Management of Impairment: Systems Used by Elders and Their Families

by

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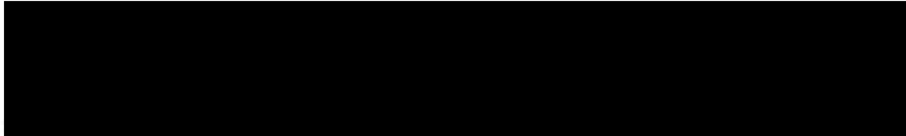

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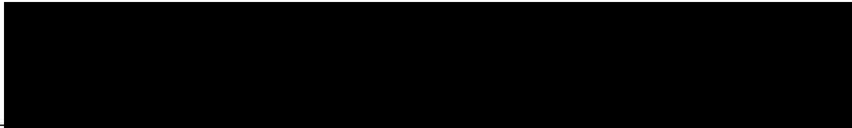

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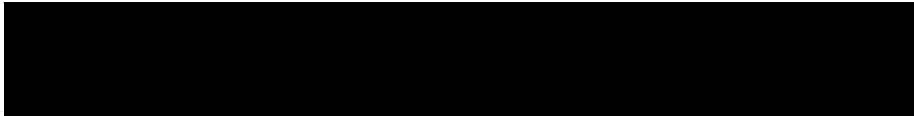

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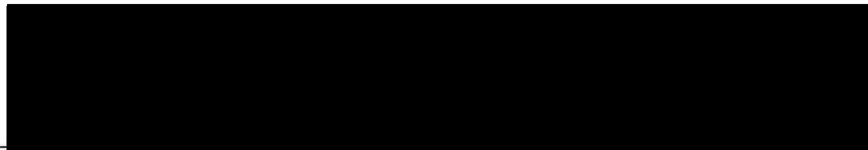

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TABLE OF CONTENTS

Chapter		Page
I	INTRODUCTION	1
	Issues	1
	Purpose of the Study	2
	Significance of the Study	3
II	METHODOLOGY	4
	Research Design	4
	Samples and Settings	4
	Consent Procedures	5
	Subjects	5
	Data Collection	9
	Data Analysis	10
	Coding	11
	Categorizing	12
	Concept Development	12
	Independent Review	13
III	INTRODUCTION OF THE FAMILY MANAGEMENT SYSTEMS MODEL	14
	Operational Definition of Management	14
	Definition of the Variables	14
	Decision Making	14
	Goal Establishment	14
	Day-to-day Management	15
	Properties of the Variables	15
	Identification of Family Management Systems	16
	Description of Four Family Management Systems	19
	Elder Self-management	19
	Elder-family Cooperative Management	23
	Family Management	26
	Family-professional Cooperative Management	29
IV	LITERATURE REVIEW	33
	Theoretical Framework: The Family as a Management System for Impairment in Elderly	33

Social Gerontology Literature. 33
Family Support of Impaired Elderly 34
Organizational Behavior Literature 42

Literature Related to the Variables and Properties of the Family Management Systems Model. . . . 45

Decision Making. 45
Norms, Values, and Goals 52
Distancing 54
Dependency, Independence, and Interdependence. 55
Cognitive Impairment 57
Sense of Duty and Competing Obligations. 58
Resources and Day-to-day Management. 61
Summary. 62

V DISCUSSION AND RECOMMENDATIONS 64

Discussion of Findings 64
Recommendations. 66

Implications for Nursing Practice. 66
Social Policy Issues 66
Suggestions for Further Study. 67

REFERENCES. 68

APPENDICES. 73

ABSTRACT

LIST OF ILLUSTRATIONS

Table		Page
1	Demographic Data on Elderly Subjects (N = 34)	7
2	Demographic Data on Family Members (N = 27)	8

Figure		
1	Characteristics of the Four Family Management Systems	17

CHAPTER I

INTRODUCTION

Issues

Statistics documenting the increasing age and health care needs of the United States population are cited frequently. As the percentage of persons over 65 years of age has continued to rise, the proportion of those in the oldest age groups (75-85 and over 85 years) has increased significantly. This group is particularly vulnerable to the problems of frailty and chronic illness [Brody, 1981; Callahan, Diamond, Giele, and Morris, 1980; Treas, 1977]. It has been noted that while this population is creating a growth in the demand for nursing home care [Doty, 1984], the majority remain in the community with the suport of family members [Shanas, 1979]. Callahan et al. [1980] estimate that between 60 and 85 percent of all impaired elderly receive "significant" help from their families. Institutional placement of impaired elderly is not determined by functional ability but by the availability of a "family caring unit" [Brody, Poulshock, and Masciocchi, 1978].

Family support of impaired elderly is becoming a major social policy issue. However, the role of the family is still somewhat obscured. On one hand, the myth of the demise of the family as a support system for elderly is so persistent that Shanas [1979] has called it the "hydra-headed monster." On the other hand, a societal

preoccupation with affective and emotional ties in family relationships has prompted Jarrett [1985] to issue a warning:

> ... the emerging popular enthusiasm for home care of the dependent aged seems to assume an emotional closeness and, in so doing, promises to subject intergenerational bonds to a severe test. The kind of affectionate caregiving envisioned by policy makers ... merges with popular demands for cost reduction in social programs.

Governmental efforts aimed at service cost reduction and deinstitutionalization of impaired elderly (i.e., Medicare "DRG's"--diagnostic related groups--and Medicaid "waivers" for community-based care) have serious implications for nursing practice. These programs affect the availability, characteristics, and quality of health and social services that are needed by impaired elderly and their family members. The myths surrounding family caregiving also affect nursing practice with this population. Nursing assessment and intervention may sometimes rely more heavily on assumptions and value judgments than on knowledge about these families.

There is a great need for increased knowledge about impaired elderly and their family caregivers on which to base nursing practice, health care programs, and social policy. As Hofer [1980] states, "Whatever the reason for the myths, the role of families needs to be portrayed in its true dimension and presented forcefully to influence public opinion and decision making."

Purpose of the Study

The purpose of this study is to examine the experience of managing physical and cognitive impairment from the perspectives of the

affected elders and their family members or significant others. The study describes the way in which management of impairment occurs among Medicaid-eligible elderly in a rural area.

Significance of the Study

Previous studies point to the primary role of the family in providing home health and social services and in determining the need for institutional care of impaired elderly in the United States. It is also anticipated that changes in family characteristics combined with a growing population of impaired elderly may greatly alter the picture of family caregiving in the future. However, little is really known about how elders and their families manage physical and cognitive impairment at home.

Gerontological nursing research has just begun to contribute theoretical knowledge in the area of family management of impairment in elderly [Archbold, 1980, 1982; Hirschfeld, 1983; Smallegan, 1981, 1985]. This knowledge is paramount to developing a sound basis for nursing practice with caregiving families.

This study will provide knowledge about management of physical and cognitive impairment that can be used in nursing practice with impaired elderly and their families. Implications for social policy and further research will also be discussed.

CHAPTER II

METHODOLOGY

Research Design

This exploratory study focuses on the experience of managing physical and cognitive impairments from the perspective of affected elders and their families. It is part of a larger longitudinal, descriptive study of institutional and community-based service utilization by frail rural elderly in Oregon [Archbold and Hoeffer, 1981]. Both this study and that of Archbold and Hoeffer utilized the qualitative methods of focused, in-depth interviews and participant observation, as well as quantitative measures (Placement Information Base).

Samples and Settings

Subjects for this study were drawn from the larger study conducted by Archbold and Hoeffer between August, 1981 and October, 1982. An Oregon state service agency provided the researchers with the names, placements, and functional assessment scores of Medicaid-eligible elderly (65 years and over) in four rural counties. From this list the researchers developed four subsamples based on placement of the elderly individual: (1) community, (3) nonfamily foster care, (3) homes for the aged, and (4) nursing homes. Subjects in each of these subsamples were matched to the level of function of the most impaired persons in the community using the total weighted scores on a functional assessment instrument. Those who qualified, based on the matching procedure, were contacted regarding participation

in the study. A family member or friend who was identified as the person who helped the elderly subject the most was also asked to participate in the study. This person will be referred to as the "family member" in this study.

Consent Procedures

Before data collection began, the researchers sent letters to all potential subjects regarding participation in the study (see Appendices A and B). Notification about the study was given by telephone to the persons in charge of nursing homes, homes for the aged, and foster care homes in which potential subjects had been identified. These facility directors were also contacted by telephone once the investigator arrived in the rural area to begin data collection.

If the potential subject agreed to participate in the study, the investigator explained it in more detail and obtained his/her written permission for participation in the study (see Appendix C).

Each subject was asked to identify the family member or friend who helped her/him the most. The investigator then attempted to contact the family member and explain the study. If the family member was willing to participate, her/his written permission was also obtained (see Appendix C).

Subjects

The subjects for this study were drawn from two of the larger study subsamples: (1) community, and (2) homes for the aged. This study sample of 34 elderly individuals included 22 community

residents and 12 homes for the aged residents. In addition, 27 family members (19 from the community and 8 from the homes for the aged subsamples) participated in the study.

Of the 34 elderly subjects, two were unable to name one person who helped them the most, and three named family members who were not in the area at that time. One family member was unable to attend the interview due to an emergency at home, and another refused to be interviewed because she was "too busy."

The elderly subjects ranged in age from 67 to 94, with a mean of 82.5 years. There were 24 females and 10 males, all but one of whom were Caucasian. The majority of elderly subjects were widowed and had completed between five and eight years of education (see Table 1).

The 27 family members interviewed ranged in age from 27 to 77 years, with a mean of 56.7 years. All but one were Caucasian. There were 22 women and 5 men in this group. Twenty-three were actually family members: 10 daughters, 5 spouses, 2 daughters-in-law, 2 sons, 1 granddaughter, 2 sisters, and 1 nephew. Of the four non-relatives acting as "family members," one was a neighbor and three were paid care-providers (two housekeepers and one homes for the aged manager). The majority of family members were married and had attended or completed high school (see Table 2).

TABLE 1. Demographic Data on Elderly Subjects (N = 34)

		Number	Percentage
Age:	65-74	5	15
	75-84	15	44
	85+ above	14	41
Race:	Caucasian	33	97
	Other	1	3
Gender:	Female	24	71
	Male	10	29
Marital Status:	Married	8	23
	Widowed	20	59
	Divorced	2	6
	Never Married	4	12
Education:	⩽ 4 years	8	23
	5-8 years	15	44
	9-11 years	4	12
	12 years	2	6
	⩾ 13 years	1	3
	(missing)	4	12

TABLE 2. Demographic Data on Family Members (N = 27)

		Number	Percentage
Age:	25-34	1	4
	35-44	2	7
	45-54	4	15
	55-64	8	30
	65-74	10	37
	75 and above	2	7
Race:	Caucasian	26	96
	Other	1	4
Gender:	Female	22	81
	Male	5	19
Marital Status:	Married	22	81
	Widowed	4	15
	Divorced	0	0
	Never Married	1	4
Education:	≤ 4 years	1	4
	5-8 years	4	15
	9-11 years	7	26
	12 years	9	33
	≥ 13 years	6	22

Data Collection

Data collection occurred during interviews with elderly subjects and family members. Methods included (1) focused, in-depth interviews, (2) participant observation, and (3) the Placement Information Base (PIB).

Focused, in-depth interviews were conducted utilizing two instruments developed and field-tested by Archbold and Hoeffer [1981]. The instruments address issues salient to the management of impairment in rural elderly individuals: family and social relationships, physical and mental health, daily routines and assistance patterns, financial status and management, and utilization of services. Pertinent demographic data were also included (see Appendices D and E). The probes used for some of the questions are from the OARS (Older Americans Resource and Services Program) functional assessment tool developed by the Duke Center for the Study of Aging and Human Development [Fillenbaum and Smyer, 1981].

The interviews averaged two hours each. Elderly subjects were interviewed in their places of residence. Family members were interviewed in their homes, at their places of employment, or while visiting the elderly subject's place of residence. Whenever possible, subjects and family members were interviewed separately. However, in some instances, they were interviewed together.

During the interviews, participant observation was used to obtain additional information about: (1) the physical environment of the homes or institutions, (2) the functional status of the

elderly subjects, and (3) verbal and nonverbal interactions between subjects and family members.

In addition to the actual interview time, approximately one to two hours immediately following each interview were spent completing interview notes, recording participant observations, and rating the elderly subjects with the PIB instrument (see Appendix F).

The PIB is a functional assessment tool developed for the FIG Waiver Project (1979). The instrument measured the subject's functional status at the time of administration in seven areas: (1) communication, (2) mobility, (3) household and food management, (4) social and emotional functioning, (5) finances, (6) health, and (7) self-care. Each area was assessed by using a five-level format ranging from average or better functioning (level 1) to severe problems with functioning (level 5). Validity and reliability were established through field tests of five versions of the instrument.

Data Analysis

Qualitative analysis is a type of field research which aims to describe the dominant processes within the area of study. The analysis generates theoretical constructs which explain these processes discovered in the data. This is an inductive method which leads to the discovery of "grounded theory" [Glaser and Strauss, 1967]. The conceptual framework is therefore generated

from the data and grounded in the empirical reality of the participants in the field.

Qualitative analysis is a back-and-forth process of coding, categorizing, and conceptualizing the data. For this reason, it is also referred to as "qualitative comparative analysis" or "continuous comparative analysis" [Stern, 1980].

Coding

During this process a line-by-line analysis of the data occurs. Each piece of data is compared with every other piece. Notes are made as themes and processes are identified. This is sometimes called "substantive coding" because it relates to the substance of the data and often uses the words of the subjects themselves [Stern, 1980].

The primary process identified by subjects and family members was "management." Quotes from family members included the following:

> "He manages by being careful about getting up."
>
> "You don't just run out when it's rough. You get older and you manage."
>
> "I'd never put him in a rest home unless I just couldn't manage."

Regarding the availability of services, elderly subjects said:

> "It is the only way I can manage."
>
> "It is necessary. I couldn't manage without them."

Other themes and processes included the following: independence versus dependency; changes in decision making; the meaning of home to the subject; the family member's sense of duty to self, the elder, and others; and availability of elderly individual, family member,

and community resources.

Categorizing

These notes regarding themes and processes were then moved to a higher level of abstraction through categorization. Categories are coded data which seem to cluster together. During this process, three major categories of behavior emerged: (1) major decision making, (2) establishing goals, and (3) day-to-day management.

Concept Development

As the three behavioral categories were developed, further examination of the management process also took place. It became apparent that elderly subjects and their family members utilized varied systems for management of physical and cognitive impairment. The structure of these management systems seemed to be determined by the way in which each family made major decisions, established goals, and provided day-to-day management.

A selective sampling of social organization and family resource management literature was then conducted. The findings were consistent with the theoretical framework. Decision making, goals, and coordination of day-to-day activities were found to be elements of both social organization and family resource management systems. These three major categories were therefore identified as the core variables of the family management systems.

Selective sampling of the data was then done in order to validate the importance of the core variables and to elaborate the

properties of those variables. Properties related to both elderly subjects and family members were identified. Relationships of the properties to their core variables were determined and defined. In this way, the model of family management systems emerged.

Independent Review

In order to further examine the validity of the core variables and family management systems model, an independent review of cases was done. Three reviewers each read interview data and field notes from two subjects and their family members. The reviewers then assigned each subject to a management system based on criteria related directly to the core variables and properties. Only one of six cases was assigned to a management system different from that chosen by the investigator. Following a reexamination of decision making and need for distancing it was agreed that the latter assignment was correct.

CHAPTER III

INTRODUCTION OF THE FAMILY MANAGEMENT SYSTEMS MODEL

Operational Definition of Management

Management is the process by which a system's functions are directed and coordinated. Directive efforts include major decision making and goal establishment. Coordination includes development and utilization of resources and strategies related to health problems and functional impairment. These coordination efforts may be referred to as "day-to-day management."

Definition of the Variables

Decision Making

Decision making is a process of weighing and choosing alternatives. Major decision making among impaired elderly and their families involves choices regarding place of residence, extent of family involvement in providing care, acceptance of help from friends and neighbors, and utilization of formal services.

Goal Establishment

Goal establishment is the process of setting the primary objectives or aims toward which elders' and families' efforts are directed. Goals are determined by individual and societal norms and values. Whether elders' and family members' goals are the same or different, they are subject to modification as the needs of the elders and the perceptions of the family members change over time.

Day-to-day Management

Day-to-day management allows impaired elders to complete the activities of daily living and to continue living with their chronic illnesses and health problems. This requires material and human resources: money, time, energy, knowledge, etc. Elders and their families must develop strategies to obtain necessary resources and to manage health problems and impairments. However, resources and strategies differ considerably from one family to the next.

Properties of the Variables

One purpose of this study was to examine the experience of managing physical and cognitive impairment from the perspectives of the affected elders and their family members. Analysis of the data identified behavioral categories and properties which characterize that experience. Properties associated with decision making include: (1) the elderly subject's level of cognitive function, and (2) the family member's sense of duty to the elder versus competing obligations to self and others. Properties of goal establishment include: (1) the elderly subject's need for independence, and (2) the family member's need for distancing (this may include physical distance, psychological separation, or both). Properties of day-to-day management include: (1) development of strategies for management of health problems and functional impairment, and (2) obtaining and utilizing resources.

Identification of Family Management Systems

Another purpose of the study is to describe the way in which management of impairment occurs. Examination of the management process as described in the data led to the identification of the behavioral categories as core variables in family management systems. Further concept development produced a model consisting of four family management systems: (1) elder self-management, (2) elder-family cooperative management, (3) family management, and (4) family-professional cooperative management (see Fig. 1).

It is theoretically possible that two other nonfamily management systems also occur: (2) elder-professional cooperative management, and (2) professional management. Three subjects without family or significant others in the area seemed to exemplify the professional management system. However, they were eliminated from the analysis due to insufficient data on core variables and properties. One would also logically predict the occurrence of the elder-professional cooperative management system among impaired elders without family or significant others. However, information about this system was unavailable because those individuals were not included in the study sample.

The following section provides a description of the four family management systems which occurred in this study sample. Each system will be described using examples from the data to illustrate the core variables and properties. The examples will be followed by a notation to indicate the source of the quotation: an elderly subject (E), a family member (FM), or an investigator (I). Quotations indicate statements by subjects.

FIGURE 1. Characteristics of the Four Family Management Systems.

System	Core Variables	Properties of the Variables
Self-management	1) Elder makes decisions.	1) • Elder has good cognitive function. • Family member has low sense of duty to elder or competing obligations outweigh sense of duty.
	2) Elder's goal is independence; Family member's goal is distancing.	2) • Elder has high need for independence. • Family member has moderate-high need for distancing.
	3) Elder does day-to-day management.	3) • Elder has strategies for management of health problems. • Elder has resources for day-to-day management.
Elder-Family Cooperative Management	1) Elder makes decisions *or* elder and family member share decision making.	1) • Elder has good-fair cognitive function. • Family member has moderate-high sense of duty to elder and/or competing obligations do not outweigh sense of duty.
	2) Elder and family member share goal of independence for elder.	2) • Elder has moderate-high need for independence. • Family member has low-moderate need for distancing.
	3) Elder does day-to-day management *or* shares responsibility with family member.	3) • Elder has strategies for management of health problems; family member may have some also. • Elder and family member have resources for day-to-day management.

FIGURE 1 (continued).

Family Management	1) Family makes decisions.	1) • Elder has fair-poor cognitive function. • Family member has high sense of duty to elder and/or competing obligations do not outweigh sense of duty.
	2) Elder and family member share goal of family caregiving.	2) • Elder has moderate-high need for dependency. • Family member has low need for distancing.
	3) Family does day-to-day management.	3) • Family has strategies for management of health problems; elder may have some also. • Family has resources for day-to-day management.
Family-Professional Cooperative Management	1) Family makes decisions.	1) • Elder has poor cognitive function. • Family members has low sense of duty to elder or competing obligations outweigh sense of duty.
	2) Family has goal of good care for elder.	2) • Elder has high need for dependency. • Family member has moderate-high need for distancing.
	3) Professionals do day-to-day management.	3) • Professionals have strategies for management of health problems. • Professionals have resources for day-to-day management.

Description of Four Family Management Systems

Elder Self-management

Decision making. In this system, the elderly subject has primary responsibility for major decision making. The major issue presented by this group is place of residence. The subjects made strong statements regarding their decision about where to live:

> "Don't want to go to a [nursing] home. I wish I could get someone to stay here. Don't want to be around just older people. As long as I can get around, will stick it out here."

> "I will always stay here in the trailer."

> "I would not go to any [nursing home] unless absolutely necessary."

> [Regarding nursing home residence] "I'd never consider that. Wouldn't send a dog to one."

Those living in homes for the aged had chosen to do so. Examples of statements regarding the decision are:

> "I figured on going to Arizona, but I liked it here, so I just stayed." (E)

> "She made this decision on her own. She just told me she thought she'd go to the [home for the aged]." (FM)

One property of decision making among self-managers is good cognitive ability. They demonstrated attentiveness, concentration, and understanding during the interview process. Their abilities to reason and communicate were evaluated positively by others:

> "Mrs. K. is a strong woman, well-read and articulate. She knows her mind ... and appraises situations realistically." (I)

> "He's very intelligent ... really adds something to the atmosphere." (FM)

The second property of decision making relates to the family member. In self-management systems, the family member either feels a low sense of duty to the elder or has competing obligations to self or others which outweigh the sense of duty. Examples of statements reflecting these concepts are:

> "It is clear that the family feels no responsibility for managing the problems. ... 'She's a self-centered person. ... We've never gotten along.'" (I, FM)

> "I have to find something else, I just can't be tied down constantly ... he's good as gold but I can't let him ruin my life." (FM)

> "My husband has MS [multiple sclerosis]; my health isn't good either. Couldn't take care of them both [husband and mother]." (FM)

Goal establishment. The first property of goal establishment for elderly self-managers is a great need for independence. This is usually symbolized by staying at home. Elders expressed strong feelings regarding this subject:

> "Means everything to me. ... I could not live away from home ... would go against my grain to live with someone else."

> "It is very important to me to live in my own place."

For those living in homes for the aged, maintaining self-care abilities represents independence. The need to perceive oneself as independent may be reflected in statements which deny the need for help altogether:

> "I really don't need [help]. ... I can do everything myself."

The second property of goal establishment--the family member's

need for distancing--generally supports the subject's goal of staying at home. Examples of the relationship between elder independent living and family distancing are:

> "I think it's great as long as he[father] can [live at home]--he feels better and I do too. ... I don't know how it would be [to move him in]--would cause problems between my husband and myself ..." (FM)
>
> Life is much easier for this family since the mother moved to a trailer court instead of on their land. ... This enables the family to avoid contact with the mother. This suits them well. (I)

Day-to-day management. These elderly subjects are responsible for day-to-day management. In order to accomplish this, they must develop strategies for management of health problems and functional impairments. These strategies are often multiple and complex. Some descriptions of these are:

> "Arthritis manages me. ... I take pain pills with codeine now and then. Also Motrin. It is hard to use my hands." (E)
>
> Mail [is] picked up by friend/neighbors. Can use walker on pavement. Housekeeper does shopping and bill payment. Constipation is a problem. 'I take Metamucil at night when I go to bed, but lately it's not working so good.' (I, E)
>
> [The subject] uses walker out of trailer--has house arranged to promote mobility with walker inside. [Medications] devised a clever system for organizing meds with 3 containers. ... Fills boxes herself each week. (I)

Development of these strategies is closely related to the second property of day-to-day management, obtaining and utilizing resources.

As the self-manager's own resources (money, physical energy, motor skills) diminish, she/he must find ways of compensating for

these losses. Examples of their losses and compensation strategies are:

> Money factor enters in. "They [government] don't like to help needy people. We pay too much out. Would help if [government] provided housing we could afford." (E)
>
> "I just got too old. I did care for my place up to last year; now have to have someone in to help mow the lawn." (E)
>
> "Cannot get around at all; any trips mean depending on others." (E)

Their first choice of support is the family. However, government support and community services are acceptable if the elderly individual is needy and the family is unable to provide care. Some statements reflecting these beliefs are:

> "If I couldn't afford it, would be alright. I paid taxes since 1911--think I've got a little something coming." (E)
>
> "I wish I could pay for it but I can't ... so it's okay with me if the [Social Security] does." (E)
>
> "I think the family should take care of older people. If they cannot, then Welfare should step in." (E)

Self-managers utilize these resources in order to meet their goals and accomplish day-to-day management. Some elders describe the relationship between service utilization and goal attainment quite clearly:

> "I can stay in [my own] home because of my grandchildren [who are paid by Welfare]. It means everything to me."
>
> [Regarding government services] "It is the only way I can manage. What else can I do?"

"I want to stay in our home if possible. We need a helper. There is no way I could manage without one [government housekeeper]."

Elder-family Cooperative Management

Decision making. This system is characterized by two types of decision making. In the first type, the elder is primarily responsible for decision making, with the family member acting to support or influence the decisions. Statements illustrating this type are:

[Mother] doesn't need too much guidance with decisions.

[Daughter] told mom that she most of the time could make decisions--95% up to her.

The second type is shared decision making. Examples of this type are:

[Husband and wife] both make decisions together--never do anything without consulting one another.

[Mother and daughter] "We discuss decisions which affect both of us."

Elderly cooperative managers have good-to-fair cognitive function. Family members and others make statements regarding the elders' cognitive abilities:

"That lady [mother] is sharp--no mental problems at all." (FM)

[Stroke] kinda affected his mind--couldn't talk, walk. His mind is better, getting better." (FM)

"Sometimes he's sharp, sometimes a bit senile. He appears depressed--responds slowly to questions, but is accurate. He cannot follow when spoken to quickly. His answers are brief and concrete." (I)

Cooperative family managers have a fairly high sense of duty to

the elderly subjects. Statements illustrating this concept are:

> "Happy we are able to do it. ... I feel it's a duty, too. I don't mean it in a negative sense. [I] think we should care for our own." (FM)

> "It's the feeling that everyone needs someone. Someone had to do it." (FM)

> "Sense of satisfaction--can do nice things for them [parents]. They did for me when I was growing up." (FM)

If there are competing obligations, they do not outweigh that sense of duty. Some examples of the predominence of duty to the elder over competing obligations are:

> [Family member's daughter] "resents it sometimes. But normal for an adolescent. She is an only child and used to be the center of attention before [she] moved in with us." (FM)

> "We do have a lack of privacy but she is very considerate. ... Don't really miss not having the house alone." (FM)

<u>Goal establishment</u>. Subjects and family members share the goal of independence for the elder. As with the self-managers, the expression of this is often quite clear:

> "Us older people, we can do our own taking care of and we should ... older people should be independent." (E)

> "I'm stubborn ... a fighter. ... Here in my home means freedom of activity ..." (E)

Family members understand this need. They have a low-to-moderate need for distancing and may share a residence with the subject or live nearby. This allows them to provide support which promotes the elder's independence. Examples of this strategy are:

> "Here [in trailer on family member's property] he can be independent but still have us to depend on." (FM)

> "Having her--we like us better because we do it. ... She doesn't humble herself to ask for help because we are here [maintains dignity.]" (FM)

The elder's need for independence may be a stronger determinant of residence than is the family member's need for distancing. One family expressed this quite eloquently:

> [Daughter] "To move in with us wouldn't bother me as much as her. ... Mom likes to be [the] ultimate authority."
>
> [Mother] "don't believe in moving in with my children. ... No house is big enough for two ruling women."

Day-to-day management. Again, two variations occur in the cooperative system. In the first, the elderly subject is responsible for day-to-day management. This allows for separate residence. The advantage of this arrangement was described by an elderly cooperative manager:

> "It is wonderful to live in your own home. I could not live with anyone. I have my own ways of running things."

More often, day-to-day management is shared by subjects and family members. Both develop strategies for management of the elder's health problems and functional impairment. Examples of cooperative strategies are:

> "Take medications ... [daughter] bought container for me. [She] fills them up for the week and I take them." (E)
>
> "I have to help him dress sometimes. Had to sponge him [after stroke] but now he can take a shower." (FM)
>
> [Shopping] "We have a brigade. ... We both pick out what we want. I push my cart and [daughter] pushes me [in wheelchair]." (E)

Like self-managers, elder-family cooperative managers utilize resources in order to meet goals and accomplish day-to-day management. Families may provide direct services or help the elder obtain services from the community or government. The following statements illustrate the variation in resource and service utilization:

> "I shave him. ... I give him his bath when I can talk him into it. I have to catch him when he is just in the right mood." (FM)

> "I used to fix her dinner every day, help with her bath ... clean ... do yard work. Now Ella helps [private live-in housekeeper]." (FM)

> [The subject] is quite [physically] impaired and depends completely on the services of the [government] homemaker [bathing, dusting], housekeeper [cleaning], and her son and daughter-in-law who shop and manage her finances. (I)

Family Management

Decision making. In this system, the family member makes major decisions. The elderly subject may be consulted, but the family manager is ultimately responsible. Examples of family decision making are:

> "I do [the decision making]. We talk things over, but I manage things." (FM)

> "She doesn't make decisions. ... She needs directions with everything." (FM)

Participation in decision making is often difficult for the elderly subject because cognitive function is fair to poor. Family members describe the elders' difficulties related to decision making:

> "He's not gone mentally. Slowness in thinking. Then I just have to be forceful when he can't figure things out."

> [Husband] describes confusion as most difficult problem. "She lost her mind. Always has been a little confused but worse now." (I, FM)

The family member's sense of duty to the elderly subject is high, outweighing any other obligations. Some made strong statements regarding their commitments to the elders:

> "Fifty-two years of marriage. No one can understand what we mean to each other. I don't want anyone else to do it for her. I'll take care of her."

> "It's confining. The emotional stress of it. It's heavy but life is going to be like that. You take vows--you don't just run out when it's rough. You get older and you manage."

> "Everyone has an obligation in life. If you don't care about people around you, you don't have much left."

<u>Goal establishment</u>. The elderly subject and family member share the goal of family caregiving. If institutional care is not totally rejected, it is mentioned only as a last alternative:

> [Husband] "I can take care of her better than anyone. ... Wouldn't want it any other way." (FM)

> [Wife] "I'd never go in one [nursing home]." (E)

> "I think we should care for her--she is my mother. I hope she will die in her sleep so that she won't have to go to a nursing home. That sounds cruel but I mean it in a nice way." (FM)

> "I'd never put him in a rest home unless I just couldn't manage. As long as I'm able and vice-versa, we want to be in our home." (FM)

The relationship is characterized by dependence of the elderly subject and by the family member's low need for distancing. Examples of statements reflecting this relationship are:

> "She's forgetful. She can't remember anyone. I look out for her." (FM)
>
> "It is wonderful that my daughter can take care of me." (E)
>
> "It's very important [to care for mother at home]. We like to have her closer so we can see her. When other family members come we can all be together." (FM)

Day-to-day management. In this system, the family member must develop strategies for management of the elder's health problems and functional impairment. If capable, the elder may also participate to some extent. Some of these strategies are described by the following statements:

> "She can brush teeth. I dress her but she can help. ... Housekeeper bathes mother. Eating was a problem because of back pain when sitting. Better now with Tylenol ..." (FM)
>
> "I do most things--it is really like she is in a nursing home. I think it's good for people to feel responsible, so I have her take her medicines herself and dust in her room." (FM)

The family manager is also responsible for obtaining and utilizing resources. Most services are provided by family members, although they may also utilize government resources. Family members described some of the services and/or financial assistance which they received:

> "Husband decided to bring her in with us. I decided she should get help from Adult and Family Services because we are on a fixed income and it is not fair to him."
>
> "You know, you don't want to be on assistance. It's sad but [I] don't know what to do about it. ... Just couldn't manage financially. We just wouldn't go for medical help unless really bad off."

Family-professional Cooperative Management

Decision making. In this cooperative system the family members make all major decisions. Again, the elderly subject may be consulted, but the family manager actually makes decisions. Statements which describe this process are:

> [The daughter] makes all important decisions [about finances, where she'll live, etc.]. (I)
>
> [The sister] decides about moving, clothes [asks if she likes them], finances, everything. (I)
>
> "I was the boss. ... He [husband] wouldn't argue with me. ... We looked at places in Ashland and Medford. [Husband] chose this place." (FM)

Other family members and the physician may influence decision making, but the family manager is primarily responsible. Statements which illustrate decision-making roles of family members and the physician are:

> [Mother] "leaves it up to the kids. ... I lived the closest, so I took care of her. ... My brothers look to me [the daughter] to do everything." (FM)
>
> "The doctor recommended the home for the aged. ... [The wife] makes all the decisions and has done this for some time." (I)

The elderly subject is unable to participate significantly in decision making because cognitive function is fair to poor. Statements which reflect the elder's inability to make decisions are:

> Her problem is mainly in her mind ... ever since her teens. ... You might go and she'll be good, then other times she's not. (FM)
>
> She has mental damage in speech and language. She knows but the 'how to' is gone due to stroke three years ago. (FM)

> He had a stroke about ten years ago ... it affected his articulation and thinking processes. ... He's gone downhill since then. Also, has a drinking problem; had for years, got worse ... (FM)

Family members either have a low sense of duty to the elderly subject or have competing obligations which outweigh that sense of duty. The following examples illustrate these concepts:

> [Husband and wife] haven't been very close because of his drinking ... alienated family by his behaviors. (I)

> "I was afraid he'd really hurt himself ... he'd pass out. I'd call an ambulance ... I just shook all the time. ... I had an awful lot of worries ..." [Since husband went to home for the aged], she's not so nervous, sleeps better. (FM, I)

> At the beginning [the daughter] was reluctant to admit that she had any problems with her health, and said the only reason she put her mother back into a home for the aged was due to a change in their lifestyle [more traveling, camping, etc.] after their children left home. Later she admitted that "I can only do so much" and that her husband's health problems also influenced her decision. "It came down to choosing between them, and I felt my first obligation was to my husband." (I, FM)

Goal establishment. The family member's goal is good care for the elderly subject. They are concerned about quality of care and choose facilities in accordance with the elder's needs and wishes whenever possible. Family members' efforts in this regard are described in the following statements:

> [Mother] "knew the people there and that they'd take good care of her." She and her husband had lived at Sunny Point several years before. (FM, I)

> [Husband] chose this place. The people [in the home for the aged] could take care of themselves. ... Lots of them [in the nursing homes] were bedridden. He didn't like that. (FM)

> Her sister feels their mother should be in a nursing home, but [the family manager] feels that "[The home for the aged] is a much healthier atmosphere ... at least if she sits, it's with other people, elbow-to-elbow, like a real home." (I, FM)

The relationship is characterized by the elder's dependency and the family member's need for distancing. The following description illustrates one daughter's need for physical and emotional separation from her severely impaired mother:

> She loves her mother very much, and it upsets her terribly that her mother has changed so much since her stroke three years ago. ... She feels guilty that she can't keep her mother at home, although she 'knows' that she couldn't handle it emotionally and probably physically, now that her mother is becoming more disabled. (I)

Day-to-day management. Because of the elderly subject's dependency and the family member's inability to provide care on a daily basis, institutional placement occurs. Although the size of the facilities may vary, their functions are essentially the same: to provide day-to-day management. In this system, professionals (home-for-the-aged managers and staff) develop strategies and obtain resources for management of the elder's health problems and functional impairment. The home-for-the-aged staff provides personal care, administers medications, and provides meals and housekeeping services. Government funds (Medicaid) pay for these services.

Although professionals are primarily responsible for day-to-day management, family members are also involved. They usually retain responsibility for financial management and are involved in negotiations with health and social service systems. Statements illustrating these responsibilities are:

> [The wife] takes his railroad check to the home for the aged for him to sign. "The home doesn't handle his money." (I, FM)
>
> "I do all that. ... Just a couple of calls about eligibility." (FM)

Family members also provide special services like visiting and buying things for the elder that would not be provided otherwise. Family members gave the following descriptions of the services they provided:

> [Mother] goes out occasionally to visit their home or to family get-togethers.
>
> "I take candy and jam ... buy clothes for him."
>
> "Treats ... I usually buy her clothes with my own money." Visits one to two hours 2-3 times a week.

In this way, the family member works with the professionals to achieve the goal of good care for the elder. Professionals are responsible for the instrumental tasks of caregiving. The family oversees the day-to-day management, connects the elder with the outside world, and gives affective support which the institution is unable to provide. The affective, expressive nature of family support was described by a family cooperative manager:

> [Regarding the role of the family] "... maybe the emotional stability ... and caring to know if everything is adequate ..."

This chapter has introduced the family management systems model. Definitions of management and the core variables have been presented. The four management systems which occurred in this study sample were described using examples from the data to illustrate the core variables and properties.

CHAPTER IV

LITERATURE REVIEW

The review of literature pertinent to this study will be presented in two major sections: (1) theoretical framework--the family management system as the focus of study, and (2) variables and properties of the family management systems model. The purpose of a literature review in qualitative research is to establish the degree to which the existent knowledge supports the proposed conceptualization.

Theoretical Framework: The Family as a Management System for Impairment in Elderly

There are two bodies of research literature which are related to the family management model presented in the previous chapter. First is the social gerontology literature focusing on kinship networks and family support of impaired elderly. A discussion of organizational behavior literature will follow, including systems theory and management/leadership principles.

Social Gerontology Literature

Kinship networks. This literature provides a background for the study of elders and their families because it examines "normal" intergenerational relationships. These studies document the importance of mutual aid, intergenerational solidarity, and reciprocity between all generations of family members [Bengtson et al., 1976; Litwak,

1965; Streib, 1965; Sussman, 1965; Wentowski, 1981]. However, they also indicate that the helping behavior of adult children increases with dependency needs of their elderly parents [Bengston et al., 1976], and that the flow of aid from middle-aged children to the grandparent generation increased during the 1960's [Sussman, 1965]. This research also identifies a "new" norm for families in industrialized societies: "intimacy at a distance" [Rosenmayer and Kockeis, 1963]. The generations prefer to live in separate dwellings, but not isolated from family members. This allows for frequent contact and exchange of services between generations [Shanas et al., 1968]. This literature supports the concepts identified in the conceptual framework of this study including the elder's need for independence, the family member's sense of duty and the need for distancing as important properties of family management of impairment.

Family Support of Impaired Elderly

Classic studies. Support for the concept of family management of impairment is evidenced by Shanas' [1979] classic study of non-institutionalized elderly in the U.S. About 3% of this national probability sample (N = 2143) were bedfast and 7% were housebound [Shanas, 1975]. The majority were living in their own homes or with family members. The disabled person's primary source of help during illness was the spouse; adult children were the next most frequent source of support. Men, who were more likely to be married, were taken care of by their wives. Women, who were more likely to be widowed, were cared for by their adult children. Paid helpers were

sometimes used, particularly by elderly spouses. Social services were rarely mentioned as sources of support. This finding contrasts with the fairly frequent use of social services in this study which used a convenience sample of Medicaid-eligible elders.

Using a two-stage sampling design, Brody et al. [1978] studied 186 chronically ill or disabled elderly who were residents of private and public nursing homes or who were community residents served by a home health agency. They found that older persons receiving home health care in the community were as impaired as those in skilled nursing facilities with regard to dressing, bathing, toileting, grooming, eating, ambulation, bowel and bladder control, and paralysis. The presence of a "family caring unit" (spouse and/or children) was the variable which determined community versus institutional placement of the impaired elder. The findings of this study support the concept of the family as a management system which determines how and where care of impaired elderly members will occur.

Caregiving dyads. Subsequent studies of family support have focused primarily on the caregiving dyad and the impact of caregiving on the caregiver. The focus of these studies has been either the impaired elder and caregiving spouse or the impaired parent and adult child caregiver. A few studies have examined the experience of caring for an impaired spouse. An early study of Golodetz, Evans, Heinritz, and Gibson [1969] pointed out the significance of the work role assumed by caregiving wives. They noted that elderly wives often face heavy physical and emotional caregiving demands at a time

when they too need care for their own illnesses. Later studies by Fengler and Goodrich [1979] and Crossman, London, & Barry [1981] also found elderly wives to be a particularly high-risk group of caregivers. They advocate support and respite services to maintain the health of wives and decrease the need for institutionalization of the impaired husbands. Although based on a sample of young and middle-aged spouses, a study by Klein, Dean, & Bogdonoff [1967] offers an interesting perspective. The authors found the spouse's illness caused "interpersonal tension and somatic symptoms" in male and female caregivers. They state that although the physician has primary responsibility for chronic illness management programs, "the patient's family [is] a meaningful variable in the management of illness situations" [p. 241]. These studies support the concept of management of impairment as difficult work which may compete with the caregiver's obligation to self.

Far more studies have focused on the impaired parent/adult child dyad and particularly on those with adult daughters as caregivers [Archbold, 1980, 1982; Brody, 1981; Robinson and Thurnher, 1979; Sherman, Horowitz, and Durmaskin, 1982; Stoller, 1983]. In most of these, caregiving roles or tasks are considered in the context of the caregivers' other roles, responsibilities, and life processes. Brody [1981] termed parentcaring daughters and daughters-in-law "women in the middle" due to their age, generational status, and competing role demands of labor force participation. Treas [1977] also expressed the concern that changes in women's work roles have created obligations which compete with parentcare.

Sherman et al. [1982] used a secondary analysis of three regional

and national study samples which included 705 caregiving daughters to examine the impact of women's work status on types of care provided to elderly parents. Working and nonworking daughters provided equal proportions of very similar types of care to both healthy and disabled parents. The authors conclude that the relationship between parentcare and work status is characterized by "role management" rather than "role overload." They caution, however, that more knowledge about the consequences of this phenomenon needs to be explored regarding the impact on the caregiver and the quality of care the parent receives.

Stoller's [1983] in-depth study of caregiving by adult children was drawn from a probability sample of noninstitutionalized elderly (N = 753) and their informal helpers (N = 502). This rural northeastern study looked at the competing demands of marriage and work status as variables affecting the number of hours spent by sons and daughters in caring for their elderly parents. Marriage was a significant variable in decreasing the time spent by both sons and daughters in parentcare. (The author suggests that this may be because the caregiver role is often assumed by unmarried children.) However, the work status variable was significant only for sons in reducing the time spent caregiving. Daughters spent the same number of hours caregiving whether or not they were employed. The author concludes that daughters manage their increased workloads by "reallocating domestic production activity" and decreasing leisure time. Both the Stoller [1983] and Sherman et al. [1982] studies support the notion that family caregivers can manage both eldercare and competing

obligations if their strategies and resources are adequate.

Robinson and Thurnher's [1979] longitudinal, in-depth study focused on the impact of family cycle transitions--retirement and the empty nest--and parentcare on a purposive sample of 49 adult children. They found that although men were just as likely to report helping parents, women were more involved in providing complete care. Men tended to be involved primarily in instrumental tasks (such as managing finances), while women also felt responsible for their parents' emotional well-being. Parentcare is described as a process which includes a series of phases that extend over 2-5 years. During this time the adult children experienced increasing anxiety, tension, and sense of confinement. Parents were institutionalized only after their increasing mental and physical deterioration caused "severe psychic stress" in the adult child. The two primary sources of stress seemed to be the parent's mental deterioration and the adult child's perception of caregiving as confining. This study supports the concepts of elder cognitive impairment and caregiver need for distancing as determinants of family management ability.

In an exploratory study of parentcaring by 30 Caucasian women, Archbold [1982] identifies and describes two types of caregiving roles: care provision and care management. (A third role--care transfer--is suggested but not discussed.) Parentcare is described as a dynamic process brought about by the continuous weighing of costs and benefits and evaluation of available resources. The care provider role is assumed when limited financial resources prohibit the purchase of needed services, or when previous experience as a caregiver has been

very positive. However, most women who have adequate financial resources become care managers when their parents are suddenly or severely impaired. The costs of caregiving are more severe for providers: loss of freedom (present and future), lack of privacy, and chronic daily irritation. Costs to care managers include invasion of personal time, career interruptions, and financial burdens. This study provides support for the importance of resources and day-to-day management strategies in determining which family management system will occur. It also points out the dynamic nature of these systems which is reflected in the weighing of duty versus competing obligations and the variation in need for distancing among family caregivers.

Household types. In a new approach to describing family support, some authors are imposing a "household type" structure to the study of variables influencing caregiving [Myllyluoma and Soldo, 1980; Noelker and Wallace, 1985; Soldo and Myllyluoma, 1983; Soldo and Sharma, 1980]. Soldo and Sharma [1980] used secondary analysis of a national multipurpose survey to study a subsample of 845 households representing one of two "extremes" in elderly parentcare: intra-household care and institutional care. They state that a change in the caregiving system (from home to institutional care) is probably due to an alteration in the family circumstances or the condition of the elder, or to an interaction between the two. Soldo and Myllyluoma [1983] used another subsample of 2,338 households from the same survey to examine the care needs of the elder and competing demands on caregivers in three household types: elderly couples living

alone, elderly couples living with others, and unmarried elderly living with others. They found the third type to be most vulnerable to disruption, but cautioned that the reliability of their findings is dependent upon assumptions used to determine "primary caregivers" in the multi-person households.

Noelker and Wallace's [1985] data were drawn from interviews with 597 primary intrahousehold caregivers. Three sociodemographic variables (sex, marital status, and dependent children) were combined to create six household types. Although the elders often had substantial physical and cognitive impairment, only 40% of the families in the sample were connected to health or social service agencies. This finding contrasts with the more widespread use of these services by this study sample. This study of a large probability sample yielded an interesting finding: 56% or more of the caregivers did not experience activity restrictions, financial burden, disrupted family relationships, or health deterioration as a result of caregiving. The authors suggest that further study of "successful" caregiving may be more enlightening than investigations of the negative consequences of caregiving.

Chronic illness management. Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, and Wiener's [1984] qualitative analysis of chronic illness offers a unique perspective in the study of family management of impairment. The experience of living with chronic illness is viewed in the context of work to be performed by both the impaired person and the family members. Both directive (such as the

"regimen control agent") and coordinating (such as ordinary symptom monitoring and daily regimen management) functions are described. The author notes that health professionals know little about how families manage chronic illness at home:

> What happens in the home is mostly over the horizon, is partly or completely invisible to them. ... what is involved in managing chronic illness at home can be very complex and, as always, involves far more than the strictly 'medical' aspects of illness management [p. 99].

In addition to the illness "trajectory work" and the ordinary "home work," there is also important "psychological work" to be done. This may include maneuvers by the caregiver to boost the spirit, increase the perception of independence, and maintain the sense of identity of the impaired person. There is also a tremendous amount of psychological work to be done by the impaired person: coming "to terms" with a failing body, a changed body conception, and alterations in "biographical time." When the work becomes unbearable, "overload" may occur. The caregiver may seek respite care or may elect to work outside the home in order to get relief from the "work" at home. In extreme situations, divorce or institutionalization may result.

Strauss et al.'s [1984] work supports the concept of family management of impairment as complex work which involves both directive and coordinating functions. Descriptions of the very important "psychological work" support the concept of independence as a central issue for both elders and family members.

Summary. Kinship network literature provides a background for and supports the notion of family management as described in Chapter III.

However, it provides little information about how the family system changes in response to the task of caring for an impaired elderly member.

Most family support literature, however, has a very narrow focus with regard to family management of impairment in elderly. Recent studies have carefully scrutinized the caregiving dyad, particularly that of the impaired elder/adult child. Unfortunately, the role of the impaired elder in the system is largely neglected in the search for the impact on the caregiver. Another "side" of the caregiving experience may also be missing because small convenience samples obtained from clinical agencies were used in many of these studies.

Strauss et al.'s [1984] qualitative study of chronic illness provides the most comprehensive view of family management "work." Directive and coordinating functions are described, as well as an examination of the very complex "psychological work" of the impaired person and the family members.

Organizational Behavior Literature

Organizational systems theory. Organizational behavior literature suggests a theoretical model for viewing social organizations as open systems. The system's functions include input (availability of human, technological, and material resources), throughput (how the resources are utilized), and output (the material or service product) [Huse and Bowditch, 1973; Katz and Kahn, 1966; Miringoff, 1980; Parsons, 1952].

All social organizations consist of patterned activities which

are interdependent or complementary, relatively enduring, and bounded in space and time. However, because they are open systems, there is also a dynamic interplay between internal (organizational) and external (environmental) forces [Katz and Kahn, 1966].

Organizational systems theory provides a framework which is consistent with the family management systems model. The family is regarded as an open system which responds to the needs of its impaired elderly member by obtaining resources and developing strategies for utilizing those resources in order to "manufacture" the services needed by the elder. This theory supports the notion that both intrafamilial processes and environmental forces will influence the utilization of resources and the quality of the service product.

Management and leadership principles. The manager is a subsystem of the social organization [Huse and Bowditch, 1973; Katz and Kahn, 1966]. Management is a complex, shifting set of relationships which involve multiple roles. The manager must interact with many people at a variety of levels both inside and outside the organization [Huse and Bowditch, 1973]. The function of the managerial subsystem is to preserve or maximize the organization by coordinating the other subsystems (production, maintenance, boundary, and adaptive) and organization-environmental relationships [Katz and Kahn, 1966]. These definitions are consistent with the roles and tasks of elder and family managers in this study.

Huse and Bowditch [1973] cite a number of management studies to support their concept of the manager as a coordinator. The authors

state that "the manager's true function is to serve as the linking mechanism whereby balance among subsystems is maintained" [p 166]. They acknowledge that leadership is also an important, although relatively small part of a manager's job. Typical managers spend 25% to 35% of their time working with subordinates. The manager-subordinate relationship gives the manager formal authority to direct, motivate, and control subordinates' activities in order to meet organizational goals. However, as a leader the manager must also respond to the needs of subordinates and act on their behalf in negotiations within and outside the organization. This manager-subordinate relationship correlates with that of the family systems managers and other group members. Group members may include the elder, other family members, and service providers involved in the management of impairment.

Fiedler and Chemers [1974] also address the relationship between leaders and subordinates ("group members"). While they subscribe to the definition of leadership as a relationship based on control and influence, they point out that the interpersonal relationship between the leader and group members is the most important variable which determines the leader's control and influence. The authors developed a personality measure which indicates a leader's behavioral preferences and goals. From this they have identified a "motivational hierarchy": at the "high" end are leaders who seek strong emotional and affective ties with group members; at the "low" end are leaders whose primary goal is task accomplishment. The authors state that leadership effectiveness is related not only to the leader's style of interacting with group members but also to the nature

of the task situation.

These findings point to the importance of family relationships, goal establishment, and needs of the elder as important factors in determining the effectiveness of the management system.

Summary. Families as social organizations are viewed as open systems whose functions include input (obtaining resources), throughput (developing strategies for utilizing resources), and output ("manufacturing" services needed by the elder). Management is a process which involves multiple roles and interactions both within and outside the organization. The family manager coordinates activities within the system and maintains organizational relationships with the environment. Leadership is one management role which involves direction and control of activities (e.g., decision making) in order to meet organizational goals. Management effectiveness is determined by intrafamilial processes and environmental forces which influence the utilization of resources and the quality of the service product.

Literature Related to the Variables and Properties of the Family Management Systems Model

Decision Making

Decision making is a process of evaluation in the choice or resolution of alternatives and is determined by values, goals, and resources [Deacon and Firebaugh, 1981]. Studies relevant to decision making in families with impaired elders address the following concerns: rationality of decision making, family decision styles,

different parent/adult child perceptions of decision making, and family decisions regarding nursing home admission.

Rationality of decision making. Many authors have discovered that decision making in families and other social organizations does not always follow a logical, "rational" model [Deacon and Firebaugh, 1981; Hill, 1965; Katz and Kahn, 1967; Lynott, 1983]. The concept of "bounded rationality" is described by Katz and Kahn [1967] as an organization's limitations in identifying and utilizing alternative courses of action. The organization has an established repertoire of responses to problems and does not consider all possible solutions. The tendency is to maintain (versus change) the system. Attention will be given first to the solutions under the control of the decision maker or the organization, and then to those not under organizational control. This supports the findings of this study regarding elders' preference for family support and reluctance to accept "outside" help.

In his study of decision making and the family life cycle, Hill [1965] found that the "grandparent generation" exhibited the least degree of "rational decision making." The grandparent generation also made the fewest plans and took the fewest actions, but fulfilled the highest proportion of its plans. They were second to the "parent" generation regarding satisfaction with the outcomes of their decisions and actions. These findings support the observation that elders in this study made decisions in favor of home care whether or not this was a "rational" choice.

Lynott's [1983] descriptive study of families caring for members

with Alzheimer's disease focuses on the impact of dementing illness on family decision making. He argues that caregiver tolerance and burden do not follow a linear, parallel course with the disease process, but are "matters of ongoing interpretation." Likewise, rationality is not representative of the decision-making process; instead it is an "artifact" of that process. Deacon and Firebaugh [1981] agree that families often do not fit a rational model, but have a wide range of approaches which also include "falling into" alternatives and intuition. These studies support the finding that families caring for cognitively impaired elders varied considerably in their decision making and goals.

Family decision styles. Price [1973] refers to "decision style" as a holistic view which includes all factors involved in a decision-making situation. She used a simulated decision-making game with 40 young families (couples with teenagers) in rural Washington. Tools to assess "management style" and "self-actualization" were also used. Two decision styles were identified.

"Decision Style I" families often sought much information from outside sources. There was a strong emphasis on task-orientation, goal accomplishment, and the "good of the group" versus individual preferences. The individuals scored low on self-actualization (measured with a psychiatric health tool), except in the area of self-acceptance. Educational level was lower than for the second group.

"Decision Style II" families focus primarily on the individuals involved. The problem is viewed as part of a much broader area of

life. These families had strong value commitments regarding ethics (finding "the right decision"), time (concern with long-term effects and tendency to postpone decisions), and intimacy of decision making (closely related to those involved). The individuals scored higher on self-actualization and were more human (versus task) oriented. They were also more independent, inner-directed, and had higher educational levels.

These findings support the variations in decision making, values, goals, and independence among family management systems. The complexity of the decision-making process described also helps to explain the difficulty in interpreting qualitative data related to family decision making.

Different perceptions of decision making. Studies by Bromberg [1983] and Townsend and Poulshock [1986] report differences between elders' and their adult children's perceptions of decision making. Both studies cite theories (symbolic interactionism, social exchange, and cognitive social psychology) which could explain differing reports regarding caregiving tasks and decision making.

Townsend and Poulshock [1986] studied decision making in a purposive sample of 101 families with impaired elderly parents (both widowed and married). They asked elders and their adult children to place names of helpers in concentric circles representing caregiving and decision-making networks. From this data they described both the centrality and number of decision makers and caregivers. Elders and their children agreed that the decision-making network was much

smaller than the caregiving network. However, children named a larger number of extended family and nonfamily helpers for both networks. Most married elders and their children included the elder in decision making. But married elders were just as likely to name their spouses as central, while children named the elder as central. They also had very different perceptions of the adult child's place in decision making. Children included themselves more often as participants in the decision-making network, while parents included children more often as participants in the caregiving network.

Widowed elders and their children were closer in agreement about decision making. Both included the elders as the most important decision maker and agreed that adult children had the most influence in decision making. Both named professional and paid helpers, but these were assigned mostly to the "outer circles" of decision making, and children named them more often.

The authors note that their sample included elders with moderate to severe physical problems, but little or no cognitive impairment. They suggest that the findings could change with a more cognitively impaired population.

Townsend and Poulshock's [1986] study supports the finding during data analysis of this study that elders and family members may have different perceptions regarding caregiving and decision making. This points to the importance of interviewing both the elder and family member and to the usefulness of the participant observation methodology. The authors' suggestions regarding cognitive impairment support this study's identification of the elder's cognitive

impairment as a major determining factor in family decision making.

Decisions regarding nursing home admission. A few studies have examined the relationship of family decision making to nursing home admission. Teresi, Toner, Bennett, and Wilder [1980] studied a random sample of 162 primary caregivers to elderly New York City community residents. They looked at the effect of elder and family characteristics (elder role functioning; family race, ethnicity, household composition, extendedness, tradition, attitudes toward elder, and perception of inconvenience of caregiving tasks) on "institutional decision making." This term is defined as the amount of planning by family members, key supports, and professionals regarding nursing home placement. It is a "process construct" which looks at planning while the elder is still in the community. The authors found that "perceived inconvenience" was the major predictor of institutional decision making in families. The number and frequency of contacts of the elder and caregiver with other family members also had some effect on decreasing planning for nursing home admission. Inconvenience was lower among spouses and children who didn't live with the elder, and highest among single children living with a parent. It seems that the concept of "inconvenience" supports the finding that caregiving which "competes" with other obligations may be a predictor of family-professional cooperative management.

Two nursing studies by Smallegan [1981, 1985] also examined decision making related to nursing home admission. The first was a pilot study which identified decision makers among 19 residents of

long-term care facilities, their family members, and professionals. The author states that about half of the elders were involved in the admission decision and about two-thirds concurred with the decision. Half of the elders who were not involved in decision making were demented or retarded. This supports the finding that cognitive impairment among elders is a major determining factor in decision making and, therefore, in determining which family management system will occur.

Smallegan's [1985] later study explored the antecedents to nursing home admission of 288 elderly individuals. She describes nursing home admission as a family management strategy used when "there was nothing else to do." History of serial caregiving often occurred, with changes in family caregivers over time. The author states that the family members' inability to manage care for long periods of time and the patients' difficult behaviors led to changes in family "patterns of care":

> According to self-reports, caring for the patient at home was too much work for over one-third of families or friends to manage. ... The most common reason for change in the pattern of care was that the patient became less well. ... However, in one-fifth of the cases the person admitted was simply considered by the family to be a difficult individual whom they could no longer manage [p. 368].

These findings support the concept of family management as a dynamic process which effects changes in the management system over time. The study also supports the notion that changes in the elder, the family caregivers, or both, may alter decision making, goals,

and the management system itself.

Summary. Family decision making is a process of evaluation of alternatives determined by values, goals, and resources. It does not follow a "rational model" in that families rarely consider all possible solutions and often rely on intuitive processes to arrive at decisions. Decision-making style and perceptions may also be influenced by generational position, marital status, and cognitive status. Family decisions regarding nursing home admission may be due to change in the health status of the elder or in the ability of the family to continue caregiving. Nursing home admission usually occurs after the family has exhausted all the solutions in its repertoire and is no longer able to manage the caregiving work at home.

Norms, Values, and Goals

Brody's [1985] and Brody, Johnsen, and Fulcomer's [1984] studies examine parentcare as a normative family experience governed by the values of those involved. The 1984 study, which examined a purposive sample (N = 403) of three generations of women revealed both similarities and differences in values as expressed by attitudes, opinions, and preferences. All three generations indicated that adult children should adjust their family schedules and help meet expenses of medical care for the elderly mother when needed. Majorities of the two younger generations and a large percentage of the oldest generation stated that adult children should not adjust their work schedules to provide parentcare. Although majorities of each generation recommended that adult children not share a household with

the mother, the youngest was most likely and the middle generation least likely to favor shared housing. This supports the finding that both elders and family members (except spouses) preferred separate residences whenever possible. There was also a tendency among all generations (and particularly the youngest) to expect a nonworking married daughter or a working unmarried daughter to share a household with the mother. The oldest generation preferred adult children as providers of emotional support and financial management, but not income. The middle generation was least in favor of financial or instrumental help from children and were most likely to prefer formal services. These findings support the elders' preference for family members as caregivers, the acceptance of government financial assistance by both elders and family members, and the relatively high utilization of government services.

Values provide the criteria through which goals are formulated [Deacon and Firebaugh, 1981]. Hirschfeld's [1983] study of family caregiving and senile brain disease found that "mutuality" was determined by the value attached to the impaired member's presence in the home. Mutuality allowed the caregiver to find gratification in the relationship and meaning in the caregiving experience. The degree of mutuality determined the family's goals and ability to manage home care. "High mutuality" families found satisfaction in caregiving and were able to meet the goal of family care. "Low mutuality" families were losing or had lost any positive values associated with the impaired member or the caregiving experience. Their goal had changed to good care in an institution or, in some cases, death of the

impaired member.

These findings point to the importance of the family member's perception of the elder and the caregiving situation. Mutuality may be an important factor in determining the family member's sense of duty to the elder and need for distancing. Therefore, it affects the goals and the effectiveness of the family management system.

Distancing

Numerous studies have identified distancing as an important intergenerational norm. Rosenmeyer and Kockeis [1963] called it "intimacy at a distance"--the preference among young and older generations to live apart, but not in isolation from each other. Townsend [1965] also noted that older people want to live close to their children, but not to impose upon them too much. Jarrett [1985] points out that this norm is responsible for physical distancing which allows "independent lifestyles" to evolve without generational conflict. Bromberg [1983] studied a purposive sample of 75 elderly widows and their daughters. She states that the need for psychological distancing ("psychic autonomy") is a "normal crisis point" in middle age and plays a major role in intergenerational relationships. Cicirelli [1983] examined adult children's "feelings of attachment" and their "attachment behaviors": proximity to the parent, frequency of visiting, and frequency of telephoning. Adult children who were more "attached" lived closer and visited and telephoned more frequently. These studies support the concept of distancing as an important property of family goal establishment and a major influence

upon the development of family management systems.

Other studies identified caregiving stressors which seemed to be related to distancing. Robinson and Thurnher [1979] found that physical and psychological distancing were related closely to perception of confinement--a major stressor among caregivers. Because men were less likely to feel responsible for their parents' emotional well-being, they were better able to distance themselves in the caregiving role. Archbold's [1982] concept of "lack of freedom" as the most severe cost to care providers and Hirschfeld's [1983] concept of "tension" as a result of "being tied down" are also related to the caregiver's need for distancing.

Dependency, Independence, and Interdependence

Townsend and Poulshock [1986] state that the elder's dependency is central to both caregiving and decision-making networks. However, the elderly parent's and adult child's perceptions of dependency and, consequently, need for caregiving and decision-making help, may differ considerably. This supports the finding that dependency is an important concept in family management systems.

Some authors have suggested that dependency affects the family member's attitude toward caregiving and relationship with the impaired elder [Horowitz and Shindleman, 1981; Teresi et al., 1980]. The elder's dependency may have an effect on the caregiver's perception of inconvenience with regard to activities of daily living [Teresi et al., 1980]. Horowitz and Shindleman [1981] found that dependency resulted in increased "emotional closeness" between the

elder and caregiver. However, it also caused a decrease in the caregiver's enjoyment of the time spent with the elder and resulted in more difficulties in day-to-day interactions. The findings of these studies seem to indicate that by affecting the family member's sense of duty and need for distancing, the elder's dependency may have an indirect influence on goals and family management systems.

Wentowski's [1981] longitudinal anthropological study found that independence is a "key concern" for all elders, but their definitions and strategies vary considerably. Some use "balanced reciprocity" and "deferred exchange" to reinforce kin obligations. When balanced exchange is no longer possible, they use "tokens" to continue the appearance of reciprocity, thereby maintaining their self-esteem. Others, however, are "loners" who use immediate exchanges to minimize obligations by others and maximize personal autonomy. These findings support the variations in dependency noted in this study that help to identify the family management systems which occur. It may be that self-managers have been "loners" who equate autonomy with independence, whereas elder family cooperative managers may have a history of deferred exchange and balanced reciprocity.

Two other studies also suggest that an exchange of support between elderly parents and adult children occurs. Bankoff [1983] found that aged parents were the most crucial source of support for their grieving widowed daughters. In her study of mother-daughter relationships in later life, Bromberg [1983] concluded that interdependence, rather than independence, was important to both and characterized helping patterns more accurately. She states that

interdependence is important to both mothers' and daughters' developmental growth and is "a natural reweaving of what is given and received during the life course." This is an interesting perspective which may also help to explain the variations in dependency as well as the family member's perception of sense of duty to the elder.

Cognitive Impairment

Few community-based studies are available to provide information on family managment of cognitive impairment in elderly. Zarit, Reever, and Bach-Peterson [1980] found that family caregiving to members with Alzheimer's disease was related to the strength of the caregiver's social network, but not to the level of cognitive impairment. Hirschfeld's [1983] study of family caregiving and senile brain disease also found that level of cognitive impairment was not related to the family's ability to continue home care. In addition to the major influencing factor, "mutuality," three other important variables were identified: caregiver management ability, morale, and tension. "Management ability" included the caregiver's use of instrumental and emotional support and ability to cope with stress. These studies seem to refute the concept of cognitive impairment as an important influence in family management systems. However, they may also support the notion that family management ability is not determined by cognitive impairment alone, but by the family's ability to develop and utilize resources and strategies in response to cognitive impairment.

Other studies by Archbold [1982], Brody et al. [1984], and Robinson and Thurnher [1979] identify cognitive impairment as a

stressor in parentcare. Robinson and Thurnher [1979] found that mental deterioration of the parent was very stressful for adult children and resulted in a deterioration of their relationship as well. In a study of work status and parentcare, Brody et al. [1984] found that women who quit their jobs to provide parentcare ("ex-workers") had the highest percentages of cognitively impaired mothers. Archbold [1982] states that cognitive impairment may add to the typical problems of shared housing due to chronic irritating behaviors. These studies support the concept of cognitive impairment as a major influence on family management systems.

Noelker and Wallace [1985] found that despite a relatively high incidence of intrahousehold caregiving to cognitively impaired elders, the majority of the caregivers in their study did not experience "stress effects." They suggest that among the "nonclinical" population of caregiving families, the ability to change its structure and functions allows the family to respond positively to caregiving demands. Although this study does not support the concept of cognitive impairment as a determining factor in family caregiving, the findings do support the concept of the family as a dynamic, open system capable of responding to the demands of caring for a cognitively impaired elder.

Sense of Duty and Competing Obligations

Jarrett [1985] presents the view that kinship is a set of formal relationships and that families are systems of rights and obligations. He states that kinship is characterized by a sense of positive concern for the well-being of elders. It is "activated by need

and fueled by a willingness to give whatever help one can" [p. 8].

Horowitz and Shindleman [1981] also found that a sense of duty or obligation to the elder was a primary reason that families initiated and increased their caregiving involvement. However, they found that reciprocity and affection often played important parts in caregiving as well. Reciprocity is an obligation felt by the caregiver as a result of services provided by the elder at an earlier time. It can also initiate and increase caregiving by the family. Although assumption of the caregiving role was not related to affection, it was a factor in the extent to which the family provided assistance. Furthermore, affection decreased the negative effects of caregiving on the family. These findings seem to support the concept of duty as a major determinant of family management which may also include reciprocity and/or affection.

Cicirelli [1983] suggests that sense of duty is mediated by family history. When there has been rejection, alientation, or other conflicts, there may be little willingness to help elderly parents.

Soldo and Sharma [1980] found that the adult child's sense of duty to the elderly parent varies inversely with the competing obligation to the immediate family. Soldo and Myllyluoma [1983] suggest that spouses have "greater normative expectations" regarding their duty to provide care, while adult children have a "lower threshold" for the competing demands of parentcare. These studies support the notion that the weighing of duty and competing demands is a determining factor in decision making and family management systems.

Brody [1981] and Treas [1977] have suggested that middle-aged

woman are experiencing increased work force participation and responsibilities to their own families as competing obligations to parentcare. However, there is some lack of consensus in the literature regarding these issues.

Myllyluoma and Soldo [1980] suggest that households where adult children are providing care to a widowed parent are most vulnerable to disruption due to the presence of caregiver employment as a competing demand. Soldo and Myllyluoma [1983] state that, in addition to labor force participation, responsibility to the immediate family also competes with parentcare.

Stoller [1983] found that marital status was a competing demand, with married men and women providing less help to parents. However, labor force participation was a significant factor in decreasing time spent on parentcare for men only. Women continued to provide the same amount of care by decreasing their own leisure time.

Sherman et al. [1981] also found that working and nonworking daughters give very similar types and amounts of assistance to elderly parents. They state that "role management" characterizes the relationship between women's labor force participation and parentcare.

Brody et al. [1984] identified two "new" groups of working/nonworking women: the "exworkers" who quit their jobs in order to care for their parents, and the "conflicted" workers who experienced the most interference with time for themselves, their husbands, and their jobs. The authors identify the woman's work/parentcare relationship as a dynamic, evolutionary process which calls for further in-depth, longitudinal studies. These findings support the notion that although

marriage and labor force participation may be competing demands regarding family caregiving, they may be outweighed by the family member's sense of duty to the elder.

Resources and Day-to-day Management

Descriptive studies by Archbold [1980, 1982] and Strauss et al. [1984] yield the most relevant information regarding resource utilization and day-to-day management in families caring for impaired elderly. Strauss et al.'s [1984] description of the types of chronic illness "work" done by the family involves both health management strategies (crisis, symptom, and regimen management) and resources (time management, body resource work, and psychological work). He states that the way the work is done will depend upon the types of impairment, financial resources, and the availability of "physical substitutes." These findings strongly support the concept of day-to-day management as comprised of health management strategies and resources.

Studies by Archbold [1980, 1982] also support the findings that resources, strategies, and management of impairment are closely related. Her 1982 study of parentcare indicated that adequate financial resources were the most important determinant of care manager status. Care managers also had more professional resources and a broader range of social supports. More knowledge and skills in communicating with bureaucratic systems facilitated coordination of multiple sources of help. Care providers, in contrast, were "immersed" in day-to-day management. Performance of tasks required to accomplish activities of daily living often involved heavy physical labor.

The care providers had no energy left over for meeting their own or the elder's psychosocial needs. The primary management strategy used by care providers was to plan rigidly and control the schedule of daily activities. They relied heavily on repeat-use plans; novel solutions to caregiving problems were not sought so long as the system was running smoothly. In an earlier study, Archbold [1980] noted that parents also use rigid scheduling, which may help provide a "feeling of security." Care managers had a much wider variety of strategies. They consulted family, friends, and professionals, maintained the system of providers, and used environmental manipulation and behavior modification.

Noelker and Wallace [1985] offer another perspective regarding resource utilization and needs among intrahousehold caregiving families. Although most families utilized both formal and informal help, they indicated that the amount of help received was inadequate. There were no significant differences in utilization of services or unmet needs by household type.

Summary

The literature related to elder and family decision making helps to explain the difficulty in interpreting data related to this concept. Elders and family members may have very different perceptions of decision making and may not follow a logical, "rational" model. The literature supports the variations in decision making and its relationship to the other variables and properties described in this study.

The importance of norms, values and goals in determining family management of impairment was supported in the literature. The concept of distancing was supported in several studies as an important property of goal establishment and a major influence on the development of family management systems. The literature also identified independence as a "key concern" for elders and supported the notion that dependency also influences goal establishment and development of family management systems.

There is some disagreement in the literature about the effect of cognitive impairment on family management ability, but some studies provide strong support for the concept as a major influence on family management systems. Other studies support the concept of the family as a system capable of responding to the needs of a cognitively impaired elder if resources and strategies are adequate. The literature provides strong support for the importance of health management strategies and resources in determining family management ability.

Many studies provided support for the notion that the weighing of duty to the elder and competing demands is a determining factor in decision making and family management systems. There is some disagreement in the literature regarding the concept of labor force participation as a competing demand. Many of these studies consider work a competing demand only if it results in a discernible difference in the care provided to the elder. However, other studies support the notion that although working may be a competing demand, if it is outweighed by sense of duty to the elder, it may be "managed" along with caregiving by the family member.

CHAPTER V

DISCUSSION AND RECOMMENDATIONS

Discussion of Findings

For most impaired elderly in the United States the family is not only a support system but also a management system. Functional impairment brings about the realization that the elder "can't manage" without assistance. Although the elder and the family caregiver may perceive the situation differently, there is generally a recognition by both that there is additional "work" that needs to be done. How the work will be done, however, is subject to considerable variation from one family to the next.

Variation in family management systems is related to differences in goals. Norms and values determine goals related to management of the elder's impairments. American society places a high value on self-determination and independence, but each individual may interpret this concept differently. Intergenerational norms prescribe "intimacy at a distance"--frequent contact and exchange while maintaining separate households. Norms and values are deeply rooted in the family's history. Some elders have always used balanced exchanges to promote interdependence of family members. Others are "loners" who have used immediate exchange strategies to minimize obligations by others and maximize personal independence. Some families are characterized by a high degree of mutuality and affection, while others have histories of alienation and conflict.

The elder's need for independence and the family member's need for distancing and perception of competing obligations also affect how and by whom the management work will be done. When the elder requires considerable help with decision making and day-to-day management because of impairment (particularly cognitive), the family caregiver's ability to determine goals is strengthened. Goal determination and achievement are directly related to health management strategies and resources. If elders or family members highly value home care, they will develop health management strategies and utilize resources necessary to achieve that goal.

When strategies or resources are inadequate, the elder perceives that she/he "can't manage," and the caregiver experiences "overload" or other "stress effects." Attention will be given first to familiar solutions under the control of the existing management system. The elder's first choice of help is the family. Community services and government "assistance" may be acceptable if the family is unable to provide support and if the elder perceives her/himself as "needy" of the services in order to meet the goal.

A change in the level of impairment, perception of duty versus competing obligations, success of health management strategies, or availability of resources may require a change in the management system itself. This brings about changes in the decision-making network and day-to-day management strategies. The elder's increasing cognitive impairment may result in movement from an elder-family cooperative to a family management system. However, if the elder later develops difficult behaviors for which the family's strategies

and resources are inadequate, family-professional cooperative management may result. Institutional placement is a health management strategy used by families to achieve "good care" when "there was nothing else to do."

Recommendations

Implications for Nursing Practice

For nurses working with impaired elderly in the community, assessment of needs for health education and services is of major importance. The family management systems model could be used to develop an assessment tool that would indicate not just the elder's but also the family's needs for education and services. Information about the family's decision-making network, goals, sense of duty, and competing obligations would provide a basis for interventions based upon the family's needs rather than upon the nurse's opinion of what constitutes appropriate care for the impaired elder.

Social Policy Issues

Just as health professionals must exercise caution in prescribing what "ought" to be done by caregiving families, so should social policymakers. Government "incentives" for family care must be based upon the family system's need for support rather than upon the government's need for service cost reduction. Deinstituionalization of impaired elders can be deemed successful only if it meets elders' and families' needs, and not because it is a less expensive care alternative. A truly responsive community-based care system may not in fact cost less than institutional care. But if a care system is

developed which helps elders and families to achieve their goals, it will improve the quality of life for a large segment of society in the future.

Suggestions for Further Study

This qualitative study has provided an in-depth examination of the experience of managing physical and cognitive impairment from the perspectives of the affected elders and their family members. A model of family systems management has also been presented which describes the way in which management occurs among Medicaid-eligible elderly in a rural area.

In order to develop measures of the concepts identified in the model, methodological studies are needed. Further studies should use larger and more varied samples (with regard to geographic location, income levels, and connection to governmental agencies) to test the validity of the model. More data on the relationship of income levels and resource utilization could provide valuable information about the development and operation of family management systems.

Longitudinal data are needed to study the movement from one family management system to another. This could provide information regarding antecedents and consequences of the different systems.

Further studies using probability sampling of caregiving families could provide insight into all areas of family management from the perspectives of "successful" managers. From these examples nurses could learn to use their skills to empower families in family management roles rather than to assume a professional care-manager role themselves.

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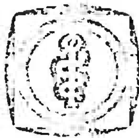
APPENDICES

APPENDIX A

home



UNIVERSITY OF OREGON

HEALTH SCIENCES CENTER

GERONTOLOGICAL NURSING PROJECT
SCHOOL OF NURSING

Area Code 503 225-8539

3181 S.W. Sam Jackson Park Road

Portland, Oregon 97201

Dear

We are nurses and faculty members from the School of Nursing, University of Oregon Health Sciences Center, who are interested in the lives of older people. The Department of Human Resources helped us locate you.

We are asking you to help us in a study about older people in rural areas. We want to learn more about some of their health care concerns and what kinds of support services they need or use.

We would like to talk with you for one to two hours at two different times. We are interested in how you see your life and health care needs, and what services you want or receive. We would also like to talk with a family member or close friend who you think helps you the most.

We will contact you soon, and hope you would like to talk with us. If you agree, we will make an appointment to interview you.

Sincerely,

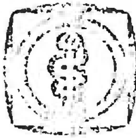
Patricia G. Archbold

Patricia G. Archbold, RN, DNSc
Project Director
Gerontological Nursing

Beverly Hoeffer

Beverly Hoeffer, RN, DNSc
Associate Professor
Department of Mental Health Nursing

APPENDIX B



UNIVERSITY OF OREGON
HEALTH SCIENCES CENTER

GERONTOLOGICAL NURSING PROJECT
SCHOOL OF NURSING

Area Code 503 225-8839

3181 S.W. Sam Jackson Park Road

Portland, Oregon 97201

Dear

We are nurses and faculty members from the School of Nursing, University of Oregon Health Sciences Center, who are interested in the lives of older people. The Department of Human Resources helped us locate you.

We are asking you to help us in a study about older people in rural areas. We want to learn more about why people decide to use nursing homes or other residential care services.

We would like to talk with you for about one to two hours. We would also like to talk with the family member or close friend who helps you the most.

We will contact you soon. We hope that you would like to talk with us. If you agree, we will make an appointment to interview you in the home.

Sincerely,

Patricia G. Archbold

Patricia G. Archbold, RN, DNSc
Project Director
Gerontological Nursing

Beverly Hoeffer

Beverly Hoeffer, RN, DNSc
Associate Professor
Department of Mental Health Nursing

APPENDIX C

SCHOOL OF NURSING

INVESTIGATION: Utilization of Institutional or Community-based Services by Frail Elderly in a Rural Area

INVESTIGATORS: Patricia Archbold, RN, DNSc.
Associate Professor
Project Director, Gerontology Project

Beverly Hoeffer, RN, DNSc.
Associate Professor
Department of Psychiatric and Mental Health Nursing

PHONE: 225-8839

Patricia Archbold and Beverly Hoeffer, nurses and faculty members at the School of Nursing, University of Oregon Health Sciences Center, are doing a study of the utilization of institutional or community-based services by frail elderly in a rural area.

If I agree to participate in this study the following will happen. I will answer questions in two interview sessions requiring approximately one hour each. The interviews will be recorded in writing. The recordings will be handled in a manner to ensure confidentiality. Any publications from this study will include the necessary precautions to protect my identity.

Sharing my thoughts and experiences with Dr. Hoeffer or Dr. Archbold may not provide any comfort to me directly, and there may be no benefit to me personally. The findings of this study may be of benefit to others in the future.

If I have comments or questions about participation in this study, I should first talk with Dr. Archbold or Dr. Hoeffer. She has agreed to answer any questions that I have. I understand that I may refuse to participate, or withdraw from this study at any time without affecting my relationship with, or treatment at, the University of Oregon Health Sciences Center or the Department of Human Resources.

It is not the policy of the Department of Health and Human Services, or any other agency funding the research project in which I am a part, to compensate or provide medical treatment for human subjects in the event the research results in physical injury. The University of Oregon Health Sciences Center, as an agency of the state, is covered by the state liability fund. If I suffer any injury from the research project, compensation would be available to me only if I establish that the injury occurred through the fault of the Center, its officers or employees. If I have further questions, I should call Dr. Michael Baird, M.D. at 503/225-8014.

I have read the foregoing and agree to participate in this study.

__________ DATE   ____________________ SIGNATURE OF SERVICE PROVIDER

__________ DATE   ____________________ SIGNATURE OF WITNESS

APPENDIX D

Revisions
2/26/82

OREGON HEALTH SCIENCES UNIVERSITY
SCHOOL OF NURSING

INTERVIEW WITH ELDERLY INDIVIDUAL

1. Subject Number____________________

2. Subject's Address____________________
   Street and Number City State

3. Subject's Phone ( ) ____________

4. Date of Interview____________

5. Time Interview Began____________

6. Interviewer's Name____________________

7. Name of family member or friend____________________

8. Place of Interview (specify home or type of institution)

   ____

9. Subject' Residence if not the place of interview

   ____

10. Subgroup A - Home

    B - Foster care-family

    C - Foster care-non family

    D - Home for aged

    E - Nursing home

11. Description of Interview Setting (include observations of physical environment, water, heat, etc.)

12. Description of Interviewee

*13. Sex of Subject

1 Male
2 Female

*14. Race of Subject

1 White (Caucasian)
2 Black (Negro)
3 Oriental
4 Spanish American (Spanish surname)
5 American Indian
6 Other
- Not answered

*15. Age of subject

a. When were you born? ______________________________________
(Month) (Day) (Year)

b. How old are you? ____________

1 65-69
2 70-74
3 75-79
4 80-84
5 85-89
6 90-94
7 95-99
8 100+

*16. How far did you go (have you gone) in school?

1 0-4 years
2 5-8 years
3 High school incomplete
4 High school completed
5 Post high school, business or trade school
6 1-3 years' college
7 4 years' college completed
8 Post graduate college
- Not answered

*17. Are you single(never married), widowed, divorced, or separated

1 Single (never married)
2 Married
3 Widowed
4 Divorced
5 Separated
- Not answered

*18. Who lives with you? (include relationship to person)

Family History Members	Age	Distance	Quality of Relationship	Contribution to caregiving

*19. Please tell me how well you think you (and your family) are doing financially as compared to other people your own age?

2 Better
1 Same
0 Worse
- Not answered

Explain:

*20. How well does the amount of money you have take care of your needs?

2 Very well
1 Fairly well
0 Poorly
- Not answered

Probe: Would you say you:

3 ___ do without many needed things
2 ___ have the things I need but none of the extras
1 ___ have the things I need and a few of the extras

*21. Do you feel that you will have enough for your needs in the future?

2 Yes
0 No
- Not answered

Explain:

*22. What is it like for you being an older person?

a. What is it like for you in this area?

b. How was it decided that you would live here?

Probe: What does it mean to you to be living in your (own home? a foster home? home for aged? nursing home?)

*23. a. How would you rate your overall health at the present time?

3 Excellent
2 Good
1 Fair
0 Poor
- Not answered

Explain:

b. What health or medical problems do you have?

c. How do you manage these problems? What do you do for them?
(Meds, hearing aides, canes etc.)

*24. Is your health now better, about the same, or worse than it was five years ago?

3 Better
2 About the same
0 Worse
- Not answered

Explain:

*25. How much do your health problems stand in the way of your doing the things you want to do?

3 Not at all
2 A little
0 A great deal
- Not answered

Explain:

26. What kinds of activities do you usually do during a day?

27. Tell me about a recent typical day.

28. Tell me what you usually eat during the day.

a. How many meals do you eat each day?

29. 1) Assistance patterns.
(Ask general questions first and record response and perceptions. Then probe for each of the follow II areas if not covered.)

a. What kinds of activities do you need help with?

b. Who helps you, and how much time is involved?

c. How was the initial agreement for assistance worked out with caregiver?

d. Who was involved? (note AFS)

e. What part did you play in making the decision?

f. How has the agreement to provide service for what you need changed over time?

g. When? Why?

h. What is it like for you (does it feel like) to receive this help?

i. How important was the activity (role) for you in the past?

2) Managing medical regimes (taking meds, dressings, etc.)

PROBES: Do you need assistance?
Has someone else always managed?
Was it an important part of your role?

3) Home keeping:
(repeat probes under #2)

4) Home maintainance:
(repeat probes under #2)

5) Meal preparation:
(repeat probes under #2)

6) Shopping:
(repeat probes under #2)

7) Transportation:
(repeat probes under #2)

8) Money Management:
(repeat probes under #2)

9) Contact with the outside world:
(repeat probes under #2)

10) Negotiation of health and social service systems:

a. relative

b. nature of help
   forms
   phone
   assessment of service

c. caseworker
   extent of assistance

30. In what way has the kind of assistance you receive changed over the last year?

How did you feel about the change?

If you needed more assistance, would "X" be able to provide it?

How would you work that out with him/her?

*31. How many people do you know well enough to visit within their homes?

3 - Five or more
2 - Three to four
1 - One to two
0 - none
- - Not answered

*32. a. About how many times did you talk to someone--friends, relatives, or others on the telephone in the past week (either you called them or they called you)?

(IF SUBJECT HAS NO PHONE, QUESTION STILL APPLIES)

3 - Once a day or more
2 - 2-6 times
1 - Once
0 - not at all
- - not answered

b. PROBE: Who were the people you talked with and how satisfied were you with the contact?

*33. a. How many times during the past week did you spend some time with someone who does not live with you, i.e., went to see them, or they came to visit you, or you went out to do things together?

3 Once a day or more
2 2-6 times
1 Once
0 Not at all
- Not answered

b. Who were the people? What did you do together? How satisfactory was the contact?

34. How happy are you with the amount of contact you have with your friends and relatives?

1 happy
2 somewhat happy/unhappy
3 unhappy
- not answered

Explain:

*35. Do you have someone you can trust and confide in?

2 Yes
0 No
- Not answered

Probe: Who is it? How often do you see them, etc.

*36. Do you find yourself feeling lonely quite often, sometimes, or almost never?

0 Quite often
1 Sometimes
2 Almost never
- Not answered

Probe: What do you do if you feel lonely?

*37. Is there someone who could give you any help at all if you were sick or disabled, for example, your husband/wife, a member of your family or a friend? (PIB 17 - natural support)?

1 Yes
0 No one able to help
- Not answered

(IF "YES", ASK a. through c.)

a. Is there someone who could take care of you indefinitely (as long as needed)? who?

b. Is there someone who could take care of you for a short time (a few weeks to six months)? who?

c. Is there someone who could help you now and then (taking him to the doctor or fixing lunch, etc.)? who?

- Not answered

Probe: Is this person willing to help you?

*38. Taking everything into consideration, how would you describe your satisfaction with life at the present time?

2 Good
1 Fair
0 Poor
- Not answered

Probe: What would make life more satisfying?

39. Has there been a time in the past when the family needed to rally around a member? Explain

PROBE: In general, how do your family members react in time of trouble?

40. Have you (or your spouse) ever been ill? If so, what arrangements were made? Who helped you?

41. If you are having trouble making ends meet (financial problems), could you call on your family or relations? If so, what can you expect?

42. Some people feel that in time of trouble, it is better to let off steam and show their emotions. Others prefer to keep their feelings to themselves. Which describes you?

44. If something happened to you that you had trouble handling yourself, who is your family likely to turn to?

_____ the family
_____ relatives
_____ friends
_____ professionals
_____ others (identify)

45. How often do you worry about things?

0 Very often
1 Fairly often
2 Hardly ever
- Not answered

Probe: What kinds of things do you worry about most?

46. How would you rate your overall mental health at the present time-- excellent, good, fair or poor

3 Excellent
2 Good
1 Fair
0 Poor
- Not answered

Explain:

47. Is your mental health better, about the same, or worse than it was five years ago?

3 Better
2 About the same
1 Worse
- Not answered

Expalin:

48. What services do you think the government (local, state, or federal) should provide for older persons?

What role do you think family and friends should play in providing services to older people?

49. What services do you know of in the community?

PROBE: How did you find out about them?

50. Which do you receive? Did you receive?

51. Here is a list of services that may be offered in the community. Have you received any of these services (hand card to subject)?

52. Which would you like to recieve? (Would have been useful to you when you were in your home? For example, visiting nurse, house-keeping, meals on wheels, etc.)

53. What benefits have you gotten from having X service? What problems have X service caused for you?

54. What would it mean to you to no longer receive X service?

55. How do you feel about relying on services (e.g. homemaker) provided by your community? County? State?

56. If (when) you could no longer stay in your home, what alternatives would (did) you consider? Describe them.

Probe: Here is a list of supervised residential settings that may be found in some communities. Did you consider any of these?

Who would be involved in the decision about your moving from X to Y?

57. Evaluate respondent's behavior during the interview on a 3-point scale, ranging from low, medium, to high.

ITEM	LOW				HIGH
Attention & concentration	Mind wanders frequently	3	2	1	Attended entire interview
Interaction with inter-viewer	No contact	3	2	1	Very responsive
Interest	Very casual	3	2	1	Intense interest
Cooperativeness	Barely civil	3	2	1	Went out of way to be helpful
Comfort	Tense	3	2	1	Relaxed
Openness	Guarded	3	2	1	Frank
Understanding	Confused	3	2	1	Comprehending
Mood	Sad	3	2	1	Happy

APPENDIX E

Revisions
2/26/82

OREGON HEALTH SCIENCES UNIVERSITY
SCHOOL OF NURSING

INTERVIEW WITH FAMILY MEMBER

1. Subject number ______________________

2. Subject's address ____
   Street and Number City State

3. Subject's phone ( ) ______________________________

4. Date of interview ______________________________

5. Time interview began ______________________________

6. Interviewer's name ______________________________

7. Relationship to elderly family member ______________________________

8. Place of interview

   ____

9. Subject's residence if not the place of interview

   ____

10. Subgroup A - Home

    B - Foster-care family

    C - Foster care - non family

    D - Home for aged

    E - Nursing Home

11. Description of interview setting (include observations of physical environment: water, heat, etc.)

12. Description of interviewee

*13. Sex of Subject

1 Male
2 Female

*14. Race of Subject

1 White (Caucasian)
2 Black (Negro)
3 Oriental
4 Spanish American (Spanish surname)
5 American Indian
6 Other
- Not answered

*15. Age of subject

a. When were you born?______________________________
(Month) (Day) (Year)

b. How old are you?____________

1 65-69
2 70-74
3 75-79
4 80-84
5 85-89
6 90-94
7 95-99
8 100+

*16. How far did you go (have you gone) in school?

1 0-4 years
2 5-8 years
3 High school incomplete
4 High school completed
5 Post high school, business or trade school
6 1-3 years' college
7 4 years' college completed
8 Post graduate college
- Not answered

*17. Are you single(never married), widowed, divorced, or separated

1 Single (never married)
2 Married
3 Widowed
4 Divorced
5 Separated
- Not answered

18. Who lives with you? (include relationship to person)

Who is in your family?

19. Tell me about your older family member. (Include nature of relationship (historical and current) and description of physical and mental health).

PROBE: a. How much guidance does X need to make decisions?

b. How adaptable is X to change?

c. How involved are you in assisting X in making decisions?

d. How has that changed during your relationship with X?

PROBE: Overall, how would you rate your relationship with X?

Five years ago: ____ excellent ____ good ____ fair ____ poor

Currently: ____ excellent ____ good ____ fair ____ poor

20. Assistance patterns:

A. What kinds of help does X need?

B. What kinds of help does X expect from you?

C. What kinds of help do you provide and how much time is involved?

D. How was the initial agreement for assistance worked out?

Who was involved?

What part did you play in the decision-making?

E. How has the agreement changed over time?

When? Why?

PROBE WITH:

(1) Personal care (bathing, dressing, mobility toilet, eating)

(2) managing medical regimes (taking meds, dressings, etc)

(3) home keeping

(4) home maintainance

(5) meal preparation

(6) shopping

(7) transportation

(8) money management

(9) contact with outside world

(10) negotiation of health and social service systems

a. To what extent are you involved?

b. What official assistance do you receive (e.g. caseworker)?

(11) other

21. SANFORD'S TOLERANCE OF DISABILITY

Does your older family member have any of the following problems? If so, how difficult is it for you to live with?

Problem	Occur.	No Problem	Management	Difficult	Intol.
Sleep disturbance					
Incontinence - F					
Incontinence - U					
Inability to get out of bed					
Inability to get off commode					
Dangerous behavior					
Inability to walk					
Personality conflict					
Physically aggressive					
Inability to dress					
Inability to wash					
Inability to commu.					
Daytime wandering					
Inability to climb stairs					
Inability to feed self					

22. How do you manage these problems? What advice would you give others experiencing the same problem?

23. What does it mean to you to care for your older family member?

Probe: What are the benefits to you?

Probe: What are the costs to you?

24. What changes have you made in your life since the assumption of caregiving activities? What do you feel abou these changes?

a. Leisure activities

b. Income and expenditures

c. Community activities

d. Employment status

e. Social/family relationships

f. Other

g. Overall, do the costs of caregiving outweigh the benefits, or the benefits outweigh the costs?

costs outweigh benefits _____

benefits outweigh costs _____

25. Have you any health problems limiting your own ability to provide care for your older family member?

26. What services do you think the government should provide for older persons?

What services do you know of in the community?

27. What role do you think family and friends should play in providing assistance to older people?

28. What help do your receive in providing care for your older family member?

a. From family and friends?

b. From community providers?

Probe: Here is a list of services that may be offered in the community. Have you or your older family member received any of these?

29. How did you find out about x community services? (Describe the process of obtaining services)

Probe: What was the experience of getting and maintaining the service like for you?

30. What would it mean to you to no longer have x service?

31. What help, if any, do you think your older family member needs, but is not receiving?

Who should provide the help?

Why do you think it is not available?

32. (IF family member holds an AFS contract)
What are the pros and cons of the official contract?

33. How do (did) you feel about your older family member living in his/her own home?

34. What alternative living arrangements would you/did you consider for your older family member?

1. Long term care facilities ______
2. Board and Care homes ______
3. Senior citizens housing ______
4. Present residence with supportive community services and family ______
5. New, more efficient residence ______
6. Residence with family member ______
7. Other, explain ______

(Describe in detail the informant's evaluation of these alternatives and what role the respondent and other family members will play.)

35. Who participated (would participate) in decision making about an appropriate residence for 'X' your older family member?

To what extent was X involved in that decision?

36. How would you/did you feel about your older family member going into the alternative living situation?

37. Please tell me how well you think you (and your family) are doing financially as compared to other people your own age?

2 Better
1 Same
0 Worse
- No answer

Explain:

38. How well does the amount of money you have take care of your needs?

2 Very well
1 Fairly well
0 Poorly
- No answer

Explain:

Probe: Would you say you:

3 do without many needed things
2 have the things you need but none of the extras
1 have the things you need and a few of the extras

39. Do you feel that you will have enough for your need in the future?

2 Yes
1 No
0 No answer

Explain:

40. How would you rate your overall health at the present time?

3 Excellent
2 Good
1 Fair
0 Poor
- No answer

Explain:

41. Is your health now better, about the same, or worse than it was five years ago?

3 Better
2 About the same
0 Worse
- No answer

Explain:

42. How much do your health problems stand in the way of your doing the things you want to do?

3 Not at all
2 A little
0 A great deal
- No answer

Explain:

43. Taking everything into consideration, how would you describe your satisfaction with life at the present time?

2 Good
1 Fair
0 Poor
- No answer

Probe: What would make life more satisfying?

44. How often do your worry about things?

0 Very often
1 Fairly often
2 Hardly ever
- No answer

45. What kind of things do you worry about most?

46. Has there been a time in the past when the family needed to rally around a member? Explain.

47. In general, how do your family members react in times of trouble?

48. If you are having trouble making ends meet (financial problems), could you call on your family or relations? If so, what can you expect?

51. If something happened to you that you had trouble handling yourself, who is your family likely to turn to?

_____ The family
_____ Relatives
_____ Friends
_____ Professionals
_____ Others (identify)

52. Do you have someone you can trust and confide in?

2 Yes
0 No
- Not answered

Probe: Who is it? How often do you see them/talk with them?

53. How would you rate your mental health at the present time?

3 Excellent
2 Good
1 Fair
0 Poor
- No answer

Explain:

54. Is your mental health better, about the same, or worse than it was five years ago?

3 Better
2 About the same
1 Worse
- No answer

Explain:

APPENDIX F

EPARTMENT OF HUMAN RESOURCE
ENIOR SERVICES DIVISION

PLACEMENT INFORMATION BASE (PIB)

PROGRAM	BRANCH	S.S. NUMBER	WKR. ID
NAME			

DATE

INSTRUCTIONS: For each scale, choose and write in the answer space that one level which, from your observation and knowledge of the person, and/or conversation with him or her, best describes how the person is usually functioning these days. When you are not sure which of several levels to choose, because the wordings of two or more levels seem to fit the person's usual function about equally well, or because the person regularly varies among levels, select the lower numbered level. If you cannot make a reasonable choice after attempting to get the information, write a zero (0) in the answer space.

Cluster One: Communication

1. SELF-IDENTIFICATION
   1. Individual states name, address, phone number, time, and place accurately and appropriately, and communicates information fluently and with detail appropriate to the situation.
   2. States name, address, phone number, accurately and appropriately, but without adjustment to the situation, or uses I.D. for these purposes.
   3. Identifies self only sometimes or only partly.
   4. Hardly ever identifies self, even with I.D., or does so inaccurately at least some of the time.
   5. Does not state name/address/phone number information accurately and appropriately, does not use I.D. for these purposes.
2. VISION (with glasses, if used – if the person is confused, make the best estimate you can)
   1. Normal or minimal loss, without glasses, or with old prescription. Sees adequately in most situations; can see newsprint, public notices, television, medication labels.
   2. Normal or minimal loss, with glasses prescribed within the last year.
   3. Moderate loss, can read large print, see simple pictures, and see obstacles, but not details, usually can count fingers at arm's length.
   4. Severe loss, cannot find way around without feeling or using cane, cannot locate objects without hearing or touching them; can tell light from dark.
   5. Total blindness. No vision at all. Cannot tell light from dark.
3. HEARING (with hearing aid, if used – if the person is confused, make the best estimate you can)
   1. Normal or minimal loss, without hearing aid or with old prescription. Hears adequately in most situations, can carry on an unrestricted conversation or otherwise responds appropriately to being addressed without speaker raising voice or altering normal pace and style of diction in groups as well as one-to-one; TV or radio; addressed from behind; etc.
   2. Normal or minimal loss, with hearing aid prescribed or with correction rechecked within the last three years.
   3. Moderate loss, hears adequately only in special situations, i.e., one-to-one, with firm, clear diction, raised volume of radio, etc.
   4. Severe loss, hears with difficulty even in special situations, i.e. conversation restricted, many misunderstandings, or frequently fails to respond, etc.
   5. Total deafness, no hearing at all useful for communication.

Cluster Two: Mobility

4. TRAVEL (by those means which are available and accessible)
   1. Uses private and public transportation properly and appropriately, on own. Can drive safely.
   2. Uses public transportation properly and appropriately, with a little help. Cannot or should not drive.
   3. Uses public transportation for both short and long trips with a moderate amount of help.
   4. Manages short trips with moderate assistance, but totally dependent on others for long or unusual trips.
   5. Totally dependent on help from others when any travel is necessary.
5. MOBILITY, WITHOUT AIDS (the extent to which the individual gets around alone, without aids: walker, cane, wheelchair).
   1. Has no difficulty and takes regular outside walks for exercise.
   2. Walks or gets around without difficulty both inside and outside.
   3. Walks or gets around easily inside, can get to various rooms alone, but needs some help outside.
   4. Gets around in own room, but needs assistance beyond that.
   5. Does not get around, even in room, without continuous assistance by another person.
6. MOBILITY WITH AIDS (the extent to which the individual gets around alone, using whatever aids (walker, cane, wheelchair) he/she has).
   1. Walks or gets around without difficulty both inside and outside.
   2. Walks or gets around easily inside, can get to various rooms alone, but needs some help.
   3. Gets around in own room, but needs assistance beyond that.
   4. Gets around in room, but uses wheelchair and needs help to transfer; may or may not need assistance to go further.
   5. Does not get around, even in room, without continuous assistance by another person.

Cluster Three: Household and Food Management

7. HOUSEKEEPING
   1. Takes complete care of his/her living space and that of others in living situation.
   2. Takes care of his/her own living space, both light and heavy work.
   3. Consistently manages own light housekeeping, but not heavy work.
   4. Does light housekeeping, but inconsistently or inadequately.
   5. Does not take care of own living space.
8. PERSONAL SHOPPING (gets such items as newspapers, toilet articles, snack foods, within physical limitations and any other restrictions)
   1. Does personal shopping regularly and properly without assistance or reminding.
   2. Does personal shopping without help, but must be reminded from time to time.
   3. Does personal shopping without help, but must always be reminded.
   4. Needs assistance from another person to get some items.
   5. Another person gets all items.
9. SHOPPING FOR AND PREPARING FOOD
   1. Does food shopping and preparation of meals.
   2. Shops with help; usually prepares meals.
   3. Does not shop, but usually prepares meals.
   4. Does not shop; prepares meals about half the time.
   5. Does not shop or prepare meals, or needs special diet, does not prepare it.

DATE

10. NUTRITIONAL HABITS
1. Eats three meals a day; daily, eats at least two servings of each of (a) fruits, (b)vegetables, (c) whole grain products, (d)fish, poultry, or meat, and (e) dairy products.
2. Eats three meals a day; daily, eats at least one serving of each of (a) fruits, (b) vegetables, (c)whole grain products, (d) fish, poultry, or mean, each day, and (e) dairy products.
3. Eats three meals,a day; but usually omits at least one of (a) fruits, (b) vegetables, (c) whole grain products, (d) fish, poultry or meat, each day, and (e) dairy products.
4. Eats two meals a day, but does eat at least one serving of (a) fruits, (b) vegetables, (c) whole grain products, (d) fish, poultry or meat, and (e) dairy products.
5. Eats sporadically, primarily carbohydrates and soft foods; or doesn't remember to eat, so needs reminding and/or supervision; or doesn't stop eating without reminding or supervision.

11. EATING (with special equipment if regularly used)
1. Feeds self, chews and swallows solid foods without difficulty.
2. Feeds self, chews and swallows solid foods which have been cut or pureed.
3. Needs assistance with feeding, but chews and swallows solid foods (which may have to be cut or pureed)
4. Needs assistance with feeding and has difficulty with chewing or swallowing, even with food cut or pureed. May need to be fed by tube.
5. Must be fed intravenously.

Cluster Four: Social and Emotional

12. SOCIAL ACTIVITIES
1. Involved regularly in activities with (a) family, (b) neighbors, and (c) church/fraternal/occupational/social/political organization(s). Extensive and satisfying social relationships.
2. Involved regularly in activities with at least one of these three kinds of groups.
3. Will participate in activities with at least one of these three kinds of groups if reminded and/or assisted to do so; only some of the relationships may be satisfying.
4. Will go to or be present at activities of at least one of these three kinds of groups if reminded and/or assisted to, but needs prompting and encouragement to actually participate; or is responsive when visited by one of only a limited number of people.
5. Not willing to go to activities of any of these kinds of groups, nor to be involved if present at them. Is not responsive to visitors, no social relationships.

13. PERSONAL INDEPENDENCE
1. Accepts change: actively adapts, makes plans, handles crises well, is confident.
2. Accepting, but needs some help in adapting and making plans and decisions.
3. Actively resistive; refuses to make decisions; consistently negative or hostile.
4. Neutral or passive. Requires regular assurance and/or guidance.
5. Withdrawn, afraid, or insecure; needs near constant support.

14. EMOTIONAL CONTROL
1. Personal problems, disturbances, emotional states do not particularly restrict the individual's type of living arrangement and companions.
2. Personal problems, disturbances, emotional states restrict individual's type of living arrangement and companions, but things work out O.K. in present set-up.
3. Personal problems, disturbances, emotional states restrict the type of living arrangement and companions, and things are not working out O.K. in present set-up.
4. Person is dangerous or violently abusive to self or others, but is controllable with medications.
5. Person is dangerous or violently abusive to self or others, not controllable with medications, requires physical restraints.

15. TELEPHONE
1. Makes and takes calls appropriately, fluently, with normal frequency.
2. Makes and takes calls appropriately, but infrequently.
3. Makes few calls, but takes calls and handles most of them appropriately.
4. Makes few or no calls, but takes some calls and handles at least some appropriately.
5. Neither makes nor takes calls appropriately.

16. ORIENTATION FOR LIVING ALONE (Oriented means: explains details of care, if any; reasons for it; how long it will be needed. Responsible means actually does the tasks he or she is supposed to do as part of the care).
1. Fully oriented and responsible for care of self, if needed.
2. Fully oriented but needs to be checked up on one or twice a day.
3. Fully oriented but needs help with activities of daily living.
4. Is sometimes confused, needs reminders and/or help for activities of daily living, but does not physically wander off.
5. Is sometimes or frequently confused, needs reminders and/or help for activities of daily living, and physically wanders off regularly.

17. NATURAL SUPPORT (friends/family/neighbors/volunteers)
1. One or more persons available to give care indefinitely.
2. One or more persons available to give care regularly for several months.
3. One or more persons available to give care from time to time for several months.
4. Several persons available to help out, one at a time or in rotation, from time to time, but there is no one to take overall responsibility for helping on a regular basis.
5. No person available to help except perhaps under extreme circumstances.

18. PERSONAL ACTIVITIES
1. Spends most of the time each day in a variety of personal activities, including reading, hobbies, crafts, occupations (not including passive entertainment.)
2. Spends most of the time each day in a limited set of personal activities (other than passive entertainment).
3. Spends mornings, afternoons, or evenings each day in personal activities (other than passive entertainment).
4. Spends 1 to 2 hours a day in personal activities (other than passive entertainment).
5. Spends less than an hour a day in personal activities (other than passive entertainment).

DATE

Cluster Five: Finances

19. MONEY MANAGEMENT
1. Writes checks, pays bills without any help. Keeps expenses within income.
2. Writes checks, pays bills without any help, but needs some advice or help each month to balance checkbook or perform similar tasks.
3. Manages day-to-day buying, but needs help with writing checks and/or paying bills.
4. Can handle purchasing of some personal items, but cannot handle all day-to-day buying.
5. Completely unable to handle money.

Cluster Six: Health

20. HEALTH CONDITION
1. Excellent or good physical health; no significant illnesses or disabilities; only routine health care such as annual checkups.
2. Mild health problems needing short-term attention or corrective measures (wounds requiring dressing changes, bed sores, etc.)
3. Has one or more moderate medical problems which may be painful or which require medical attention periodically (gets dizzy on movement, etc.)
4. Highly impaired, confined to bed, requires full time medical assistance or nursing care to maintain certain vital bodily functions (for example, turning for pressure relief and repositioning because of stroke, paralysis, weakness, or other reason)
5. Unconscious, unable to respond, needs total care for all bodily functions.

21. MANAGING MEDICATIONS (Consider the person's currently prescribed oral, topical, and injectable medications. Select the one category which fits best).
1. Needs no medications; or if needs them, manages medications alone. Knows what to take, takes them at correct times, keeps them properly.
2. Medications must be laid out for him/her each week, but no problems taking correct ones at correct times.
3. Must be given direct daily reminders, but follows them.
4. Does not manage own medications, needs to have some medication administered to him/her by someone else regularly but less than daily.
5. Does not manage own medications, needs to have some medication admisistered to him/her by someone else regularly, and daily or more frequently.

Cluster Seven: Self-Care

22. GROOMING AND DRESSING
1. Grooms and dresses self without any help. Combs hair, does nails, manages buttons, ties shoes, etc.
2. Grooms and dresses self without any help, but must be reminded to do so on some days.
3. Grooms and dresses self without any help, but must always be reminded to.
4. Needs help from another person to do some parts of grooming, or some parts of dressing, such as managing buttons or tying shoes; may or may not need reminding.
5. Needs help from another person to do all of grooming, or all of dressing, or both, and or may not need reminding.

23. BATHING OR SHOWERING
1. Bathes or showers self regularly, without reminders and without help for any task including turning the water on and off.
2. Bathes or showers self without any help, but must be reminded at least some of the time.
3. Bathes or showers self, but must have help for turning the water on and off.
4. Bathes orshowers self, but must have help for more than turning the water on and off.
5. Does not do any part of bathing or showering, requires another person to do everything.

24. USING TOILET
1. Gets to and from toilet, adjusts clothes, cleans self, etc., without help.
2. Needs help getting to toilet, but needs no other help.
3. Gets to toilet, but needs some help once there.
4. Gets to toilet, but needs total help.
5. Does not use toilet. Neither gets there, nor handles function without at least some help.

25. CONTINENCE (To what extent are the individual's natural excretory functions under personal control, day and night, whether naturally or with ostomy, catheter, etc; aid means having another person give an enema, insert a suppository, clean an appliance, etc.)
1. No accidents, or infrequent accidents; no problesm, needs no help or aid.
2. Accidents one or twice a week, or needs help or aid once or twice a week.
3. Accidents three to five times a week, or needs help or aid three to five times a week.
4. Needs assistance regularly (daily or more frequently) with specific parts of activity.
5. Needs moderate to great assistance. Someone must be present every time to assist with all, or nearly all, parts of the activity.

INITIAL) DATE ____ WORKER SIGNATURE ____

REVIEW) DATE ____ WORKER SIGNATURE ____

REVIEW) DATE ____ WORKER SIGNATURE ____

REVIEW) DATE ____ WORKER SIGNATURE ____

AN ABSTRACT OF THE THESIS OF

CHERYL LYNN BABB, B.S.N.

For the MASTER OF NURSING

Date Receiving this Degree: June 13, 1986

Title: MANAGEMENT OF IMPAIRMENT: SYSTEMS USED BY ELDERS AND THEIR FAMILIES

Approved: ______________________________

Patricia Archbold, R.N., D.N.Sc. Thesis Advisor

This exploratory study examines the experience of managing physical and cognitive impairment from the perspectives of the affected elders and their family members or significant others. The study describes the way in which management of impairment occurs among Medicaid-eligible elders in a rural area.

Subjects were drawn from a larger longitudinal, descriptive study of institutional and community-based service utilization by frail rural elderly. This larger study was conducted by Archbold and Hoeffer [1981] between August, 1981 and October, 1982. A state service agency provided the researchers with the names, placements, and functional assessment scores of Medicaid-eligible elderly (65 years and over) in four rural counties. Subjects for this study included 22 community residents and 12 home-for-the-aged residents. In addition, 27 of their family members or significant others participated in the study.

Data collection occurred during interviews with the elderly subjects and their family members or significant others. Methods included (1) focused, in-depth interviews, (2) participant observation, and (3) the Placement Information Base (PIB).

Qualitative analysis of the data revealed a model consisting of four family management systems: (1) elder self-management, (2) elder-family cooperative management, (3) family management, and (4) family-professional cooperative management. Major variables which determined the systems used by the families included decision making, goal establishment, and day-to-day management.

Factors which limit the generalizability of the study findings include the small convenience sample and geographic and economic characteristics of the sample population (rural Medicaid-eligible elders). The family management systems model provides a useful conceptual framework for nurses working with impaired elders and family caregivers. The model can be used in assessment of the elder's and family's needs and in interventions designed to empower them in elder/family management roles.