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**FAMILY DECISION-MAKING: EXPERIENCES OF ADULT
SONS AND DAUGHTERS WITH ELDER CARE DECISIONS
FOR PARENTS SUFFERING FROM DEMENTIA**

presented by

STEPHEN J. YANCA

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Ph.D. degree in Family and Child Ecology



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**FAMILY DECISION-MAKING:
EXPERIENCES OF ADULT SONS AND DAUGHTERS
WITH ELDER CARE DECISIONS
FOR PARENTS SUFFERING FROM DEMENTIA**

By

Stephen J. Yanca

A DISSERTATION

**Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of**

DOCTOR OF PHILOSOPHY

Department of Family and Child Ecology

2002

ABSTRACT

FAMILY DECISION-MAKING: EXPERIENCES OF ADULT SONS AND DAUGHTERS WITH ELDER CARE DECISIONS FOR PARENTS SUFFERING FROM DEMENTIA

By

Stephen J. Yanca

Americans are living longer, leading to increasing numbers of frail elderly persons in need of care. At the same time, families are having fewer children, so there are fewer adult offspring available to provide family care. Accompanying these trends has been an influx of women into the work force. The increase in work force participation by women, who have been the traditional caregivers in the family, raises concerns about the availability of family care. Adult sons and daughters are more likely to have to make caregiving decisions for at least one aging parent. This study explored decisions that families have to make in these situations and how they are able to make them successfully. It also attempted to discover if family members use previous experiences with family decision-making or if they develop new ways of reaching decisions together.

This is an exploratory qualitative study of experiences of adult sons and daughters in six families who have successfully made elder care decisions together for a parent incapacitated by dementia. The sample of seventeen participants was recruited from families in Saginaw and Bay Counties in Michigan. An effort was made to interview every sibling; only two from different families did not participate. Respondents were interviewed in person, by telephone, and in one case by e-mail using an interview guide.

They were asked to describe what decisions were made, how the family made them, important factors that influenced the decisions, and how they felt about the process. Participants also were asked to describe how their parents made decisions, how they make decisions in their own marriage, and how they made decisions as parents. They were asked if they saw any influence from these situations on how they made decisions with their siblings about elder care. Basic demographic data were collected.

These families reported using extensive communication and consensus in reaching decisions together for their parent. They described a system of shared responsibility and shared decision-making. Siblings who lived at a distance made contributions such as handling finances and investments, researching the disease process and resources, providing emotional support for the siblings on the scene, and traveling to Michigan to assist in selecting placements and moving their parent.

Most respondents recalled a more individualized form of decision-making by their parents and reported only some influence from these experiences on decision-making with their adult siblings. Twelve of the seventeen respondents were married or widowed and never divorced, and two were successfully remarried. They all described more egalitarian marriages with decision-making being joint with discussion. They saw the greatest similarity between these experiences and decision-making with their adult siblings. Decision-making as parents was seen as less similar, with some participants describing this situation as the husband deferring to his wife.

Implications for future areas of study and for the use of technology in conducting research are discussed.

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Dedicated to my wife and my family:

Your patience, sacrifice, and support

made all of this possible.

ACKNOWLEDGMENTS

I owe a great deal of thanks to the members of my committee who have stayed with me over the past ten years as I completed my course work and undertook this study. My first course was research methods with Bob Boger, whom I credit with giving me a firm foundation in conducting research. Diane Levande from the School of Social Work gave me her wisdom and insight in studying elder care and taught me about theory construction in my profession as a social worker and a social work educator. Anne Soderman always greeted me with a smile and was a source of support every time I met with her either individually or in committee meetings. I cannot say enough about my chair, Barbara Ames, who has been my mentor and my inspiration. I am thankful for her patience and understanding as I juggled the demands of learning to be a teacher, raising my family, and making progress toward completing a Ph.D. Her guidance helped me to select a really wonderful group of people for my committee. I am thankful for her gentle prodding as I plodded through years of course work and more years completing this study. I appreciate her feedback and her candid advice about every aspect of the work that I have done. I also want to thank Norma Bobbitt, from whom I took three of my most fundamental courses. She inspired me to pursue a qualitative study for my dissertation, for the richness of the data, and I am all the more enriched by that experience and by having known her. The secretaries in the Family and Child Ecology Department, Ruth Sedelmaier and Mary Faloon, have been helpful in bridging the distance between Saginaw and East Lansing. They treated me as if I were a member of the faculty and

made my tasks a lot easier.

I would like to thank the administration at Saginaw Valley State University where I teach for their support. I especially want to thank my Dean, Don Bachand, whose support and assistance was invaluable in helping me complete this project. I also want to thank Mary Troester and Diane Boehm of the Writing Center at Saginaw Valley for editing this manuscript.

I want to acknowledge the support that I received from my family. It is not easy growing up with a father who is working on a Ph.D. while also working full time and teaching overloads to pay for tuition. Catherine, Caroline, and Jonathan have been patient and understanding. They have spurred me on when I thought about quitting because I felt guilty about taking too much time from them. They have encouraged me with my education as I have encouraged them with their own. It is also not easy being married to a husband who is in this circumstance. My wife and my best friend, Beverly, has been my rock. I could not have done this without her support. Our experiences with elder care for her parents and for my father sparked my interest in this area of study.

Finally, I want to acknowledge the contributions of the families who gave their time and let me join their family for a brief moment. Their courage in sharing their experiences and their even greater courage in facing these difficult circumstances is inspirational. To a person, they expressed the hope that in some small way their participation might help other families who are faced with making decisions for an elderly parent who has dementia. I share this hope with them.

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CHAPTER ONE

INTRODUCTION

Background of the Problem

Substantial demographic, social, and economic changes occurred during the 20th Century. Longer life expectancy has led to increasing numbers of frail elderly persons in need of care. The post-WWII "Baby Boom" will further inflate these numbers in the first half of the 21st Century. An increase in the number of frail elderly persons means families are more likely to have to make caregiving decisions for at least one aging member. At the same time, families are having fewer children. Thus, there are fewer adult offspring available to provide family care. In addition, economic conditions have changed during the transition to a global economy, and the United States has moved to a more technological, but also service-based economy. Accompanying this transition has been an influx of women, especially mothers, into the work force. This increase in work force participation by women, who have been the traditional caregivers in the family, raises concerns about the availability of family care.

The researcher's interest in family decision-making for elderly parents began in the early 1980s as a supervisor at a community mental health center that included an elderly outreach program. Early involvement with elder care included coordinating and delivering a series of training programs for family and professional caregivers. A grant was written and funded for an adult day activity program for people with dementia. Over the years, the researcher's family and in-laws experienced caregiving decisions for

impaired parents.

The researcher's involvement with the adult day activity program raised questions about how caregiving decisions were made by families as they faced the difficulties of caring for an impaired parent. In talking with families and with other professionals, it was obvious that people were feeling their way through this on their own. This was confirmed by personal experiences. Another question was what professionals might do to facilitate successful decision-making. Exploring the literature, it seemed that little was known about the decision-making processes that adult sons and daughters use when they have to make these decisions. A few studies attempted to gain some insight, but appeared to be limited by the constraints of having to collect data that could be quantified. This resulted in the decision to use a qualitative approach for this study. It was felt that a qualitative study might open the way to a deeper understanding of how families make these decisions. In particular, exploring families who were successful might uncover patterns that could provide a foundation for models that professionals could use in working with families. It is hoped that this dissertation study will spur others to also take up this quest.

Purpose of the Study

The purpose of this study was to better understand family decision-making by adult siblings regarding care for elderly parents suffering from dementia. Important aspects of the decision-making process itself were explored, since little is known about how families arrive at the decision to use various forms of elder care. Most studies have looked at demographics and dependency needs as factors, but have not explored the

actual process families use when making decisions about care. A few studies have begun to examine family decision-making in elder care, but have relied on reports from individual respondents and used quantitative methods of analysis (Pike & Bengston, 1996; Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; and Lieberman & Fisher, 1999).

This qualitative study was based on reports from most or all of the adult siblings in each family. It sought answers to the following primary research questions:

How do selected families make decisions about finances, guardianship, and the use of family care, home care, adult day care, adult foster care or nursing home care for elderly parents with dementia?

How do selected families use prior decision-making experiences from their family of origin, their marriages, and their parenting to make decisions about elder care?

How do selected families use various decision-making procedures (conflict, discussion, negotiation, change or consensus) in making decisions for parents suffering from dementia?

Can a pattern of decision-making procedures be identified for selected families that reflects a family pattern regarding family decision-making?

Caregiving for elderly parents can take many forms, and it may not be clear how various terms are used. For the purposes of this study, family care is considered to be caregiving that is provided by family members either in their own home or in the home of their parent. Home care is caregiving provided by paid caregivers in either the home of

the parent or in the home of a family member. Adult day care is a program that provides care for impaired adults during the day at a facility. Adult foster care is a facility that is licensed by the state to provide residential care in either a private home or in a group home that is staffed by paid employees. Nursing homes are facilities that are licensed to provide nursing care in larger residential settings that meet federal and state standards.

The study utilized qualitative methods to describe decision-making processes used by adult siblings regarding elder care and the evolution of these processes in their families. Six processes identified by Scanzoni and Szinovacz (1980) were considered, including conflict, discussion, negotiation, power, change, and consensus. An open-ended interview guide was used to explore family experiences in making caregiving decisions. A qualitative approach was used to identify relationship variables and potential decision-making models that serve as a foundation for further study. The development of models to facilitate family decision-making may be possible, if successful processes can be identified.

Importance of the Problem

Studying family decision-making regarding elder care is important for many reasons. Adult sons and daughters often must make decisions for their parents with dementia. There is no precedence for this in the family. It is expected that parents will make decisions for themselves and for their children until the child is an adult and is able to make his or her own decisions. Parents continue to make their own decisions. However, their ability to make and carry out decisions is impaired if dementia develops. Generally, the spouse takes on this responsibility if the parent is married. However, the

responsibility for decision-making typically falls on adult offspring, if the parent is widowed or divorced or the spouse is incapacitated. In essence, the roles in decision-making are altered with sons and daughters making decisions for their parent. This would be labeled as "dysfunctional" by family practitioners if it were to occur without the impairment of the parent, especially when the offspring are young. However, the situation also might be labeled as "dysfunctional" if adult offspring fail to take on responsibility for decisions when the parent is impaired, especially if they are available. So, family members are likely to feel uncertain about how to proceed. They may not know what is expected of them. The appropriate process for arriving at decisions may be unclear. It appears that answers to these and other concerns are being created by families as they go along. If successful processes can be identified, then professionals can develop approaches that will facilitate family decision-making when a parent is unable to make autonomous decisions.

This study explores the extent to which selected families rely on past experiences to develop a decision-making process for an impaired parent. Adult sons and daughters may follow established family decision-making patterns. They may act as if they were in the parent's position and use an approach they had observed their parents using. Thus, the parents may have modeled certain decision-making processes as the siblings were growing up. There may have been earlier experiences with caregiving decisions. Adult sons and daughters may have used decision-making processes in their marriages and as parents that were similar to what they experienced growing up. Thus, earlier decision-making experiences may establish patterns of decision-making. On the other hand, variation in experiences among family members may make it more difficult for adult

siblings to agree on how they will make decisions for their parents.

The types of care utilized and the timing of various forms of care are two examples of the decisions that families may face. These decisions have important financial implications for the family and for state and federal governments. The escalating cost of home health care and nursing home care threatens the financial well-being of elderly persons. Medicaid is available when assets are sufficiently depleted, but this shifts the burden to state and federal governments, creating important implications for public policy. Alternative forms of care such as adult day care are typically underutilized despite the fact that they can save costs by extending the length of family care.

Currently, family elder care is viewed as a tradition. However, until recently, the likelihood of caring for an elderly spouse or parent was much less than it is now, due to shorter life expectancy and larger families. Fewer parents lived long enough to need care, and larger families meant there were more offspring to provide care. New patterns of caregiving over the life span may be evolving from the increased use of non-family care for children. For example, greater willingness to purchase non-family care for children could lead future generations to make similar choices for aging family members.

The movement of women into the work force has produced greater variability in child caregiving arrangements. Other major industrialized nations provide childcare based on need. United States public policy has mainly left meeting the demand for childcare to the market system. The result is a random pattern of childcare that is available based primarily on either eligibility or parents' income, and not on what children or parents need. A question to be answered is whether similar random patterns

of care will emerge in the care of elderly parents. The majority of elder care is currently provided by the family. However, this care is mainly by women in a cohort who did not experience the same patterns of work force participation and childcare utilization as the so called "sandwich generation" (Brody, 1990). As caregiving passes from spouses to adult sons and daughters, greater variability in caregiving arrangements for elder care also may take place. Families may use home care, adult day care, and adult foster care as alternatives to nursing home care. It remains to be seen what other models of care will be developed in the future.

Greater longevity and lower fertility have changed the structure of the family. When life expectancy was much lower and fertility rates higher, families were more likely to have fewer generations alive, but had greater membership in living generations. However, during the latter part of the 20th century this changed for families in developed countries. Cees Knipscheer (1988) describes the "verticalization" of the family in which there are more generations living during the same period of time with fewer numbers in each generation. This is likely to bring about radical changes in intergenerational relations within the family and a greater likelihood that family caregiving decisions will be needed.

Theoretical Framework

The conceptual map for this project evolved from theories by Bubolz and Sontag (1993), Paolucci, Hall, and Axinn (1977), and Scanzoni and Szinovacz (1980). It has a central framework of family ecological theory similar to Bubolz and Sontag (1993). Their ecological theory was selected because it includes the family as a system and its

interaction with the environment. Decision-making is among the primary activities/processes that take place within the family. Paolucci, Hall, and Axinn (1977) stated that the transacting process between families and environments is one of “deciding, acting, and reacting” (p. 2). Family ecosystem structure was conceptualized by Bubolz and Sontag (1993) as families of diverse characteristics (structure, ethnic origin, life stage, and socioeconomic status) with individual and family attributes (needs, values, goals, resources, and artifacts) interacting in and with diverse environments (natural physical-biological, human-built, and social-cultural). Family ecosystem processes involve the transformation of matter-energy and information by engaging in the key process of adaptation through activities and processes (decision-making, perception, organization, communication, management, use of technology, sustenance activities, and human development). The outcomes of these ecosystem processes occurring at the micro and macro level affect the quality of life of humans and the quality of the environment (at both levels), which in turn have consequences for the realization of values and environmental goals (human betterment and stewardship and sustainability of the environment). These outcomes provide feedback to the structural and process aspects of the family ecosystem and influence structure and process.

In Bubolz and Sontag’s (1993) description of family ecology theory, decision-making is relegated to a similar position as several other activities/processes in the family. In this study, however, decision-making is considered the core process in adaptation. The other activities/processes are seen as either products of decision-making or influencing factors. This is consistent with Bubolz and Sontag’s view that decision-making is the central control system of family organization. Thus, for the purposes of

this study, Bubolz and Sontag's (1993) description of family ecology theory for the process level is reformulated as follows: Families transform matter-energy and information by engaging in the key process of adaptation through decision-making activities/processes and other activities/processes (perception, organization, communication, management, use of technology, sustenance activities, and human development) interacting with decision-making.

Intergenerational family decision-making is the main focus for this study. In particular, the decision-making process used by adult siblings regarding aging parents was studied. The examination of family decision-making by Paolucci, Hall, and Axinn (1977) used a family ecosystems approach that is similar to that of Bubolz and Sontag (1993). In considering decision-making in families, Paolucci, Hall, and Axinn described how decisions are interrelated and changing. They proposed two basic patterns in which decisions are linked, central satellite and chain patterns. Central satellite is characterized by a main central decision with various minor decisions radiating from the central decision. An example of this in elder care would be an adult son or daughter making the decision to have a widowed parent move in because of a disability (central decision). Rearranging bedrooms, planning meals for a special diet, and arranging for participation in a day program would be satellite decisions.

With the chain pattern of family decision-making, there is a sequence of decisions in which each decision is dependent on those that precede it (Paolucci, Hall, & Axinn, 1977). For instance, seeking guardianship for a parent with diminished capacity requires a series of steps with related decisions as one has evaluations completed and retains an attorney leading up to the court date when a decision is rendered.

Scanzoni and Szinovacz (1980) explored the influence of sex role modeling on family decision-making. They made a convincing argument for sex role modeling as an important factor in how families make decisions. In addition, their inclusion of context factors, time, third parties, and placement in the life span makes their model ecological. Their examples of hypothetical families include different influences of historical events on each generation of the family. They also considered decisions involving marital couples across the life span, parents and children, adult children and their aging parents, and alternative lifestyles, family decision-making and social policy. Thus, Scanzoni and Szinovacz include the necessary elements of both an ecological perspective and an intergenerational approach. Their work was used as the primary decision-making model for this project because it adds to the understanding of family decision-making.

It appears that Scanzoni and Szinovacz's model (1980) (see Figure 1.1) is a version of the chain pattern. It is not the classic chain pattern in which a sequence of decisions is necessary to produce a certain outcome. Instead, the model chains past, present and subsequent decision-making. This is similar to what Paolucci, Hall, and Axinn (1977) referred to when they describe decision-making as "a process rooted in the past, carried on in the present, shaping the future" (p. 5). Scanzoni and Szinovacz saw family decisions as beginning with Evaluation of Prior Decision-Making followed by consideration of Current Context Factors. Decision-Making Processes then take place, leading to an Outcome. Current context factors interact with prior decision-making and influence current decision-making processes. A good fit between current and past circumstances reinforces a similar decision process with the expectation of a similar outcome. A poor fit between context factors or a poor outcome to prior decision-making

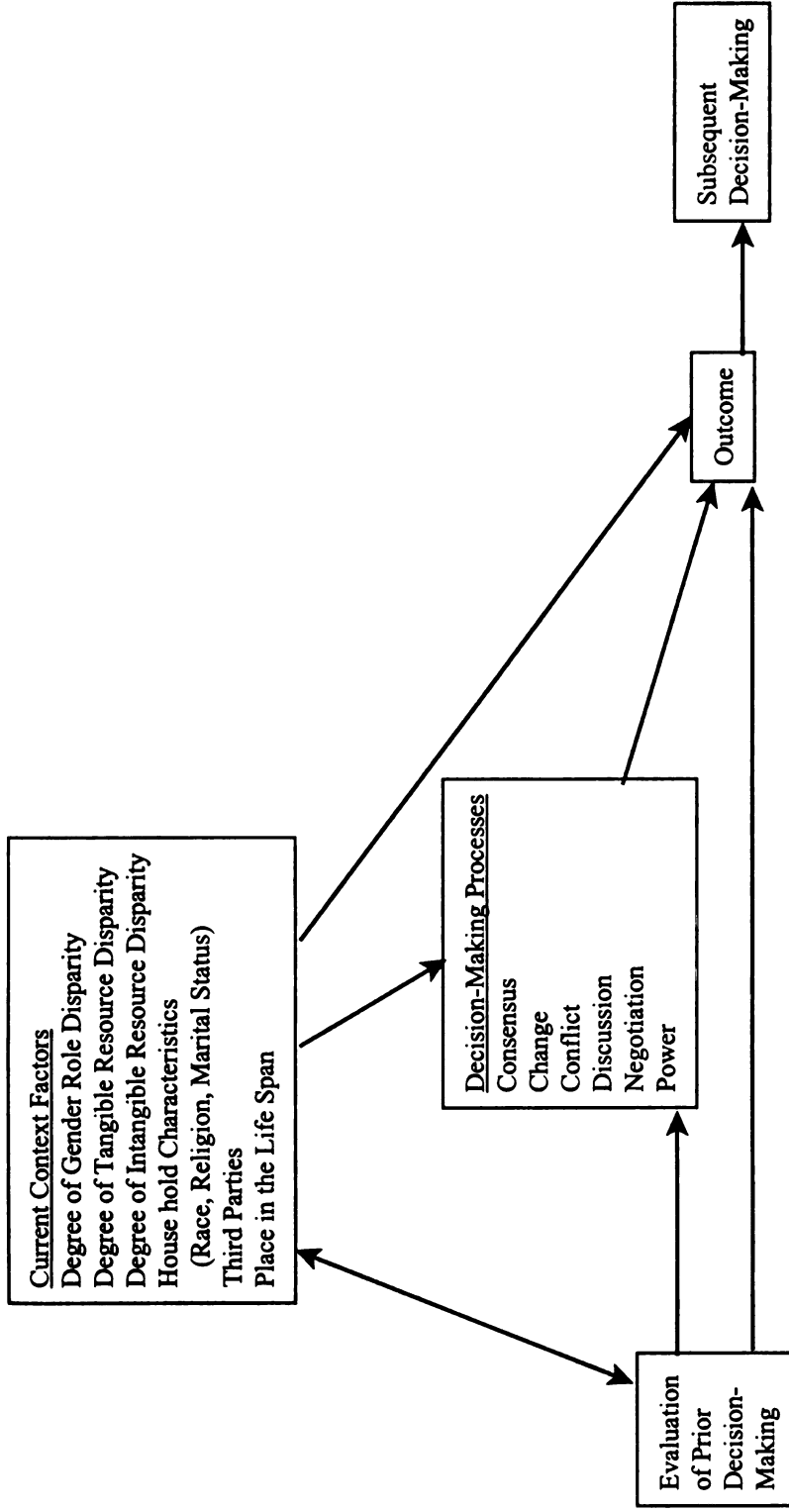


Figure 1.1 - A Model of Explicit Family Decision-Making Showing Effects of Current Context Factors and Evaluation of Prior Decision-Making Experiences on Decision-Making Processes, Outcome, and Subsequent Decision-Making from Scanlon and Szinovacz, 1980 (p. 100).

is more likely to lead to changes in the process with an expectation of a successful outcome. Evaluation of prior decision-making, current context factors, and decision-making process converge to form an outcome which influences Subsequent Decision-Making.

Theoretical Map

A comprehensive theoretical map was constructed to demonstrate how an ecological model of family decision-making is developed by blending Bubolz and Sontag's(1993) Family Ecosystems Processes with Scanzoni and Szinovacz's (1980) Decision-Making Processes. Elements from Bubolz and Sontag (1993), Paolucci, Hall, and Axinn (1977), and Bronfenbrenner (1996) were added under Current Context Factors, Family Ecosystems Processes, and Outcome.

The theoretical map in Figure 1.2 illustrates the development of the conceptual map for this project. Table 1.1 highlights the sources for the theoretical map. Age Cohort and Generational Placement were added to the theoretical and conceptual maps by this researcher under Place in the Life Span to make this an intergenerational family decision-making model. Family of Origin was added by this researcher to Evaluation of Prior Decision-Making to represent the influence of decision-making patterns experienced while growing up. This is consistent with Paolucci, Hall, and Axinn's (1977) premise that decision-making is a learned process that is rooted in the past. In considering these experiences, the most relevant decision-making processes are those that were used by parents in their marriage, with their children, and with grandparents (especially as grandparents age). Marital was added to reflect the decision-making processes that evolved in the marriage of procreation. These processes are influenced by

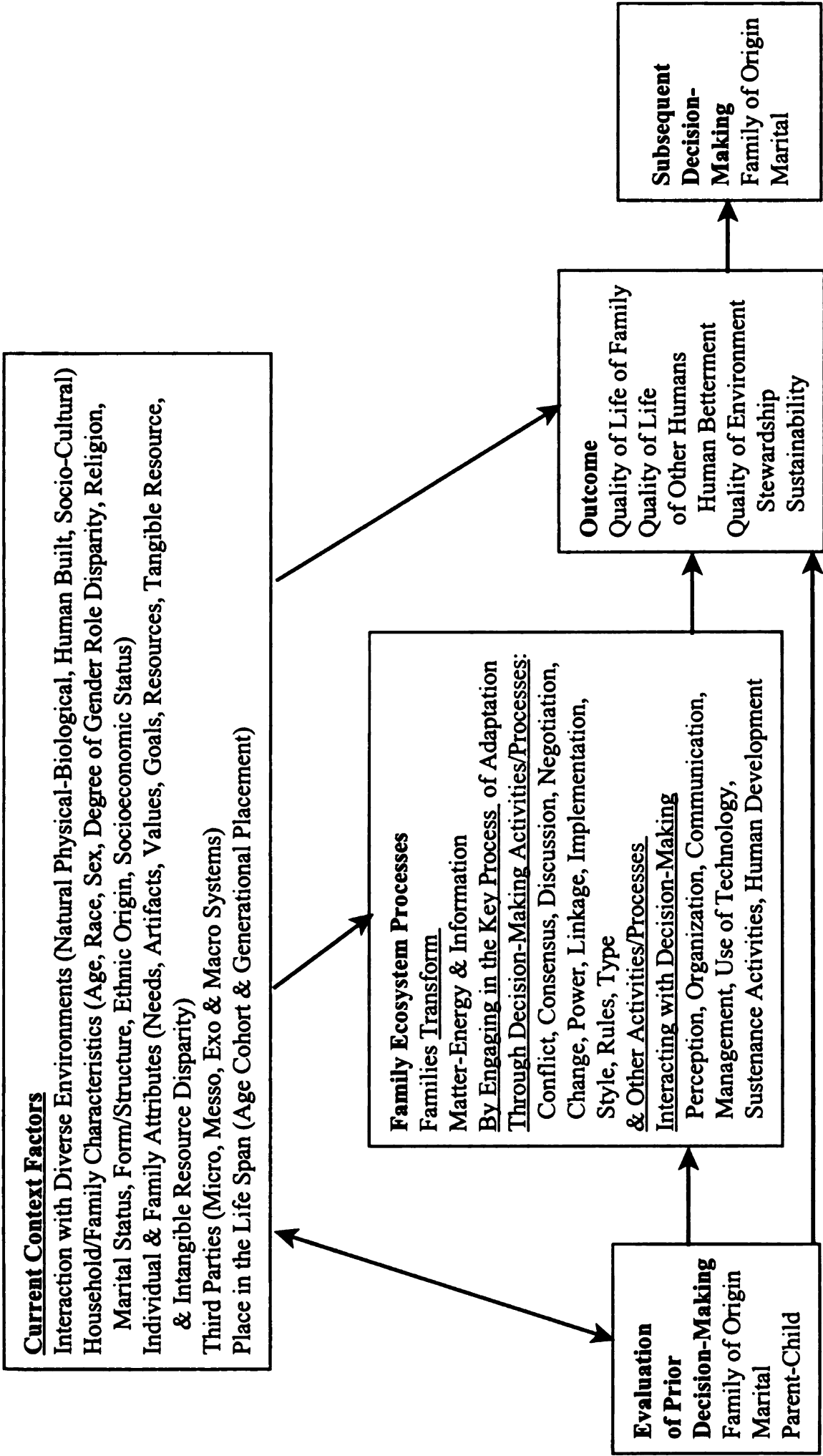


Figure 1.2 -Theoretical Map of Family Decision-Making Utilizing a Modified Version of Scanlon and Szinovacz's (1980, p. 100) Model of Explicit Family Decision-Making Integrated with Concepts of Family Ecological Theory from Bubolz and Sontag (1993, p. 438) and Components of Family Decision-Making from Paolucci, Hall, and Axinn (1977) with Bronfenbrenner (1979) and Yanca added.

Table 1.1 - Sources for Theoretical Map of Family Decision-Making Utilizing a Modified Version of Scanlon and Szinovacz's (1980) Model of Explicit Family Decision-Making Integrated with Family Ecological Theory from Bubolz and Sontag (1993) and Family Decision-Making from Paolucci, Hall, and Axinn (1977) and Systems Levels from Bronfenbrenner (1989).

Scanlon & Szinovacz	Bubolz & Sontag	Paolucci, Hall, & Axinn	Bronfenbrenner
<u>Evaluation of Prior Decision-Making</u>			
<u>Current Context Factors</u> <u>Household Characteristics</u> : Sex, Race, Religion, Marital Status <u>Degree of Gender Role Disparity</u> <u>Third Parties</u> : <u>Place in the Life Span</u> :	Interaction with Diverse Environments: Natural Physical-Biological, Human Built, & Socio-Cultural <u>Family Characteristics</u> : Structure, Ethnic Origin, Socioeconomic Status <u>Individual & Family Attributes</u> : Needs, Artifacts, Values, Goals, Resources	Family Form, Age, Tangible Resource Disparity, Intangible Resource Disparity	Micro, Meso, Exo, & Macro Systems
Conflict, Consensus, Discussion, Negotiation, Change, Power	<u>Family Ecosystems Processes</u> <u>Families Transform Matter-Energy & Information By Engaging in the Key Process of Adaptation Through Decision-Making Activities/Processes & Other Activities/ Processes Interacting with Decision-Making</u> : Perception, Organization, Communication, Management, Use of Technology, Sustenance Activities, Human Development	Linkage, Style, Rules, Type, Implementation	
<u>Outcome</u>	Quality of Life <u>Quality of Life of Other Humans</u> : Human Betterment <u>Quality of Environment</u> : Stewardship & Sustainability		
<u>Subsequent Decision-Making</u>			

the experiences of each spouse. Parental refers to decision-making by parents for children in the family of procreation. The addition of these elements is necessary in order to complete the development of an intergenerational model.

The same concepts were added to Subsequent Decision-Making except that the influence is on future decisions. This is an important distinction in that the model is intended to capture decisions that are made in the future, including those that might be made within the marriage of procreation, with children who are maturing, and with parents who will eventually be aging. Quality of Life of the Family was added to Outcome to highlight concerns family members may have about their own family's life situation as caregiving decisions are made.

Evaluation of Prior Decision-Making

Evaluation of prior decision-making was the starting point in using this model to examine family caregiving decisions. The earliest decision-making processes that people experience are in their families of origin. Later in life, as an adult, people typically make decisions in their marriage and as parents. Modification of the various elements of Scanzoni and Szinovacz's (1980) model is necessary to reflect how decisions are reached by adult siblings regarding their elderly parents. For instance, this study does not focus specifically on the effects of gender on decision-making, as Scanzoni and Szinovacz did. Instead, it explores whether there is evidence for certain basic decision-making processes proposed by Scanzoni and Szinovacz. This study does not include power in the same form as Scanzoni and Szinovacz, since adult siblings generally live independently from each other. However, evidence of the use of power in the decision-making process was noted and discussed in the interviews, particularly as it relates to the power to make and

implement decisions. Using Scanzoni and Szinovacz's model, one would look to see how decisions have been made in the past to see how current decisions might be made.

Current Context Factors

Current context factors represent factors that are influenced by prior decision-making and also influence prior decision-making, family ecosystem processes, and outcome.

Interaction with Diverse Environments. Interaction with diverse environments refers to the environments that make up the family's ecosystem. The natural physical-biological, human built, and socio-cultural systems are the larger contexts in which the family operates.

Household/Family Characteristics. Household/family characteristics include race, age and sex which are biologically determined, but also carry some important social and cultural implications. Bronfenbrenner (1996) felt that these were so important to process and outcome that they should be included in every research design for the study of human development. Ethnic origin and religion also have cultural implications. Sex and age are important since many ethnic groups value males over females, and some value older adults more than others. Younger children tend to have less power than adolescents, and adults more power than minors. In addition, limitations on power and resources for groups suffering from discrimination and oppression limit their options and ability to influence outcomes. For example, Scanzoni and Szinovacz (1980) found that lower socioeconomic status tended to limit power and resources and also increased the likelihood of traditional sex roles in marriage.

Marital status influences who is involved in decisions and how they are made.

People who are single, divorced or widowed may make decisions alone or may consult others, such as extended family members or people outside of the family. Married couples may also consult others, but generally will rely on the processes they have developed within the marriage. Scanzoni and Szinovacz (1980) found that cohabitating couples tended to act as marital couples, except that the lack of a formal commitment tended to weaken the influence of the partner.

Paolucci, Hall, and Axinn (1977) considered various family forms as a factor in family decision-making. They identified the following forms: 1) nuclear family (first marriage, single or dual career); 2) nuclear family (remarried, single or dual career); 3) nuclear dyad (childless or no children at home, single or dual career); 4) nuclear dyad (same but remarried); 5) single-parent family (career or non career); 6) three generation family (with any variant of the above); and 7) kin network, and emerging experimental (commune, unmarrieds, etc.). The family forms of concern in this study included all but those under kin network and emerging experimental.

It is assumed that first marriage couples will differ in their decision-making process from the single or remarried. Remarried couples bring a history from their earlier marriage that may complicate the process. Failed marriages could be expected to involve decision-making processes in which there was conflict. Stepchildren and former spouses can affect certain types of decisions. Scanzoni and Szinovacz (1980) found differences in power for spouses who work versus those who do not, especially for wives. This was included under resource disparity.

It would seem that decision-making processes in three-generational families would be influenced by several factors. For instance, the reason the three generations are

living together may be important. If it is a case of an impaired parent living with an adult son or daughter with children, then there might be a decision-making process similar to nuclear families. However, if it is an adult son or daughter (with children) living with a parent, there might be conflicting processes due to the adult status of the son or daughter. It is assumed that there would be differences between decision-making in which the adult offspring is living with a biological parent versus living with an in-law. In addition, the history of the relationship between the biological and in-law parties would be important in a family in which the elderly parent(s) is competent, especially if it is his or her home.

The degree of gender role disparity (Scanzoni & Szinovacz, 1980) refers to the disparity between the sexes in gender role preferences that are strongly traditional, traditional, modern and strongly modern. The degree of traditionalism-modernism determines how and why various decisions are made. For instance, a couple who prefer traditional or strongly traditional gender roles will not bring up certain decisions because they are "givens." Decisions that do arise are the husband's to make. Negotiation or conflict over the outcome is not expected. However, the greater the disparity in gender role preferences, the more likely that issues are raised, and reaching a decision requires discussion, negotiation, change, conflict, and/or consensus (Scanzoni & Szinovacz, 1980). If there is an age disparity, it tends to favor the older spouse, especially the husband. Religion or membership in certain ethnic groups can influence gender role preferences and disparity. Some religions and cultures teach dominance of the husband, and others are more egalitarian. If the spouses are of different religious and/or ethnic backgrounds, there may be more of a mixture of preferences with greater gender role disparity.

Individual and Family Attributes. Individual and family attributes include needs, artifacts, goals, values, resources, tangible resource disparity, and intangible resource disparity. Bubolz and Sontag (1993) identify needs for having, relating, and being. The need for having refers to having the matter-energy and information necessary to sustain life. The need for relating refers to love, acceptance and communication. The need for being is the need to grow and develop. Artifacts are the physical objects that families possess. Resources are the matter-energy and information that a family has at its disposal. Values are conceptions of what is desirable, good, right, or worthwhile. Goals are ends that the family wishes to achieve.

Tangible resource disparity (Scanzoni & Szinovacz, 1980) is the difference in income, education, or job status between individuals. The greater the disparity, the more likely that the person in the superior position will be perceived as more powerful. Intangible resources are such things as self-esteem or self-confidence. The person with high self-esteem or self-confidence generally is perceived as more capable of making decisions.

Values held by the family can play an important role in decisions regarding elder care. Messages about filial responsibilities and feelings about attachment and separation may intensify the importance of the decisions and influence the outcome. For example, if there is an established family value such as "we all pull together," then it is consistent for the family to redistribute responsibilities as needed. They would feel a strong sense of cohesion and satisfaction in "doing the right thing." However, this value could increase conflict if family members do not assume responsibilities. On the other hand, if individualism has been highly valued, then decisions may be different, both in outcome

and effect.

Third Parties. Scanlon and Szinovacz (1980) included kin, friends, clergy, and counselors under third parties. Bronfenbrenner would refer to them as members of the microsystem. Micro, meso, exo and macro systems from Bronfenbrenner (1996) are included in this model. The micro system includes the nuclear family, grandparents, mutual friends and neighbors, perhaps a minister, other kin and anyone else with whom the family interacts in the immediate environment, such as peer groups, people in work or school settings. Meso systems involve the relationships between two or more micro systems. Each system in the micro system is an exo system for other family members who are affected by the system, but are not direct participants. The macro system is the larger culture or context in which the family lives. If there is a strong cultural expectation of family care, then this will be a factor in deciding how to assist elderly parents. Various factors at each level will influence what the family decides, how they decide it, and why they reached a particular decision.

Place in the Life Span. Place in the life span includes ages of each generation and the effects of historical events on each (Scanlon & Szinovacz, 1980). This is a life course model. Even though this is not central to Paolucci, Hall, and Axinn (1977), it is consistent with their model and family ecological theory. Age cohort and generational placement are added by this researcher as important aspects. Age cohort captures much of what Scanlon and Szinovacz refer to as historical events. However, it also includes the cumulative effect of events experienced by an age group as it passes through the life course. The effect of an event depends on the age at which one experiences it. For example, experiencing WWII as an adult would have been very different from

experiencing it as a child, especially if one were a young male in military service as opposed to a child. For purposes of this study, generational placement refers to whether one is a child, a grandchild, a great-grandchild, young married with children, mid-life with older children, a grandparent, or a great-grandparent. This is a further elaboration of Scanzoni and Szinovacz, but captures the sense of the variety of roles and experiences that would be associated with membership in a larger extended family, especially one that was "verticalized."

Family Ecosystem Processes

In the theoretical map, Family Ecosystem Processes are influenced by Evaluation of Prior Decision-Making and by Current Context Factors. In Bubolz and Sontag's (1993) conceptualization of family ecology theory, families "transform matter-energy and information by engaging in the key process of adaptation" (p. 438). This occurs throughout the day during the family's entire life course. The family may decide on different outcomes, depending on what information it has. For example, a family unaware of available adult day care will not consider that an option. On the other hand, a family aware of adult day care options, could mobilize its energies to make it possible for the family member to attend. The use of adult day care would be an adaptation, but it also might require other adaptations, such as arranging transportation.

Decision-Making Activities and Processes. Scanzoni and Szinovacz (1980) include conflict, consensus, discussion, negotiation, power, and change as important aspects of decision-making. Gender role disparity and tangible and intangible resource disparities are sources of power. A multi-unit sequence of interactions characterize each of these

processes. Context factors, along with the response by the other person, determine which of these are likely to result from a given sequence. This is a process-oriented model. For instance, the process of developing a consensus can involve discussion, change, or discovery of an immediate consensus. Conflict can lead to negotiation, change, or discussion in the development of a consensus. Each of these depends on the response of the other person at any given point during the sequence. For this study, a consensus was considered to be the desired outcome of a successful family decision-making process. Conflict is to be managed so that consensus can be achieved.

Discussion, negotiation, and change were studied as processes that families use to manage conflict and to reach a consensus. Prior experiences, new experiences, and information were added as aspects of these processes. Information or experiences may affect how decisions are made. For example, a family member who lives out of state and has not had regular contact with the parent may be reluctant to support a decision to use day care or nursing home placement. However, his or her position may change if he or she visits with the parent and experiences first hand the level of impairment. Experiences that support the decision were expected to increase the likelihood that a consensus can be reached and the same process will probably be used again. Conversely, experiences that do not support a consensus were expected to decrease the likelihood that the same process will be used.

Paolucci, Hall, and Axinn (1977) included style, rules, type, linkage and implementation in their concept of family decision-making. Style refers to the mode and time perspective of the decision-making process. Modes are hypothetical, factual and action-suggestive. Decision-making rules are the methods by which alternatives are

evaluated. Paolucci, Hall, and Axinn referred to three such rules developed by Bustrillos (1963): preference ranking, objective elimination, and immediate closure. In the first rule, the options are rank ordered by a subjective criterion. In the second, the decision is apparent based on limitations imposed by the environment. In immediate closure, only one alternative is considered.

Paolucci, Hall, and Axinn (1977) defined the type of decision according to formal properties, such as the degree of rationality and substantive characteristics. The latter refers to the nature of the situation in terms of social, economic, or technical. Linkage is whether the decision is a chain pattern or central satellite as described earlier.

Implementation refers to how the decision is executed.

Other Activities/Processes Interacting with Decision-Making. Bubolz and Sontag (1993) described perception as a process that registers environmental information by the senses, organizes it, and makes it available for use. Organization is the structure of relationships among various elements of a whole. Communication is a process of interaction that creates and transmits information. Management is a process that involves "the attainment, creation, coordination, and use of resources for the meeting of goals and realization of values" (p. 436). Use of technology refers to applying human knowledge to the solution of practical problems. Sustenance activities are intended to meet needs and ensure survival. Human development "is a process of ongoing and interrelated changes in an individual's ability to perceive, conceptualize, and act in relation to his or her environment" (p. 437). Each of these influences decision-making in different ways. Various combinations may be more or less important depending on the situation.

Applying these concepts from Bubolz and Sontag (1993), more options are

created by having more matter-energy, information, and resources. A positive outcome is more likely if the family is able to process decisions in a manner that preserves its relationships and well-being. On the other hand, excessive conflict may cause a deterioration in these, resulting in greater difficulty in reaching decisions as care demands increase. The family can mobilize itself to bring about an outcome, if it is able to discuss options and reach a consensus. The use of preference ranking with a high degree of rationality could improve the chances of doing this (Paolucci, Hall, & Axinn, 1977). The decision has both economic and social aspects, so the family will need to consider such things as role expectations and cost-benefit. The power exercised by each member is important, but resentment could build if power is overused or used in a negative manner (Scanzoni & Szinovacz, 1980).

Perceptions of the situation and potential options can influence the decision-making. For instance, if the family perceives nursing homes in a negative light, it will seek other alternatives. The organization of the family around decision-making processes and activities determines how decisions are made and who makes them. Management and use of technology affect the family's ability to obtain the resources necessary to reach goals. Sustenance activities may detract from the family's ability to mobilize its resources. Human development is important in terms of the maturity and competence needed to reach and implement equitable decisions (Bubolz & Sontag, 1993).

Outcome

A desired outcome for families is a positive quality of life for family members and other humans and a quality environment (Bubolz & Sontag, 1993). Human betterment, stewardship, and sustainability are included as values that represent these outcomes.

Quality of life for the parent is often a primary concern in selecting from various caregiving options. Quality of life of the family is added by this researcher to emphasize quality of life for family members as a consideration in family decision-making.

Subsequent Decision-Making

Decision-making experiences in the family of origin, in marriage, and as a parent were added by the researcher under Subsequent Decision-Making from Scanzoni and Szinovacz (1980). Current decisions are likely to influence later decisions in many areas of a person's life. Satisfaction with the process and the outcome strengthens a relationship and increases the likelihood that difficult decisions can be reached in the future. Dissatisfaction weakens the relationship and increases the likelihood that future decisions will be difficult to reach and implement. Each family member has had experiences in the family of origin that are likely to influence subsequent decision-making. Similarly, experiences in marriage and as a parent can influence what is expected in future decisions.

Conceptual Map

The conceptual map for this project was derived from the theoretical framework described above and was the focus of this study. (See Figure 1.3.) Evidence of conflict and consensus were examined to see how discussion, negotiation, power, and change may be used to reach decisions. In addition, the family members were asked to describe how prior decision-making influenced decision-making for their elderly parent and what decision-making process they planned to use in the future. As indicated, Current Context Factors appear as an influence on family decision-making. However, the specific factors

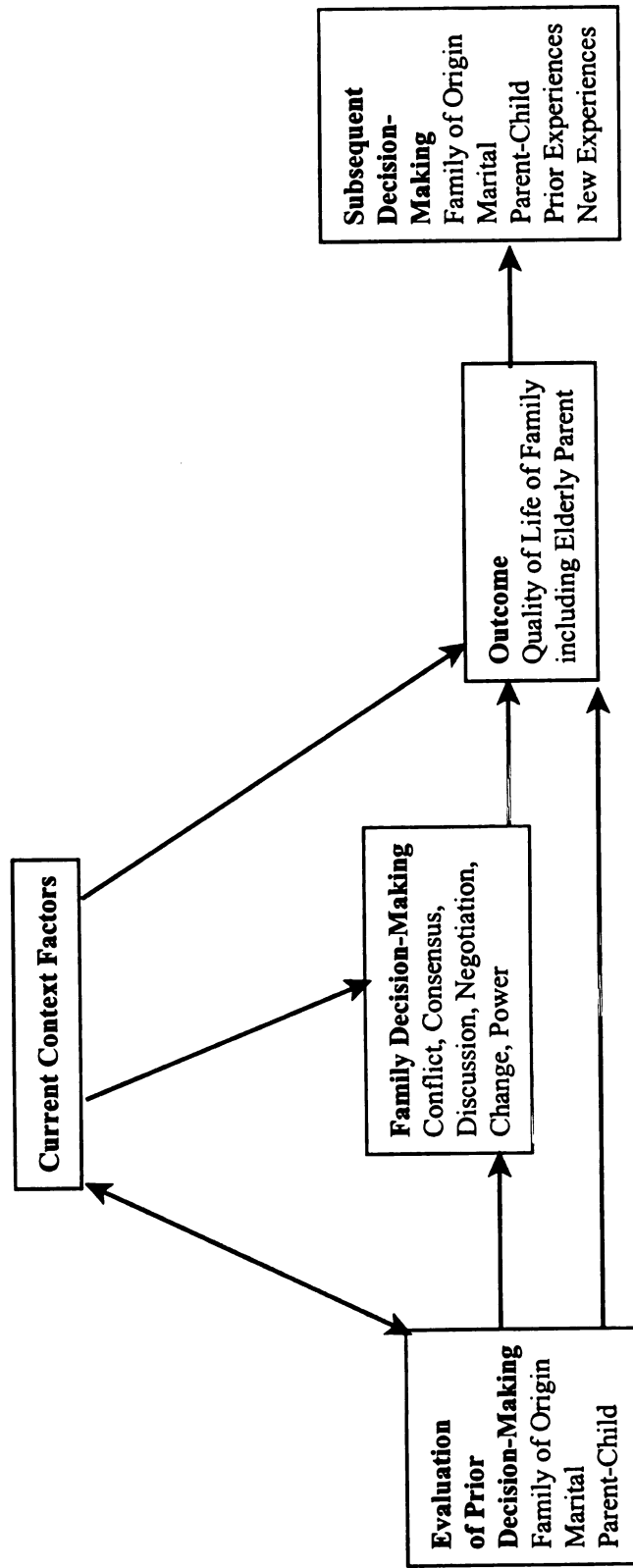


Figure 1.3 - A Conceptual Map of Family Decision-Making for Elderly Parents Suffering from Dementia

were not the primary focus as these factors were considered to be more appropriate for quantitative methods of study. Family members were asked about current context factors, and these were noted and identified as variables for future study.

Prior Experiences and New Experiences were added by this researcher since they may be prominent elements in influencing decisions made by families. They are intended to highlight the fact that information or experiences that do not directly involve the decision-making process may still affect how decisions are made.

Definition of Terms

1. Prior decision-making

Theoretical: Decision-making processes that were used at an earlier point in time.

(Scanzoni & Szinovacz, 1980)

Operational: Descriptions by respondents of the decision-making styles and processes their parents used during the respondents' childhood years (family of origin), the respondents used with their spouse during any marriage (marital), or the respondents used with their spouse(s) in raising any offspring or stepchildren (parental or parent-child).

2. Current contextual factors

Theoretical: Demographic and situational factors that may influence a decision (such as race, gender, ethnicity, socioeconomic status, or parental impairment from Theoretical Framework section above).

Operational: Any factors in the situation that are identified by respondents as having an influence on the decision-making process and any demographic patterns

that are noted from the Demographic Information form in Appendix C.

3. Family decision-making

Theoretical: Decisions made by one or more related family members (Bubolz & Sontag, 1993).

Operational: Decisions made by one or more related family members on behalf of an elderly parent who is suffering from dementia.

4. Conflict

Theoretical: Disagreement, resistance or opposition to a suggestion, idea, or proposal (Scanzoni & Szinovacz, 1980, p. 62).

Operational: A description by a respondent of a disagreement between one or more adult sons or daughters, or resistance or opposition to suggestions, ideas, proposals, options, or considerations by at least one adult son or daughter regarding finances, guardianship, or various forms of elder care for a parent who is suffering from dementia.

5. Consensus

Theoretical: The process of discovering or developing an agreement or a decision marked by conformity among the parties involved (Scanzoni & Szinovacz, 1980, p. 54).

Operational: Agreement among adult sons and daughters regarding finances, guardianship, or various forms of elder care for their parent who is suffering from dementia.

6. Discussion

Theoretical: Suggestions, ideas, proposals, options, or considerations exchanged

between two or more parties in an effort to reach a consensus or agreement
(Scanzoni & Szinovacz, 1980, p. 57).

Operational: A description by a respondent of an exchange of suggestions, ideas, proposals, options, or considerations between two or more adult sons or daughters in an effort to reach an agreement regarding finances, guardianship, or various forms of elder care for their parent who is suffering from dementia.

7. Negotiation

Theoretical: An effort to find ways to deal with or overcome resistance or opposition by offering compromises (Scanzoni & Szinovacz, 1980, p. 63).

Operational: An effort by an adult son or daughter or a third party to deal with or overcome resistance or opposition by offering compromises regarding finances, guardianship, or various forms of elder care for a parent who is suffering from dementia.

8. Change

Theoretical: A modification in one's position (Scanzoni & Szinovacz, 1980, p. 55).

Operational: A description by a respondent of a modification in position, thinking, opinion, attitude, or belief by the respondent or other participants in the decision-making process.

9. Outcome

Theoretical: "how the decisioning parties evaluate the present status of their discussions, negotiations, or arrangements regarding a certain matter"
(Scanzoni & Szinovacz, 1980, p. 95).

Operational: A description by a respondent of the process and product of a decision-making process regarding finances, guardianship, or various forms of elder care for a parent who is suffering from dementia.

10. **Subsequent decision-making**

Theoretical: Decision-making styles and processes that will be used in the future (Scanzoni & Szinovacz).

Operational: Descriptions by respondents of the decision-making styles and processes they plan to use in the future to make decisions within their sibling group regarding finances, guardianship, or various forms of elder care for a parent who is suffering from dementia (family decision-making), decisions in a marriage (marital), or decisions in raising any offspring or stepchildren or with their adult offspring (parental or parent-child).

Assumptions

Several assumptions were made about how families make elder care decisions and about how members would respond during interviews. It was assumed that conscious and unconscious processes are at work when decisions are reached within the family. It was assumed that family members would accurately recall conscious processes that were used in making decisions for their parent. It also was assumed that patterns would emerge for each family representing some of the conscious and unconscious processes. A critical assumption was that participants would be open and honest in their responses and that their recollection of experiences would be representations of actual events. At the very least, the information that was gathered was treated as perceptions of the experiences that

were described. It was assumed that there would not be substantial differences between respondents who were interviewed in person and those who were interviewed by telephone. However, it was recognized that there may be some differences in the responses given by people in face-to-face versus telephone interviews.

Triangulation and the inclusion of all or most family members in the study were intended to overcome difficulties that might be posed by some of these assumptions. It is more likely that accurate descriptions can be obtained if all or most of the family members are interviewed. It was assumed that consistency among members' descriptions would indicate greater accuracy and a greater likelihood of open and honest responses. On the other hand, inconsistency would indicate differences in perception that could represent less accuracy and differences in the levels of openness. Inconsistencies between in-person and telephone interviews may indicate less reliability for the information obtained by one of these methods. At the very least, this would indicate difficulty in mixing these two forms of data collection.

Families were recruited from several types of organizations. It was assumed that this variation would not confound the findings. Families were asked about their use of various forms of care, and comparisons were made to determine any differences in how decisions were made. Recruitment means that families were self-selected and not randomly determined. It was assumed that self-selection would result in participant families who were more satisfied with the decision-making process and the results as opposed to those who were dissatisfied. This is consistent with part of the purpose of this study, which is to identify decision-making processes that are successful and can be duplicated.

Limitations

The findings for this study are considered to be a valid indication of decision-making processes that families can use to successfully reach decisions about elder care. However, the findings are not considered to be exhaustive. It is recognized that the decision-making processes that emerged may not be used by all families. It also is recognized that other processes may be used by other families. The use of modified methods of pattern matching, analytic induction, and grounded theory increases the extent to which findings can be considered exhaustive for the participating families.

The sample was drawn from families who identified themselves as being successful at reaching decisions about the care of their elderly parent. In addition, the need to secure an agreement to participate from other siblings means that the sample was limited to families that could be expected to be more cooperative with each other and have fewer disagreements. It was expected that some families would have experienced conflict earlier, but were able to manage it and develop a successful process. However, none of the families that were recruited reported any conflict. As a result, the findings are limited to families that are able to avoid conflict and did not include families that were able to manage conflict that arose.

Families that participated used various forms of paid caregiving. This means there are class limitations to this study. Families of lower socioeconomic standing do not have the same options, if they cannot afford them or government subsidies are not available. It was expected that most of the families would be middle-class, and the findings are limited to middle-class families. Education and occupation were included under demographic information and were used to determine the socioeconomic class of

each family.

The sample was drawn from a Midwest geographical area that is semi-rural, suburban, and small city. Experiences of families living in large metropolitan areas or in more rural areas were not addressed. While a spectrum of options may be available to the population studied, it may not represent all of the options available in more populated areas. However, availability of services in large metropolitan areas may be limited by high demand. More rural areas may have fewer options.

Racial and ethnic diversity were not addressed. Diverse families were not excluded. However, the small sample would preclude making substantial comparisons among racial and ethnic populations. Ethnicity was included as demographic data and was considered as a context factor.

CHAPTER TWO

REVIEW OF THE LITERATURE

The following is a selective review of the literature on family decision-making, elder care, and intergenerational relationships. The literature on family decision-making is somewhat limited, especially regarding decisions about caring for impaired parents. A large volume of literature in the area of elder care is beginning to accumulate from various disciplines. Concern about changes in demographics related to aging is driving many researchers to consider the effects of a large elderly population on the social and economic well-being of America and other developed countries. Concerns about intergenerational relations are surfacing in response to these demographic changes.

Family Decision-Making

The examination of family decision-making described earlier by Paolucci, Hall, and Axinn (1977) used a family ecosystems approach, as did Bubolz and Sontag (1993). Paolucci, Hall, and Axinn described how decisions are interrelated and changing. Scanzoni and Szinovacz (1980) explored the influence of sex role modeling on family decision-making. While they did not label their model as ecological or intergenerational, the basic elements of each of these were included.

Several studies have begun to examine how families cope with the demands of elder care and how decisions about care are made. These studies are an important source of support for this dissertation. Stoller, Forster, and Duniho (1992) investigated parent care systems within sibling networks. The parents in their sample reported relatively

good health with few impairments, so their results are relevant for only the very early portion of parent care. They found that geographical proximity was the most important factor in explaining adult offspring involvement in providing assistance to parents. They did not find support for a hypothesis that widowed parents would select opposite-sex offspring to perform gender-linked tasks their spouse had performed. Instead, they found some support for a preference for same-sex helpers. Their results confirmed that daughters or other women provided more help to parents who needed routine daily assistance and that daughters helped with a broader range of tasks.

Keith (1995) conducted a qualitative study of family caregiving systems. She interviewed siblings regarding the division of caregiving labor in the family. Her analysis of the data suggested three models that reflect certain values to particular families. She found evidence for primary caregiving systems in families of all sizes. These reflected a particularly strong affiliation between an offspring and the parent. A partnership model was seen as requiring at least two offspring of the same gender in a family of three or more siblings, along with a commitment to equitable sharing of responsibility and authority. A team model was established to protect the siblings from a critical or demanding parent. This required a larger number of siblings committed to providing care while protecting each other. The usefulness of these models in describing decision-making by the families in this study will be discussed in Chapter Five. Keith advocated for less emphasis on the concept of “primary caregiver” and more assistance to families in developing caregiving systems that will share the burden and maximize cooperative caregiving.

There are some strong parallels between Keith’s (1995) study and this study. She

used a semi-structured interview guide which was designed to elicit a detailed account of the respondent's experience with caregiving and his or her perception of how and why the division of labor occurred. Her topics included responsibilities and tasks of each sibling communication, decision-making, changes over time, negotiation, conflict, conflict management, and family relationships. The interviews were audio-taped and transcribed for analysis. Keith's sample was limited to elderly mothers. Living arrangements included living in their own or an offspring's home, a group home, or a nursing home.

Another study that provides support is by Mittelman, Ferris, Shulman, Steinberg, and Levin (1996). They studied family intervention to delay nursing home placement for dementia patients. They found that a program of comprehensive support and counseling for spouses and families can substantially increase the time that patients receive care at home. All of the caregivers in the study were spouses. Family counseling and support diminished the negative aspects of family caregiving while enhancing the positive, supportive aspects. Caregivers' expectations were more realistic and more likely to be met either by the family or by other resources. These results support the importance of this study by demonstrating that family care can be extended by interventions. It also shows that cooperation within the family system is a key component. Models for facilitating cooperative decision-making can be developed by identifying successful family decision-making processes.

A study by Lieberman and Fisher (1999) looked at the effects of family conflict resolution and decision-making on the provision of help to an elderly parent with Alzheimer's disease. They employed a patient and family assessment battery with 211 families to measure variables that influence the kinds and amounts of help offered. They

found that a focused decision-making style and positive conflict resolution methods resulted in families providing more help and concluded that it is very important to consider the family system of care in disease management.

While Lieberman and Fisher's study is similar to this dissertation study, there are important differences. First, over half of their patients were living with their spouse or with their spouse and an offspring. This study explores decision-making by the sibling group because there is no spouse present. Next, Lieberman and Fisher's dependent variable was help provided to an elder with Alzheimer's disease. The independent variables were decision-making techniques and style and positive conflict resolution. Further, they surveyed one offspring from each family to assure independence among respondents. This study includes all or most of the siblings to explore the interdependence among family members and to identify specific decision-making techniques and positive conflict resolution. Lieberman and Fisher used scales to measure positive decision-making techniques, focused decision-making, and conflict resolution. This did not provide for insight into specific processes that the families used in making decisions. In their review of the literature, the authors noted that despite the proliferation of studies, the vast majority of research has not addressed the family as an integrated system responding to and being affected by the disease. Thus, in several ways, Lieberman and Fisher's work provides support for this dissertation study by indicating the importance of studying the family as a system, including decision-making in elder care situations.

A study by Smerglia and Deimling (1997) gives further support for this study. They looked at care-related decision-making and caregiver well-being. The authors

found that satisfaction with decision-making is related to adaptability and lack of conflict. They were surprised to find that the sizes of the helping and decision-making networks were not important factors. Level of dependence and cognitive impairment of the care receiver were also not important factors. Smerglia and Deimling speculated that the interaction related to caregiving decisions was a part of broader family relationships and reflected those relationships. The implications included the recommendation that practitioners shift their focus from ameliorating the effects of impairment. Instead, practitioners should work with families on enhancing their flexibility, adaptability, and decision-making skills. The authors suggest that further research is needed to examine the influence of flexibility and rigidity in family functioning on caregivers' emotional burden.

Similar to Lieberman and Fisher (1999), Smerglia and Deimling used closed questions and scales. Their sample consisted of the impaired elderly person, the elderly person's spouse, and at least one proximate adult child caregiver. Thus, their study also provides support for this study, but is fundamentally different in many of the same ways as Lieberman and Fisher's study.

In an earlier study, Streib, Folts, and LaGreca (1985) examined autonomy, power, and decision-making in retirement communities. Residents were content with letting others make decisions, and autonomy was mainly latent. Pratt, Jones, Shin, and Walker (1989) looked at autonomy and decision-making between single older women and their caregiving daughters. In their study, mothers were highly involved in decisions, but caregiving daughters were influential, especially as the mother's dependence increased. However, a consistent desire to respect autonomy was noted. Rainardy (1992) found

decisional control had a positive influence on health after admission to a nursing home.

Stuifbergen (1990) found that families with greater conflict perceived a greater effect of illness on the family than those who were more cohesive. Smith, Smith, and Toseland (1991) documented the existence of family conflict as a major complaint of caregivers in counseling. Strawbridge and Wallhagen (1991) found 40% of offspring caregivers reported serious conflict with other family members, and this correlated positively with burden that was felt and poor health reported by the caregiver.

Cicirelli (1992) identified autonomy and paternalism as issues in care of the elderly. He cited sources that support autonomy as a critical factor in maintaining the health and well-being of frail elderly persons. Mothers in his study held a stronger belief in paternalism than their daughters. Daughters were more reluctant to intervene in their mothers' decisions, but mothers expected them to be involved. Cicirelli believed the differences arose from more traditional family backgrounds for mothers and different social trends for daughters. He thought adult children might be less ready to make paternalistic decisions on behalf of their parents than parents are ready to submit to such decisions. Cicirelli looked at the influence of demographic variables, family structure, and dependency indicators. He found diverse life events impose restrictions on either mother or daughter that seem to result in less belief in the elderly parent making independent decisions and a greater belief in maintaining independence through shared autonomy. He considered the greatest conceptual importance of his findings to be factors that influence a daughter's belief in paternalism. Paternalism was related to educational and occupational levels (higher paternalism for less education and lower status), marital status (unmarried were more paternalistic than married), mother's age (the older, the

greater the paternalism), and the number of adult sons (the more sons living, the higher the paternalism).

Bubolz and Sontag (1993) conceptualized family decision-making as one of several family ecosystem processes used in adaptation to transform matter-energy and information. The outcomes of these ecosystem processes affect the quality of life of humans and the quality of the environment, which in turn have consequences for the realization of values and environmental goals.

Groger (1994) took a small sample of elderly black persons and examined the process of decision-making for nursing home placement. She proposed four conceptual models, including autonomous decisions that led to satisfaction, imposed decisions that led to dissatisfaction, imposed decisions that were accepted (coping/satisfaction), and joint decisions (suggestion-negotiation-satisfaction). Fisher and Lieberman (1994) found siblings and in-laws displayed less anxiety, depression, and somatic symptoms when they reported positive family functioning and more of these difficulties when they reported negative family functioning. The same authors found the use of mechanisms to avoid family conflict and the use of guilt led to lower health and well-being in offspring (Fisher & Lieberman, 1996).

Stern, (1995) found the largest effects on decisions regarding long-term care were from parents without a spouse and children living at a distance. Pyke and Bengston (1996) looked at individualism and collectivism in families. They found that families who emphasized individualism provided minimal family care and relied more on formal care. On the other hand, collectivist families used caregiving to construct family ties. At times, they may have provided even more care than needed. The authors predicted that

current trends in policy that transfer care of elderly persons from formal care to family care would have the greatest effect on individualist families. They suggested that demographic trends of longevity, fewer children and geographic mobility would mean that fewer families would be able to implement and maintain collectivist caregiving strategies. Adding to this uncertainty are other trends, such as the increase in workforce participation by women who have been the traditional family caregivers, and the increase in divorce, which signals instability in marital and parent-child relations. The authors pointed out the need to examine caregiving systems.

Sorensen and Zarit (1996) conducted a study of multi-generational families and examined preparation for caregiving. They found evidence of discussion, but little concrete planning. Those who did plan were more satisfied than those who did not. Bromley and Blieszner (1997) found that planning for long-term care was rare. However, when it did occur, daughters were more likely than sons to engage in discussion with parents. Considering, discussing, planning, and deciding appeared as sequential steps in the process.

McAuley and Travis (1997) looked at influences on decisions leading to nursing home care. They found research about decision makers has been rare. They also found that professionals can have a profound effect on this decision. Gaugler, Zarit, and Pearlin (1999) studied perceptions of family conflict and socioemotional support involved in institutionalizing a family member. They found that husbands reported greater increases in family conflict and wives and daughters indicated greater socioemotional support. The authors saw the need to use interventions that account for strain and conflict in the family and social network when facilitating adjustment to nursing home care. Cochran (1999)

proposed the use of the Advanced Elder Care Family Planning model to assist families in planning ahead to reduce stress and conflict.

Mills and Wilmoth (2002) looked at attitudes and decisions regarding life-sustaining medical treatment for three generations, using the 1991 Southern California Longitudinal Study of Generations. They found that the older generation considered mental capacity, family burden, and pain as most important factors. For the middle generation, family burden was not important, but the type of treatment was. The youngest generation saw mental capacity and pain as important. Checkovich and Stern (2002) used the National Long Term Care Survey to study shared caregiving responsibilities of adult siblings. They found that women provided more care than men, distant offspring provided less care, full-time employment reduced care, and larger families meant less care was provided by any given sibling. A higher level of education by the parent also was related to less care, apparently the result of greater financial resources.

In reviewing the literature, it appears that research on family decision-making processes in nuclear families is limited. Research on family decision-making in elder care situations is even more limited. The outcomes of family decision-making seem to be studied more than the processes families use.

Elder Care

There has been a proliferation of studies on caregiving for the elderly in recent years. Mentioning all of them would be well beyond the purpose and scope of this study. Therefore, this review highlights selected research, especially literature reviews and recent studies related to family care.

Brody's prolific research has marked her as a primary expert in the area of women and parent care. She described the aging of the family (Brody, 1966 & 1978), filial behavior and aging (Brody, 1970), relationships between parents and children as they age (Brody, 1979), and the "sandwiching" of the current generation in terms of child care and elder care demands along with work (Brody, 1981, 1985, & 1990). Brody & Schoonover (1986) found competing work roles reduced the caregiving ability of adult offspring.

Cicirelli produced several publications related to elder care, especially with regard to attachment and to types of decision-making. He found that present helping behaviors, attachment behaviors, and feelings of attachment by adult offspring had the strongest influence on commitment to provide future help (Cicirelli, 1983). Cicirelli (1993) found attachment and filial obligation were motives for caregiving behavior and were related to the amount of help provided. Stronger attachment related to less subjective burden. Stronger obligation related to greater burden. Cicirelli (1995) developed a measure to assess the strength of adult daughters' attachment to their elderly mothers. The Adult Attachment Scale (AAS) contained 16 items representing four domains: 1) seeking security or comfort; 2) distress upon separation; 3) joy upon reunion; and 4) feelings of love. He suggested the instrument would be valuable for testing predictions from life span attachment theory or for relating the strength of attachment to caregiving variables.

Studies have reported that adult offspring are more likely to provide help to parents if they are: women (Dwyer & Coward, 1992); divorced, widowed, or never married (Stoller, 1983); the oldest offspring (Hanson, Sauer & Seelbach, 1983); live nearby (Finley, Roberts & Banham, 1988); or are the only offspring (Coward & Dwyer, 1990). However, Dwyer, Henretta, Coward, and Barton (1992) reported that 50.7% of

those offspring who initially provided assistance with activities of daily living (ADLs) and 29.9% of those providing assistance with instrumental activities of daily living (IADLs) eventually stopped doing so in later years. The probability that an offspring would provide care was directly related to the probability of other offspring providing care, pointing to a greater willingness to join in if others helped. This suggests that the ability or willingness of the offspring to provide care may change over time. They concluded that cooperation among siblings is an important factor in the initiation and continuation of care by offspring. Studies have indicated differences in the roles played by adult sons and daughters in providing assistance to their parents. Daughters were more likely to provide personal care (Horowitz, 1985; Dwyer & Coward, 1991; Chang & White-Means, 1991). Sons were more likely to provide assistance with home repair and finances (Stoller, 1990).

Horowitz (1985) found emotional support from siblings mediated strain felt by caregivers. Earlier, Zarit, Reever, and Bach-Peterson (1980) obtained similar results regarding support from other relatives. On the other hand, Brody (1989) found many caregivers (45-60%) complained that they did not receive as much help as they should from their siblings. Matthews and Rosner (1988) reported that conflict among siblings can reach a point where responsibilities were no longer shared.

Hagestad (1988) looked at demographic changes during this century brought on by declining mortality and fertility. The death of a child is much less prevalent, and the deaths of parents tend to be later and more predictable. People can expect to be parents and grandparents for extended periods of their lives, and divorce has replaced death as a premature disruption of marriage.

Brubaker (1990) did an overview of the literature on family caregiving in later life. Studies showed that families provided extraordinary care, and many were reluctant to use extra-familial assistance. Women were overwhelmingly represented in elder care. However, except for age, there were fewer differences identified between husband and wife caregivers. Both were as likely to quit paid employment, and both had similar assistance patterns. He identified several studies that indicated wives experienced greater subjective burden than husbands early in the caregiving experience. Employment of daughters was a factor in the types of care, but not on the amount. There were indications of stress on the marriage for married daughters. Brubaker stated that this underscored the need to explore the caregiver relationship from the perspectives of the caregiver and caregiver's family of procreation. He raised the question of whether the apparent differences between women's and men's contributions to caregiving would disappear as more egalitarian daughters and sons provided care for dependent parents.

Dellmann-Jenkins, Hofer, and Chekra (1992) conducted a five-year review of the literature on caregiving. They found considerable demands and stresses associated with caregiving, especially since the advent of DRG's in 1983, which meant that elderly patients were discharged "sicker and quicker." Adult children were seen as juggling roles of spouse, parent, and worker along with that of caregiver. Demands of parent care were predicted to increase during the 1990s and to become long term. Formal assistance programs were seen as responding to acute care needs rather than those that were chronic. For the future, they looked at promising avenues that might enhance family caregiving capacities. They discussed corporate-sponsored assistance, such as information on services, education, flextime, and leaves. They identified an untapped resource for

informal respite care from university students and older adults. The authors advocated the development of parent care systems for families and non-kin back-up systems for those without families to share the caregiving. Finally, support services for the caregivers and recipients and cognitive restructuring were seen as ways of reducing stress.

Mui (1995) compared adult sons and daughters regarding emotional strain. Daughters experienced higher levels of emotional strain, especially regarding interference of caregiving in work. The author speculated that this may be due to greater complexity of women's roles, particularly as this is related to household responsibilities and work. Starrels, Ingersoll-Dayton, Dowler, and Neal (1997) found that cognitive and behavioral impairment is more strongly linked to employed caregivers' stress than are the parents' physical impairments. The parents' ability to assist in their own care reduced stress. For both men and women, there was a strong association between caregiving tasks and time taken off from work, which raised caregiver stress, especially for men. Neal, Ingersoll-Dayton, and Starrels (1997) did not find any differences between employed men and women with respect to the provision of personal/health related tasks or of care management tasks. This is contrary to the bulk of the previous caregiver research. However, the sample had a low average level of impairment for the elderly parent. Consistent with prior research were findings indicating that males were less likely to provide social/emotional support or help with household chores, except for maintenance. Females were still more likely to be the primary caregiver, provided more tasks, and spent more hours providing care.

Suitor and Pillemer (1994) examined the effects of caregiving on marital satisfaction during the first year of care. Changes were related to variations in emotional

support or hindrance by husbands. This was affected by the husbands' perception that caregiving interfered with their wives ability to perform "traditional family roles." Husbands' instrumental support was not related to changes in their wives' marital satisfaction. This indicates that emotional support from husbands is more important than instrumental support in the transition to caregiving. Later, these same authors looked at sources of support and interpersonal stress over a two-year period. Sources of emotional support came primarily from friends, especially those who had cared for a family member themselves. Sources of instrumental support and interpersonal stress came from siblings (Suitor & Pillemer, 1996). Stephens and Franks (1995) studied the spillover between daughters' roles as wife and caregiver. For many women, the positive and negative spillover effects went in both directions. Negative experiences in either of these roles can interfere with both roles. However, positive experiences in one role can enhance both roles. In addition, positive spillover was more often related to caregiver well-being than negative spillover. Franks and Stephens (1996) followed up this study by looking at support provided by husbands to their caregiving wives. Receiving support from the husband had a positive effect on marital satisfaction regardless of the amount of caregiving stress.

Martire, Stephens, and Franks (1997) found that caregiver role adequacy was positively related to family cohesion and marital satisfaction. Wife role adequacy had a positive effect on family cohesion and mother role adequacy predicted less negative affect. Voydanoff and Donnelly (1999) investigated the relationships between psychological distress and the roles of employee, spouse, parent, and adult-child. Hours helping and caring for parents increased distress, mainly for mothers. Role satisfaction

for the roles of paid worker and spouse reduced distress. Role strain associated with these roles increased distress. The role of parent was unrelated to distress. Piercy, and Blieszner (1999) studied the link between perceived responsibility to care for elderly parents, other family needs, and their service utilization. Families sought assistance to balance safety needs for the parent with caregiver needs for personal and marital fulfillment. Stephens, Townsend and Martire (2001) examined inter-role conflict for women. Parent care stress exerted a negative effect on well-being when it was incompatible with the roles of mother, wife, and employee.

Brody, Litvin, Hoffman, and Kleban (1995) examined the marital status of caregiving daughters that co-reside with dependent parents. Parent disability was not the only reason for co-residence. Separated, divorced, and never-married caregivers often began co-residing before their parents needed care and were more likely to mention economic reasons. Married women fared the best with higher incomes, more helpers, better well-being, less depression, less financial and social strain, and the greatest satisfaction with their family lives and friendships.

Marks (1996) examined caregiving across the life span using the National Survey of Families and Households 1987-88 to estimate in- and out-of-household caregiving for persons of all ages. He found caregiving was a common experience, and child and spousal caregiving was predominant over elder care. Married women were most likely to be caregiving, even with aging parents, and this was associated with poorer health. He argued for a life span perspective, given the data that caregiving was done by adults of all ages and cuts across gender, race, and class. Ward and Spitze (1998) analyzed a sample from the National Survey of Families and Households and reported that helping both

children and parents was relatively unusual. They concluded that high satisfaction found in midlife marriages was maintained in spite of occasional burdens from parents or children.

Wolf and Soldo (1994) considered allocation of time to employment and care of elderly parents by married women. They found no evidence of reduced propensities to be employed, or changes in work schedules, due to the provision of parental care. Gerstel and Gallagher (1994) looked at gender, employment, and the privatization of care. They found wives gave more care than husbands, but this can be partly due to employment. While employed wives gave much more care than employed husbands, they gave less than did homemakers. Those employed in positions similar to men provided care in ways similar to men. They suggested these findings offer evidence for theories that base women's caregiving in social structures confronted in adult life, rather than personality formed in early life. However, studies by Moen, Robinson, and Fields (1994) and Robison, Moen, and Dempster-McClain (1995) found no evidence that increased work force participation by women has decreased caregiving responsibilities. Stern (1996) concluded that the decision of offspring about where to live was made independent of future caregiving responsibilities. Once the parent began to need care, the family decided on arrangements while considering the location of each offspring, but not their work responsibilities. Then the primary caregiver decided on whether to reduce work hours.

Ettner (1996) found that caregiving for parents had a large negative effect on the labor supply of both men and women. The effects of co-residence and the effects on women were larger. Ingersoll-Dayton, Starrels, and Dowler (1996) studied the effects of gender and relationship status on care by employed caregivers. Women provided more

help than men, primarily social support and household tasks. There were no gender differences in the amount of health care and management provided. There were no indications of same- or cross-gender patterns of caregiving and no differences in help provided by sons-in-law and daughters-in-law. Parents and parents-in-law received similar amounts of care. Older women provided and received more care than older men. Farkas and Himes (1997) found that the voluntary activities of midlife and older women were not reduced as a result of caregiving and employment. They speculated that the caregivers in their study may have used outside activities to relieve stress, and may have been adept at balancing roles, or caregiving might not have been intense enough to interfere with these activities.

Couch, Daly, and Wolf (1999) studied the allocation of time and money to older parents. They found that the response of adult children to their parents' circumstances was strongly influenced by economic factors. Households with higher wages relied more on cash transfers and (except for married women) less on time transfers. The presence of minor children in married households increased time spent in maintaining the household, and decreased work time and monetary transfers to parents, but not time transfers. They also found that families who gave money also gave more time. The authors concluded that their results suggested future increases in women's wages relative to men's would increase financial contributions to parents. This could lead to greater demands for formal caregiving if families decide to purchase care instead of providing it themselves.

Peek, Coward, and Peek (1998) found a positive relationship between parental expectations of care and the actual amount of care received from their adult children.

Silverstein and Angelelli (1998) examined parental expectations of moving closer to their

children. Their results indicated these parents were older, female, and had at least one offspring that was better off financially than the parent. They were more likely to expect to move closer to a daughter than to a son and greater impairment increased this tendency.

Ganong and Coleman (1998) studied attitudes about family obligations to help parents and stepparents. They found general agreement regarding some responsibility to help elderly divorced parents, but no consensus on the type of help. Maintaining contact was an important factor for both parents and stepparents, but the gender of the parent was not. The needs of the adult children and their children were ranked higher than the obligation to help an elderly divorced parent or stepparent. Kinship alone was not enough to justify responsibility for care, but the absence of legal or genetic ties did not exclude stepparents from being considered as deserving assistance. Ganong, Coleman, and McDaniel (1998) looked at the effects of remarriage in later life on these same attitudes toward care. They found that the obligation to parents was perceived to be greater than to stepparents, and closeness was an important factor with regard to assisting stepparents. There was a perception that men and women were equally obligated to provide care, but there was no consensus regarding the types of assistance that should be provided. Stein, Wemmerus, and Wade (1998) also studied feelings of obligation to provide care to one's parent in young adults and their middle-aged parents. Their results indicated that women of both generations felt greater obligation toward their parents than did both generations of men. Both genders felt more obligation if one parent was living than if both were alive. The younger adults felt greater obligation to their parents than middle-aged parents felt to their parents.

Wolf, Freedman, and Soldo (1997) studied the division of family labor among

siblings. Caregiving behavior was related to parents' needs. Daughters took on more parent care roles, but they adjusted their efforts to the needs of others, including their children. As the efforts of siblings increased, care efforts of a given offspring decreased, but not on an hour-for-hour basis, so overall, more care was provided. Thus, larger families tended to provide more help. However, willingness to provide care was reduced in proportion to the number of sisters, suggesting greater complexity in the decision-making processes regarding care. Mathews and Heirdorn (1998) looked at how sibling groups with only brothers provided care. They found that brothers' goals were likely to be to maintain or reestablish parental independence, which matched parents' wishes. The brothers' wives provided care, but this appeared to be tied to the quality of the relationship with their in-laws. Carruth (1996) developed and validated a scale to measure the dimensions of caregiver reciprocity. Four factors were found to be valid: warmth and regard; intrinsic rewards of giving; love and affection; and balance within family caregiving.

Crispi, Schiaffino, and Berman (1997) studied attachment and burden in offspring of institutionalized parents with dementia. Findings suggested that secure attachment protected caregivers from some of the strain of caregiving. Preoccupation with the attachment relationship contributed to burden. Parrot and Bengtson (1998) found that a history of affection in parent-child relations increased the likelihood of exchanging help and support in later life. A strong sense of obligation to family at an earlier time was related to a strong sense of obligation with fathers, but not with mothers. In these exchanges, adult children gave more than they received. Earlier conflict between parents and adult children did not affect the exchange of help and support later in life.

Lach (1999) highlighted the fact that less than one in three parents discussed long term care with their adult children. Studies indicate that most families do not deal with this until care is required. Cooper-Kazzaz, Frieland, and Steinberg (1999) found that the wishes of many dying patients were not known to health care providers or by the offspring. Thus, the decisions were paternalistic, made by a surrogate, and were based on cultural, intuitive, and emotional factors.

Pezzin and Schone (1999) found that divorce had an adverse effect on exchange at the end of life. Ikkink, Tilburg, and Knipscheer (1999) looked at normative and structural explanations for support exchanges. The greater the level of filial responsibility of parent and child, the more support given to the parent. Mothers received more support as did those who were older and in need, especially if the parent did not have a partner. Adult children being employed or having children did not influence the support received by parents.

Iecovich (2000) found a variety of sources of stress between patients, families, and personnel in care settings. She suggested intervention strategies aimed at changing attitudes and stereotypes, improving communication, and humanizing the care setting. Piercy and Chapman (2001) studied how adult children become caregivers. Factors included family rules, religious training, expectations, role-modeling, and role-making. Lieberman and Fisher (2001) studied the effects of nursing home placement on family caregivers. They found no difference in caregiver health and well-being over time following nursing home placement compared with those families who kept the elder at home or in the community. They also found that female caregivers and spouses experienced greater declines in health and well-being over time regardless of whether or

not nursing home placement was used.

Research on aging and on elder care is growing as the elderly populations of developed countries grow. However, studies have focused mainly on the effects of caregiving on families, caregivers, and receivers of care. Little has been done to study the processes involved in providing care for elderly persons. The fact that most studies use a quantitative approach makes it more likely researchers will be measuring outcomes rather than looking at processes.

Intergenerational Relations

Brody and colleagues looked at work, the changing roles of women, and their attitudes toward elder care across three generations (Brody, Johnsen, Fulcomer, & Lang, 1983; Brody, Johnsen, & Fulcomer, 1984; Brody, Kleban, Johnsen, Hoffman, & Schoonover, 1987; Brody, Kleban, Hoffman, & Schoonover, 1988). They found women continued to work and provided elder care with increasing stress, but the current generation of caregivers did not want to see their daughters being burdened with their care.

Thompson, L. and Walker, A. J. (1984) examined three generations of women and their patterns of aid exchange and attachments. Mothers reported greater attachment than daughters in older pairs. High reciprocity relationships showed greater attachment than other aid patterns. Mothers and daughters perceived attachment differently in nonreciprocal relationships, but not in relationships that were reciprocal. Patterns of reciprocity were bolstered by a generalized moral norm, early experiences between caregiver and child, and cumulative interaction within the pair. Since mothers and

daughters maintained attachment with little or imbalanced material exchange, then research must look beyond the universal norm of reciprocity for an explanation of relationship maintenance. The authors found it was the giving and not the receiving that seemed to count.

Umberson (1992) examined relationships between adult children and their parents and found divorce tended to have negative effects, and fathers affected the adult child's well-being less than mothers. Children seemed to be less involved with their parents as they got older. There were indications that co-residence of adult children may be detrimental to intergenerational relations.

Hareven (1994) looked at aging and generational relations over time using a life course perspective. She dispelled myths about co-residence and generational assistance. She also looked at how demographic changes influenced the timing of life course transitions and changed how aging parents were supported. Hareven found the nuclear family has been the preferred household throughout much of American history. Families pressured the youngest daughter to remain at home to care for aging parents or arranged various types of boarding and lodging to support parents. Longer life expectancy made transitions during the life course much more predictable, more individual (based on age), and less closely synchronized with the needs of the family. Hareven saw the "empty nest" stage as emerging only recently. An important change that occurred since WWII was an apparent shift away from expecting support from one's children and more reliance on governmental assistance. She saw this as an area for future research.

Brown, Subbaiah, and Sarah (1994) conducted a cross-cultural study of the relationship between older women and their younger female kin. Their findings

suggested the relationships were patterned and predictable, determined by the role of women in subsistence activities, by rules of post-marital residence, and by descent. Fisher (1995) explored the meanings older people attached to successful aging and life satisfaction. Five features of successful aging were identified: interactions with others, a sense of purpose, self-acceptance, personal growth, and autonomy. He suggested generativity contributed to successful aging and remained a vital developmental task in later life. Starrels, Ingersoll-Dayton, Neal, and Yamada (1995) examined parent care by employees. Several surprising results were contrary to expectations. They found that participants with more family-friendly policies provided less care, including fewer hours of help and less health care, social support and home maintenance. Employees that worked longer hours provided more health care, and those that worked for larger corporations had less reciprocal relations with their parents. The authors speculated that employees with heavier caregiving responsibilities probably experienced more stress, leading them to misperceive their employers policies. Another possibility was that organizations with flexible policies may have offered more information about and access to alternative sources of care.

Bergstrom and Nussbaum (1996) studied life-span stage, conflict styles, depth of conflict, and conflict satisfaction. Younger adults preferred a controlling conflict style, and older adults preferred a solution-oriented conflict style. The results indicated a difference in conflict behaviors and satisfaction that could affect the relationship between older adults and younger care providers. Silverstein, Chen, and Heller (1996) proposed that moderate amounts of intergenerational social support was beneficial to the psychological well-being of older parents. However, high levels of social support

reduced well-being.

Henard (1996) examined cultural aspects of aging related to gender and intergenerational equity. He raised the question of aging as a cultural construction, since old age is not a specific social group in some cultures. He found persistent inequities in income, health, and social support related to age, gender, and social class. These were due to differences in status and resources related to position in the labor market and domestic division of labor. To cope with these issues, Henard called for aging and later life to be considered in a life-span perspective. Possible solutions included better sharing of jobs and economic wealth and the development of meaningful activities.

Rosenthal, Martin-Mathews, and Mathews (1996) conducted a cross-sectional analysis of the experience of being "caught in the middle" and the extent to which adult children in various roles provide help to their parents. They found the majority of middle-aged children did not provide frequent help to their parents. The highest proportion of daughters providing assistance did not have children at home any longer. Soldo (1996) found the image of middle-aged adults balancing parent and child care duties was not appropriate and stressed the need for panel data to evaluate reciprocity in the form of assistance from parents and children, which would offset the volume of claims on resources. Loomis and Booth (1995) found change in family responsibility had little or no effect on caregivers' well-being. They attributed this to intimacy, to caregiving responsibility falling on those most able, and to caregivers having values that stressed the importance of caring for others.

Fingerman (1996) explored sources of tension in the aging mother-adult daughter relationship. Differences in the stage of adult development (developmental schism) may

foster tension. Those who described sources of difficulty not related to developmental differences were more positive about their relationship. Silverstein and Bengtson (1997) investigated the structure of intergenerational cohesion. They examined social-psychological, structural, and transactional aspects of adult child-parent relations. They concluded that adult intergenerational relationships in American families were diverse, but generally possessed the potential to meet the needs of their members. Silverstein and Parrott (1997) studied age differences in attitudes toward public support for elderly persons and whether contact with grandparents during childhood moderated the differences. Young adults were least supportive, but greater childhood contact with grandparents reduced their opposition.

A number of authors examined the issue of intergenerational equity. Lee (1994) proposed a new approach to studying population age structure, intergenerational transfer, and wealth. His findings indicated a larger accumulation of federal transfer wealth as opposed to debt in state/local wealth and intergenerational transfers. Sabelhouse (1994) proposed that budget deficits were a form of intergenerational transfer and needed to be included in reforms in the system of transferring wealth. Adams and Dominick (1995) looked at generational equity. They saw those who raised this issue as hoping to extend the attack on public spending for families to the more popular and better defended entitlement programs for elderly persons, as part of a larger attempt to privatize the welfare state. They stated that critiquing Social Security on grounds of generational equity could be understood as part of a class war that widened the gap between rich and poor and increased economic insecurity. Logan and Spitze (1995) explored self-interest and altruism in intergenerational relations. Altruism rather than self-interest governed the

attitudes of the older generation, and this should reduce the potential conflicts over issues of intergenerational equity. Page (1997) proposed alternative approaches toward achieving a satisfactory combination of intergenerational efficiency and equity.

Henretta, Hill, and Li (1997) looked at the effects of past parent-to-child financial transfers on selection of the adult child to provide assistance with basic personal care for unmarried parents. They found substantial evidence that this played a role in determining which child in the family would provide assistance. In contrast, McGarry and Schoeni (1997) found intra-family transfers were compensatory, directed disproportionately to less well-off members, but they found no evidence parents provided financial assistance to their children in exchange for caregiving. Pezzin and Schone (1997) studied the allocation of resources in intergenerational households. The share of income controlled by the adult child had a positive effect on the household's demand for prescription drugs for the parent. Home ownership increased the child's time to market, and resource control improved labor supply and informal care. This was seen as having implications for designing and implementing family long-term-care policies.

Coleman, Ganong, and Cable (1997) examined perceptions of women's intergenerational family obligations to provide support before and after divorce and remarriage. They found a sense of obligation to assist those in need, but it was conditional. The obligation of older generations toward younger was stronger, as was obligation to biological kin over in-laws. Perceived obligations toward step-grandchildren were considerably weaker than toward grandchildren.

Piercy (1998) looked at the role of responsibility in family caregiving and the meaning of familial responsibility. This frequently encompassed shared responsibility

among several family members, including contributions from adult grandchildren. Shared responsibility was multi-generational and included feelings of responsibility toward other family members. Respect for autonomy was reported by all three generations. Caregiving involved more than hands-on tasks and included "socioemotional aid," which she considered a critical component. Goldscheider and Lawton (1998) found several factors that influenced support for intergenerational co-residence with aged parents, including having lived with parents and grandparents, having many siblings, and espousing traditional roles for women. Income had no effect, but educational level had a negative effect with a college education related to less support.

Hirshorn (1998-99) identified intergenerational issues and various responses in terms of intergenerational programs. Henkin and Kingson (1998-99) proposed a wide range of intergenerational programs for the next century. Schorr (1998-99) outlined family patterns of intergenerational supports. He pointed out that arrangements between the elderly and their families are complex in terms of economic exchanges and services. He saw more affluent families as being more likely to live apart and lower income families as more likely to live together. He proposed modifying the Social Security system to provide more support for independent living for the elderly.

Allen, Blieszner, Roberto, Farnsworth, and Wilcox (1999) found that nearly two-thirds of their small sample of older adults had lived the conventional pattern of intact marriage, raising children to adulthood. However, less than one-fourth of their participants reported that their children had lived the conventional pattern. Over three-fourths experienced pluralism in family structure, including divorce, remarriage, single-parenthood, non-marital parenthood, and long-term cohabitation. They were surprised to

find that a third of the older adults also had experienced such pluralism. The authors suggested the need to update information about the changing family structures of older adults and their offspring.

Sheehan and Donorfio (1999) looked at the “invisible” dimensions of filial caregiving, the impact on the mother-daughter relationship. This included the “cognitive, motivational, and interpersonal components of the meaning systems that mothers and daughters employ to make sense out of their caregiving relationship.” The authors contrasted this with most studies that focused on tasks and burden. They found four themes that emerged in their qualitative study. The first was the development of relational tolerance linked to knowledge of the other and the time-limited nature of the relationship. Both mother and daughter saw more tactfulness in their interactions. They had reworked their relationship, accepting each other as adults with imperfections. The second theme associated caregiving with the opportunity to repay the mother for previous help, such as child-rearing and care when sick. The third theme was the impact of caregiving on age awareness and fears of aging. The final theme was the fact that caregiving took place in a broader family context with a hierarchy of familial responsibility. The authors called for greater sensitivity to the range of experiences, attitudes and emotions in the caregiving relationship.

Pyke (1999) examined the power and emotional dynamics between older parents and adult children. She found that older parents had more power in individualist families than in collectivist families that provided higher levels of care. She saw this as indicating a trade-off between power and care. The data also suggested that when parents do not reciprocate with deference, relations become strained and offspring are likely to set limits

on their caregiving. Pyke suggested that exchange principles and power processes need to be considered in studying caregiving along with values of filial piety and obligation.

Bengtson (2001) proposed that multi-generational relations will be more important in this century because of the demographic changes of population aging, the growing importance of grandparents and other kin, and resilience of intergenerational solidarity. Fingerman (2001) suggested that a positive relationship between older parents and adult offspring can meet older adults' need for intimacy when they do not have a spouse or romantic partner. She recommended that clinicians work with older parents and adult children to achieve this. She saw the greatest barriers to intimacy in situations in which there were feelings of being criticized or judged, rather than being accepted by the other party.

Sherrell, Buckwalter, and Morhardt (2001) proposed looking at caregiving as a midlife developmental task. They saw this as a growth process in which one mourns the old and familiar before moving on to the next stage of life. They identified midlife challenges as "(1) contributing to the welfare of society, (2) developing a sense of generativity, (3) preserving values and ideals that one wants to pass on to future generations, and (4) accepting one's own mortality." Changes in health status and becoming a caregiver were seen as external forces that influence the tasks and crises of midlife. The authors suggested that caregiving for parents can enhance the growth potential for this stage of life.

The literature on intergenerational relations is emerging. For families with aging members, this is focused on caregiving relationships and on issues of resource equity and intergenerational transfers. There is a mixture of positive and negative findings in these

areas. These differences may represent a wide variety of experiences by families. The one universal finding seems to be the need for further study.

Summary

The literature in the areas of elder care and intergenerational relations has increased a great deal over the last two decades. This is especially true for elder care. The literature on family decision-making is much less prolific. Research on elder care appears to be concentrated on quantitative studies that look at product rather than process. The focus is mainly on the effects of caregiving on caregivers, care receivers, and families. Research on intergenerational relations is emerging and reflects a more descriptive approach that focuses on intergenerational programming and the potential for conflict over intergenerational transfers.

There is some movement toward examining family decision-making regarding elder care. Several studies were identified under family decision-making that provide support for this study. These studies are important to this study in two distinctly different ways. First, they support the need for further study by pointing out in literature reviews the lack of research in this area. These studies generally conclude that further research is needed to increase knowledge about family elder care decisions as the population ages in the United States and other developed countries. Secondly, these studies support the need for this study in indirect ways. Since little is known about how families go about making these decisions, the ability to design studies and construct hypotheses for testing seems limited. Qualitative studies of family decision-making for impaired parents can be used to identify processes that families use. This lays the groundwork for further study for

both quantitative and qualitative researchers.

CHAPTER THREE

RESEARCH DESIGN AND METHODS

Research Questions

The research questions for this study included the four primary research questions identified in Chapter 1 along with related questions. Research questions were designed to be descriptive and exploratory. They are categorized as descriptive, interpretive, and theoretical.

Descriptive Questions:

How do selected families make decisions about finances, guardianship, and the use of family care, home care, adult day care, adult foster care, or nursing home care for elderly parents with dementia?

Who participates? Who does not?

What procedures or processes are used?

How are conflicts or disagreements managed?

What are the important contextual factors that influence the decisions?

What are the expected outcomes?

What helps the family to reach the decision? What makes it more difficult?

Interpretive Questions:

How do selected families use prior decision-making experiences in the family of origin, marriages, and parenting to make decisions about elder care?

How do selected families see the current processes and outcome as influencing future decision-making as the parent continues to age?

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Theoretical Questions:

How do selected families use various decision-making procedures (conflict, discussion, negotiation, change, power, or consensus) in making decisions for parents suffering from dementia?

Can a pattern of decision-making procedures be identified for selected families that reflects a family pattern regarding family decision-making?

Methodology and Research Design

This was a triangulated qualitative study that included theory, method, and data triangulations. Denzin (1978) described multiple triangulations of these forms along with investigator triangulation as generating a reliable and valid set of data. Patton (1990) saw triangulation as the ideal way to strengthen a qualitative study. It is especially valuable in overcoming errors linked to any single method of study.

Theory Triangulation

Theory triangulation adds to the rigor of a study (Patton 1990). There is greater confidence in the data, the analysis, and the findings of a study when they support an existing theory, since the study becomes a form of replication. If more than one theory is supported, then the confidence in the data, the analysis, and the findings is increased provided the theories are compatible, or at the very least, do not inherently conflict with each other. The theories used to construct the conceptual map for this study were derived from Bubolz and Sontag (1993), Paolucci, Hall, and Axinn, (1977), and Scanzoni and Szinovacz (1980). These theories seem quite compatible and for the most part were either additive or redundant. The data and findings were compared with the conceptual

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map to determine if the map was supported. In addition, an analysis of various aspects of the conceptual map represented by these theories (see Table 1.1, page 14) is included in the findings.

Method Triangulation

Denzin (1978) discussed the need to use multiple methods of data collection in order to overcome the shortcomings of each. The data collected for this study were from in-depth interviews. Face-to-face and telephone interviews and an interview by e-mail were used as three methods of data collection to reduce some of the shortcomings of using only one method for in-depth interviews.

Denzin (1978) described four sources of invalidity in the interview. These include self-presentation by the interviewer in the interviewers' role, the relationship between interviewer and subject, the situation, and the act of observing. The best way to overcome these is to include a second method of collecting data. The use of face-to-face and telephone interviews changed the context of the interview situation itself, thereby changing the self-presentation of the interviewer, the relationship between interviewer and subject, and the observations that can be made. The use of an interview by e-mail introduced a third method of data collection.

In addition to triangulation of data collection methods, Patton (1990) described mixed methodological strategies as a form of triangulation. This means borrowing and mixing parts from pure methodological approaches by mixing measurement, design, and analysis. This study includes variations of pattern matching, analytic induction, and grounded theory. Gilgun (1992) saw these as leading to "compellingly thick descriptions." Pattern matching and analytic induction use a conceptual model based on

previous research and theory. Pattern matching uses standardized methods for data collection, and the model is not changed until data analysis is completed. In analytic induction, the method of data collection is not standardized, but changes with variations in the data. Patterns are used to change the conceptual map as these emerge. For this study, a combination of pattern matching and analytic induction were used. Data were collected using a semi-structured interview guide. This allowed for a conversational style of interviewing rather than a rigid structure. Follow-up questions were asked based on participant responses. After the first interview, two questions were asked in subsequent interviews that added to the study. Participants were asked why they thought their family was able to reach decisions successfully and what they would recommend to other families who were facing these decisions. Thus, an analytic induction method was used to allow latitude in using the interview guide and in adding two questions. Pattern matching was used to identify patterns that reflected the original conceptual map and to construct a revised conceptual map after the data was analyzed.

Grounded theory can be used to generate new theory or to confirm existing theory. In the latter case, the findings are compared with existing theory after the data are collected and analyzed (Gilgun, 1992). In this study, this method was used by analyzing the extent to which the original conceptual map was supported, thereby supporting elements of one or more of the theories upon which the conceptual map was based.

Data Triangulation

Denzin (1978) described data triangulation in terms of gathering data from different data sources. This study did not have a pure form of data triangulation because it did not seek data from greatly dissimilar groups. However, data were collected from

several families who have had different experiences with elder care. Furthermore, the inclusion of more than one member of each family in this study created multiple sources of data within each family. This was intended to provide a more accurate and deeper understanding of the processes used to arrive at various decisions about elder care. In the study by Lieberman and Fisher (1999) cited earlier, only one respondent was used for each family. The authors cited other studies that indicate a sufficient level of confidence that single respondents will reflect family responses. The fact that their sample was large and the questions were closed or scaled allowed for statistical analysis to control for this to some extent. In this dissertation study, validation of the data was increased by using multiple sources. In addition, the richness of the data was increased by the inclusion of multiple perspectives.

Investigator Triangulation

Investigator triangulation is used to control for investigator bias in collecting and interpreting data. Generally this is accomplished by having multiple investigators involved in data collection and/or data analysis. Triangulation also can be accomplished by having participants verify the accuracy of the data (Patton, 1990). It was originally planned that participants would be re-contacted to verify the accuracy of the data, but time constraints did not allow for this to be included. However, the inclusion of multiple members from the same family and the consistency of responses among members reduces the shortcomings of not including this form of triangulation.

Sample

The sample for this study consisted of adult sons and daughters who have made

decisions for an elderly parent with dementia and felt that they were able to develop a successful family decision-making process. Successful families were studied to determine how they were able to reach agreement and whether they used prior experiences in doing so. The primary decisions studied included finances, placement in residential or adult day care, and various decisions involved in providing elder care for a parent with dementia. The sample was drawn from current and former users of adult day care and adult foster care (AFC) recruited through two human service agencies in Saginaw and Bay Counties in Michigan. While the experiences of families from different providers will vary, it was necessary to allow for collecting data from more than one provider in order to ensure a large enough sample for the study. The sample was drawn from an adult day activity program and from two AFC facilities that are owned and operated by a national chain. Both facilities are licensed for 24 beds and are staffed by employees. The adult day activity program and one AFC are in Bay County and the other AFC is in Saginaw County.

Recruitment began in June of 2001 after approval was received from the University Committee on Research Involving Human Subjects (UCRIHS). The first effort involved inserting copies of a recruitment letter (see Appendix B) in a newsletter for current and former families of residents at the AFC in Saginaw County. Three families volunteered and interviews began in July. A second recruitment was undertaken in July, involving families of participants at the adult day activity program in Bay County. Recruitment letters were inserted in a mailing from the program to families. This yielded two families. A third recruitment took place in August. A recruitment letter was inserted in a newsletter for families involved with the AFC in Bay County and the sixth family

was recruited.

In-person and telephone interviews were not completed until November. The delay was caused mainly by the events of September 11, 2001. It was felt that scheduling interviews immediately after this tragedy was inappropriate. In addition, the emotional reactions of participants might create some difficulty with collecting accurate data. In October, an effort was made to schedule the remaining interviews, but people were still reluctant to do so. After waiting two more weeks, the remaining participants were contacted, and the interviews were completed in November, except for a family member living in Sicily. Her employment is connected with the military, and she was not able to find time to complete the interview form until February of 2002.

It is possible that the size of the sibling group will produce variation in the decision-making process. To study this, the ideal sample was considered to be two families with two members, two with three members, and two with four or more members. The actual sample came very close to this. There was one family with two members, three with three members, and two with four members. In one of the families with four members, a sibling excluded himself from participating in decisions about the parent, and he was not included in the study. In the other family with four members, one member agreed to participate, but later declined to be interviewed, saying that he did not think he could add anything new to what his siblings had to say. Thus, the actual sample was seventeen family members from six families. It took three recruitments to obtain this sample. It was decided that the sample was a close enough fit with the ideal sample.

Methods of Recording Observations

The primary method used for recording observations was self-report by family members. A semi-structured interview guide was used with each family member (see Appendix A). Interviews were audio-taped with the permission of the participants and later transcribed. (See Appendix E for Confidentiality Agreement.) The first interview for each family was with the member who had made the initial contact. This person was considered the primary respondent. Subsequent interviews with other family members were focused on the family elder care decisions described by the primary respondents. Similarly, the interview by e-mail was preformatted using responses from the primary informant, so that the family member could describe various decisions that were made for her father.

Interview Data

Seventeen members of six families were interviewed primarily in person and by telephone, and one member was interviewed by e-mail. Telephone interviewing was necessary because all but one family had members who had moved to other parts of the country. Without telephone interviews, either some family members would not be interviewed or the number of families available to participate would not be sufficient. Ten members were interviewed in person. Six were interviewed by telephone. A local family member paved the way for telephone interviews by contacting other family members ahead of time. This alleviated much of the resistance or limitations associated with telephone interviewing. Family members were contacted, and informed consent was obtained (see Appendix D). The interview by e-mail was added at the request of a family

member who was living in Sicily, but wanted to participate. This had the added advantage of offering an opportunity to compare this method with in-person and telephone interviews.

The primary respondent was asked to talk with his or her siblings to find out if they would be interested in participating in the study. The interviews with the primary respondents were used to gather detailed information about their parents, their care needs, and decisions that were made by the families. The portion of the interviews with other siblings that covered family elder care decision-making was tailored to cover the situations and the decisions described by the primary respondent. Thus, a portion of the interviews with siblings was used as a form of validation of the information provided by the primary respondent. Siblings were asked about their own experiences with family decision-making for their parent. They also were asked about influences from prior decision-making experiences with their parents and with their spouses.

Basic demographic data were gathered before each interview (see Appendix C). Participants were asked the month and year of their birth and their marital status. They were asked to identify their occupation and that of their spouse along with their highest level of education. This information was used to determine socioeconomic status. Respondents were asked to estimate the number of hours worked during a typical week for themselves and their spouse. Participants were also asked about how many children they have and their ages. This information was used as an indication of potential time available for caregiving. Data were gathered regarding ethnicity and religious affiliation.

In addition to gathering basic demographic information, data were gathered at the beginning of each interview regarding the caregiving situation (see Appendix A).

Participants were asked about the age and diagnosis of the parent and how the diagnosis was made. They were asked about the kinds of assistance their parent needed, how long these were needed, and how long the family had to make decisions for the parent. Respondents described assistance they had given since the parent began suffering from dementia and assistance they gave during the last six months. Data were gathered about the distance family members lived from the parent at the time elder care began and currently. Participants were asked to describe changes they made in living arrangements and work as a result of their parent's illness.

The interview guide (Appendix A) was designed to gather data for each research question. It explored various decisions that families might need to make as their parent's condition progressed. Decisions about finances, guardianship, and various forms of elder care were included in the initial guide. Decisions about selling the family home, medical needs, and resuscitation were discussed with some families when these issues were uncovered in the interview with the primary respondent. Family members were asked to describe these arrangements and various aspects of the decision-making process. They were asked about agreements and disagreements, factors that influenced each decision, the desired outcome, what helped them make the decision and what made it more difficult, and their feelings about the decision and how it was reached.

In the second phase of the interview, participants were asked to describe decision-making by their parents, decision-making in their marriage, and decision-making for their children. They were asked if they saw any influence these might have had on how they made decisions with their siblings and how their experience might influence future decision-making.

The interviews were transcribed on diskettes. Content analysis was used to analyze the interview data. First, the interview guide was used as a format for compiling data for each family. Sets of questions from the guide were separated, and the responses of each family member were listed under each set. These were analyzed and coded. Similarities and differences were noted. The results were displayed in tables for each family. Tables 3.1 and 3.2 show the relationship between research questions, interview questions, and coding that was used to summarize responses to the interview questions.

Participants' responses were analyzed for evidence of family decision-making processes, including conflict, discussion, negotiation, consensus, power, and change (Scanzoni & Szinovacz, 1980). Responses that reflected communication, discussion, or "talk" were coded as discussion. Disagreement was coded as conflict. Compromise, "give and take," or similar descriptions were coded as negotiation. Agreement was coded as consensus. Power reflects who had power of attorney and how that person exercised that power. Changing one's mind, position, feeling, behavior, or opinion were coded as change.

Shared power and shared responsibility were added to reflect descriptions of their situations given by respondents. Shared power represents siblings with joint power of attorney or those who described sharing power among siblings. Shared responsibility was used to code situations in which each sibling made a contribution to the caregiving by taking on roles or completing tasks related to the elder care situation. These included family care, arranging appointments and accompanying the parent, participating in arranging residential care, managing financial affairs and investments, researching dementia and community resources, providing emotional support to other siblings, and

Table 3.1 - Summary of Interview Questions and Coding for Descriptive and Theoretical Research Questions

Research Questions	Interview Questions	Coding
<u>Descriptive Questions:</u> How do selected families make decisions about finances, guardianship, and the use of family care, home care, adult day care, adult foster care or nursing home care for elderly parents with dementia? -Who participates? Who does not? -What procedures or processes are used? <u>Theoretical Question:</u> -How do selected families use various decision making procedures in making decisions for parents suffering from dementia?	(What kind of decisions has your family had to make? Has your family had to make decisions about finances? Have you had to decide about guardianship? Has your family used family care, in home care, adult day care, adult foster care, or nursing home care? Please describe these arrangements.) -How did your family go about making this decision? Please describe the steps that took place. -Describe any assistance you received from family members, professionals, medical personnel, staff, etc. -Who brought it up? Who participated? Who did not? -How did you reach an agreement? -Did any family members seem to have more influence on the final decision? Who? Why did it seem that they were more influential?	-Conflict -Discussion -Negotiation -Change -Consensus -Shared power -Shared responsibility
<u>Descriptive Question:</u> How are conflicts or disagreements resolved?	-How did you resolve any conflict or disagreement that arose?	-Discussion -Negotiation -Change -Consensus
<u>Descriptive Question:</u> What are the important contextual factors that influence the decisions?	-What were the important factors that influenced this decision?	-Health & Safety of Parent -Health of Caregiver -Ability to Provide Fam. Care -Emergency Moves -Availability of Care -Quality of Care -Costs & Financial Resources -Sibling Relationships -Time, Distance & Proximity
<u>Descriptive Questions:</u> What are the expected outcomes? What helps the family to reach the decision? What makes it more difficult?	-What outcome did the family want to bring about? -What helped the family reach the decision? What impeded the family?	-Safety & Comfort for Parent -Need for Services -Affordable Care -Convenience -Quality of Care -Caregiver Concerns -Wishes of Parent

Table 3.2 - Summary of Interview Questions and Coding for Interpretive and Theoretical Research Questions

Research Questions	Interview Questions	Coding
<u>Descriptive Question:</u> How do selected families use prior decision making experiences in the family of origin, marriages, and parenting to make decision about elder care? <u>Theoretical Question:</u> Can a pattern of decision making procedures be identified for selected families that reflects a family norm regarding family decision making?	-Could you describe how decisions were made in your family as you were growing up? -What influence did this have on the way you approached the decisions the family has made for your parent? -Could you describe how you and your spouse make decisions? -What influence did this have on the way you approached the decisions the family has made for your parent? -Could you describe how you and your spouse make or have made decisions regarding your children? -What influence did this have on the way you approached the decisions the family has made for your parent?	-Conflict -Discussion -Negotiation -Consensus -Individual -Joint -Expertise -Influence: None Similar Same Other (Influenced by...)
<u>Descriptive Question:</u> How do selected families see the current processes and outcome as influencing future decision making as the parent continues to age?	-How will your experiences with family decision making for your mother or father influence future decisions as he or she continues to age?	-Use Discussion -Use Negotiation -Use Consensus -Change

visiting the parent while he or she was in care.

The influences of various contextual factors were described by participants and were summarized and coded. Categories of issues, concerns or circumstances that were identified included: health and safety of parent; health of the caregiver; the ability to provide family care; emergency moves; the availability of care; quality of care issues; costs and financial resources; concerns related to sibling relationships; availability of time; and distance from or proximity to the parent. These were included in the revised conceptual map. Expected outcomes also were summarized and coded into categories. These appear as the following: safety and comfort for the parent; the parent's need for services; the ability to afford the care received; convenience for the siblings; quality of care issues; concerns about the health or well-being of a caregiver; and following the wishes of the parent.

The responses were analyzed for evidence of influence from prior decision-making and desired outcomes on the process and on subsequent decision-making. These were coded as conflict, discussion, negotiation, and consensus (Scanzoni & Szinovacz, 1980). Decisions that were individual, joint, and by expertise were added to reflect categories of responses that did not fit under these categories. In addition, the respondents' perception of influence of prior decision-making was summarized as "None," "Similar," or "Same." Some respondents saw partial areas of influence and these are noted in tables for each family under findings.

Participants with a living parent were asked how their experience with family decision-making would influence future decision-making. Their responses were coded according to Scanzoni and Szinovacz's (1980) decision-making procedures (discussion,

negotiation, consensus, and change).

The data were analyzed to determine if new information emerged that indicated a departure from patterns expected from the original conceptual map. A revised conceptual map was constructed to illustrate the results of this analysis. The original and revised conceptual maps were compared to determine if the findings reflected theories that were used to construct the original map.

CHAPTER FOUR

FINDINGS

The findings for this study are descriptive and exploratory. Data for the six families are categorized in terms of demographic data followed by a description of each family with their decision-making experiences with elder care and their patterns of family decision-making for each family. The data are organized by family for the sake of continuity. There is a summary of family decision-making experiences with elder care and a summary of decision-making patterns. There is a comparison of the revised conceptual map with the original map to determine support for aspects of the theories used in its construction. These are used to address the primary questions raised in the first chapter regarding the purpose of the study along with the research questions identified in Chapter Three. The primary questions were as follows:

How do selected families make decisions about finances, guardianship, and the use of family care, home care, adult day care, adult foster care or nursing home care for elderly parents with dementia?

How do selected families use prior decision-making experiences from their family of origin, their marriages, and their parenting to make decisions about elder care?

How do selected families use various decision-making procedures (conflict, discussion, negotiation, change or consensus) in making decisions for parents suffering from dementia?

Can a pattern of decision-making procedures be identified for selected

families that reflects a family pattern regarding family decision-making?

Demographic Data

The first member of each family (M1) was the person who initiated the contact in response to the recruitment letters and was considered the primary respondent. As described in Chapter Three, the interview format for other family members was modified and used to validate the reports of the primary respondents regarding family elder care decisions. The family number indicates the order in which the first member of each family was interviewed (F1-F6). Other family members are listed in the order in which the interviews took place (M2, M3) for members of that family. The demographic data are displayed in Table 4.1.

All primary respondents were interviewed in person. Four of the primary respondents for the study were females and two were males. All of the participants were Caucasian. The parents receiving care were evenly divided between mothers and fathers. All of the primary respondents had either sole or joint medical power of attorney or guardianship and were central figures in either delivering care or arranging for it. Five of the families used legal and medical powers of attorney to carry out financial, medical, and elder care decisions. One family (F3) used guardianship and conservatorship. The four female primary respondents are involved in the medical field. They include a nurse, a pharmacist, a clinical laboratory scientist, and a receptionist in a doctor's office. The two males are a salesman and a teacher.

All of the families are middle class as determined by their education and

Table 4.1 - Demographic Data for Sample

Family # Member #	Sex	Year of Birth	Mar Stat	# of Ch	Occ: M/Sp	Hours: M/Sp	Ethnicity	Rel	Edu	Parent
F1M1	F	1934	W	3	W/W	40/40	En Gr Fr	C	RN	Mother
F1M2	M	1937	M	0	B/0	20/0	Gr En	N	C 1-2	Mother
F1M3*	M	1952	M	2	W/W	40/40	Gr En	C	BA	Mother
F2M1	F	1958	M	2	W/W	23/50	Gr	C	C 1-2	Father
F2M2	M	1952	S	0	W	50	Gr	N	BA	Father
F2M3*	F	1954	M	2	W/W	20/40	Caucasian	N	BA	Father
F2M4	M	1956								Father
F3M1	F	1960	M	3	W/W	50/45	Gr Po En Fr	C	BA	Mother
F3M2*	F	1950	M	1	0/W	0/60	Caucasian	C	BA+	Mother
F3M3*	F	1947	D	0	W	60-80	Gr	C	MA	Mother
F4M1	M	1947	M	4	W/W	40/40		C	BS	Mother
F4M2	F	1944	R	3/2	W/W	40/0	En Ir Du	P	MA+	Mother
F5M1	F	1947	M	1	W/W	32/60	Po	C	BS	Father
F5M2	M	1945	M	2	B/B	0/30	Po	C	HS	Father
F5M3**	F	1941	D	4	W	40	Po	C	MSW	Father
F5M4	M	1949								Father
F6M1	M	1945	M	1	W/W	60	Gr Ir	P	MS	Father
F6M2*	F	1943	M	2	W/W	45/10	Gr Ir	N	MA	Father
F6M3*	F	1939	R	5	W/W	20/0	Gr Ir	C	BS	Father

Legend:

*Telephone Interview

**Interviewed by E-Mail

Sex: F=Female M=Male

Marital Status: M=Married
(Mar Stat) D=Divorced

S=Single

R=Remarried

W=Widowed

of Children: 1st/2nd Marriage
(# of Ch)

F2M4 and F5M4 did not participate in the study.

Occupation (Occ):

(M/Sp=Member/Spouse)

B=Blue Collar

W=White Collar

Hours:

(M/Sp=Member/Spouse)

Ethnicity:

Du=Dutch

En=English

Fr=French

Gr=German

Ir=Irish

Po=Polish

Religion: (Rel)

C=Catholic

P=Protestant

N=None

Education: (Edu)

BA/S=Bachelors

C=some college

HS=Highschool

MA/S=Masters

occupations. This was expected given the fact that recruitment was from residents of two for-profit AFC's and an adult day activity program. The activity program is nonprofit and partially subsidized by the state of Michigan, but it also charges program fees on a sliding scale. Thirteen of the seventeen participants have college degrees, with five having a master's degree and one with a specialist degree beyond the master's level. Three others have some college, and one completed highschool, but did not attend college. One participant was not employed or retired, but has a degree and is married to a very successful businessman. Two participants were considered as having "blue collar" or wage-earning occupations, and the rest would be considered as "white collar" or salaried/professional. Eleven have intact marriages, two are remarried, one is widowed, two are divorced, and one is single, never married. Twelve of those who are married have spouses with white collar occupations or professions. One spouse would be considered blue collar, and one is a homemaker.

The Adams Family

The first family is the Adams family (F1) with members named Ann (F1M1), Ben (F1M2), and Carl (F1M3). Ann was 67 years of age and was the oldest participant in the study. She is a registered nurse and has been widowed since 1995. Her husband was a housing inspector and a foreman. She is Catholic and has three grown children. Ann had both medical and legal power of attorney to handle her mother's affairs. Her mother was just short of her 92nd birthday at the time of the interview. She experienced memory loss that was diagnosed at a local geriatric office, but there was some uncertainty about whether it was caused by Alzheimer's disease. She required assistance with toileting,

bathing, and personal hygiene, and she could not prepare meals or do housekeeping. She appeared to be in the middle stages of care. Ann described her mother as ambulatory with a walker, and she was able to feed herself. She was residing at the AFC in Saginaw after transferring from a small AFC where she had resided for about three years. Ann has two younger brothers, Ben, age 64, and Carl, age 49. Ben is semi-retired and working part-time managing a self-storage facility. He was interviewed in person. Carl lives in Nevada with his wife and two young children. He is a retired construction analyst for the federal government, and his wife is an accountant. Carl was interviewed by telephone.

Adams Family Decision-Making Experiences with Elder Care

Ann had both medical and legal power of attorney over her mother's affairs. However, she actively pursued joint decision-making with her two brothers, maintaining an ongoing pattern of regular communication with both of them. She had the central role in this process. Nearly all of the interaction was between her and each of her brothers, with much less communication between Ben and Carl. Their mother was responsible for making the decision for Ann to have both powers of attorney. In 1991, she put Ann's name on all of her financial affairs. In 1993, she had a will drawn up, and Ann also was given power of attorney. Ben participated in making decisions and carrying out changes in care for his mother. Ann kept Carl informed of their mother's situation, and he assisted with financial affairs including recommending investments. The decisions to move their mother into a small AFC and then into the larger, staffed AFC were initiated by declines in their mother's health. The first move came when she was hospitalized after a fall. She needed 24-hour care, so she was moved into adult foster care. All of the siblings were working at the time, and Carl lived too far away and had young children at

home, so none of them were able to provide family care. When their mother's needs became too great, the owner told Ann that her mother would have to be moved. Ben heard about an opening at the staffed AFC in Saginaw, and they were able to secure a bed.

The Adams family did not report experiencing conflicts or disagreements with regard to decisions about the care of their mother. Ann stated:

“We have been very agreeable. We call my brother in Nevada and tell him everything that is going on and my brother and I talk it over so we know what's going on.”

All three reported that their ongoing communication and discussion kept everyone informed prior to and during decision-making. It also appears that each sibling found a way to make a contribution to necessary tasks:

Ann: “I always call to let them know what's going on and then my brother in Nevada is more financially astute than I am. So I keep getting these reports from investments that we have. So, I just ship everything off to him and let him check into it to make sure that everything is going well.”

The contextual factors that influenced their decisions were primarily emergency situations that necessitated moving their mother and the availability of space. They needed to make a move and there was a bed available. The family also felt with both moves that the facility afforded a safe and comfortable place for their mother, which was an important outcome.

Decision-Making Patterns in the Adams Family

The Adams family decision-making is illustrated in Table 4.2. Ann described decision-making by her parents as “probably my mother made most of the decisions”

Table 4.2 - A Comparison of Elements of Conceptual Map with Family Decision Making by the Adams Family

	Prior Decision Making	Influence	Current Context Factors	Family Decision Making	Outcome	Subsequent Decisions
Ann	FO: Mother made decisions. Father made some.	None	Health & safety Emergency moves Availability & cost	Discussion & Consensus	Safety & comfort	Continue with discussion & consensus
	M: Discussion & compromise	Similar	Time & proximity	Shared Power		
	P: Ann made decisions	None	Maintain positive sibling relations	Shared Responsibility		
Ben	FO: Joint with discussion	Similar	Health & safety Emergency moves	Discussion & Consensus	Costs, safety, & comfort	Continue with discussion & consensus
	M: Joint with discussion	Similar	Availability	Shared Power		
	P: NA		Time & proximity	Shared Responsibility		
Carl	FO: Joint with discussion	Similar	Health & safety Emergency moves	Discussion & Consensus	Safety, comfort & location	Continue with discussion & consensus
	M: Joint with discussion	Similar	Availability	Shared Responsibility		
	P: Joint with discussion	Similar	Distance Support for siblings			

*Left = Medical Power of Attorney *Right = Legal Power of Attorney
FO = Family of Origin M = Marital P = Parental

because her father was working a lot. She recalled her father making some decisions.

Ann stated:

“I don’t remember ever hearing any discussions between my mother and dad about things that were going on. I wasn’t home a lot.”

During World War II, Ann babysat for the people who lived next door. They both worked long hours at a local plant making war materials. She did not remember any disagreements between her parents. She did not see a connection between their decision-making and that which she and her brothers used. They were much more likely to discuss decisions than her parents were. Ann stated:

“It was just that when my mother gave me charge of all this, I thought I needed to involve everybody and I just don’t want to make my own decisions, because I think they all need to be aware of what is going on.”

Ann described decisions in her marriage: “We usually talked them over.” She stated that when there was a disagreement: “We usually would compromise.” She saw decision-making with her brothers as follows:

“I think we are probably more open with each other, probably, than my husband and I were. I do much more communicating with them....They know I have power of attorney and power over her health care and things. I don’t want them to see me as being the mean person who can do whatever she wants to do without consulting anybody, even though I do have that.”

Ann described how her mother’s family had a very negative experience related to an inheritance and she did not want to see any hard feelings with herself and her brothers:

“...I felt that I tried very hard to always include them in everything and to get their viewpoints in anything....My mother and her family were split apart about things like that and I hate to see the same thing.”

With her children, Ann made most of the decisions and was the main disciplinarian. Her husband did childcare early in their marriage when she worked staggered shifts at the

hospital. He handled matters when he was home with the children. She did not see any connection between their parenting decisions and her decisions with her brothers.

Ben recalled decisions being made between his mother and father. He reported that they talked about the decision and decided what they were going to do. He did not recall any disagreements. Ben saw some similarities in how decisions are made with his sister and brother regarding his mother. Ann calls him and his brother, and they talk about what to do. In his marriage, Ben and his wife talk about decisions. If either one of them disagrees, then one has to compromise or they do not implement a decision. He saw discussion as a major aspect of decision-making in both his marriage and in making family decisions about the care of his mother. Ben and his wife do not have any children, so he did not describe parenting decisions.

Carl stated that he grew up more like an only child due to the age disparity between himself and his brother and sister. He recalled that his parents made decisions together. He said they discussed things at the dinner table. Carl saw his parents as a traditional couple in terms of his mother staying home and taking care of the household and his father going to work. When they had a disagreement, they would let it be for a period of time and get back to it at a later date. He saw similarities between his parents' decision-making and that which he and his siblings have used. Carl and his wife use communication to make decisions. If they disagree, then they drop it and do not go any further with it. Again he saw a similarity between decisions in his marriage and with his siblings in terms of the use of communication. Carl and his wife use joint decision-making as parents and this is similar to what he and his siblings use.

There is a discrepancy between Ann's recollection of her parents' decision-

making and that of Ben and Carl. However, she qualified her response by saying “probably my mother made most of the decisions.” Then Ann described how she started working at age nine and was gone most of the time, indicating that she was not sure how her parents made decisions when she was not there.

Important context factors for the Adams family included the declining health of their mother that resulted in emergency moves each time her care was changed. The availability and cost of care were factors. Time, proximity, and distance influenced the decisions to use AFC care, to have Ann appointed sole power of attorney, and to share various responsibilities. Positive relations among the siblings were also considerations in making decisions. All three siblings were consistent in describing family decision-making for their mother, and the fact that they used discussion, agreement (consensus), and shared power, even though Ann had sole power of attorney. They described how they have shared responsibility with each one making a contribution. Carl saw his role as the least of the three, but Ann viewed it as important in terms of having funds to pay for her mother’s care. All three described the desired outcome in terms that related to the need for their mother to be safe and comfortable. Costs were mentioned by Ben and location by Carl. All three reported being satisfied with their decision-making process and expected to continue to use communication (discussion) and reaching an agreement together (consensus).

The Baker Family

The Baker family (F2) is comprised of four members. Donna (F2M1) was the primary respondent. She was 42 years old and had medical power of attorney for her

father, who was approaching his 80th birthday. He was at the AFC in Saginaw and required complete care except for feeding, which was beginning to be difficult. He was ambulatory, but was beginning to show signs of difficulty maintaining his balance. It appeared that he was entering the later stages of care. Donna attended college, but does not have a degree. She works part-time as a receptionist in a doctor's office. She is married and has two teenagers who live at home. Her husband is self-employed as a paint contractor. Donna's father was diagnosed with Alzheimer's disease after having numerous tests to rule out other forms of dementia. Donna has two older brothers and an older sister. Eric (F2M2), age 49, has a B.A., and is an accountant. He is single and has never been married. He had legal power of attorney and handled all of his father's financial affairs. Eric lives in the area and visited his father regularly. Fran (F2M3), age 47, has a B.A. in occupational therapy, and is employed part-time. She is married and has two teenagers at home. Her husband is an engineer. Fran lives in California, but returned to the area for visits and to participate in important events such as major moves with her father. Greg (F2M4) is 45 years old and also lives in California. He did not participate in any decisions or responsibilities related to his father's care and did not participate in the study. Fran maintains telephone contact with him and keeps him informed of the situation.

Baker Family Decision-Making Experiences with Elder Care

Donna had medical power of attorney, and Eric had legal power of attorney. Both live in the area, so a major reason for this arrangement was their availability. The decision was made at Fran's initiative while their father was still able to participate and sign the papers. Donna described the process as follows:

“There were no arguments about [Eric] taking over the finances or my being the health care power of attorney. There was not an argument among us when it was time to get together to tell Dad he needed to move. Not with taking the car away. We have been really fortunate that we have all wanted things to go as smoothly with the best results for Dad.”

Fran had a great deal of influence because of her background as an occupational therapist. She has professional experience working with elderly patients and added to her knowledge by attending Alzheimer’s Association meetings and by gathering information about the stages of the disease and various resources. Each step along the way she informed Donna and Eric about the next stage and how to prepare for it. She saw this as her contribution since she lives so far away. Eric handled finances and investments since he is an accountant. Donna either did not work or worked part-time, which allowed her to assist with housekeeping when her father lived in his home, and to arrange for medical and dental care. As mentioned earlier, Greg was not involved in his father’s care or in decision-making. Fran kept him informed, but he did not call her or anyone else in the family.

The Bakers had to make decisions about moving their father into a retirement community where he lived for about three years. When he was no longer able to function there, they decided to move him to a smaller facility with staff that could manage his condition (AFC). They planned each move ahead of time and were satisfied with the outcomes. In both situations, the safety and comfort of their father were important factors. They did not feel that they could provide family care. Their father had purchased a long term care policy because he did not want to be a burden to them. Donna reported:

“I think it was after his mother died that he bought the long-term care policy, because she did live with his brother and his wife for a period of time before going into a nursing home.... I think that really spurred him. ‘I

don't want anybody to have to take care of me. I don't want to have me in your home and I have this policy and I don't want to be a burden.' So he made it very clear on what he wanted in his own steps to provide for himself and I think that with my sister's leadership and our desire to put that first, we made sure what he wanted and what he needed was done."

Donna has children at home, and Eric is single and works full-time. Fran lives in California, and they did not want to uproot their father and have him live there. Eric mentioned that having the financial ability to afford the care was important. The Bakers did not report any conflict or disagreement about these decisions:

Donna: "We have always known that we would be backed up by the other two. We have always known that, because the decisions were mutual."

The family members attributed this to their planning and communication. It also appeared that sharing responsibility was a major part of their success:

Donna: "Well you know [Eric] kept an eye on stuff anyway...he's a comptroller for the city so he has a financial background. We all settled into our boxes as we call them....I was always the one who was there kind of looking after and taking care of the house. [Eric] was always the one who kept an eye on things just to make sure. He's the natural financial man because that's his job. [Fran] was always the one who, I don't know if I want to say intellectual, she was the one who had more drive. More desire to know more all the time. And being far away where she couldn't follow through with things here, it was natural for her to be a kind of starting point for us....She had seen a lot of Alzheimer's patients in her job and kind of knew maybe what would come next or what should be done or what they were doing in her area."

Each of them had an important role to play in managing elder care for their father.

Decision-Making Patterns in the Baker Family

Decision-making in the Baker family is displayed in Table 4.3. Donna stated that her father made the major decisions in the family. She described this as follows:

"My dad made them. What he said went. My mom was not a meek personality by any means, but she was of that age that she gave up her home to move to where he lived. She gave up her religion to become his

Table 4.3 - A Comparison of Elements of Conceptual Map with Family Decision Making by the Baker Family

	Prior Decision Making	Influence	Current Context Factors	Family Decision Making	Outcome	Subsequent Decisions
*Donna	FO: Father made major decisions. Mother made decisions about children.	Influenced by father's planning	Need for care, supervision, & safety Support from siblings Time & proximity	Discussion & Consensus Shared Power Shared Responsibility	Atmosphere, trained staff, & location Father's wishes	Continue discussion & consensus
	M: Joint for major decisions	Similar				
	P: Joint. Donna implements.	Influenced by family decision making				
Eric*	FO: Do not remember. Both parents disciplined children.	Similar in planning	Safety, supervision, & socialization Time & proximity Financial resources Positive sibling relations	Discussion & Consensus Shared Power Shared Responsibility	Atmosphere, socialization, activities	Continue discussion & consensus
	M: NA					
	P: NA					
Fran	FO: Father was autocratic.	Similar in research & planning	Safety, supervision, & socialization Financial resources Distance Positive sibling relations	Discussion & Consensus Shared Responsibility	Safety & supervision	Continue discussion
	M: Joint with discussion	Similar				
	P: Joint with discussion	Similar				

***Left = Medical Power of Attorney *Right = Legal Power of Attorney**

FO = Family of Origin M = Marital P = Parental

and she stayed home and raised the kids. He made the money and he made the decisions about what to do with the money. I don't think of her as down-trodden in anyway. She got what she wanted like we all do. She never lacked for anything, but she just deferred to him because she thought he would, I don't know if he would make better decisions, but that was comfortable for her. He did the grocery shopping all my years, which I thought was hilarious. She made the list, he did the shopping because 'she bought too much junk.' So if we wanted to use the car, we went to Dad....So he made all of the decisions. That's all he knew."

The only similarity she saw with how she and her siblings made decisions was the fact that her father planned ahead, and they have been successful by discussing plans ahead of time. Donna described her own marital decision-making:

"I think it's more of a mutual thing than I perceived my parents to be, and again, if that's the case or not, I don't know. But it is opposite in the case that I do the checkbook. I pay all the bills on top of doing the rearing of the children and that just came about."

She saw a similarity with her siblings:

"In the fact that we kind of hash everything over and, you know, do the good, the bad, and the ugly thing before deciding that's what we should do....I think the older we all get, the bigger the picture we look at. When you're young, you're only focused right here. Me, me and me. Now as you get married and have children, and now have to take care of parents, you have to look at a larger scale of issues."

Donna and her husband discuss their expectations regarding raising their children and then she implements those decisions and is the main disciplinarian. She felt that working with her siblings by discussing plans ahead of time and making decisions actually influenced the way her and her husband approach parenting decisions. Donna described this as follows:

"I would have to say doing what we have done for my dad maybe has changed the way I do things at home....I see how beneficial it has been to look at the next stage ahead of time and throw out every possibility and, you know, give more thought and reject it and make decisions. So now I think that has helped with [my son] being a junior now, saying we better

look ahead now to college and what he needs to do. Where I think maybe my head would have been more in the sand a little....He's my first kid....So in that respect, maybe that has helped me see a bigger picture and know that it worked so well with my dad to do things ahead of time, that gosh maybe that should spill over into other areas. Why wouldn't that work out just as well?"

Eric did not recall very much about how his parents made decisions. He recalled that each of his parents would discipline the children depending on who was home. Occasionally his mother would wait until his father came home, if it was a major problem. However, his mother dealt with most of the day-to-day discipline. Eric is single, has never married, and does not have any children. He stated that it is different for him, since he is the only one making decisions.

Fran validated what Donna described. She saw decision-making with her parents as her father being autocratic. She thought there must have been some joint decisions made, since they had 125 foster children in their home, but she does not recall actually seeing her parents make decisions together. The only influence she saw on how she and her siblings made decisions was that they researched things beforehand and planned ahead as her father did. Fran and her husband use a "democratic process" for making decisions in that they both have full say. If they disagree, one is likely to go along with the other if the decision is in an area of strength for that person. For instance, with the children, her husband tends to go along with what she thinks, and with money she tends to go along with what he thinks. She saw a lot of similarity in how she and her sister and brother made decisions, especially with getting each other involved and getting input. She tried to include Greg, but he chose not to be involved.

All three siblings identified safety and supervision needs for their father as

important context factors. The fact that their father planned ahead and also purchased a long term care insurance policy allowed for sufficient financial resources and indicated his wishes. Time and proximity determined the roles that Donna and Eric played. Distance limited Fran's role. Positive sibling relations contributed to the success of their decision-making. All three described their decision-making for their father as including regular communication, discussion, and agreement (consensus) about what to do. They shared power by splitting the powers of attorney between Donna and Eric. Fran had power in the fact that she is knowledgeable about dementia and about resources. She took this on as her share of the responsibility, while Donna and Eric shared responsibilities in Michigan. The desired outcome each described was to have a safe and positive atmosphere for their father. Donna mentioned having a trained staff and a convenient location. Eric talked about socialization and activities. Fran added supervision. All three reported being pleased with their decision-making process and expected to continue communicating, discussing, and reaching an agreement as they faced future decisions.

The Cook Family

The Cook family (F3) is comprised of three sisters. Hannah (F3M1) was 41 years of age and was the primary respondent. She has a B.A. in pharmacy and works full-time. She is married and has three young children at home. Her husband is employed full-time in sales. Hannah's mother died at age 78 in December of 2000. Thus, the Cook family had completed their caregiving for their mother. Before her mother's death, Hannah had guardianship. As the only sibling living in the area, she was very involved in her

mother's care. Her mother was diagnosed with Alzheimer's disease by her family physician. Hannah's father was caring for her mother at home until he died suddenly in January of 2000. After his death, Hannah's mother lived at the AFC in Saginaw. She moved to the county hospital for rehabilitation after she fell and broke her kneecap. Later, she moved to a local nursing home. Jan (F3M2), 51, lives in North Carolina. She is married with one adult child. Jan has a B.A. with some postgraduate education. She was not employed. Her husband is the chief financial officer for a major corporation. Jan made a number of trips to Michigan to visit and to participate in securing care for her mother. Karen (F3M3) was nearing 54 years of age when she was interviewed. She has a master's degree and is employed as a director of benefits for a hospital in Philadelphia. She is divorced with no children. Karen was her mother's conservator and was responsible for all of her financial affairs. She made several trips to Michigan to visit and participate in care planning.

Cook Family Decision-Making Experiences with Elder Care

Hannah is the youngest of the three sisters in the Cook family. She is 10 years younger than Jan and 13 years younger than Karen. Hannah is the only one who lives in the area. She reported that living here, along with her background as a pharmacist, were major factors in the decision that she have guardianship. Karen is the oldest and was named the administrator of her parents' will, so she assumed conservatorship over her mother's financial affairs. Hannah described this as follows:

“[Karen] is better with money than I am, so it was natural that she do that. I am better at understanding my roles than she is, so it is natural I be the guardian. Whoever was going to be wherever mother lived was going to be the guardian. There was talk at one point of moving her to North Carolina or to Pennsylvania. But her family and the things she knows the

most were all here, so we decided to leave her here.”

The sisters had to make decisions about moving their mother into three facilities. Each time the decision was made under some duress. The move to the AFC in Saginaw was made after the death of their father, who had been caring for their mother. The move to the county medical care facility was made when their mother broke her kneecap and could not return to the AFC. The move to a nursing home was made because they felt their mother was not receiving appropriate care in the county medical care facility. The Cook family decided not to use family care based on their circumstances and their mother’s wishes. She had stated that she did not want to move in with any of them as her own mother had done with her. Hannah said:

“...when she first became ill she was cognitive enough that she never wanted me to move her back home and she never wanted to move in here. That was always a given that we would never do that. My grandmother came to babysit when my sister [Jan] was born in 1950 and she never left until 1990. So you see I grew up with Grandmother in the house and Mother said ‘I will never do that to you. I don’t want you to take me in and I won’t come if I am in my right mind. I will not come to your home. There’s just no way I would do it.’”

In addition, Jan and Karen live out of state and Karen is divorced and works full-time.

Hannah works full-time and is raising young children.

The Cook family reported that they were able to make decisions successfully without conflicts or disagreements. They felt that part of this was due to the emergency nature of the moves and having few alternatives. They also felt that regular communication and knowing what their parents wanted was helpful. The outcome they were trying to attain was to have a safe and comfortable place where their mother would be treated with dignity and respect:

Hannah: “That she be treated with respect and dignity. We were actually hoping that she would be able to stay there until she left this earth. We wanted to make sure that her wishes would be carried out to the end....”

They reported being satisfied with the decision-making process with all three moves, although they were not happy with the care at the county medical facility.

Decision-Making Patterns in the Cook Family

Decision-making by the Cook family is depicted in Table 4.4. Hannah could not recall seeing her parents make decisions together. She described this as follows:

“Mom really was the caregiver. I mean it was the typical early 60’s kind of thing where Dad went to work. And back when I was a kid I don’t think any dad had a whole lot to do with their children. I credit my mother with giving me most of my beliefs and values and belief in God that I’ve got. I credit her with that.”

“Did they ever co-make decisions? Not that I can remember. I can remember when, like I said, my grandma came to babysit in 1950 and she didn’t leave until she died in 1990.”

Hannah and her husband make decisions by deferring to the one with the most knowledge or expertise:

“Well he has areas that he is better in than I am, so I say ‘you know about this more than I do. I trust your judgment, go with it.’ I tend to trust him very much. When it is something that he knows about, he talks it over with me. He’ll explain to me and I say that sounds fine. The things that I know about, he trusts me to make those decisions. Things I know more about, then I do it. Where he knows more about it, he does it, and that’s fine. That seems to work. I feel comfortable with it.”

She viewed the decision-making with her sisters as being the same as that which she and her husband use. Hannah and her husband discuss child-rearing together. She saw this as being similar to how she and her sisters made decisions.

Jan recalled that decisions were made primarily by her father and that he never consulted anyone else. Her mother made child-rearing decisions in the home, but her

Table 4.4 - A Comparison of Elements of Conceptual Map with Family Decision Making by the Cook Family

	Prior Decision Making	Influence	Current Context Factors	Family Decision Making	Outcome	Subsequent Decisions
*Hannah	FO: Does not recall joint decisions. Mother made decisions about children.	None	Father's death Emergency moves Quality of care issue Time & proximity	Discussion & Consensus Shared Power Shared Responsibility	Treated with dignity & respect Mother's wishes	NA (Mother died)
	M: Defer to each other's expertise	Same				
	P: Joint with discussion	Similar				
Jan	FO: Mother made child rearing decisions. Father made remainder.	None	Father's death Emergency moves Quality of care issue Time & distance	Discussion & Consensus Shared Power Shared Responsibility	Safety & comfort	NA (Mother died)
	M: Joint with discussion	Similar				
	P: Joint with discussion	None				
Karen*	FO: Mother made child rearing decisions. Father made remainder.	None	Father's death Emergency moves Quality of care issue Financial resources Time & distance	Discussion & Consensus Shared Responsibility	Safety & comfort Parents' wishes	NA (Mother died)
	M: Individually	Opposite				
	P: NA					

*Left = Medical Power of Attorney *Right = Legal Power of Attorney
FO = Family of Origin M = Marital P = Parental

father decided what school they attended. Jan did not see any similarity in the way she and her sisters made decisions. Jan and her husband discuss decisions and make them together. They also use discussion when there is a disagreement. She saw her role with her sisters as that of peacemaker since Hannah and Karen do not get along well with each other. Jan and her husband made decisions as parents together. She did not see any similarity with how she and her sisters made decisions.

Karen remembered her mother made child-rearing decisions and her father made decisions about everything else. She did not see any influence of this on the way she and her sisters made decisions for their father. When Karen was married, she and her husband worked different shifts, so they made decisions individually. They did not have any children. She saw herself as having emulated her parents more in her marriage than she did with her sisters in making decisions for their father. She and her sisters made decisions in the opposite way.

All three sisters described their parents' decision-making as more or less individualized and did not see any influence on their elder care decision-making. The first two changes in care took place under emergency circumstances. The first move came as a result of the sudden death of their father. The second was caused by her mother's injury. The third move was in response to concerns about quality of care. Time and the wishes of her mother dictated the need for placement for Hannah. Proximity dictated that Hannah have guardianship. While Jan lives out of state, she has had the time to participate in each move. Karen also lives out of state, but she had less time than Jan. She participated in the first move, but not the last two moves. All three sisters reported their decision-making for their mother as including communication (discussion)

and agreement (consensus). For example, Hannah stated:

“...Everything was always done by committee. [Jan] will say ‘I didn’t do anything,’ but she really did. She would listen to the both of us and make suggestions, and really, everything except the end of life prayer was done by all of us.”

The Cook family shared power and responsibility, with Hannah having guardianship and Karen having conservatorship. Hannah saw the desired outcome as carrying out her mother’s wishes to not be a burden to her daughters and also having her mother treated with dignity and respect. Karen also saw the desired outcome as carrying out her parents’ wishes. She saw safety and comfort for her mother as important, as did Jan. Since their mother died, future family decision-making for elder care was not applicable.

The Davis Family

The Davis family (F4) is comprised of two adult siblings. Larry (F4M1) was 54 years of age, has a B.S. degree, and is employed full time in sales. Larry is married and has four adult children, and his wife is employed as a college instructor and a tutor. Larry had joint medical and legal power of attorney with his sister, Meg (F4M2). Their mother was 88 years old and had been residing at the AFC in Bay County for about three years. She had dementia and also suffered from macular degeneration. While a formal diagnosis was not made, there was some suspicion that her dementia may have been caused by mini strokes or multi-infarct dementia. She could feed herself and was ambulatory with a walker, but needed assistance with dressing, bathing, and routine daily activities. Thus, the Davis family appeared to be in the middle stages of care. Meg, 57 years of age, has been married to her second husband for twenty years. He also was

previously married. Meg has three adult children from her first marriage and her husband has two from his first. Meg has a master's degree plus thirty credit hours beyond her master's and is employed full-time as an elementary school counselor. Her husband is a retired stock broker. A unique aspect of the Davis family is the fact that their mother raised them as a single parent. Their father died when Larry was three and Meg was six years old, and their mother never remarried. Both Larry and Meg were interviewed in person.

Davis Family Decision-Making Experiences with Elder Care

Larry and Meg shared joint power of attorney over their mother's affairs. Larry arranged appointments and took his mother, since he has a flexible schedule. He made an interesting observation about this experience:

"Generally I take my mom to the doctors, probably 90 percent of the time, and I get comments from the nurses and the doctors: 'You are such a nice son to do this.' Well they're just not used to having sons do this probably as much as daughters...."

Meg handled the checkbook since she lives closer. Larry handled the investments:

"We have a split in a way. My sister takes care of the writing of the checks and so forth out of a checking account that is Mother's money. So my sister really does the day-to-day writing of the checks. I primarily deal with the financial investment end of my mother's funds....It's always a consensus opinion. I mean we always have agreement on what we are going to do...."

Prior to placing their mother at the AFC in Bay County, they had to make decisions for her while she lived in her home. This included surgeries that she was reluctant to have and bringing help in to care for her. They felt that they have always been close and have a great deal of respect for each other, and this helped them to make decisions together. In addition, they knew what their mother's wishes were, and they discussed everything and

planned ahead. They reported no apparent conflicts or disagreements. With their full-time employment and their mother's level of need, it would have been difficult to provide family care. A difficult decision was the sale of the family home. It was mainly difficult for Meg. Larry was patient and waited for her to be ready before they put it up for sale.

The Davis family felt very positive about their ability to make decisions together.

Each of them had an important role to play. Larry described this as follows:

"We make the decision together but there is never, I mean there is very, very seldom a unilateral decision....we have a pretty definitive separation of our duties, and they have changed through the last ten years, too. And you know, with Mother in a facility now on a twenty-four hour basis, it has minimized both of our duties here. I would say my sister still has more daily duties, probably, because she has to write checks. I guess I would still say I probably provide the drive. If I recognize that there is a problem, I am more apt to go after it and find a solution, then present her [Meg] with some kind of solution, and then we do it together."

The outcome the Davis family wanted was to make sure that their mother was safe and comfortable. Larry attributed some of their success to having the money to make choices. It helped that neither of them had to pay for their mother's care. Larry also felt that it has been easier to get along since there are only two of them. He wondered if larger families might have more trouble agreeing with each other simply because there were more people involved.

Decision-Making Patterns in the Davis Family

Decision-making by the Davis family is displayed in Table 4.5. His father had died when Larry was three. He remembered his mother using her father for advice about decisions that she made:

"...I mentioned my father died when I was three, and in our family I think a lot of decisions were made between my grandfather and my mother. I think Grandpa had a lot to say about things, but again my mom was very

Table 4.5 - A Comparison of Elements of Conceptual Map with Family Decision Making by the Davis Family

	Prior Decision Making	Influence	Current Context Factors	Family Decision Making	Outcome	Subsequent Decisions
Larry	FO: Father died. Mother made decisions. Consulted maternal grandfather. M: Joint with discussion, consensus & compromise P: Wife made most decisions.	Keeps records & investigates Similar in terms of discussion None	Declining health Financial resources allowed for choices Time & proximity Positive relations with sister	Discussion & Consensus Shared Power Shared Responsibility	Safety & comfort	Continue discussion & consensus
Meg	FO: Father died. Mother made decisions. Consulted maternal grandfather & uncles. M: Joint with discussion P: Joint with discussion	None Similar Similar	Declining health Time & proximity Positive relations with brother	Discussion & Consensus Shared Power Shared Responsibility	Safety & comfort	Continue discussion & consensus

*Left = Medical Power of Attorney *Right = Legal Power of Attorney
 FO = Family of Origin M = Marital P = Parental

young...and her father was right there in town so it blended quite well.”

His mother did a lot of planning and organizing. He recalled that she would involve him and Meg in discussing and planning vacations. The similarity that he saw in making decisions with his sister was that he kept records and investigated before making a decision:

“One thing Mom would do, is she kept records. She kept records and I know that is how I make decisions. I keep files and...I investigate things before I make decisions....”

Larry and his wife talk about almost every decision. He feels that they do a good job of discussing:

“...we talked about almost every decision. I really think we do a real good job of discussing. I don’t think either one of us would make any major decision, I mean say over a hundred-dollar decision, without talking to one or the other about it....I think there is almost always a consensus. I think we would pass on something that one was against. Even if one felt strongly about it, and one felt against it, I don’t think we would do it.”

He saw his approach with his sister as different from that which he used with his wife, although he and Meg discussed their decisions. Larry saw his wife as making most of the decisions with their children since he was gone a lot. He did not see any similarity in this and how he and Meg made decisions about their mother.

Meg described the situation as her mother being in charge. She validated Larry’s description of her grandfather’s involvement and added that uncles also were consulted. She recalled the discussions about vacations, but felt that it was mainly her mother who would make a suggestion about where they would go and Meg and Larry would agree. Meg did not see very much similarity in how she and Larry made decisions since her mother was a single parent, and they did not get to see negotiation and interaction. She

felt that their mother taught them to respect each other, and so they tried to work things out as a way of “honoring” her. Meg and her husband talk about major decisions. They were married when her children were young, so they accepted him more as a father than a stepfather. She felt that she and Larry also have done well at discussing decisions together.

Context factors for the Davis family included their mother’s declining health that caused Larry and Meg to bring someone in to care for her, to make decisions about surgeries, and to move her into an AFC. Time and proximity determined who took care of what tasks. Both mentioned their positive relationship as important in reaching decisions successfully. Larry mentioned the fact that financial resources allowed them to make choices freely. Both described ongoing communication (discussion) and agreement (consensus) as important aspects of their decision-making together, along with knowing their mother’s wishes:

Larry: “...I think my sister and I have been extremely fortunate that we have been able to make these decisions concerning my mother’s health, and we have done it without arguments. Again, I think it’s planning that my mother did ahead of time. We absolutely know her decision. We are not trying to anticipate her wants and desires...”

The Davis family shared power and responsibility by having joint powers of attorney and coordinating tasks between them. Their mother’s safety and comfort were desired outcomes. They expected to continue to use the same decision-making process in the future.

The Green Family

The Green family (F5) is comprised of two sisters and two brothers. Nancy

(F5M1) was 54 years of age and was the primary respondent. She is married with one adult daughter who is in college. Nancy has a B.S. degree and is employed 32 hours a week as a clinical lab scientist at a hospital. Her husband is employed as a teacher. Nancy's father was 86 at the time of the interview and was residing for about three years at a county medical care facility. He was diagnosed with Alzheimer's by a geriatrician. He was totally incapacitated and needed to be fed and bathed and changed. Thus, the Green family was in the very last stages of caregiving. Prior to entering the facility, their father lived at the AFC in Bay County for three months and a nursing home in Saginaw County for three months. Nancy had both medical and legal power of attorney. Her mother was alive when these moves were made, but the family was instrumental in bringing them about since she was reluctant to move him into care. Nancy's mother died of colon cancer about six months after the last move. Nancy visited her father as often as possible. Pete (F5M2) was 56 years and is married with two adult children. Pete is a retired auto worker. He lives in the home that his parents built and in which they raised their family. Pete's wife is employed part-time as a restaurant worker. He visited his father at least weekly and in the past would take his parents to appointments since he worked third shift. Rachel (F5M3) was 60 years of age, has a Master of Social Work degree, and is employed full-time as a clinical social worker in Sicily. She requested to participate in the study by e-mail and was sent a preformatted interview form which she filled out and returned by e-mail. Rachel is divorced and has four adult children. She traveled to Michigan for visits and to participate in care decisions earlier in her father's care when she lived in the United States. With her background, she has been an important resource person for the family. Sam (F5M4) is four years younger than Nancy.

Initially he agreed to participate in the study, but declined to schedule an interview either in person or by telephone, stating he did not think he could add anything to what his sisters and brother had to say. His right to refuse was respected.

Green Family Decision-Making Experiences with Elder Care

Nancy had sole power of attorney over her father's affairs. She made a conscious effort to share responsibility for decisions with her brothers and her sister. She stated: "I would not make any major decisions without consulting them." Nancy felt that they have a right to participate, since it is their father too. Her mother was involved in the three decisions about care for Nancy's father. However, Nancy and Rebecca were the force behind these moves. Their mother began having health problems and could no longer care for their father. All of the siblings were employed full-time and their spouses also worked, so it was difficult for any of them to provide family care. They were able to convince their mother to go along with the moves that were made. The decisions were discussed with Pete and Sam and they were in agreement:

Nancy: "...we had a family conference, I think, once. We sat down and said yes. Just simply you know it's time for Dad to go to the nursing home. They both agreed basically. It wasn't any long drawn-out conference. They agreed."

Rebecca had considerable influence over these decisions because of her background in social work and the fact that she is the oldest sibling. However, since she lived in California and in Sicily, it was not feasible for her to have any power of attorney. Still, Nancy used her as a source of advice and support on a regular basis.

After their mother's death, the Green family had to make decisions about the sale of the family home, medical treatment, and a "do not resuscitate" (DNR) order for their

father. Medical treatment decisions were made primarily by Nancy and she kept her siblings informed. The DNR was discussed and papers were signed by all four siblings indicating agreement:

Nancy: "...I happened to be visiting them, and so on and so forth. We would just have a conversation....We discussed it and decided and sort of came to a consensus that if something should happen again...let them do whatever they can do and not take him to the hospital again."

The Green family wanted their father to have a safe, caring place where he would be comfortable. The initial move to the AFC in Bay County was made to relieve their mother of the stress of caring for him. They hoped that it would help her in dealing with her own health problems. They had to move him to a nursing home in Saginaw County when the AFC could not meet his care needs. Nancy was not satisfied with the quality of care in the nursing home and was able to move him into the county medical facility. She tried to visit during meal time so she could feed him and assist in his care. Pete and Sam also visited regularly, although not as often as Nancy.

Decision-Making Patterns in the Green Family

Table 4.6 compares elements of the conceptual map with family decision-making for the Green family. Nancy described decision-making in her parents' marriage as her mother making all of the decisions:

"Mom made them all basically. Mom made all the decisions...Mother was ruler of the roost...what Mom said went."

She saw the opposite in her own marriage where she would rather have her husband make decisions. However, most of the time they discuss decisions and come to a mutual agreement:

Table 4.6 - A Comparison of Elements of Conceptual Map with Family Decision Making by the Green Family

	Prior Decision Making	Influence	Current Context Factors	Family Decision Making	Outcome	Subsequent Decisions
Nancy	FO: Mother made decisions. Father laid back. M: Prefer husband make final decision, but usually joint with discussion. P: Ann made decisions	Not confrontational (like father) None None	Mother's declining health & death Quality of care issue Maintain positive sibling relations Time & proximity	Discussion & Consensus Shared Power Shared Responsibility	Safety & comfort Father's wishes	Continue discussion & consensus
Pete	FO: Mother in home, father outside. Joint with discussion. M: Joint with discussion P: Joint with discussion	Similar Similar Similar	Mother's health Positive sibling relations Time & proximity	Discussion & Consensus Shared Power Shared Responsibility	Safety & comfort Relieve mother's stress Quality of life	Continue discussion & consensus
Rachel	FO: Mother appeared dominant, but joint with discussion. M: NA P: NA	Some similarity None None	Mother's health Quality of care issue Maintain positive sibling relations Distance	Discussion & Consensus	Safe, caring place Take care of mother's needs Parents' wishes	Continue discussion

*Left = Medical Power of Attorney
FO = Family of Origin M = Marital

*Right = Legal Power of Attorney
P = Parental

“Actually when it comes to something really major, I’d say probably 95 percent of time we are in agreement.”

Once in a while Nancy will say that something has to be a certain way, but she is generally not very confrontational. She did not see a similarity in how she and her siblings have made decisions for her father except for the fact that she is not confrontational, much like her father. Nancy recalled that she and her husband discussed parenting decisions, but had some disagreements in raising their daughter, primarily because her family was more strict. However, as their daughter got older, Nancy backed off and her husband became more strict, so the situation was reversed. She said that when they had a disagreement, she would not talk to him for a couple of days, then they would sit down and discuss it. She did not see any similarity to her family decision-making with her father.

Pete recalled his mother making the decisions within the home and his father making them outside of the home. He remembered them sitting down and talking about decisions. He did not see them openly disagreeing and whatever the resolution was, it took place in private. He saw the influence on decision-making with his sisters and brother as discussion before decisions are made and nobody having total control. In his marriage, he and his wife talk about decisions. This was how he saw himself and his siblings approaching decisions. Pete described parental decisions as being made together by discussing them unless only one of them was present and the decision had to be made immediately. In those instances, the parent on the scene would make the decision and inform the other parent of it later. This was similar to how he saw himself and his siblings making decisions.

Rachel remembered her mother being the one who appeared dominant, but in reality neither of them made a major decision without the other. She saw similarity in the fact that they did not take decisions about their father away from her mother while she was still alive. Rachel is divorced and single so she wrote that the question about marital decision-making was not applicable, and she saw no influence on how she and her sister and brothers made decisions. Rachel also wrote that the question about parental decisions was not applicable, and there was no influence on how she and her siblings made decisions.

Context factors that influenced family decision-making by the Green family began with the declining health of their mother, who was the primary caregiver for their father. While she participated in the decisions regarding care, Rachel and Nancy were the driving force behind those decisions as their mother's health declined. The need for more intensive care caused a move from AFC to a nursing home. Concerns about quality of care made the last move necessary. Nancy had both powers of attorney as a result of her proximity to her parents when care began. She was not able to move her father into her home since she and her husband were caring for her husband's father. Nancy reported being conscientious about including her siblings in decisions, and she wanted to maintain positive relations with her siblings. This also was important for Pete and Rachel. Pete lived about twenty miles away before their mother's death. Now that he lives in the home their parents built, he is close by. When he was working, he had time during the day to assist with appointments because he worked third shift. Rachel made trips home to assist with decisions about care when she lived in California. Now that she lives in Sicily, distance makes it impossible to actively assist in care, but she is an important source of

information and support for Nancy.

All three siblings reported using extensive communication (discussion) and reaching agreement without conflict (consensus):

Nancy: "Communication, I mean you have to really say just say what you feel and this is what I feel is right and try to state as many reasons as I can to support why I feel this is the proper thing to do. But having enough sense to also listen to what they have to say, and if it makes more sense than what I think should be done, that would be probably something that I would have to keep in mind and be open-minded about it. And not just because I think it should be, then that's the right decision. I have to be open-minded enough...to listen and say maybe she does have a point."

While Nancy has had sole power of attorney, she reported actively seeking to include everyone in decision-making. She did not see herself as being the one in charge, but as acting for her siblings. She felt that they have a right to share in decision-making since her father is their father too. Pete and Rachel agreed and saw active discussion and agreement as characterizing the process. While Nancy handled the bulk of the responsibility, Pete reported that he assisted with appointments and made visits. All three mentioned safety for their father as a desired outcome. Nancy and Pete mentioned their father's comfort as important. Pete and Rachel saw their mother's needs as a factor. Nancy talked about carrying out her father's wishes and Rachel included both of her parents in this. Nancy expected to continue to use discussion and reaching agreement (consensus) in future decision-making together:

Nancy: "...I think basically we'll be in agreement as far as anything to do with Dad unless it's something that one of them really can't live with."

Pete and Rachel were in agreement with this expectation.

The Hill Family

The Hill (F6) family is comprised of a brother and two sisters. Ted (F6M1) was 56 years of age and was the primary respondent. He has a master's degree and works full-time as a teacher. He is married to Nancy (F5M1), and they have one adult daughter. Ted actually initiated the contact and mentioned that his wife also would be interested in participating with her family if it was possible. Both families were included in the study because of the difficulty in recruitment and the opportunity to study a couple each of whom was dealing with family decision-making for elderly parents. Circumstances resulted in Nancy being interviewed before Ted.

Ted's father died at age 93 in July of 2001. At the time, he had resided for seven months at the AFC in Bay County from which the Davis family was recruited. However, Ted actually initiated contact through the recruitment of families who were using the adult day activity program in Bay County. Ted and his wife cared for his father in their own home for about five years after he suffered a stroke that left him partially paralyzed on the left side. He also had dementia. Ted had medical and legal power of attorney. Ted's mother suffered from osteoporosis for many years prior to her death in January of 2000. His father cared for her until he could no longer manage. For fifteen years, she had spent at least part of the year with each of her two daughters. After her husband could not care for her, she stayed with them full-time. Veronica was just short of her 58th birthday when she was interviewed. She is married with two adult children. Veronica has a master's degree and is employed full time as a guidance counselor in Florida. Her husband is semi-retired and works in sales part time. She shared the care of her mother with her sister until her mother was no longer able to travel. Wendy (F6M3), 62, is

married with five children. Wendy has a B.S. degree and works part time as the director of a preschool program in Alabama. Her husband is a retired college professor. Wendy's mother lived with them full time at the time of her death. Thus, the Hill family had completed caregiving for both of their biological parents.

Hill Family Decision-Making Experiences with Elder Care

The Hill family was faced with parent care decisions for both of their parents. As mentioned earlier, Veronica and Wendy began caring for their mother on a part-time basis many years prior to her death in 2000. They assumed this responsibility full-time when their father could no longer care for her. Ted began caring for his father after his stroke. About a month before, his father had signed papers for Ted to have medical and legal power of attorney. This was done at Wendy's urging after their experience with their mother. Ted was the only sibling in Michigan and was taking care of their father, so it made sense that he would have power of attorney:

Ted: "I think just for the fact that I was present, physically here in Michigan while they were in Alabama and Florida and they had the power of attorney for Mother....There was never any problem with that. They felt that I would be the best one to do it."

Decisions were made regarding the use of help in caring for their father in Ted and Nancy's home, the use of an adult day activity program, and their father's placement at the AFC in Bay County. In each case, the sisters encouraged Ted ahead of time to use these resources, but it took some time before he did so. Thus, they reported no disagreements from them, just relief that some of the stress Ted and Nancy were feeling was alleviated. All three siblings engaged in regular telephone contact with each other regarding the care of both of their parents. In addition, they made it a point to visit

regularly. Ted summarized this as follows:

“...we constantly kept in contact by phone and back and forth, and as I said, twice before both sisters flew in and visited my father. They also went out to visit almost a half a year before he was at [the AFC]. They came and I took them around at least and showed them the facility and tried to come to some agreement, at least, whether this was the place we felt comfortable or not.”

The safety and comfort of their father were a primary concern for the Hills. In addition, both Wendy and Veronica were concerned about Ted and Nancy's health and the stress on their relationship. The decision to have someone stay with their father was made because he could not be left alone. Ted decided to do this because he was not ready to have his father placed in care. Later he was convinced to try the adult day activity program and found that it was ideal for him and Nancy and his father:

“Greatest decision I ever made. Cried tears flowing down my face the last day I had to think of my father there, because then I had to take him to [the AFC]. I think that's when they made the suggestion, well why don't you try asking if there was some way we could have both of the same worlds. And if it would be possible, I could make arrangements and still bring him over here...they agreed at [the day program]. So I felt great...I still wanted him to keep that contact with them because he had really made some friends over there.”

The day program afforded his father some socialization and gave Ted and Nancy time to get tasks done or to have time to themselves. The decision to place his father in the AFC was made after Ted's father hit him. Ted was concerned about his father's aggressiveness and his wandering at night.

Decision-Making Patterns in the Hill Family

Table 4.7 shows decision-making by the Hill family. Ted recalled his parents making joint decisions, but he could not remember any discussions between them. He stated:

Table 4.7 - A Comparison of Elements of Conceptual Map with Family Decision Making by the Hill Family

	Prior Decision Making	Influence	Current Context Factors	Family Decision Making	Outcome	Subsequent Decisions
Ted	FO: Joint but does not recall any discussion.	Similar	Declining health Wandering & aggressiveness	Discussion & Consensus Shared	Availability, level of care.	NA (father died)
	M: Joint with discussion, but he has had more influence.	Some similarity	Time & proximity Support from sisters	Responsibility (with care of mother & father)	Safety & comfort	
	P: Joint with discussion.	Similar				
Veronica	FO: Father made decisions when home. Mother made decisions about children.	None	Declining health Aggressiveness	Discussion & Consensus Shared	Safety & comfort.	NA (father died)
	M: Joint with discussion.	Similar	Stress on Ted & Nancy Distance	Responsibility (with care of mother & father)	Take stress off Ted & Nancy.	
	P: Veronica has more influence.	None	Support for brother			
Wendy	FO: Father made decisions.	None	Declining health Aggressiveness	Discussion & Consensus Shared	Ted & Nancy's health & marriage.	NA (father died)
	M: Wendy makes most decisions & he steps back.	None	Stress on Ted & Nancy Distance	Responsibility (with care of mother & father)		
	P: Joint with discussion.	Same	Support for brother			

*Left = Medical Power of Attorney
FO = Family of Origin M = Marital

*Right = Legal Power of Attorney
P = Parental

“...my mother and father working together...whatever they felt was necessary at the time, that’s what they did...”

Ted indicated that he had a lot of freedom to make his own decisions. He saw a similarity in general terms with how he and his sisters made decisions. When his parents had a disagreement, it was not openly discussed, but there would be tension for several days. He did not know how these situations were resolved or if they were resolved. Ted said that he would like to think that things are fifty-fifty with him and Nancy. However, he thought that it was not that way with their decisions about his father. Ted felt that he kept taking on more, while Nancy expressed concern that he was getting overloaded:

“I would like to think that we are making them fifty-fifty at times as far as with my dad...I probably forced more on [Nancy] than what she probably was willing. She put up with like quite a bit. That’s my feeling. It was different though. I guess that was more of a major decision. Also, how far can I go, and I felt I can do okay and [Nancy] kept saying, ‘well I think you’re going to rupture....’”

Ted saw their disagreements as being resolved by talking them out. He felt that he and Nancy made decisions jointly as parents. He stated that their child was a great daughter so they did not have as many decisions to make. He saw a parallel in how he and his sisters made decisions regarding the care of their parents.

Veronica remembered her father making all of the decisions when he was around. She said that the differences in the ages of herself and her siblings meant that they kind of grew up in three different households. She recalled that her father was gone a lot, so her mother made the child-rearing decisions. She felt that she and her siblings were able to work together on decisions because they were close growing up and did not have any real conflicts. They have a lot of love and respect for each other. She also described how the family was ostracized by her parents’ families because her mother was Catholic and her

father was Christian Scientist. The siblings felt that they needed to show that they were worthy by being good kids.

Veronica and her husband make decisions together. In child-rearing she was more in control, in part because of her background in education. When they had arguments earlier in their marriage, she would shout and her husband would be quiet and leave. She felt that they have matured, but she still tends to be verbal and he is silent. In terms of similarity between decisions in her marriage and those with her siblings, Veronica thought that she spoke up more with her husband than with her sister and brother. She tended to step back more with her sister and brother, but she did not disagree with them.

Wendy recalled that her father made the decisions, but they were well aware of it when her mother did not agree. She did not think that these disagreements were resolved. The only similarity she saw with how she and her siblings made decisions was that she could be more authoritarian in deciding, if she felt strongly about something. She saw the situation as one in which she and her brother and sister wanted to avoid problems, and tried to keep things low-key. Wendy thought that she steps up more than her husband when it comes to making decisions as a couple. She did not see any similarity with how she and her siblings made decisions. Wendy stated that she and her husband worked together on decisions regarding their children. She saw the same thing with her siblings in terms of working together.

Context factors for the Hill family included the situation when their father initially moved in with Ted's family after a fire at his home. This arrangement became permanent as a result of their father's stroke and developing dementia. Since he and his wife both worked, Ted had a caregiver come into his home. Later Ted began to use a day activity

program to relieve their elderly caregiver and to give him and his wife some respite. This was encouraged by Veronica and Wendy. They also encouraged the move to the AFC because they were concerned about their father's aggressiveness and the stress on Ted and Nancy. Ted made the move to the AFC in response to his father's wandering at night and his aggressiveness. All three mentioned aspects of maintaining a positive, supportive relationship with each other as important.

Family decision-making procedures were described in a consistent pattern by all three siblings. They made reference to regular communication and keeping each other informed:

Ted: "...I think the communications that we have is not just something just because of my father and my mother. It's been something there all the way through our life. Even growing up, even though there is quite an age difference, and I'm the youngest of the three of them. I think we have had good communication all the way through....I have always made it a point, ever since my sisters moved out of Michigan, to try to keep a close family contact...."

They all reported agreement on decisions about caregiving. In fact, Veronica and Wendy encouraged Ted to use the activity program and the AFC before he actually did so. The three of them shared responsibility for the care of their parents by the sisters sharing care of their mother for many years before their father required care. Ted then stepped in and handled the care of his father. Ted and Veronica saw safety and comfort for their father as important outcomes. Ted discussed the need to have a certain level of care available. The sisters were concerned about the health of Ted and Nancy and their marriage. Since their father had died, questions about subsequent decision-making were not applicable.

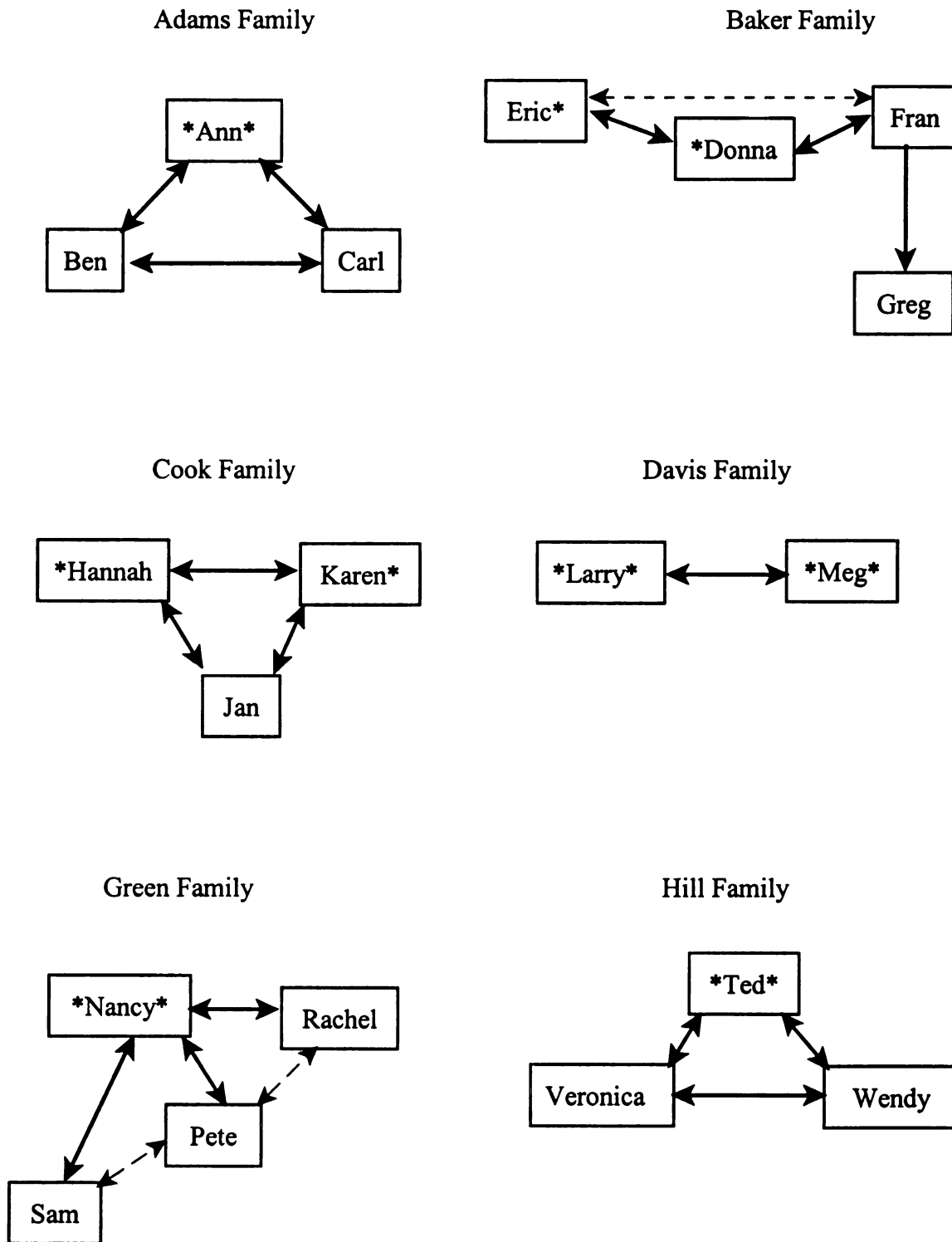
Summary of Family Decision-Making Experiences with Elder Care

Each family made a unique set of decisions, and each developed a slightly different process for doing so. All of the families reported a very consistent pattern in their decision-making processes as they progressed through various stages of elder care. Thus, decision-making patterns are presented for each family as a whole, rather than presenting each decision separately.

All of the family members described ongoing communication and discussion as the key to their success in making decisions. This appeared to make everyone feel involved, even when they did not have power of attorney or did not live close to their parent. In addition, all of the families described ways that they shared some of the responsibilities or were at least available as a support system for those who live in the area. Figure 4.1 depicts the patterns of interaction for family decision-making for each family. These are displayed together to illustrate similarities and differences. Medical and financial powers of attorney are noted. A higher level in the illustration indicates greater power or influence. Some family members had more influence as a result of specialized knowledge, age, or geographical proximity. All of the families reported little if any assistance from professionals.

Summary of Family Decision-Making Patterns

The conceptual map for this study (Figure 1.3, page 26) was constructed using several theories about family decision-making (Table 1.1, page 14). The original conceptual map reflects how evaluation and perception of prior decision-making by family members could influence the current context factors, family decision-making, and



*On left = Medical Power of Attorney
 *On Right = Financial Power of Attorney

Figure 4.1 - Patterns of Interaction for Family Decision Making for Each Family

the desired outcome. Current context factors could affect how family members evaluate and perceive prior decision-making. These factors also were seen as influencing family decision-making and the desired outcome. The degree to which the desired outcome was achieved was seen as influencing subsequent decision-making.

Prior experiences with decision-making occur in the family of origin, in marriage, and as parents. Prior decision-making experiences explored in this study included decision-making by parents of the participants (family of origin) and decision-making by participants in their marriage and in the parenting process, if they are married and if they have children. The influence on past, current, and future family elder care decisions as perceived by the participants is discussed.

Potential current context factors were depicted in the Theoretical and Conceptual Maps (see Figures 1.2 and 1.3 on pages 13 and 26). However, this study was too small for these factors to be a major focus. Instead, current context factors were studied and reported for further study. The responses of participants were summarized and coded. The primary categories of responses were found to be health of both caregiver and parent, functioning of parent, the ability to provide family care, emergency changes in care, availability of care, quality of care issues, costs and financial resources, sibling relationships, and time, distance, and proximity. These last three categories were especially important influences on whether family care was feasible, who had power of attorney, and who provided what assistance.

The family decision-making procedures that were studied were conflict, consensus, discussion, negotiation, change, and power. Shared responsibility was added because it appeared as an important aspect to which all of the families referred during the

interviews. The desired outcome in the conceptual map was related to maintaining quality of life for the family, including the elderly parent. Desired outcomes described by participants were summarized and coded. The categories that emerged were safety and comfort for the parent, the need for services (e.g., supervision, socialization, activities), the ability to afford care (affordable), convenience (location), quality of care (e.g., atmosphere, trained staff), caregiver concerns (e.g., stress, health), and carrying out the wishes of the parent. Subsequent decision-making included family decision-making by the siblings and decision-making in relevant areas, such as their marriage and their parenting. Both prior and new experiences also were seen as influencing subsequent decisions in the conceptual map.

Tables 4.2 through 4.7 displayed summaries for each family of member responses to each element of the conceptual map. The tables illustrated: (1) the influence of prior decision-making on family decision-making for these families; (2) the relevant current context factors; (3) family decision-making processes used by these families; (4) the outcomes the families hoped to achieve and how these related to quality of life for themselves and their parent; and (5) the influence families perceived these experiences would have on their subsequent decision-making. An analysis of these elements was included for each family.

Revised Conceptual Map

Revision of the conceptual map is an important aspect of this study. In the methodology section of Chapter Three, the use of a combination of pattern matching and analytic induction was discussed. It was pointed out that both pattern matching and

analytic induction use a conceptual model based on previous research and theory. In pattern matching a standardized method is used for data collection, and the model is changed when data analysis is completed. The method of data collection is not standardized in analytic induction. It changes with variations in the data, and patterns are used to change the conceptual map as they emerge. This study used a combination of pattern matching and analytic induction in that data were collected using a semi-structured interview guide to allow for a more conversational style of interviewing. Follow-up questions were asked. An analytic induction method was used to allow latitude and flexibility in using the interview guide. Pattern matching was used to identify patterns that supported the original conceptual map and a revised conceptual map was constructed.

Description of Revised Conceptual Map

Figure 4.2 is the original conceptual map and Figure 4.3 is a revised conceptual map based on the responses of members of the six families. The original map is presented here again for purposes of comparison. The revised conceptual map represents a summary of the findings described above. Any responses described in these findings in support of the original conceptual map are included in the revised map. Table 4.8 describes the sources for the revised conceptual map. Additions to the revised map that reflect the data are listed under “Yanca.” The narrative that follows explains how the responses supported the revised conceptual map.

Changes in the Structure of the Conceptual Map. The double arrow between “Evaluation of Prior Decision-Making” and “Current Context Factors” was changed to a single arrow because there was no evidence found in this study that would indicate that current context

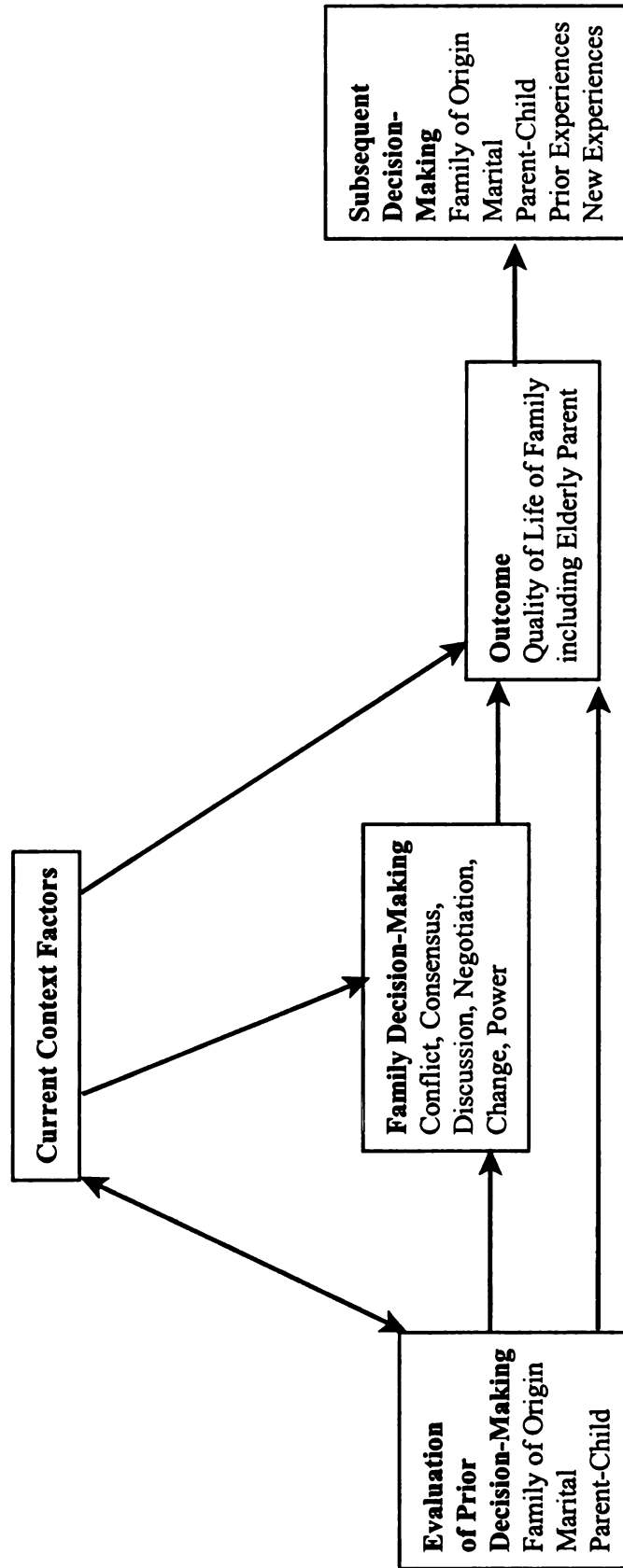


Figure 4.2 - A Conceptual Map of Family Decision-Making for Elderly Parents Suffering from Dementia

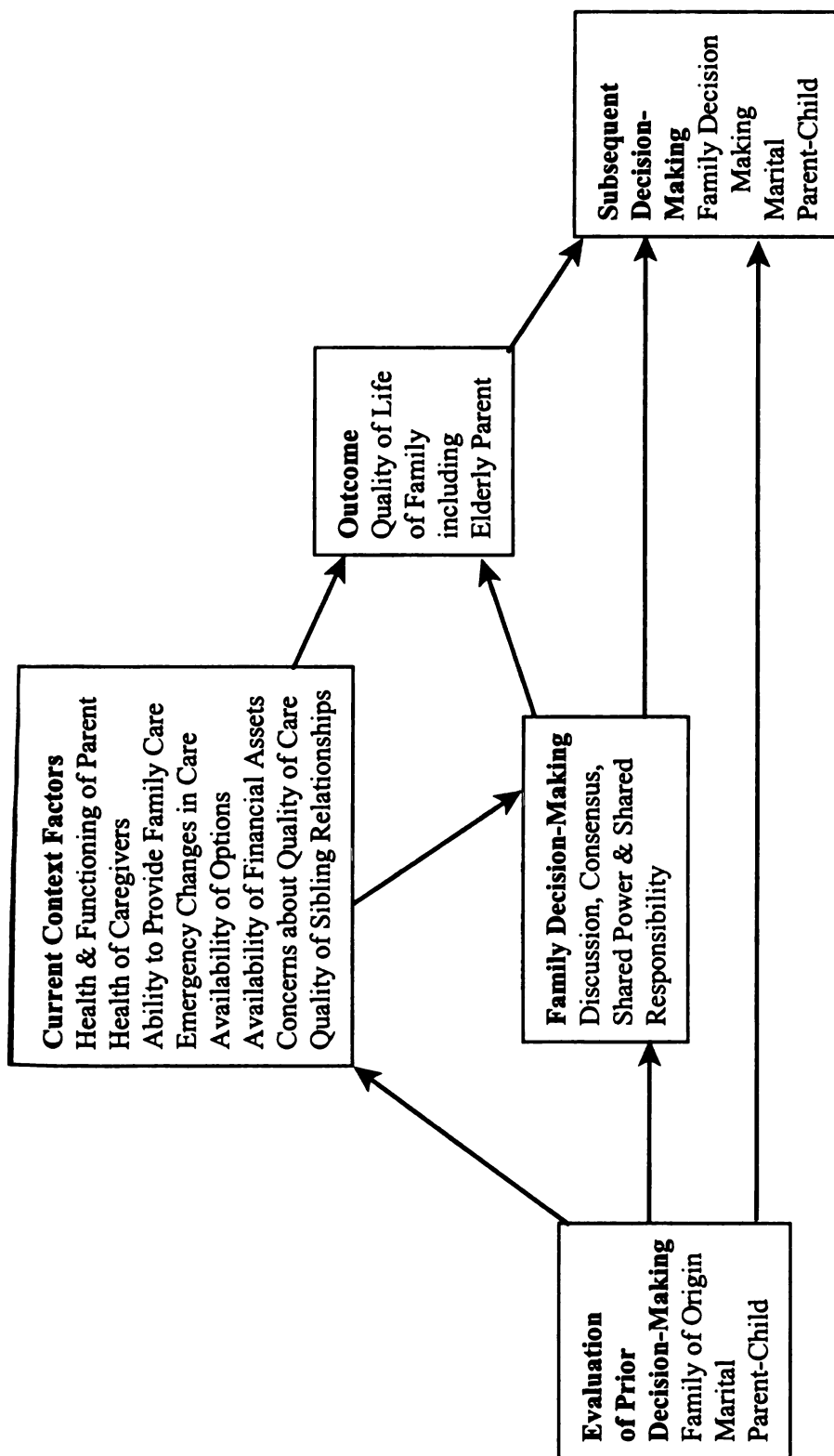


Figure 4.3 - Revised Conceptual Map of Family Decision-Making for Elderly Parents Suffering from Dementia

Table 4.8 - Sources for Revised Conceptual Map of Family Decision Making

Scanzoni & Szinovacz	Bubolz & Sontag	Paolucci, Hall, Axinn	Yanca
<u>Evaluation of Prior Decision Making</u>			
<u>Current Context Factors</u> <u>Household Characteristics:</u> Marital Status <u>Place in the Life Span:</u>	<u>Family Characteristics:</u> Structure, Socioeconomic Status <u>Individual & Family Attributes:</u> Needs, Values, Goals, Resources	Family Form, Age	Health & Functioning of Parent, Health of Caregiver, Ability to Provide Family Care, Emergency Changes in Care, Availability of Care, Quality of Care , Costs and Financial Resources, Sibling Relationships, Time, Distance, Proximity
Consensus, Discussion, Power		Style	Shared Power Shared Responsibility
<u>Outcome</u>	<u>Quality of Life</u> <u>Quality of Life of Other Humans</u>		<u>Quality of Life of the Family Including the Elderly Parent:</u> Safety & Comfort for Parent, Need for Services, Affordable Care, Convenience, Quality of Care, Caregiver Concerns, Wishes of Parent
<u>Subsequent Decision Making</u>			Family Decision Making

factors influenced the perceptions of the respondents regarding decision-making in the past. This possibility was considered before the data were collected. It was thought that negative feelings, such as guilt, might influence how participants perceived prior decision-making. For instance, a respondent might have perceived prior decision-making in a certain way in order to rationalize the decisions that were made about elder care. If this were the case, then one could at least expect inconsistency among the siblings with regard to decision-making between their parents. Thus, the high level of consistency in the descriptions of members from the same family indicated that their perceptions of prior decision-making did not appear to be influenced by current context factors. Perhaps this influence would have been uncovered with more specific questions about the relationship between current context factors and perceptions of prior decision-making. However, it was felt that this would have detracted from the primary purpose of the study.

An arrow was added from “Evaluation of Prior Decision-Making” to “Subsequent Decision-Making.” The influence of prior decision-making appeared to be fairly strong according to reports by the respondents. This was reflected in the number of areas that were “similar” or “same” under “Influence” in the tables for each family (Tables 4.2 to 4.7). This will be described in greater detail later. Prior decision-making influenced the desired outcome by the fact that one or more members of four families (Baker, Cook, Davis, and Green) mentioned carrying out parental wishes either by hearing their parent say what they wanted or by carrying out the plan that was made by the parent. This also was seen as influencing the family decision-making process to the extent that members understand what their parents’ wishes are. Thus, another arrow was added between “Family Decision-Making” and “Subsequent Decision-Making.”

Prior decision-making seemed to have an influence on subsequent decision-making according to the reports by the respondents. Participants with intact marriages or remarriages appeared to be satisfied with their marital decision-making process, as there was little indication of any intent to change how decisions are made. These changes in the revised conceptual map also reflect the fact that those participants who were still in a position of making decisions for their parent were universal in reporting their desire to continue using discussion and consensus in subsequent decision-making situations. In particular, those who saw a similarity between marital and family decision-making and were faced with future family decision-making were consistent about expecting to continue using discussion and consensus. Karen was the only participant who did not experience any direct relationship between prior decision-making and family decision-making. However, she reported an indirect relationship in describing her marital decision-making as the opposite of her family decision-making. She commented that if she and her former husband had used a similar process, they might still be married.

Taking a systemic approach, one might expect to find feedback loops running from various elements of the map to other elements. This would especially be the case for the influence of subsequent decision-making on various aspects of future decisions. However, instead of feedback loops, it is assumed that current decision-making becomes part of prior decision-making as time elapses, and subsequent decision-making becomes the current decision-making as new situations arise. Thus, time changes the position of each decision and will almost certainly change elements of the model, and perhaps the model itself. If it is the nature of systems to change over time, then models of those systems will also change.

Current Context Factors Identified by Families. “Current Context Factors” were discussed earlier under descriptions of elder care decision-making for each family. These were summarized and included in the revised conceptual map. Health and safety issues and the functioning of their parent were mentioned by all of the respondents. These factors were reported by all of the families as having an influence on the desired outcomes. The health of the caregivers was mentioned by Ted’s two sisters, and he was the only respondent who provided extensive family care in his home. All of the family members were working full time, raising children, and/or living out of state at the time that elder care began. This made it more difficult for them to provide family care in their home. Only one local family member (Ben) had a spouse that was not employed at the time elder care began. Ted was only able to work and provide family care by using a paid caregiver in his home. He also used an adult day activity program for respite. The fact that he is a teacher and his wife works 32 hours a week were important factors in having the time available to provide family care.

For all of the respondents, time, proximity, and distance were reported to be relevant issues in terms of the ability to provide family care and in the roles that each member played in providing assistance, having power of attorney or guardianship, and participating in carrying out decisions. In addition, all six families had at least one member who is employed either in the medical or human service fields. Thus, they were able to use the expertise of these members in acquiring knowledge and making decisions about care. All of the respondents expressed positive feelings about the way in which they were able to work together and reported placing a high value on positive relations with, or support from, their siblings.

Emergency moves, availability of care at the level needed, quality of care concerns, and the availability of financial assets were reported as important considerations in looking at elder care experiences. The Adams and Cook families described making decisions on an emergency basis, as circumstances forced them into unplanned moves. This meant that they had to settle for whatever bed was available, and they felt that they had little choice in the matter. The Baker and Davis families did extensive planning and were able to have options available by exploring them ahead of time. The Green family had time to explore options in their first move, but found themselves making another move because the facility was not able to manage their father's care needs. The move from the AFC to nursing home care resulted in concerns about the quality of care and led to a third move to the county medical facility. A bed was not available there when the move to the nursing home was made. The Hill family had placed their father's name on the waiting list for the AFC in Bay County. His name had come up once or twice before Ted moved his father there. None of the respondents reported using their own assets to pay for care. Having sufficient financial assets (or a long term care policy) on the part of the parent was apparently critical to having options in making care decisions. The AFC's in Saginaw and Bay Counties charged about \$3500.00 a month for a room on their memory care unit at the time of the interviews.

Decision-Making Processes Used by Families. The families recruited for this study were intended to be those who felt they were successful in making family elder care decisions. All of the families were consistent in reporting that they agreed with the caregiving decisions that were made. Thus, the "Family Decision-Making" portion of the conceptual map contains only two of the original procedures, discussion and consensus. It also

contains a modification of a third procedure. “Power” was changed to “shared power” to highlight the fact that all of the families reported sharing power in making decisions, even though powers of attorney or guardianship were held by an individual, except in the case of the Davis family. Finally, “shared responsibility” was added as a procedure that all of the families described in one form or another. As discussed earlier, these families reported that they were able to find ways for each member to make a contribution to the situation. Local family members provided the bulk of the tangible services. However, distant members provided such things as managing financial affairs or investments, providing information, and being a support system for their siblings. Most of them also made trips back to Michigan to visit and to assist in planning and/or making moves.

None of the families reported a conflict arising in their family decision-making regarding elder care. The Cook family experienced some discomfort with the situation at the county medical facility. However, there were no indications of any disagreement over the original decision. Rather, concerns were raised regarding the quality of care, which led to a decision to move to another facility. Some members of the Green family reported concerns related to selling the family home, but they reported that this was resolved before a disagreement arose. None of the participants described any procedures that could be coded as negotiation or change.

The combination of on-going communication (discussion) along with sharing power and responsibility seems to be the key for these families in reaching agreement (consensus) regarding decisions for their parents. Half of the families either split the two powers of attorney (Baker) or guardianship and conservatorship (Cook) or had joint power of attorney (Davis). The other three had sole power of attorney in the hands of one

sibling, but those who were appointed expressed a strong desire to share that power with their siblings. The reasoning behind this generally had to do with feeling an ethical responsibility to include all of the siblings in these decisions and not wanting to be left alone in making and carrying out the decisions. Most participants reported feeling that it was important to work together and to reach an agreement without undermining their positive relationship with each other.

Outcomes Desired by Families. According to the respondents, there was strong support for outcomes reflecting a desire for good quality of life for the parent. All of the respondents mentioned safety as a primary consideration in decisions about care. Fifteen mentioned comfort, atmosphere, or socialization as desired outcomes. Three specifically talked about having a convenient location, although all of the local family members selected facilities in their community. Four respondents expressed concern about the needs of the caregivers. It is not entirely clear the extent to which outcomes would influence subsequent decision-making. However, it is logical to assume that if the family decision-making process resulted in the desired outcome, family members would want to continue using that process. On the other hand, if the process resulted in something other than the desired outcome, family members would have either experienced conflict or they would have sought to change the process by which decisions were reached.

Subsequent Decision-Making. Decisions from the family of origin, prior experiences, and new experiences were left out of the revised conceptual map for “Subsequent Decision-Making.” There was no evidence that these were factors involved in subsequent decision-making. Family decision-making was added because there was strong support for subsequent family decision-making regarding elder care being influenced by prior

decision-making and by family decision-making experiences.

Influence of Prior Decision-Making on Family Decision-Making

According to the respondents, decision-making in the family of origin by the participants' parents provided the least amount of influence from prior decision-making. There were some differences in recollections among the members of several families. Some of these differences may have reflected the long period of time since these situations were experienced and the fact that the participants would have been children and teenagers. Some differences may have been a result of age gaps between older and younger members of the family.

As noted earlier, there was a discrepancy in the description of decision-making in the family of origin for the Adams family. However, Ann qualified her description by saying that her mother "probably" made most of the decisions. Ann also stated that she was gone most of the time beginning at age nine, when she began working as a babysitter. Carl seemed to feel that his parents might have been different when he was growing up since he is fifteen years younger than his brother. Ben and Carl both felt that decisions were made jointly by their parents with discussion.

In the Baker family, Eric could not recall how his parents made decisions. His sisters agreed that their father made the major decisions. All three felt that their decision-making was similar to their father's in terms of planning ahead. No one in the Cook family saw any similarity with their parents' decision-making.

The Davis siblings were raised by their widowed mother. There was some discrepancy in both the Green and the Hill families in the perception of decision-making by the participants' parents and in the perception of similarity with family decision-

making. Nancy recalled that her mother made the decisions and her father was “laid back.” She saw a similarity between herself and her father in being non-confrontational. Pete on the other hand remembered his parents’ decision-making as joint, but also said that his mother made decisions in the home and his father outside of the home. Rachel was actually in between these two perceptions, reporting that her mother appeared to be dominant, but that her parents actually used discussion and joint decision-making. For the Hill family, Veronica saw her father as dominant when he was home, and her mother made decisions regarding the children. Wendy saw her father as making the decisions. Ted thought his parents’ decisions were joint, but did not recall any discussion.

Only five participants (Ben, Carl, Pete, Rachel, and Ted) saw a similarity between decision-making by their parents and that which they and their siblings used. Seven saw no similarity (Ann, Hannah, Jan, Karen, Meg, Veronica, and Wendy). The rest saw some similarity in how one of the parents approached decisions in the use of planning (the Baker family), keeping records and investigating (Larry), and being non-confrontational (Nancy).

Most of the similarity between family elder care decision-making among siblings and prior experiences with decision-making was reported with marital decisions. Fourteen of the participants were married, remarried, or widowed. Twelve of these saw similarity between their marital decision-making and their family decision-making. The other two participants (Nancy and Wendy) did not see a similarity. The two participants who are divorced and have not remarried (Karen and Rachel) saw no similarity and as mentioned, Karen saw her marital decisions as the opposite.

Parental decisions also were reported as similar to family decision-making, but

not to the extent of marital decision-making. Fourteen participants have children. Rachel, who is divorced, did not respond to the question about how she and her husband made decisions as parents, but indicated that there was no similarity with family decision-making. Eight participants (Carl, Donna, Fran, Hannah, Meg, Pete, Ted, and Wendy) saw similarity and five (Ann, Jan, Larry, Nancy, and Veronica) saw no similarity. Two of these latter participants are mothers who reported that they made the parenting decisions and one (Larry) reported that his wife did so. The other participant (Jan) described parenting decisions as joint with discussion, but she did not see how this influenced family decision-making. Thus, according to reports by respondents, the strongest support for prior decision-making influencing family elder care decision-making came from marital decision-making. They reported parental decision-making as having an influence, but it was not as strong as marital.

Summary of Findings

The six families studied were predominantly middle class. Most had intact marriages or successful remarriages. Most were well-educated and had professional or “white collar” occupations. All six families had at least one member with a background in the medical or human services area. Half were making decisions for their father and half for their mother.

The interview data indicated that these families were in various stages of their caregiving experience. The Cook and Hill families had both parents deceased and had completed caregiving for their biological parents. The Green family described their father as totally incapacitated and bed-ridden. He could not feed himself or assist in any of his

care. Thus, they were in the very last stages of caregiving. The Baker family's father was ambulatory, but needed assistance with the rest of his care. He was still feeding himself, but was beginning to have difficulty. He was also beginning to show signs of difficulty with ambulation. So, he was entering the later stages of care. Both the Adams and the Davis families appeared to be in the middle stages of care. Their mothers were ambulatory with walkers and were able to feed themselves. They needed assistance with dressing and personal hygiene.

The families recruited for this study were self-identified as being successful in family decision-making regarding various aspects of elder care. The findings indicated that all six families were very successful in working together and making decisions. The participants reported regular communication and discussion and reaching consensus as the procedures they used in reaching decisions. There were no indications of negotiation or changing positions because they did not report experiencing conflict. They either talked things out ahead of time or had limited options due to the need to move their parent quickly. Most respondents identified maintaining good relations with their siblings as important. Power was shared either formally or informally. Formal power sharing occurred in half the families. One split the powers of attorney between two members, one split guardianship and conservatorship, and one family had joint powers of attorney. The other three families had one member with both powers of attorney, but those members reported going out of their way to include their siblings in making decisions, and this was confirmed by their siblings. Each family member found a way to make a contribution to the responsibilities either directly or indirectly. While responsibilities were not equally shared, the contribution of those with less responsibility

was valued by those with more.

Important context factors that emerged from reports by the respondents included factors related to the parent, factors related to the elder care situation, and factors related to the ability to provide family care. Health, safety, and level of functioning of the parent were mentioned by all of the respondents. Factors related to the elder care situation included emergency changes in care, the availability of options, financial assets, concerns about the quality of care, and the desire to maintain positive relationships with siblings. Factors related to the ability to provide family care included concerns about the health and well being of the caregivers, the time available for caregiving, and distance from or proximity to the parent. Employment and child rearing appeared to be important factors in the availability of time. Those family members who did not live in the area were all living out of state, with the closest being 700 miles away. All family members living in the area reported participating in decision-making and some aspect of care, but all were employed or engaged in child-rearing or both.

Most family members reported expected outcomes that were focused on the safety and comfort of the parent. A few expressed a concern for the needs of caregivers or the fact that the location was convenient. Several mentioned a desire to carry out their parents' wishes.

The responses of the participants indicated strong support for the influence of prior decision-making experiences on family decision-making regarding elder care. The strongest influence was reported from experiences with shared decision-making as spouses in successful marriages. Some influence also was indicated from experiences with making decisions as a parent. Decision-making by participants' parents (family of

origin) was seen as having the least influence. Most of this influence was related to the actions of individual parents in planning ahead. Thus, there was not clear support for the development of a family pattern regarding family decision-making. Instead, it appeared that these family members used experiences in their adult relationships (marital and parental) as models for working together with their siblings.

All respondents expressed satisfaction with the process that they used with their siblings. Those who were in a position to make decisions in the future expected to continue using discussion and consensus.

CHAPTER FIVE

DISCUSSION

This study offered good support for the methodology that was used and answered a number of the research questions posed. The first part of this discussion is focused on the design and methodology of this study. This is followed by a discussion of demographic data and the three sets of research questions: descriptive, interpretive, and theoretical. Reflections, implications, and conclusion make up the final three sections.

Discussion of Design and Methodology

A number of findings supported the study design and methodology. Theory triangulation resulted in support for a revised conceptual map that reflected elements of the three main theories used to construct the original conceptual map. Method triangulation yielded a high level of consistency of responses within families regardless of whether the interviews were in person, by telephone, or by e-mail. Data triangulation was accomplished by interviewing all or most members of each family and by using families that had different experiences with the use of various forms of care and were at different stages of their caregiving experience. Thus, triangulation accomplished the purpose of increased validity while also providing more richness to the material.

Table 4.8 identified sources for the revised conceptual map. In terms of theory triangulation, the findings supported the use of elements of the three theories from Bubolz and Sontag (1993), Paolucci, Hall, and Axinn, (1977), and Scanzoni and Szinovacz (1980). The greatest support was for the use of Scanzoni and Szinovacz's theory. This would be expected since their theory was the foundation for the decision-making

component of this study. The modified version of Paolucci, Hall, and Axinn's (1977) chain theory as the basic structure for the original map also was supported.

Only a small portion of Bubolz and Sontag's (1993) theory was used in the original map (see Family Decision-Making, Quality of Life, and Quality of Life of other Humans on Theoretical Map, Figure 1.2, page 13). The findings showed strong support for the families' desires to maintain an acceptable quality of life for their parent and some support for their concern about quality of life for caregivers. The adult sons and daughters alluded to quality of life issues for their own families when they discussed reasons family care was not available (employment and/or raising children). Several of the context factors described by the families, along with the demographic data, could be summarized under "Family Characteristics" and "Individual Characteristics" from Bubolz and Sontag's (1993) theory in Table 1.1 (Theoretical Map). The successful use of theory triangulation increases confidence in the data, the analysis, and the findings of this study.

The use of multiple methods was the second form of triangulation. The consistency in the responses of family members was very high. Family members consistently validated the descriptions by primary respondents of family elder care decision-making along with other aspects of the caregiving experience. There was less validation of perceptions of decision-making by parents in the family of origin. However, the passage of time and the age disparity between siblings in several families may account for some of these discrepancies. Overall, these findings were consistent with Fisher and Lieberman's (1996) finding of moderate correlations for family appraisals between offspring and in-laws.

There were no discernable differences in the content and the quality of the data

that were collected in person, by telephone, and by e-mail. There were, however, two differences in the e-mail response. First, the responses were generally shorter than those given in person and by telephone. This may be due to the greater time and effort required in typing responses. It also may be due to the fact that the interview guide was preformatted to specifically address the types of decisions that had been identified by the primary respondent. In addition, follow-up questions were not used as they were with the more conversational style of the other interviews. The second difference was that all of the questions were more likely to be covered directly in the e-mail interview. The use of the interview guide and a conversational style for in-person and telephone interviews led to some questions being answered through discussion rather than separated into distinct responses. In some cases, the actual question was not asked because it would have been redundant. For some interviews, one or two of the minor questions were overlooked.

The mixture of modified versions of analytic induction, pattern matching, and grounded theory as methodological strategies also was beneficial. This was a second form of method triangulation. As in analytic induction, the use of an interview guide with open questions and a conversational style meant that data collection was not standardized. In pattern matching the conceptual map is changed only after the data are collected and patterns are noted. This was the approach used in this study, and it yielded substantial support for many components of the original conceptual map. In terms of grounded theory, findings supported key elements of the three theories that were included in the conceptual map. In addition, the consistency in the responses of family members indicated that the data collected were exhaustive for these families.

Data triangulation was accomplished by using multiple sources in each of the

families and by using families that had a variety of experiences with using various forms of elder care. Families had made decisions about the use of family care, adult day care, corporate and family-based AFC's, assisted living, nursing homes, and county medical facilities. They also had to make financial and medical decisions. Two families who have completed care were included with families who were still involved in making elder care decisions. A marital couple with two different family experiences was included. Thus, there was a rich cross-section of experiences represented.

As discussed in Chapter Three, investigator triangulation could not be included. However, the remarkable consistency of both intra-family and inter-family responses made it less likely that investigator bias would skew the findings. In addition, the exploratory nature of the study means that the findings are not intended to prove something or to be generalized, but to discover what is happening in families that are successful in making elder care decisions. The use of other forms of triangulation also compensated for the lack of investigator triangulation.

Discussion of Demographic Findings

Five of the six families in this study used powers of attorney to execute decisions for their elderly parent. The one family with guardianship and conservatorship did so as a result of the sudden death of their father, who had been caring for their mother. She lived less than a year after his death. The use of power of attorney gave these families much more flexibility and leeway in making decisions. Guardianship and conservatorship require court involvement and oversight, with extensive reporting and limits on independent decision-making. The result is a much more formal system with

accountability primarily to the court. This more formal process may be necessary in situations involving conflict in the family, but it could be restrictive for families who are able to work together. Exercising power of attorney does not require this formality. These families could exercise decision-making power among themselves and were essentially accountable to each other and their own consciences.

Only one family member lived in the area and did not work full-time. However, she worked part-time and was raising children. Only one family member used family care to any extent, and he hired a caregiver to come into his home and later used adult day care. He was the only family member who reported any change in living arrangements. Other families used paid care in the parent's home for varying lengths of time. All of the families eventually used residential or nursing home care. None of the respondents reported a substantial change in their work schedule. Checkovich and Stern (2002) found that full-time employment and distance were significant factors in decisions about how much care to provide. Earlier, Wolf and Soldo (1992) found no evidence of reduced propensities to be employed or changes in work schedules for married women due to the provision of parental care. At the same time, studies by Moen, Robinson, and Fields (1994) and Robison, Moen, and Dempster-McClain (1995) found no evidence that increased work force participation by women decreased caregiving responsibilities.

All of these family members were middle class, and most have levels of education beyond high school. Checkovich and Stern (2002) found that a higher level of education by the parent was related to less care being provided and was apparently related to greater financial resources. Statements from several family members indicated that the availability of financial resources made it easier to reach decisions to use elder care. This

also is consistent with Goldscheider and Lawton (1998) who found having a college education had a negative effect on support for co-residence with an aging parent. At the same time, they found that college-educated parents were just as willing to help their children as were those less educated. The authors saw this as supporting Caldwell's (1982) wealth-flows transition argument in which family members who were more educated were expected to be in the forefront of this transition. They were expected to invest more strongly in their children than in their aging parents. However, this study did not necessarily support Goldscheider and Lawton's view. Instead, it appears that affluence, the availability of parental assets, and parental wishes were strong influences on the decision to use paid care as opposed to co-residence.

The size of the sibling group did not seem to influence the decision-making process itself, although one family with four siblings had a member who did not participate. The other family with four siblings had a member who declined to participate in the study, but was involved in family decision-making. In addition, while the impairment of the parent was a factor in deciding to place the parent in a residential setting, it did not seem to change the decision-making process. This is similar to Smerglia and Deimling's (1997) findings that the size of helping or decision-making networks was not an important factor in decisions about care, nor was the level of dependence and cognitive impairment of the care receiver.

For participating families, three members were born in the 1930's, nine in the 1940's, six in the 1950's and one in 1960. Thirteen out of the nineteen were born between the end of World War II and 1960. People born during this period are often referred to as "baby boomers." At least one member of every family is in this group. Thus, the sample

represents a glimpse into how this large generation might be coping with elder care decisions.

An interesting demographic was the fact that all six families had parents who had intact marriages with an average number of offspring just over three. For the seventeen respondents, there was an average of two offspring. Three had no children, three others had one, and five had two. This means that over one third of these respondents will either have no offspring to care for them or only one. Almost two out of three will have two offspring or less. For these families, if one of the spouses develops an impairment, the potential for caregiver burden for their offspring will be greatly increased unless a cure for various forms of dementia can be found.

The effects of parental divorce on elder care decision-making was not a factor since there were no divorces or remarriages for the elderly parents. This was different than the findings of Allen, Blieszner, Roberto, Farnsworth, and Wilcox (1999). In their sample, one-third of older adults and over three-fourths of their adult children had experienced pluralism in family structure, including divorce, remarriage, single-parenthood, non-marital parenthood, and long-term cohabitation. In this study, there were no divorces among the care receivers. There were no divorces for twelve of the sixteen participants who had married, and only one divorce for each of the other four participants. The great majority of participants had experienced conventional family structures with intact marriages. The effects of pluralism on family decision-making was reduced in this study since the majority of respondents had experienced conventional family structures. Increases in the rates of divorce and remarriage in society mean more uncertainty for the future of family care and decision-making.

Discussion of Descriptive Findings

This portion of the discussion will focus on the descriptive research questions listed in Chapter Three. The primary areas covered by these questions are summarized as: 1) how selected families make elder care decisions; 2) contextual factors that influence decisions; 3) expected outcomes; and 4) helpful and difficult circumstances. Management of conflicts or disagreements is included under the first section and in the findings in Chapter Four.

How Selected Families Make Elder Care Decisions

The description of family decision-making procedures by respondents indicated that these families were successful at making elder care decisions because they used a strong, ongoing communication system to keep each other both informed about, and included in, decision-making. This developed into an ability to discuss the situation at hand and reach an agreement or consensus. In some cases it also led to planning for future decisions. This was consistent with Lieberman and Fisher (1999) who found that families that used positive conflict resolution methods provided significantly more help than families that did not. The families in this study seemed to place a high value on working together and on preserving positive sibling relations. In some cases, motivations for doing this were highly altruistic. For instance, two of the participants discussed the fact that they felt it was only fair to include their siblings because the parent was a mother or father to each of them. Most said that it was critical to have assistance in making these decisions and carrying them out together because it would be overwhelming to do so on their own. A study by Dwyer, Henretta, Coward, and Barton (1992) concluded that cooperation among siblings was an important factor in the initiation and continuation of

help by offspring. Mittelman, Ferris, Shulman, Steinberg, and Levin (1996) found that cooperation within the family system was important in diminishing the negative aspects of caregiving while enhancing the positive, supportive aspects.

All of the participants expressed appreciation and gratitude for being able to reach an agreement about elder care and handling their parents' affairs. They all reported being in agreement with the caregiving decisions that were made. Even though it was intended that the sample would be families who felt they were successful, the apparent absence of conflict was not expected and would be very unusual. The fact that every member reported the absence of conflict or disagreement would indicate little if any conflict was present. Perhaps this was related to the affect around these decisions. Feelings of concern about the parent might lead some of the participants to be relieved that their siblings were carrying out decisions, and they did not want to create conflict. They might feel that as long as someone takes leadership, everyone is happy, and no one wants to create waves. It is interesting that Smerglia and Deimling (1997) found that satisfaction with decision-making was related to adaptability and the absence of conflict. This implies that it is possible for families to work together and not have conflict or manage it in such a way that it is not considered a significant barrier in their relationships.

The families' reports of relief at not experiencing conflict was different from the findings of Fisher and Lieberman (1996), who found that family avoidance of conflict was related to increased caregiver stress. Apparently the reasons for the lack of conflict may be the important difference. In this study, family members reported managing conflict by using extensive communication and discussion and by including other siblings in the decision-making process. However, avoiding conflict as a means of managing

conflict may increase stress. This could account for the discrepancy with Fisher and Lieberman's findings.

These families also reported finding ways to include everyone in decision-making, even when the powers of attorney were held by only one family member. The family members with these powers reported making an effort to avoid unilateral decision-making and reached out to maintain good communication with siblings. When emergency situations arose, they may have had to act on their own. However, the family member had either prepared the siblings ahead of time or made the decision and then kept the siblings informed of the situation. Even when unilateral decisions were made, a sense of shared decision-making was maintained. This also was contrary to the findings of Fisher and Lieberman (1996). They found that families who use a single member to make decisions with input from others provided more help than those who used a more democratic method that may have been more disorganized. The families in this study did not use a democratic method per se, but used consensus. They were well-organized and went out of their way to share decision-making power. The key factors were communication and a strong desire to work together and be inclusive. Another important factor was a feeling on the part of most siblings who lived out of state that one aspect of their role was to provide emotional support for siblings who lived in the area. Horowitz (1985) found that emotional support from siblings mediated strain felt by caregivers. It is possible that this role limited those siblings in raising issues that might lead to conflict, or they may have felt some obligation to agree with decisions, even when they may have been inclined to disagree. However, four of the families had more than one sibling living nearby, and yet they still reported an absence of conflict.

In addition to sharing decision-making power, these families reported finding ways for everyone to have some responsibility or role. Those who lived locally clearly bore the brunt of caregiving and executing decisions. Those participants who lived out of state recognized this and seemed to genuinely appreciate their efforts. Some of these distant siblings provided knowledge and expertise on the disease or on resources. Others managed financial affairs or investments. These contributions tended to be valued more by local siblings than by those who were making them. Local siblings seemed to feel that an important part of their burden was lifted, especially in terms of time and having fewer things to worry about. It also was important for local siblings to feel that they were not alone in handling all of the responsibilities and decisions.

It appears that the families in this study developed models for sharing responsibilities and decision-making that are variations of those identified by Keith (1995). She identified the primary caregiver model as the most common, featured by one person handling all or most of the responsibility. None of the families in this study displayed this model. Instead, the families displayed caregiving models that resembled combinations of Keith's partnership and team models. She described her partnership model as two offspring of the same gender contributing relatively equally to caregiving and equal in authority and responsibility and in making and implementing decisions. Other siblings may be involved, but their roles were limited. Keith described her team model as siblings who perceived themselves to be organized in an integrated, planned system of care. Siblings shared responsibilities by taking on certain roles rather than sharing roles and the workload equally. However, Keith saw the purpose of the team as protecting each other from a difficult parent.

There were some indications of Keith's (1995) primary caregiver model in terms of caregiving tasks, responsibilities, and decision-making in the Hill family. However, the siblings actually split the responsibilities of caring for both parents by having the daughters care for their mother, and the brother provided care for their father when he became impaired. Thus, the daughters formed what appeared to have been a partnership model in caring for their mother and the brother became the primary caregiver for his father. However, the overall family caregiving system looked more like a team, but without the element of protection from a difficult parent.

The families in this study displayed several elements of Keith's (1995) partnership and team models. The Davis family was very close to being a partnership, except that they tended to have specific roles in certain areas. They also were different than families in Keith's sample in that they are brother and sister in a two-sibling system. Keith saw partnerships as consisting of sisters in larger sibling systems. Her two-sibling families were almost exclusively sisters (one pair of brothers) that maintained a primary caregiver system with half of them reporting negative feelings over perceived inequities in the work of caregiving. The other five families in this study seemed to act like the partnership model when it came to making decisions, but they included three siblings of mixed gender, unlike Keith's sample that had only two females. The families reported making an effort to include everyone in decision-making, and several members with power of attorney or guardianship indicated that they would not make a decision that was opposed by other siblings. These families also appeared to act like the team model when it came to roles, responsibilities and implementing decisions, but unlike Keith's sample, there were no indications of a need to protect each other from a difficult parent. They tended to

divide these activities according to availability and expertise, and maintained these arrangements rather than sharing or trading them.

A strong feeling of trust was mentioned by several respondents. While the issue of trust was not explored specifically, it is speculated that efforts to maintain regular communication and to include everyone in making decisions were essential ingredients in building this trust.

It was interesting that these families reported no conflict even with respect to financial affairs. It was probably helpful that none of the families reported having to contribute financially to their parents' care. However, it was clear that nearly everyone incurred expenses in terms of long-distance telephone bills, travel, and the time, energy, and expense of providing assistance. There were no negative feelings expressed about any of these expenses, even when it appeared that one sibling might be bearing more of these costs. In addition, there were no indications of concern about inheritances being lost or spent. This seems remarkable given the fact that it is well known that some families have been torn apart by this issue. In fact, some participants mentioned that they knew or were related to someone who experienced terrible disagreements over an inheritance. Perhaps these families were able to avoid this to some extent because their own economic status was solidly middle class. They had clearly set aside money as an issue between them. Some of them gave some insight into this by indicating that their primary concern was the care of their parent. Some also gave indications that they felt their parents' assets should be mainly used for their parents' care. This may be part of a value system or a life philosophy that made a difference for these families. There was nothing found in the literature that directly related to this observation.

The two families with four siblings had one member either not participating in the decision-making or declining to participate in the study. A description of the latter family member indicated that he was a lot like his father, who was inclined to go along with others in decision-making. Thus, all five families with more than two members had an active decision-making system of three siblings. The smaller size lends itself to reaching an agreement. More family members means more potential for at least one member to disagree. It also means that it is more likely that at least one member will opt out of the process. While larger families may have more members who could assist with care, they also require a more complex communication system, and the chances of factions arising increases with greater size. The aim of uncovering the effects of family size on decision-making was not met, even though the sample was almost ideal in configuration. Keith(1995) also experienced situations in which a sibling was uninvolved or declined to participate, but it was not clear if there was any pattern with respect to family size.

These families consistently reported reaching an agreement about elder care without conflict. As a result, they did not describe using negotiation and change as procedures for managing conflict. These procedures would be expected in families that experienced conflict, but were able to successfully manage it and make decisions. The sample was intended to be limited to families who felt they were successful in making elder care decisions together. It was expected that most of these successful families would experience at least some disagreement at some time during their decision-making, but they would find ways of managing the conflict. However, the families that presented themselves for this study did not report this. Perhaps the families in this study did experience conflicts that were managed, but forgot it or chose to not report it. If this were

the case, it is equally remarkable that no one offered any indication of disagreements, and everyone maintained the same position. It is possible that those who had experience with managing conflict were less likely to voluntarily come forward for fear of “rocking the boat.” Or, they may not have wanted to risk exposing their disagreements to an outsider. In any case, this study demonstrated that siblings can build a system for making decisions that facilitates agreement and consensus if they use good communication, shared power, and shared responsibility.

Contextual Factors That Influence Decisions

Contextual factors that influenced decisions also were covered in the findings. Of note was the fact that the overwhelming concerns reported by these families revolved around the elder care situation and the difficulties in finding suitable care. Very little assistance was provided by professionals. For the most part, the families were on their own in securing proper care. This included making decisions about the appropriateness of the setting for their parent. The fact that every family had at least one member with a medical or human services background meant that there was at least one member who had some knowledge about human services. It is of some concern to think about other families who do not have this kind of expertise available. There are some information and referral services that are becoming available in major metropolitan areas, usually for a fee. However, in other areas these services are not available. It is a matter of searching through the telephone book or relying on word of mouth. For families in these circumstances, it is clear that what is needed is access to assessment of care needs, a system for tracking the availability of beds in various settings that will meet various needs, and a system for assisting families who are faced with emergency or crisis

situations that require immediate placement in an appropriate setting. Immediate placement is unlikely to be available unless the care receiver is hospitalized.

Unfortunately, in order to receive assistance from medical professionals in arranging an emergency placement, the family may have to force the issue by refusing to take their member from the hospital when a discharge is scheduled, but a discharge plan is not completed.

An interesting pattern was noted with regard to distance and proximity. All of the Michigan siblings in the study were within twenty miles of their parent at the time care began. At the time of the interview, these siblings were within fifteen miles, and most were less than ten. On the other hand, those who lived further than fifteen miles were all out of state. They were living in California, Nevada, Florida, Alabama, North Carolina, Pennsylvania (Philadelphia), and Sicily. This represented a dichotomy of siblings living either very close to the parent or at a long distance. The next closest sibling beyond fifteen miles was at least 700 miles away. This is an interesting pattern, and at the very least, shows that families can be successful at working together even across great distances.

Expected Outcomes

The expected outcomes were described in Chapter Four. Reports of desired outcomes generally related to concerns about quality of life for the parent. Fewer responses reflected concerns about quality of life for the family. Respondents mentioned the need for availability and convenience, but this was not over-emphasized. However, there were some indirect indications of concerns about quality of life for the family in other areas. For instance, family members who worked full-time were not expected to

quit work to care for their parent. Those who were raising children were not expected to move their parent into their home to care for him or her. In fact, several parents had expressed a desire not to live with their adult sons and daughters or become a burden to them. Others may not have said this directly, but had made plans to receive care in other ways by arranging for financial resources, purchasing long-term care insurance, or indicating some of their wishes through consent documents.

Issues regarding quality of life for participants and their family of procreation were not mentioned by participants for themselves. However, one might speculate that this contributed to consideration of various options as decisions about care were made. The situation with the one family that provided extensive family care provided some insight into the experience of living with a parent suffering from dementia. The caregiver described the stress of having high demands on his time, but also feeling guilty when he took time to do something when he could have been at home. He described loss of sleep when his father was up at night. He also had to go after his father when he left the house at night. His sisters expressed concerns about the stress that he and his wife were experiencing. His wife felt that he was overburdened and under too much stress. In the end, he decided to make the move into an AFC after his father hit him. These were glimpses into the deterioration in quality of life that many families face when they engage in family care.

Helpful and Difficult Circumstances

Questions about what was helpful or made decisions about elder care difficult seemed to confuse the respondents more than they yielded any new information.

Participants tended to reiterate information related to contextual factors, especially those

related to finding appropriate care, planning ahead, and having financial resources. Difficulties were mentioned associated with moving one's parent out of his or her home, taking away a driver's license, or watching their abilities decline. Thus, these questions did not serve their intended purpose of uncovering positive or negative aspects of the decision-making process.

Discussion of Interpretive Findings

This discussion focuses on the effects of prior decision-making on family decision-making regarding elder care and how family decision-making and outcomes can influence future decision-making. The families also were asked about important factors that influenced decisions and what outcomes the family wanted. These questions did not result in any discussion of the importance of the decision-making process or of the outcome. Instead, respondents talked about the circumstances and the product of their decision (outcome).

The Effects of Prior Decision-Making on Family Decision-Making

According to the respondents, decision-making in marriage and as parents had a strong influence on the process of family decision-making in elder care. The strongest influence was reported with marital decision-making. Participants generally saw a great deal of similarity between their marital and their family decision-making with their siblings. This may be due to the fact that one's spouse and one's siblings are generally in a similar age group, so similar patterns of decision-making might be used with each. It also might reflect similarity with respect to socioeconomic status. Most participants who had successful marriages or remarriages described their marital decision-making in terms

that related to discussing decisions and reaching a joint agreement or consensus. Even those who did not describe this expressed a desire for it. One respondent saw herself as the more dominant decision maker, but wanted her spouse to be more involved. The other saw herself as preferring to have her husband make the final decision, but using discussion and agreement. Similar results were seen with parental decision-making, only these were not as strong, mainly due to husbands deferring to wives in child-rearing situations. These findings appear to be new. There were no studies found that investigated a relationship between family elder care decisions and decisions siblings make in their marriages or as parents.

There was less similarity reported between decision-making by the parents in the family of origin and family decision-making by siblings. Most of the parents had marriages that respondents described as one partner being dominant or decisions being split along gender lines. For most of these family members, their mothers made child-rearing and household decisions and their fathers made decisions outside of the home. For participants, there was some indication of similarity with this latter arrangement in their own marriages. As noted, some husbands were more likely to defer to their wives in child-rearing decisions. The overwhelming majority of respondents reported a form of egalitarian decision-making in their marriage. This was different from the recollections of most participants regarding their parents' marriages. Again, no references to this were found in the literature.

The Influence of Family Decision-Making and Outcomes on Future Decision-Making

There was strong support reported for family decision-making by siblings influencing future experiences with decision-making for parents. All of the families

reported positive feelings about their ability to communicate and discuss decisions, reach an agreement, and share power and responsibility. Thus, all of them expressed satisfaction, appreciation, and gratitude for being able to do so. Some felt that the process had actually made them feel closer to each other. Those who were still involved with elder care decisions expected to continue to use this process. There were no indications that family decision-making influenced future marital decision-making processes directly. However, some participants alluded to the need to make one's wishes known regarding elder care and resuscitation. They also mentioned the need to set up wills, trusts, and powers of attorney ahead of time. In terms of the influence on future parental decision-making, only four participants were still raising children, and only two of those had children below age twelve. So, little if any effect could be expected. However, as discussed earlier, one respondent felt that her experiences with her siblings influenced how she and her husband made parenting decisions. The finding that prior decision-making influenced expectations about subsequent decision-making was consistent with Scanzoni and Szinovacz's (1980) theory.

The influence of expected outcomes on future family decision-making was not readily apparent. However, it is assumed that satisfaction with the outcome would lead to continuing to use the same decision-making process. On the other hand, dissatisfaction with the outcome would tend to create conflict or a change in the way decisions are made. Since families expressed satisfaction with the process and an intention to continue using it, this would indicate that the outcome reinforced continuing with the same decision-making process for future decisions. These assumptions would fit with Scanzoni and Szinovacz's (1980) theory.

Discussion of Theoretical Findings

An original research question for this study was about the use of decision-making procedures from Scanzoni and Szinovacz (1980) by families in making decisions for a parent suffering from dementia. The answer to this was discussed earlier under descriptive findings. Basically, families reported using discussion and consensus. They did not report experiencing conflict, so they did not use negotiation or change. Power was shared according to the respondents. A second question was whether there were indications of a pattern for family decision-making.

Indications of a Pattern for Family Decision-Making

A theoretical question for this study was whether a pattern of decision-making procedures could be identified that reflected a family pattern regarding family decision-making. Smerglia and Deimeling (1997) speculated that family interactions regarding elder care decisions were part of broader family relationships and reflected these relationships. The findings of this study supported the emergence of a pattern, in that family members were very consistent in describing how decisions were made for their elderly parents. However, the source of this pattern appeared to be primarily related to generational placement and changes in society, rather than a pattern that was passed down through the family from an earlier generation. Findings indicated that marital and parental decision-making had a very strong influence on family elder care decision-making by siblings. Thus, decisions between spouses in successful marriages and as parents were seen as the main sources for the pattern of using discussion and consensus in family decision-making. For the most part, the influence on these families was not coming from their parents. The use of shared power and shared responsibility also

reflected the more egalitarian marriages that the participants described. The high percentage of intact marriages and successful remarriages is further evidence that discussion and consensus are valid procedures for decision-making in long-term relationships.

The results did not indicate that a family pattern influenced family decision-making. Instead, changes in society seemed to be influencing a family pattern. For these families it appeared that some of the changes in the larger society helped them to find ways of working together as adult siblings. In essence, the findings indicated that couples who chose egalitarian marriages also were likely to have egalitarian relationships with their siblings when it came to elder care decisions. If nothing else, they seemed likely to expect an egalitarian relationship. There was nothing found in the literature that would link shared marital decision-making to shared decision-making among adult siblings faced with elder care decisions. Further research in this area is needed to determine if this represents a broader pattern in society.

Reflections

There were several surprises in conducting this study. First, the candor of the respondents was surprising. They seemed eager to tell their stories. Even the telephone interviews did not require any significant “warm up.” It appears that having a local sibling helped a great deal, but I still wondered if I would experience some reluctance to share the details of their families’ lives with a complete stranger. Of course, this may be due in part to the fact that I sampled for families who felt that they were successful. Families experiencing conflict might be more resistant and not so candid. They also

would have to be recruited differently. Still, even with successful families, they were being asked to talk about a real family tragedy. For these family members, it was as if they had been waiting to tell someone about their experience. For the most part, all I had to do was get them started and they poured out their stories.

I did not expect that the families would be unanimous in reporting an absence of conflict, relying only on discussion and consensus. While I sampled for families that felt they were successful, I thought at least half of them would report experiencing at least mild disagreements, but they would have found ways of managing this by using negotiation, compromise, and changes in position or attitude. Thus, they would have become successful by learning to manage conflict. This was apparently not the case for these families. It is possible that they forgot about conflicts, choosing to see or report only the positive side of their relationships with their siblings. They may have perceived the situation in a way that precluded any conflict. For example, they might have felt that “good families” do not argue about taking care of their parents. Thus, the participants may have been reluctant to share any negative experiences. Sampling bias may have excluded families in which conflict occurred and was managed. However, family members consistently reported no conflict and added remarks about feeling “lucky” or “grateful” that they were able to make these decisions together. Several also commented about knowing about situations in which families were experiencing a great deal of conflict. Either these families were good at hiding their conflict and did so with a united front, or they were indeed able to find a way to work together without experiencing conflict. Their reports consistently indicated that they were able to make these difficult decisions without conflict.

This leaves open questions about families that do experience conflict. How do they manage conflict? How do they reach decisions when there is a disagreement? What effect does conflict have on their decision-making process? What are the positive and negative aspects of experiencing conflict and managing it? How can practitioners help families that experience conflict? What are the most effective approaches and techniques? How can previous experiences with managing conflict be used to manage this conflict? Lieberman and Fisher (1999) attempted to answer some of these questions by asking participants to rate the frequency with which family members gave in, a compromise was reached, conflict was avoided, the family resolved the conflict, the family handled it in a positive manner, or members felt pressured or coerced. However, their use of quantitative, scaled responses did not give much insight into how families actually go about using any of these methods.

It was interesting to find that only one of these families used lengthy co-residence to provide elder care. I expected to see more of a progression from paid or family care in the parent's home, to family care in the adult son or daughter's home, and finally to residential care. These families clearly had older parents with substantial impairments. The parents ranged in age from 78 to 93 years. Two of them had died before the interviews had taken place, and three more had died when I re-contacted participants regarding using direct quotes. Several families tried hiring a paid caregiver in the parent's home, but this generally lasted only a short time due to high costs and difficulty in finding reliable caregivers. Only one family made extensive use of family care in the home of an offspring. It was unusual that this was a son, and he did more of the caregiving than his wife.

It was surprising to find that these adult sons and daughters did not report changing their work schedules or their living or work arrangements. No one moved because of their parent's illness. This was consistent with Stern (1996) who concluded that the decisions of sons and daughters about where to live was made independent of future caregiving responsibilities. He proposed that once the parent began to need care, the family decided on arrangements while considering the location of each offspring. There were indications of this with most of the families. However, Stern found that families did not consider the work responsibilities of siblings, but families in this study did. He also indicated that the primary caregiver then decided on whether to reduce work hours. These families did not reduce their work schedules. No one quit working or cut back their hours. Only one family member noted an adaptation in that she did not add a fourth day to her work schedule when it was offered. One respondent changed his living arrangement, and that was the son who provided family care in his own home.

None of the families reported having to spend their own funds on care, although several expressed a willingness to do so if necessary. Several respondents cited the availability of financial resources as an important factor in the decisions that were made. It appears that these families used those resources to purchase care, rather than saving money in exchange for time. The majority of respondents were college graduates and apparently had occupations and careers that provided a good family income when combined with their spouses' income. Their relative affluence, along with that of their parents, expanded their options considerably. This might in part account for the lack of any apparent conflict.

It was disconcerting to find how little help these families reported receiving from

professionals. I thought that successful families might be those who were able to access the system to smooth the way through caregiving arrangements. Instead, professionals were conspicuous by their absence. One family member, a nurse, described how they had to force the issue by refusing to accept her mother for discharge from the hospital in order to get the discharge planner to locate a residential placement. Other members described the greatest difficulty as being on their own without any assistance in locating a suitable place that would provide the appropriate level of care. Family members used their informal network of friends and relatives or started with the telephone book more than they were able to use professional services.

Probably the biggest surprise was the indication that these families used decision-making with their spouse as a model for working with their siblings. I thought that I might see more influence from the family of origin. I expected to find sons and daughters who had seen their parents discussing and making decisions together, but this was generally not the case. These respondents described decision-making by their parents as mainly a more individual style of decision-making. This was probably related to the age cohort of the parents.

If I were to do this study again, I would continue recruiting until I had more families with four or more members to see if size made decision-making more difficult. I also would try to recruit families that experienced conflict, but were able to manage it and become successful. I would probably ask the AFC's or the day program to refer me to families so that I could look for this. I would do more pretesting and refinement of my instrument to make sure that I got the most amount of information. As I pointed out, there were a few questions that did not generate the information that I was seeking. I also

would want to get training in the use of a software program that would analyze and organize the data. This would serve as an investigator triangulation. I found that the program I purchased was too complicated for me. I felt that it was taking me too much time to learn coding and data entry along becoming familiar with the large number of options for analysis and data displays. With the small sample I had, I decided that it was best to simplify the analysis and concentrate on displaying the data in a way that would provide a rich description of each family. Thus, I used only the hand analysis which I had planned.

Implications

As an exploratory study, it is hoped that this dissertation might stimulate interest and a direction for further research. The need for research in this area will certainly grow, barring any sudden cures for the various diseases and conditions that cause dementia. Demographic trends project a large increase in the number of elderly persons, especially those over 80 years of age. More families may be faced with having to make decisions for an impaired parent, since increased age appears to be a factor in the incidence of dementia.

Further research in the area of family decision-making for elderly parents is needed. This includes further examination of context factors that influence decisions, decision-making processes and procedures, desired outcomes, and the use of previous decision-making to develop successful decision-making processes. Research is needed into how families manage conflict when they experience disagreements in elder care situations and how professionals can assist families in doing this, so they do not have to

learn it on their own. This is supported by Smerglia and Deimeling (1997) who recommended that practitioners shift their focus away from the effects of impairment of the care receiver on the family and focus on enhancing the family's flexibility, adaptability, and decision-making skills. This should include ways that conflict can be managed when siblings live long distances from each other.

Research into the effects of positive and negative elder care experiences on the children of adult sons and daughters would yield insights into future trends for the next generation of elderly persons, especially the "baby boomers." In addition, studies should explore the effects of divorce, distance, transience, live-in relationships, half- and step-sibling relations, and various family forms on family decision-making processes for impaired members. Studies are needed on the effects of demographic factors such as race, ethnicity, religion, social and economic status, age, and gender constellation on family decision-making for elderly parents.

Replication of this study is needed to see if samples of other families report an absence of conflict. If so, it would be important to examine whether this reflects undetected flaws in the research design, a desire to avoid conflict at any cost, or if families are truly able to manage conflict through extensive communication and shared decision-making and responsibility. Follow-up research could test whether conflict arises with other issues. One area for study might be to look at how the estate is settled as compared to how decisions are made about elder care. It would be interesting to see if care receivers who do not have dementia perceive the caregiving and conflict in the same way as their families. Further study is needed to test the findings that marital and parental decision-making may influence family decision-making in elder care. If this is supported,

then studies might investigate the effects of macro systemic influences and time on these decisions.

This study indicates a need to develop professional services that can facilitate access to important resources and services needed by families as they face caregiving decisions. It is essential that professionals be available to help families negotiate the “system,” or what appears to be the lack of a system. There is a need to develop models for facilitating the decision-making process for families, especially those who are experiencing conflict. In addition, planning ahead and having financial resources are vital to giving families choices.

In terms of education, this study indicates a need to provide educated professionals who can work with families faced with these difficult decisions. As a social work educator, the overwhelming majority of students I see are interested in working with other populations, especially children, rather than the elderly. However, in the future, the increased demand for services will clearly be in areas related to aging. The families in this study received little if any help from professionals, not because they did not need it or want it, but because they were either unaware of it, or it simply was not available. This indicates a need for services to assist families in locating resources and negotiating the caregiving system. This includes services that are designed to assess the levels of care that are needed, coordinate service availability and delivery, track the availability of residential openings, and assist with application processes for various services. There also is a need to train professionals to work with families on their communication, problem-solving, decision-making, and conflict-management skills.

This study has implications for public policy. Couch, Daly, and Wolf (1999)

concluded that future increases in women's wages relative to men's will increase financial contributions to parents and could lead to greater demands for formal caregiving. This study clearly indicated that middle class families will use their parent's assets to purchase care. However, these families did not seek out nursing home care as a first option. In fact, it tended to be a last resort. Support for alternative forms of care is greatly needed. Waiting lists at nursing homes and staffed AFC's mean that there is little competition, and thus, no real incentive to lower or contain costs. And yet, assistance from the government is generally not available, except for Medicaid payments to nursing homes, the most expensive option. As these governmental expenditures skyrocket, this assistance is not likely to keep up with demand and will probably be reduced, especially during times of cut-backs in spending. At the very least, if the government tries to hold the line on these costs, the net effect will be that fewer families will receive assistance even as demand grows. Instead of waiting for the inevitable reduction in support, the federal and state governments need to aggressively support the development of more affordable alternatives to institutional care.

Finally, families need to use technology to communicate and work together, and professionals need to use technology to serve families with members who live great distances away. The use of technology and mixed methods of data collection, especially the use of telephone interviews and the internet, was supported by this study. With new technology, including long distance voice and video capability and advances in voice recognition programs, the use of internet interviews looks very promising. The increased costs associated with research of any kind can be overcome by further validation of these and similar methods. Changes in society and in the family, along with increased

mobility, have made it more difficult to study families. In cases of elder care, studying adult siblings who are very mobile is particularly challenging. It also is very difficult for families to work together under these circumstances. It is equally as difficult for professionals to provide comprehensive services to families. The development of inexpensive and effective research techniques is vital to conducting research in these important areas.

Conclusion

This study explored the experiences of six families in making decisions for elderly parents suffering from dementia. It provided an in-depth look at decision-making for these adult siblings, and described the processes by which they were able to successfully make these difficult decisions together as a family. This study provided insight into the contexts that influenced elder care decisions for these families and the outcomes that they expected. It provided a glimpse into how these respondents used other decision-making experiences to shape the way in which they made decisions for their parents. The family members in this study were universal in their desire to help other families by sharing their experiences. They are to be commended for their generosity and courage in doing so. I share their desire and hope that others will take an interest in the challenges families face when a parent or any family member becomes impaired.

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APPENDICES

APPENDIX A

Interview Guide

How old is your mother or father? What is his/her diagnosis? How was this diagnosed?

What kinds of assistance does your mother/father need as a result of her/his dementia?

How long has your mother/father needed this assistance ?

Please describe any assistance that you have given to your mother/father since he or she began suffering from dementia.

Please describe any assistance that you have given to your mother/father during the last six months.

About how far away do you live from your mother/father? How far away did you live during the time that she/he first began suffering from dementia? What changes have you made in your living arrangements as a result of your parent's illness?

How long have you or your brothers and sisters had to make decisions for your mother/father?

What kind of decisions has your family had to make?

Has your family had to make decisions about finances? Please describe these arrangements.

Have you had to decide about guardianship? Please describe these arrangements.

Has your family used family care, in home care, adult day care, or nursing home care? Please describe these arrangements.

(The following are used for each of the above that apply)

-How did your family go about making this decision? Please describe the steps that took place. Describe any assistance you received from other family members, professionals, medical personnel, staff, etc.

-Who brought it up? Who participated? Who did not?

-How did you reach an agreement?

-How did you resolve any conflict or disagreement that arose?

-What were the important factors that influenced this decision?

-What outcome did the family want to bring about?

-Did any family members seem to have more influence on the final decision? Who? Why did it seem that they were more influential?

-What helped the family reach the decision? What impeded the family?

-Please describe your overall feelings about this decision and how it was reached.

APPENDIX A (continued)

Could you describe how decisions were made in your family as you were growing up? What influence did this have on the way you approached the decisions the family has made for your parent?

Could you describe how you and your spouse make decisions? What influence did this have on the way you approached the decisions the family has made for your parent?

Could you describe how you and your spouse make or have made decisions regarding your children? What influence did this have on the way you approached the decisions the family has made for your parent?

How will your experiences with family decision-making for your mother or father influence future decisions as he or she continues to age?

Do you have anything that you would like to add to what we have covered?

Do you have any questions of me?

APPENDIX B

Sample Letter

Dear Family Caregiver:

My name is Steve Yanca and I am a doctoral student in Family and Child Ecology at Michigan State University. My purpose in contacting you is to ask if you and your brothers and/or sisters would be willing to participate in my dissertation research on family decision-making for elderly parents who suffer from dementia. I am looking at the process that families use in arriving at decisions about family care, in home care, adult day care, nursing home care, finances, and guardianship. I am also interested to see if families use earlier experiences with decision-making or if they have to develop new ways to do this. My goal is to shed light on how families are coping with these difficult decisions. I hope that this study will stimulate others to find ways of helping families face the challenge of caring for their elderly parents.

I am looking for families who are willing to share their experiences through personal or telephone interviews. Your privacy will be protected throughout this project to the maximum extent allowable by law. All interviews will take place at a time and place that is convenient for you. I will reimburse you for any expenses you may incur that we agree on beforehand. You may receive twenty-five dollars as compensation for your time. You may choose to receive this in the form of a check, a gift certificate toward an outing (such as dinner or a movie), or a contribution to a charity of your choice. You may decline to receive compensation if you wish.

If you and your family are interested in participating or would like to know more, please contact me at (517) 753-0893.

Thank you and I look forward to hearing from you.

Sincerely,

Steve Yanca

APPENDIX C

Demographic Information

Family # _____ Member # _____

Please check the appropriate response or fill in the answer to the question.

A.1. What is your date of birth?

_____ Month _____ Year

A.2. What is your marital status? (Check all that apply)

_____ Single _____ Married _____ Divorced

A.3. What is your occupation and your spouse's occupation?

Your occupation:

Your spouse's occupation:

A.4. How many hours a week do you and your spouse work in a typical week?

Your hours:

Your spouse's hours:

A.5. How many children do you have?

A.6. How old is your youngest and oldest child?

Youngest _____ Oldest _____

A.7. What is your ethnic background?

A.8. What is your religious affiliation?

A.9. What is your highest level of education?

APPENDIX D

Informed Consent

The purpose of this study is to explore family decision-making by adult sons and daughters for elderly parents who have dementia. It will consider making decisions about family care, in home care, adult day care, adult foster care, nursing home care, finances, and guardianship. There also will be questions about decision-making in your family as you grew up, in your marriage, and as a parent. The study will include in person or telephone interviews with you and your brothers and sisters.

Please read this form carefully. It describes your rights as a participant in this doctoral dissertation research project. Your signature indicates that you have read this form, have been informed of your rights, and voluntarily agree to participate in this study. It is estimated that it will take less than two hours of your time. The first interview is estimated to be sixty to ninety minutes. This time can be broken up into shorter interviews if you wish. A follow up interview is estimated to be twenty minutes.

You voluntarily agree to participate in this research project and agree to the following terms: 1) You may receive twenty-five dollars as compensation for your time. You may choose to receive this in the form of a check, a gift certificate toward an outing (such as dinner or a movie), or a contribution to a charity of your choice. You may decline to receive compensation if you wish. 2) You can refuse to participate or withdraw from this research project at any time without penalty or loss of any benefits to which you are entitled. 3) You can refuse to answer any question. 4) You can ask the researcher a question at any time during the research process. 5) Your identity will be confidential. A false name will be used in all written papers, both published and unpublished to disguise your identity. Only the researcher will know the name assigned to you. Direct quotes and descriptions of responses may be included in findings that are reported. 6) While it is not the intent of the study to uncover sensitive information that would be harmful if revealed, it is possible that you may say something that you do not want repeated or included in the study. If you feel that way you may ask that any or all information be excluded, not quoted, or not used in the study. 7) You consent to audio taping all interviews. All tapes will be destroyed or erased after the dissertation is complete. The researcher will retain the transcripts of the audio tapes. 8) You consent to the publication of this study and accept that your privacy will be protected to the maximum extent allowable by law.

If you have any questions or concerns about participating in this study, you may contact Steve Yanca at (517) 753-0893 or write to him at: 343 Brown Hall, University Center, MI 48710.

You may also contact the Chair of the University Committee on Research Involving Human Subjects (UCRIHS) at Michigan State University, David E. Wright, at (517) 355-2180 for questions about your rights as a human subject of research.

Signature of Participant _____ Date _____

UCRIHS approval for this project expires _____.

APPENDIX E

Confidentiality Agreement

You promise: 1) to hold in complete confidence the information on the tapes provided to you by Stephen J. Yanca and Michigan State University; 2) to safeguard the materials while in your possession; and 3) to return the tapes and furnish the transcripts to Stephen J. Yanca and Michigan State University without retaining any copies of them.

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