Virginia Richardson, Ph.D. or his/her authorized representative has (Principal Investigator)

explained the purpose of the study, the procedures to be followed, and the expected duration of my (my child's) participation. Possible benefits of the study have been described as have alternative procedures, if such procedures are applicable and available.

I acknowledge that I have had the opportunity to obtain additional information regarding the study and that any questions I have raised have been answered to my full satisfaction. Further, I understand that I am (my child is) free to withdraw consent at any time and to discontinue participation in the study without prejudice to me (my child).

Finally, I acknowledge that I have read and fully understand the consent form. I sign it freely and voluntarily. A copy has been given to me.

Date: __________________________ Signed: __________________________

Signed: __________________________

(Principal Investigator or his/her Authorized Representative)

Signed: __________________________

(Person Authorized to Consent for Participant - If Required)

Witness: __________________________

HS-027 (Rev. 3/87) — (To be used only in connection with social and behavioral research.)
APPENDIX C

INTERVIEW SCHEDULE
Phase One: Individual Interviews
INTERVIEW SCHEDULE
Opening and Reserve Questions
Phase One: Individual Interviews

Level One: First Interview

Opening question: Could you please describe the status of your [mother's, father's, parents'] care, how it came to be, and how you were and/or are involved in this process?

Reserve questions (To provide structure for eliciting material not generated by the opening question):

1. How were or were not decisions a part of the changes in the kind and amount of care you provide(d) your parent(s)?

2. Describe a decision experience that was especially significant for you.

3. What alternatives were (or are being) considered in the decision (or series of decisions)? How would you explain the choice made?

4. Describe the involvement of others in the decision experience.

5. How has the decision experience affected you?

6. How has the decision experience affected your parent(s)? Your family?

7. How would you evaluate the consequence(s) of the decision(s) made? What meaning does this (do these) consequence(s) have for you?

8. What do you think being a woman might have to do with your caregiving decisions?

Level Two: Second Interview

1. Individual clarification issues, and building on particulars of individual stories.

2. Please say more about approval and utilitarian considerations made in your decision(s). "Map out" considerations made.
APPENDIX D

INTERVIEW SCHEDULE
Phase Two: Focus Group Interviews
INTERVIEW SCHEDULE
Opening and Reserve Questions
Phase Two: Focus Group Interviews

Level One: First Group Session

Opening question: Could you please go around the group and describe the status of your parents' care, how it came to be, and how you were or are involved in this process?

Reserve questions (Developed from Phase One data):

1. Why are you giving care?

2. Can you identify one decision and "map it out" from beginning to end?

3. What considerations did you make in your decision(s)? Approval? Utilitarian?

4. Describe the experience of making a decision in your parent's best interest without his/her involvement.

5. What do you think being a woman might have to do with your caregiving decision(s)?

Level Two: Second Group Session

1. Please say more about "having to" and "wanting to" give care.

2. Please say more about guilt.

3. Please say more about "taking charge" of your parents.

4. Please say more about others' involvement in your decisions.
Kay: Well, how would they get along? I mean sure they do. They could end up some some place where they would be completely unhappy, but they wouldn't do that to us!

Janet: And I think that part of it is very unselfish. It's just because they are ours that you do it without question, when you know that they really need it.

Eve: You do it because you have to. Because it needs to be done. And also because we're here! And I know my sister feels terrible. She feels guilt of her own because she's away and I'm here.

Kay: Handling it all!

Eve: And I said, "Joann, I'm the one that's here and if you were the one that were here it would be the other way around.

Janet: Does she come to relieve you sometimes? relief (iv)

Eve: I haven't really needed to be relieved. If I did though, I'm sure, if I were taking a long trip or something like that, I don't think she'd hesitate.

Researcher: How often do you go over to the nursing home?

Eve: Now I'm only going about four times a week. Um, I went through a period where I had to go every day. I just felt it was necessary.

Researcher: Necessary for what reason?

Eve: For me. I think the whole basic thing of it was so that some day when she's gone I won't have any regrets.

The following are examples of actual transcript text and their edited-for-presentation counterparts:

EXAMPLE 1.
Actual text:
And it's just, it's just as well she's not asking. Um, she has never asked me what it costs to stay here. Now for a woman that's sound of mind, you'd think she would. I don't know if she thinks it's gonna upset me if she asks, or if she doesn't want to know. I think that maybe with the house, she doesn't want to know.

Edited text:
It's just as well she's not asking. Um, she has never asked me what it costs to stay here (in the nursing home). Now, for a woman that's of sound mind you think she would. I don't know if she thinks it's gonna upset me is she asks, or if she doesn't want to know. I think maybe about [what happened to] the house, she doesn't want to know.

EXAMPLE 2.
Actual text:
Janet: Well as I think Nan has said, you know they become like your kids after while and after a while they let you become their parent. They allow you to make the decisions for them. It's no longer a struggle. Uhm, and often it involves their physical being......(etc.)

(A minute later)

Janet: Uhm, I feel that the more assistance I give my Mother and Dad, the more they are going to let me do for them.

Kay: Yes. Yes.

Janet: And it's one of those things that you kind of hold back a little. Uh, you don't want to give it all. I know that sounds sort of crass, but

Researcher: Can you say more about that?

Janet: Well, I could be down there at their condo on a daily basis doing their laundry, straightening up for them going to the grocery, doing all these things that would take me from my own life.
EXAMPLE 2, continued

Edited text:

You know, they become like your kids after while and after while they let you become their parent. They allow you to make the decisions for them. It's no longer a struggle. The more assistance I give to Mother and Dad, the more they are going to let me do for them. It's one of those things that you kind of hold back a little. Uh, you don't want to give it all......I know that sounds sort of crass, but.....doing all these things that would take me from my own life.

Researcher note:

The "uhms", "uhs", and "you knows", as well as problems in syntax and grammatical errors were left in the text to preserve a sense of realism in these women's voices. Occasionally, repeated "Uhms" and "you knows" were edited from the text when they distracted from the content. Syntax problems were left unedited with the exception of occasional bracketed clarifiers (See EXAMPLE 1) Parentheses ( ) indicate a researcher note of clarification to the reader. Brackets [ ] indicate words implied but unspoken by the participant. Brackets also surround words substituted for names. e.g. [my brother] instead of "John". In other cases, "John" was changed to another name. The researcher did not follow the convention of using brackets around the first letter of a word beginning an edited quote but not beginning a sentence in the original text. (EXAMPLES 1 and 2) Grammatical errors and colloquialisms were left completely unedited.


