Transitions in Frail Rural Older People: Thinking about a Move to a More Supportive Living Environment

By

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To Phyllis Henning Clark Knoche

For being my first nursing mentor;

For nourishing me physically, emotionally, and spiritually;

For being a wonderful mother.

I am sorry I did not complete

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ABSTRACT

TITLE: TRANSITIONS IN FRAIL RURAL OLDER PEOPLE: THINKING ABOUT A MOVE TO A MORE SUPPORTIVE LIVING ENVIRONMENT

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The purpose of this qualitative study was to develop a theory of the process used by rural older people and their family caregivers in deciding whether and when the older person needs to leave the home for a more supportive living environment.

Grounded theory methodology (Glaser & Strauss, 1967) was used to analyze the transcribed interviews and participant-observation field notes. The participants were 17 families; 14 frail older people living in a rural county in the Northwest and 18 of their family caregivers. Each participant was interviewed twice between 4 to 36 weeks apart. The balancing model was developed to capture the process used by the older person when considering the decision to receive help in the home or move to receive the help needed. The components being balanced include routines, resources, and disrupters. The dimensions of balancing include centrality, urgency, permanence, and awareness. Balancing is maintained or restored by accepting, prioritizing, and taking action (the elements normally associated with decision-making). The decision-making process occurs if the older person acknowledges disequilibrium between her/his routines, resources, and disrupters and the centrality, urgency, permanence, and awareness dimensions are adjusted.

A trajectory was developed to visualize the decisions made over time: the formal and informal care received to maintain the older person's priority routines as increasing needs accumulate. The balancing model and trajectory could be used as counseling tools with families dealing with these decisions regarding care in and out of the home. Trustworthiness of the results is discussed in terms of credibility, transferability, confirmability, and dependability.

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CHAPTER I

INTRODUCTION

The overall purpose of the study was to develop a theory of the process used by rural older people and their family caregivers in deciding whether and when the older person needed to leave the home for a more supportive living environment. The specific aims of the study were to: (a) describe and analyze the process used by rural older people and their family caregivers in deciding whether and when the older person needs a more supportive living environment, (b) identify antecedent and concurrent variables that influence the process of deciding to move, (c) describe contextual variables that influence the process, (d) describe the older person's and family caregiver's perspectives regarding the decision to move and anticipated outcomes of the move. The outcome of the study was development of the balancing model to theoretically capture the process used by rural older people and their families when making decisions regarding the older person's need for help and moving to more supportive environments. The long term objective of this research was to improve nursing and health care for older people and family caregivers by learning what is needed to effectively support them during this process of deciding when additional care is needed, when care at home is no longer possible, and during the accompanying role transitions and relocation.

To provide the reader some background for the study, the demographics of aging, caregiving, and long-term care will be reviewed in general and specially for

Oregon, along with information about the unique situation of rural, older people and the decision-making process. Oregon is exceptional in providing older people and their families many choices along the long-term care continuum.

Demographics of Aging, Caregiving, and Long-Term Care

As the percentage of the American population 65 years of age and older has increased during this century from 4.1% to 12.2% (U.S. Census Bureau, 1989a), the number of elderly people reaching "old old" age has also increased. The Census Bureau predicts that the number of individuals 85 years of age and older will increase from the 3.3 million in 1992 to 18.7 million in 2080 (Vierck, 1990). Increasing age is associated with a greater number of chronic diseases and increasing functional impairment (Bould, Sanborn, & Reif, 1989; Office of Technology Assessment, 1985). Therefore the expanding population of persons 65 and older will require assistance with activities of daily living and chronic disease management for an extended period of time.

Family members and friends (informal caregivers) provide a great deal of assistance to older people in meeting their daily needs (Abel, 1990; Brody, 1981; Shanas, 1979; Stone, Cafferata, & Sangle, 1987; Tennstedt, McKinlay, & Sullivan, 1989), but at some point this assistance may not be sufficient (Smallegan, 1985; Kane, Kane, Illston, Nyman, & Finch, 1991). Almost no one wants to leave his or her home. However, as an older person's health declines with age and with the development of chronic health problems, it may be more difficult to accommodate to these changes and safely remain at home. Few studies have explored the decision-making process that led up to the older person deciding to move from the home to receive the care needed (Deimling & Poulshock, 1985; Smallegan, 1985; Tobin & Lieberman, 1976). Only one nursing study was found that proposed a specific theoretical framework for this process (Chenitz, 1983). The situation in Oregon today, with more long-term care options available for the older person needing a more supportive environment, is markedly different from that present a decade ago during Chenitz's study of the process of adaption to a move to a nursing home that involved older people located in an urban area of California.

Although Oregon has a range of options in its continuum of long-term care services, not all of these are available in rural areas or are available only in the larger communities and the surrounding counties (Baltazor, Elder, Mingus, directors of Area Agencies on Aging for three rural counties in southern Oregon, personal communication, Spring 1992). How does the available range of options influence the decision reached by the older person and family members thinking about ways to meet the health care needs of the older person? This study explored whether lack of services influenced decisions made by rural older people and family members and whether gaps in home care services lead to earlier admission to a residential setting.

Making the Decision to Move

How the moving decision is made is a poorly understood dimension of family caregiving (Hughes, 1985; Smallegan, 1985) and has been characterized as a crisis situation (Chenitz, 1983). Many of the studies on institution-alization (Branch

& Jette, 1982; Deimling & Poulshock, 1985; Lui & Manton, 1983; Nocks, Learner, Blackman, & Brown, 1986; Tobin & Lieberman, 1976; Townsend, 1965; York & Calsyn, 1977) were done when the only alternative to care in the home was nursing home care. In Oregon there are now a variety of long-term care options (home care, adult foster home, residential care, assisted living) to choose from with nursing home care considered only when care needs are extensive. This variety of options may influence the decision-making process about moving. There is limited published research that has explored this process prospectively (before the move) from the older person's perspective (McAuley & Blieszner, 1985; Béland, 1984; Branch & Jette, 1982) regardless of location, and there is little theoretical discussion regarding how this decision is made by the family (Hughes, 1985).

This study explored the decision-making process used by rural, older people and their family caregivers when deciding whether help was needed in the home or a move to a more supportive living environment was required. Before describing the study methods in more detail, a review of the literature and preliminary studies will be presented.

CHAPTER II

REVIEW OF THE LITERATURE

This review will highlight past literature that addressed the family's perspective on long-term care, the older person's perspective, rural elderly, the decision-making process, and the meaning of home. The investigator's preliminary studies will be discussed along with the theoretical foundation of the current study and the backdrop of previous family caregiving research done by others.

Family Factors and Perspective on Long-Term Care

Studies have identified the risk factors for admission to long-term care (LTC) institutions (Branch & Jette, 1982; Christ, Visscher, & Bates, 1988; Liu & Manton, 1983; Newman, Struyk, Wright, & Rice, 1990; Nocks, Learner, Blackman, & Brown, 1986; Townsend, 1965) and characteristics of the family caregiving situation prior to the admission of the older relative to a LTC institution (Deimling & Poulshock, 1985; Dick, Friedsam, & Martin, 1964; Smallegan, 1985; Tobin & Lieberman, 1976; Townsend, 1965; York & Calsyn, 1977), but few studies have explored the process that led to this move. Appendix A, Research Studies Related to Family's Perspective on LTC, contains tables outlining the specifics of the studies mentioned in this section.

Scannell (1987) explored the factors that affected the family's decisions about choice of long-term care facility for the older parent. They included attributes desired in long-term care facilities (such as homey atmosphere, appropriate level of care, meals provided, cleanliness), attitude of older person toward moving to a long-term facility, and whether this is the first, second or later move to a long-term care facility. Johnson (1990) indicated that most daughters (*n* = 16) found the decision of admitting a parent to a skilled nursing care facility with anticipation of this placement being long-term or permanent as "the hardest thing I have ever done" (p. 9). The parents were moved from one to another nursing home by three of the daughters in Johnson's study because the daughters' were dissatisfied with the care provided or the parent seemed unhappy to the daughters.

Two separate reviews of the quantitative research literature (Greenberg & Ginn, 1979; Knight & Walker, 1985) identified a variety of factors that interact to increase the risk of nursing home placement: the older person's physical condition, mental health, functional health, living situation, community and family support, the family's attitudes toward institutionalization, finances, and availability of alternatives. Almost none of these studies reported using a theoretical framework to focus the examination of factors; however Tobin and Lieberman (1976) discussed both attachment theory and Lazarus' stress and coping theory as theoretical bases.

Older Person's Perspective

Little is known about the process of deciding to make a move from the older person's perspective. Theoretical frameworks were discussed in three qualitative studies related to the relocation process of older persons. In two of these, Rowles (1983) and Hartwigsen (1987) developed models of the relocation process. Each identified what contributed to the inertia that prevented older people from moving and the crisis that resulted in the older people relocating. Both the Rowles and Hartwigsen studies saw the process occurring over time (in most cases years) with declining health and finances overcoming the inertia. Both authors explored unique populations: five older people living in rural Appalachia (Rowles) and 25 widows with high income and educational levels who chose to move to a life care facility (Hartwigsen). In the third study, Chenitz (1983) conceptualized the move of older people into a nursing home as a status passage with the importance, legitimation, desirability, voluntary nature, and reversibility of the move influencing the older people's response to it. This was a retrospective study interviewing the older people after they had moved to the nursing home, with many of the individuals being admitted to the nursing home from the hospital. Today the situation is qualitatively different than that found by Chenitz. More older people are moving directly from the home to the long-term care (LTC) setting and a variety of LTC settings are available in Oregon from which to choose in addition to the nursing home (SDSD, 1988). There is a need to re-explore this complex process, to include the new LTC alternatives, and to develop a conceptual perspective representing the empirical situation. As pointed out by Hughes (1985) in her review of 13 community-based long-term care evaluation studies, "this area has been hampered by our limited theoretical knowledge concerning . . . the process of decision making which leads one person to seek institutional care and another with similar characteristics to resist it" (pp. 481, 484).

McAuley and Blieszner (1985) asked a statewide representative sample of noninstitutionalized people 60 years of age and older to select the type of care/living arrangement they would prefer "if you became sick or disabled for a long time." Paid in-home care was chosen by 70% of the sample and 66% agreed with the statement that if they became sick or disabled for a long time they would like to have a relative (such as a husband/wife, child, or other relative) care for them in their own home. The other choices offered by McAuley and Blieszner and the respective percent agreement by the older people were: adult day care (32%), nursing home (28%), and move to home of relative (15%). See Appendix B, Research Studies Related to the Older Person's (OP's) Perspective, for tables summarizing the specifics of studies discussed in this section.

Coulton, Dunkle, Goode, and MacKintosh (1982) used qualitative interviews with older people while they were still in the hospital to identify nine factors that affected the older person's involvement in decision-making for post-hospital care: (a) level of disorientation, (b) information about choices, (c) perceived freedom of choice, (d) time available to explore choices, (e) degree of hope regarding outcomes, (f) family power structure, (g) commonality of family goals, (h) degree of social support, and (i) older person's assertiveness. Coulton, Dunkle, Chow, Haug, and Vielhaber (1988) looked at older peoples perceptions of the multiple dimensions of the decision-making process when preparing for discharge from the hospital. In the hospital discharge planning literature, many more studies focus on how the health care providers make the decisions and then advise the family and older person about housing and care needs post-hospitalization, rather than on how the older person perceives this decision and the move (Chadwick & Russell, 1989; Weaver & Bryant, 1990; see Appendix D).

The few studies that directly explored the process used by older people considering a move from their home will now be reviewed. Using qualitative interviews and observations of older people, Hartwigsen (1987) and Rowles (1983) both characterized the move as a transition that resulted after a period of inertia and a crisis. Brody (1969) found that the number of reasons initially offered for requesting admission to a voluntary home for the aged and a positive attitude toward institutionalization were both strongly related to older person one year later having relocated from the family home to an institution. Brody (1978), in another study, found that urban people who applied for their Community Housing for the Elderly (rent subsidized private efficiency apartments with a shared living room for every three apartments and social services available) did so primarily because they felt lonely and isolated, their current house was in poor condition, and they feared crime in their neighborhoods. Less than half the time was the move to the housing unit desired for reasons of access to health and social services.

Béland (1984) looked at why older urban French speaking Canadians applied for admission to a residence of some kind (low-rental housing unit, intermediate care facility, or a long-term care facility). He concluded that older people wanted to leave their homes because they did not have sufficient resources to stay in them. Socio-demographic variables and housing variables were the most important in predicting the desire to move. Number of chronic diseases and subjective estimation of health, and social and psychosocial relationship variables were also associated with older people's desire to leave their homes. He identified other variables that influenced the desire to move (a) formal help given in the home had only a marginal effect on desires for housing but frequency of doctor appointments in the last 6 months was correlated with the desire to move from home; (b) the help available from family, friends, neighbors, or volunteers did not influence the desire for different housing; and (c) functional disabilities did not result in a desire to move from the home but difficulty in doing activities outside the home in winter did predict a desire to move.

A study by Kane, Kane, Illston, Nyman, and Finch for SDSD reported in *Meshing Services with Housing* (SDSD, 1990) indicated that 23% of the private pay foster home residents and 27% of Medicaid-paid foster home residents had come from their home to the foster care residence. For comparison, 20% of the private paying nursing home residents and 28% of Medicaid-paid nursing home residents had lived at home prior to admission. For the above study Kane et al. interviewed 400 foster home residents and 400 nursing home residents regarding what led residents to seek care. Four reasons were identified: (a) a health event or something related to the heath event, (b) progressive decline in functioning, (c) decreased cognitive ability, and (d) a need to change living situation or a change with the caregiver. Many people reported multiple reasons for the move. The study found that residents at both types of facilities were generally pleased with their care.

Residents at foster homes liked the more home-like setting while nursing home residents preferred the increased social activities available. SDSD commissioned the study to assess whether patients that had their care paid for by Medicaid were disproportionally referred to foster homes compared to patients paying privately.

Bear (1990) looked at the effects of the older person's health status and social networks on the possibility of returning home from a residential care facility (RCF). Although being non-white (study setting was Florida), paying for one's own care, and having less intense network ties increased the older person's probability of returning home or to a relative's home, the older person's high functional status at 6 months was the variable most important in explaining this return home. Twelve older people out of 80 returned home.

Rural Elderly

Krout (1989) reported that there was a rate of lower health dependency (determined by nine measures of health service utilization) found for rural older people living in western New York but stated that this could be a result of services not being available or accessible. Coward and Cutler (1989) documented that the range of services was more limited in rural areas and that there were few alternatives within any one service. A survey of Area Agencies on Aging (Nelson, 1980) indicated that in rural areas the services most lacking were those for the severely disabled living in the community. Are older people considering a move from the home because there is no other way to obtain the care needed? Greene (1984) speculated that the lack of community services in rural areas of Arizona was the reason rural older people admitted to nursing homes were younger and less functionally impaired than their urban counterparts. Coward and Cutler (1989) pointed out that it is not known whether the differences in availability of community-based care in rural areas has any significant effect on the lives of older people and their family caregivers. Are the strains and rewards of caregiving different for families living in a rural setting? Dwyer and Miller (1995) indicated that the impaired rural older person's ability to provide intergenerational assistance (i.e., chores, babysitting, money, keeping company) also may serve to reduce caregiver burden. Appendix C, Research Studies Related to Rural Older People contains tables outlining specifics of the studies referred to in this section.

Weinert and Long (1991), Lee (1990), and other nurses associated with the Montana State University College of Nursing have been conducting research and developing a theoretical base for rural nursing practice. They were initially motivated to begin this work because health care programs based on urban models were not working in the rural environment, and the rural residents had not been consulted regarding their health care needs and how best to meet these needs. Examples of the discoveries made by these nurse researchers include: (a) the significance of ability to work in the rural resident's definition of health (Lee, 1990), (b) well rural residents define health in terms of physical well-being in addition to the ability to work compared to rural individuals with chronic diseases who emphasize emotional and spiritual well-being in their definitions of health (Long & Weinert, 1989), (c) rural dwellers living miles away from health care services did not consider themselves isolated (Long & Weinert, 1990), and (d) rural persons manage health problems on their own or seek help from family and friends before turning to formal services (Weinert & Long, 1987). While these studies focused on rural persons of all ages, can they be generalized to older rural residents of southern Oregon? If present, how do these concepts of health and self-reliance influence the rural older person's decisions to seek care with everyday tasks when family/friends can no longer provide the level of care needed? As Dwyer, Lee, and Coward (1990) pointed out in their decade review of the literature related to health issues of rural elderly, the empirical evidence that rural elderly have a strong informal helping network is equivocal. One cannot condone the lack of formal services in rural areas by assuming that families are available to meet these caregiving needs of older people. Krout (1988) has found no increased interaction between older persons and their children based on whether the older person lives in rural or urban areas. Lee and Whitbeck (1987) found that older rural residents in Washington state have no more contact with children than urban residents.

The Decision-Making Process

In reviewing the literature, most authors conceptualize this process of deciding whether and when to leave the home as a cognitive, linear process. The consequences of this process are more complex than a single dimension, ranging from the positives to the negatives of the move (Janis & Mann, 1977). Coulton, Dunkle, Chow, Haug, and Vielhaber (1988) identified six factors that influence the decision-making process in a study of older people's perceptions about decision-making regarding post-hospital care: (a) control, (b) restriction of choice, (c) family support, (d) certainty of outcomes, (e) hypervigilance, and (f) being rushed. Their study did not address how the decision was made. Appendix D, Research Studies Related to the Decision-making Process, contains tables of research studies mentioned in this section.

Coulton, Dunkle, Haug, Chow, and Vielhaber (1989) demonstrated that older patients who went home after being hospitalized were less anxious about the decision regarding post-hospital care, felt more control over the decision, and were satisfied with their surroundings 30 days post-hospital discharge compared with the older patients who went to a nursing home. No studies were found that explored this process when the older person needed to consider leaving the home to obtain the care needed with everyday activities. The majority of the studies found in the hospital discharge planning literature focused on how the post-hospital care decisions were made by the health care providers rather than how the older person makes the decision (Chadwick & Russell, 1989; Weaver & Bryant, 1990).

Human cognition studies have indicated that people do not use rules of logic or probability in arriving at solutions (Kahneman, Slovic, & Tversky, 1982). Solutions to the problem result from how the individual initially frames the problem. Kahneman, Slovic, and Tversky (1982), Steinbruner (1974), and Gardner (1985) have identified the factors that determine the framing of the problem: (a) how the problem is presented, (b) the present mood of the individual, (c) ability to imagine alternatives, (d) experiences with similar situations, (e) perceived effect of the problem on current life-style, (f) sense of whether the decision outcome will be a win or a loss, (g) past experience, (h) current world view that reflects values and beliefs, and (i) degree of familiarity and organization of the material being considered in making the decision. In summary, the framing of the problem and therefore the decision is affected by the information, values, emotions, and experience the older person and family possess. The primary value expressed by both caregivers and care recipients in Sims, Boland, and O'Neill's (1992) nursing study of the decision to provide home care was that home was the best place to heal.

One example of problem framing was when family caregivers thought they did not have any options when making the initial decision to provide home care (Sims, Boland, & O'Neill, 1992). When family members could no longer provide this care at home, they also felt that there was nothing else to do but admit the older person to a nursing home (Smallegan, 1985). In an earlier study by Beaver (1979) interviewing older people who had moved to a high rise HUD retirement building in downtown Los Angeles, the older people considered only a few options when moving and stressed that they had a definite opinion from the beginning about where they wanted to live. Is this how rural older people and their caregivers frame this problem, envisioning only one possible choice or outcome?

Another key element of the process identified by Sims, Boland, and O'Neill (1992) was the skill and experience of the family caregivers. In this same study, Sims et al. also discussed the difficulty of studying the process after the fact, because individuals find it difficult to describe what they thought about prior to deciding. The decision made can be remembered but it is difficult to recall the process used to arrive at the decision. This finding pointed out the need for a prospective study to interview individuals while they are in the decision-making process.

To summarize the literature, risk factors for the older person's admission to a LTC setting included advancing age (over 75 years of age), female, unmarried, living alone, childless, mental disorientation, incontinence, using ambulatory aids, using assistance to perform instrumental activities of daily living, finances, having been hospitalized recently, and the death or sudden illness of a chose relative (Branch & Jette, 1982; Christ, Visscher, & Bates, 1988; Liu & Manton, 1983; Newman, Struyk, Wright, & Rice, 1990; Townsend, 1965). The family considered having the older family member move to a LTC setting when the family saw no other options being available for the older person to receive the care needed (Johnson, 1990; Sims, Boland, & O'Neill, 1992; Smallegan, 1985). The majority of family members choosing nursing home placement for an older person considered the nursing home a positive environment providing good care and these family members reported many of their own health problems and task burden (Deimling & Poulshock, 1985). Many older people moved closer to or moved in with relatives prior to moving into a LTC setting (Dick, Friedsam, & Martin, 1964; Smallegan, 1985), and many families felt the older person needed 24-hour assistance at the time of the older person's move to the LTC setting (Smallegan, 1985). Many older people were admitted to a nursing home directly from the hospital (Chenitz, 1983; Smallegan, 1985; York & Calsyn, 1977).

The preference of many older people when they retained control of the decision-making process was to remain in their home with care provide by a relative, friends, or paid help (McAuley & Blieszner, 1985; Rowles, 1983). Many older people who chose to move to a LTC setting had a positive attitude toward the LTC setting (Béland, 1984; Brody, 1969) and felt some control over the choice (Kane, Kane, Illston, Nyman, & Finch, 1991). A group of older widows (*n* = 25) with greater financial and educational resources than most of their cohorts chose to move to a more supportive environment after crises experienced vicariously when health or financial problems were weathered by family and friends (Hartwigsen, 1987). The older person's ability to participate in the decision-making process was influenced by the individual's level of mental impairment, the time and information available to make a choice, the support and shared goals between family members and the older person, and the older person's assertiveness (Coulton, Dunkle, Goode, & MacKintosh, 1982). The rural older person was considered to have fewer choices in services than her/his counterpart in the urban setting (Coward & Cutler, 1989; Krout, 1989; Nelson, 1980). Also a 10-year review of the literature by Dwyer, Lee, and Coward (1990) found that there is a lack of empirical evidence that rural elderly have a strong informal helping network. Rural persons try to manage their health problems on their own before seeking help from either family, friends, or formal services (Weinert & Long, 1987). The influence of the meaning of home for the older person in making a decision to move will now be considered.

Meaning of Home

Hayward (1977) stated that although home is a physical space, a person's concept of home is better comprehended as a unique relationship to that space. Home is linked with one's personal history of growth and development. Horwitz and Tognoli (1982, p. 340, see Appendix E for a summary of the study) state that "home is a term used to link a state of being and a sense of self with a place"; one's meaning of home. Home was a stabilizing influence in life crises and proved important in defining one's sense of self in Horwitz and Tognoli's participants (9 out of 10 who were less than 65 years of age) in a qualitative study. If these characterizations apply to older people, it is understandable why an older person may consider a move from the home to be a crisis in its own right in addition to the initial crisis that led to considering a move. It may represent the loss of one's identity as an independent person in control of his/her space, in addition to separation from an environment that recalls many memories. Moving may therefore impose a form of deprivation. Meaning of a place may or may not be related to attachment to home. What appears as an irrational unwillingness to move from a large family home or a now dangerous and deteriorating neighborhood may be a defense against self-deprivation (Lawton, Kleban, & Carlson, 1973). Relative deprivation is a theory used to describe individual behaviors of older people in relation to place (Howell, 1983). Objective evaluations of the place will not necessarily reflect the older person's assessment of deprivation related to the same place.

The perceptions of place may be influenced by the individual's comparison of his/her situation to that of a younger cohort, his/her own cohort at an earlier stage, or a preceding cohort. If place and self are interrelated, then a rapid change in place may cause disorientation and a loss of self. It can result in difficulty placing oneself in space, time, and society. Place helps the individual retain the memory of self, events, and relationships. Béland (1984) found that the longer older urban people had lived in their homes and the more friends of the same age they had, the more likely they were to want to stay in their homes.

The complex conceptualization of meaning of home was clearly illustrated in two studies: Rubinstein's (1989) interviews with seven older urban residents and Rowles (1980) interviews with five older rural Appalachian individuals. Rubinstein identified three processes linking person to home: social-centered, person-centered, and body-centered processes. The social-centered process involved ordering or structuring the home environment according to the individual's interpretation of cultural rules. Gradations of the person-centered process that associated environmental features with a part of the self-included accounting, personalization, extension, and embodiment. The body-centered process, adjusting the environment to the person's functioning abilities, included extexturing and, for some individuals, environmental centralization.

Rowles (1980; see Appendix B for details of this study) found that being physically, socially, and autobiographically (reminiscences triggered by places) *inside* a place both currently and historically allowed the older person to accommodate to the changes of growing old. The degree to which one has this sense of being inside the place may reflect the individual's attachment to the place. If this insideness or indepth familiarity with the environment makes more likely the accommodation to aging, what happens when a move results in the loss of this advantage? An environment that has been created to be barrier free and technologically supportive for older people still cannot provide autobiographical insideness. The older person who has moved may suffer loss of place, a sense of self-deprivation and, consequently, poor accommodation to aging as well as to the change itself.

Preliminary Studies

Almost no one wants to leave his or her home; however, as an older person's health declines with age and with the development of chronic health problems, it becomes more difficult for the individual to accommodate to these changes and safely remain at home. As a member of a geriatric assessment team in an urban setting, the investigator noted that a request for an evaluation (*n* = 58) of the older person's health and care needs was initiated by the family 50% of the time, Senior Services 10%, and other agencies 40% (Wood, 1990). The family was unsure about what help the older person needed and sought outside advice regarding what decisions needed to be made to insure a safe situation for the older person. At times the family wanted an outsider to assess the situation and make recommendations because the older person was resisting the advice of family to make changes in her/his living situation, a difficult situation for both the older person and the family.

When the investigator first thought about this decision to move that the older person was facing, the process was conceptualized only in terms of a linear, cognitive model: the pros and cons of moving. Megan and Wood (1975) discuss how we create our view of the world, our "reality," and how all of our experiences are then interpreted to reinforce that view. Our language shapes this reality by not only labeling what is seen but by creating the context which determines what will be seen. This creation of reality is called a reflective activity by Megan and Wood. The investigator was unaware of the influence of this reflective activity as the pilot study (Wood, 1992) began by interviewing eight older people and two family members about how older people make the decision to move from their home. At that time the process was visualized in terms of a linear, cognitive model.

After hearing one of the participants talk about "letting things unfold, that I sort of watch what happens to me and how my feelings are, and I haven't felt any great drawing . . . [in deciding where to live]," a linear model no longer seemed adequate. The way this older person contrasted his method with the "pro and con lists," brought to mind a river moving with the flow. A river does not flow in a straight line, but meanders seeking the least resistance. At times the water is caught in an eddy going around and around, which suggested the ambivalence that many of the older people described when talking about moving from their homes.

By imposing a linear, cognitive model on this process it made it difficult to ask participants questions that did not reflect this conceptualization: "What got you thinking about the move?"; "What was most important in making the decision?"; "What experiences in your life helped you make this decision or influenced this decision?" The investigator tried to get away from this one dimensional model by asking about the meaning of home: "What does home mean to you?" However, this proved to be a difficult question for the older person to understand and answer, and did not seem to generate the in-depth descriptions hoped for, suggesting that meaning of home involved looking at values. King and Given (1991) also found it difficult for caregivers to answer questions related to values.

Realizing the limitations of visualizing the decision-process as a linear, cognitive model led to further literature review and the concept of framing of the problem (Gardner, 1985; Sims, Boland, & O'Neill, 1992; Steinbruner, 1974; Kahneman, Slovic, & Tversky, 1982). Although professional care providers usually consider the decision-making process as rational and objective, Benner (1984) has been demonstrating that it is also an intuitive process. How much the framing of this decision is influenced by values, feelings, and intuition was explored in the current study. The importance of assessing the emotions associated with the process and their association with outcomes was also demonstrated in a study by Scannell (1987). This broader conceptualization of the process (not necessarily a rational process), the need to interview family members involved in the process in addition to the older person, the need to obtain descriptions of values and emotions involved in the process, and the need to be aware of the length of time involved in deciding on a move (weeks and in one case, over 20 years in this pilot study) were considered when designing the current study. The river analogy was used during the data collection and analysis process to retain the image that the decision-making process is complex and non-linear in nature.

Family Caregiving Research

Much research in the area of family caregiving has focused on caregivers and the nature of caregiving. The care receiver's functional impairments and problem behaviors as perceived by the caregiver and caregiver burden have often been the major considerations of research studies (Deimling & Bass, 1986; Montgomery, Gonyea, Hooyman, 1985; Poulshock & Deimling, 1984; Zarit, 1982; Zarit, Anthony & Boutselis, 1987; Zarit, Reever, & Bach-Peterson, 1980; Zarit, Todd, & Zarit, 1986). Other concepts that have been used to describe the caregiving situation for the primary caregiver included depression (Poulshock & Deimling, 1984), caregiver well-being (George & Gwyther, 1986), caregiver strain (Robinson, 1983), and mutuality, preparedness, and rewards of caregiving as predictors of caregiver role strain (Archbold, Stewart, Greenlick, & Harvath, 1990). Fewer studies have sought the older individuals' perceptions of the situation (Chenitz, 1983; Coulton et al., 1988, 1989).

From clinical experience and past class research projects (Wood, 1990, 1991, 1992), the investigator had come to believe that factors described by the concepts identified by Archbold, Stewart, and associates (1990, 1993) may have a significant impact on the decision-making process used by caregivers in deciding whether their older relative needs to leave the home to receive needed care. As a member of a geriatric assessment service, the investigator learned that the patient was often referred for a complete assessment by the family, who was feeling helpless, not knowing what to do about the older person that was exhibiting memory problems and confusion, and at times, paranoid behavior. Whether the relative was able to care for her/himself at home was often a question asked by the family. Family members were trying to offer the relative help that was being refused and, at times, angrily resisted. This stressful situation resulted in the family seeking out the assessment service for evaluation of their relative. The family and older person often had very different perceptions of the situation and needs of the older person. The decisions that were made about help needed and the living situation appeared to be influenced by past family history and the relationships between family members, in addition to the objective evaluations of the older person's health status, daily needs, and how family members could meet these needs.

Some of these concepts appear to be captured in measures developed by Archbold, Stewart, and associates in their studies of caregiving (1990, 1993). Use of these measures in a pilot phase of the current study was planned to get a preliminary idea about whether and how the variables were associated with the decision-making process for the older person and caregiver(s). These caregiving variables were measured through use of self-administered questionnaires at the end of the qualitative data collecting period (at the end of the second interview). Because families who seek assistance with this decision may differ on these variables from those who don't, the study sampled both groups (help seekers and non-help seekers).

Theoretical Framework

Role theory and grounded theory methodology (Johnson, 1981), both an outgrowth of symbolic interaction, were the basis of the current study's methodology. Archbold and Stewart's (1988, 1990) conceptualization of caregiving was used for the pilot phase of current study. In symbolic interaction the human beings' ability to create and manipulate symbols is used to explain human conduct and social organization. Human beings act towards things based on the meanings that the things have for them. These meanings are a product of social interaction in human society and are modified by the individual through an interpretive process. Interdependence of human beings is a result of the sharing of common symbols and meanings. Individuals are seen as consciously taking into account one another when planning their own actions (Blumer, 1969).

Summary

The review of existing literature, the pilot studies, and anecdotal evidence indicate that the process of the older person and family deciding whether and when the older person needs to leave their home for a more supportive environment has not been described, is a decision not easily made, and will be a decision faced by more families as society ages. Nurses caring for an older person in the hospital, providing care as a home health nurse or PAS screener, or providing health information as a neighbor or friend of a rural older person (Weinert & Long, 1991) are involved in helping families make these decisions. Understanding how families and the older person make these difficult choices is essential for development of successful nursing interventions.

CHAPTER III

METHODS

This was a qualitative study to develop a theory of the process used by rural older people and their family caregivers to decide whether and when the older person needs to leave the home for a more supportive living environment. With little known about the decision-making process related to this move, an exploratory descriptive design was selected. Grounded theory methodology was used because it could generate empirically-based theory that evolves directly from nursing practice. Underlying the selection of this qualitative approach were the assumptions that all the concepts relevant to the process had not been identified, completely described, or their application was to a new area.

The data collection methodology involved formal unstructured interviewing for grounded theory with repeated contacts with the participants (Swanson, 1986). This allowed the participants to describe the phenomena in their own words and discuss what was important to them. Obtaining the participants' perspective is the foundation for grounded theory. In Glaser's (1978) words, looking at "what is this data a study of" from the participants' viewpoint often "reminds the researcher that his [her] original intents on what he [she] thought he [she] was going to study just might not be" (p. 57).

A second component of the current study involved a quantitative approach which was a pilot for a later study. As such, it was exploratory using questionnaires containing measures used in previous caregiving research (Archbold & Stewart, 1990; Archbold, Stewart, Greenlick, & Harvath, 1990) but not specifically applied to this transition in caregiving when the older person is moving from the home to a more supportive environment. The questionnaires were given to participants after the second qualitative interviews were completed so as not to influence the content of the responses during the preceding interviews. The questionnaires were not examined by the investigator before the balancing model was developed, so that questionnaire responses did not bias the development of the model from qualitative data. Upon completion of the analysis of the qualitative interviews and the formulation of the balancing model, the concepts measured by the quantitative measures were analyzed and did not appear to have a close association with the concepts in the model. Therefore, the data from these quantitative measures will not be discussed in this dissertation report.

Oregon, Older People, and Long-Term Care

Oregon, as is characteristic of the nation as a whole, is composed of an aging population with 13.7% of the citizens being 65 years of age or older. It is also a state of little racial diversity with 92.6% of the citizens white (Oregon Department of Human Resources, Office of Health Services, 1991). Oregonians prefer their privacy with the state ranking 48th in the number of persons per occupied housing unit at 2.58 (nationally, 2.71) (County and City Data Book, 1988). The 1990 Census indicated that 28% of the owner occupied housing in Oregon is owned by people 65 years of age and older and 13.6% of the renter occupied housing is rented by people 65 years or older (U.S. Bureau of the Census, 1992a).

Oregon began to develop a more extensive system of non-medical alternatives to nursing home care in 1979. In conjunction with this, a program of nursing home pre-admission screening was begun to divert people in the community or in hospitals to community-based care unless nursing facility care was required for significant medical and/or functional reasons. Oregon also had an active relocation program to move out of nursing homes those clients who required less restrictive and less intensive long-term care environments. In 1987, Oregon's private and Medicaid nursing home utilization, combined, was 37 full-time equivalent beds per thousand persons age 65 years and over compared to 55.8 beds per thousand persons in the United States in 1983 (Saslow & Dietsche, 1988). The Oregon utilization rate had decreased from 46 beds in 1980. Oregon's nursing homes have some of the lowest occupancy rates in the country (U.S. Department of Health and Human Services, 1989). This lowered utilization of nursing home beds indicates how successful the alternative care programs supported by Medicaid waivers have been.

The pre-admission screening program (PAS) was initiated with all Medicaid clients considering admission to a nursing home in 1979. The PAS included a client assessment to determine the need for nursing home care and whether these needs could be met with community-based services. In 1989 the state legislature also made PAS available to private pay patients at state expense. The hierarchy of options explored with the older person and the family at the time of the PAS includes: (a) staying in one's own home with live-in help, (b) staying in one's own home with professional in-home services, (c) moving into the home of a relative who can qualify for payment as a "relative foster home," (d) moving to an assisted living facility, (e) moving into a residential care facility (RCF), (f) moving into a non-relative adult foster home, (g) moving to an intermediate care facility (ICF), or (h) moving to a skilled nursing facility (SNF). Based on Oregon long-term care policy, the least restrictive environment is encouraged. Approximately 4,000 Medicaid and 8,000 private pay clients received a PAS evaluation in 1992 (Naomi Jasso, Oregon Senior and Disabled Services Division, personal communication, April 8, 1993).

The 1990 Census indicated that nationally, approximately 1.8 million people (5.8% of those 65 years of age and older) lived in skilled nursing facilities and intermediate care facilities while in Oregon this figure was 18,200 (4.7% of the 65 years of age and older population) (U.S. Bureau of the Census, 1992a). There are 196 nursing facilities, 119 residential care facilities, 23 assisted living facilities, and over 2,000 adult foster homes in Oregon providing supportive environments for older people (Oregon County Public Health Profiles, 1990; Senior and Disabled Services Division, 1990). This continuum of long-term care options and the PAS program developed in Oregon provided a unique opportunity to describe the process used by older people and families deciding on a long-term care setting. Other states are looking to Oregon's long-term care options when considering the options they will offer their older citizens and family caregivers.

Rural Older People and Their Unique Situation

Patton (1989) pointed out that although the majority (two-thirds to three-fourths) of older people live in metropolitan areas, older people make up a greater percentage of the total population in rural areas. This number of rural older people has been growing at a faster rate than the general population according to Longino, Wiseman, Biggar, and Flynn (1984). A study by Longino (1990) using U.S. census data to look at the three decade trend in older people's migration patterns indicated younger-old (65 to 74 years of age) people move to areas of less population density and older-old (85 years of age and older) people move to the metropolitan areas from smaller places because of declining health and dependency needs. In Oregon 13.8% of the population is 65 years of age or older; in the rural southern Oregon county that is the setting for this study, 14.3% of the population is 65 years of age or over (U.S. Bureau of the Census, 1992b). As compared to urban older people, higher rates of poverty, lower median incomes, higher transportation and utility costs are characteristics of rural older people and their situation (Krout, 1986; Nelson, 1980; Patton, 1989). The unique situation of rural older people including the accessibility to formal and informal care, availability of services related to how rural the setting, and the extent of access to innovative long-term care services were explored in the current study. These were some of the areas proposed as research priorities by Patton (1989).

Setting of Study

The rural county of Oregon which was the site of the present study has a population of just under 58,000 people with approximately 91% of these residents being white. The next two largest racial/ethnic groups in the county are Hispanic (5%) and American Indian (4%). People 65 years of age or older make up 14.3% of the county population. In 1990 the one larger town in the county contained 31% of the total county population and was the home of 31.7% of the individuals 65 years and older (U.S. Bureau of Census, 1992b), leaving the other 68.3% living outside this larger town. Two nursing facilities, one residential care center, and 66 adult foster homes were available as supportive environments for older people within the county (SDSD, 1993). To determine the location of county residents prior to their move to a more supportive environment, every nursing facility, residential care center, and foster home listed in the county Yellow Pages for 1993-1994 was called December 1993. Information about where current residents came from prior to admission to the long-term care facility was obtained. This information is contained in Table 1. The telephone survey indicated that from 21 to 55% of the older residents of these facilities came from their home.

Sampling

Initial Sampling

Purposeful sampling was done in a rural area of English speaking persons 65 years of age or older, frail, living in their own residences or with a family member or friend. Frail was defined as a person dependent or needing assistance in at least

Table 1

Older People Living in LTC* Facilities Who have Come from Home

Facilities in County		Residents		
Type	Total Number	Total Number	From Home	From Another Facility
Nursing Home	2	115	24 — (21%)	91
RCF*	1	33	8 — (24%)	25
AFH*	13	58	32 — (55%)	26

Note. *LTC, Long-term Care; RCF, Residential Care Facility; AFH, Adult Foster Home.

one activity of daily living (ADL, e.g., bathing, dressing) or two or more instrumental activities of daily living (IADL, e.g., shopping, preparing meals) (National Center for Health Statistics, September, 1990). Additional criteria for an older person participating in the research included: (a) currently thinking about getting more help with everyday tasks or moving from his or her residence to get more help, (b) receiving help from family members or friends, and (c) having family or friends who help make the decision about getting more help or moving.

Family was defined as a unit of two or more people who may or may not be related by blood, but have physical, emotional, or other bonds considered significant (Stanhope & Lancaster, 1988). In this study the families interviewed consisted of one to two caregivers (two caregivers interviewed in two of the families), who provided direct care to the older person and/or arranged for the care needs to be met. The family members interviewed were identified by the older person as individuals to whom one turned for advice regarding how to get the care needed and the possibility of moving to a more supportive environment. Caregivers can include individuals who live a long distance away from the older person, but with whom one has telephone contact and talks about care needs.

The decision to interview two caregivers if possible was made based on findings by Tilden, Tolle, and Garland (1991) describing the role of the family in making decisions about end-of-life choices for terminally ill persons. In that study the greatest increase in range of information about decision-making was obtained by adding a second family member to the informant pool. The importance of family members in helping older people make health care decisions is cited by several authors. For example, an adult child can bridge communication gaps and help negotiate treatment decisions with health care providers (Hooyman & Lustbader, 1986), provide the context for clarifying values (Brody, 1978; Cicirelli, 1981), and help the older person make decisions regarding care based on these values (Gadow, 1980).

One older person recruited declined to have a family or friend caregiver participate in the study and therefore was not included in the sample. No other older individuals directly contacted by the investigator refused to participate in the interviews. The number of older people with whom the agency personnel talked about the study but who chose not to be contacted is unknown. Two caregiving relatives declined to participate. They both initially agreed to the interview when the study was described verbally over the telephone by the investigator but then declined to sign the consent form. No definite reasons were given for these refusals. These refusals did not result in the loss of the corresponding older people in the sample because other caregivers agreed to be interviewed for these care receivers.

A total of 32 participants (14 older people and 18 caregivers) were interviewed. Ten older people were recruited through community agencies. A minister and local community volunteer suggested two participants and snowball referrals from other participants added two more older people and their respective family members.

Sixteen caregivers were identified by the older people and interviewed. An additional two spouses caring for their wives with cognitive impairments also participated. Being unable to give an informed consent, their wives were not participants. One of these wives was under 65 years of age. A total of 18 caregivers were interviewed.

Theoretical Sampling

Components of the decision-making process were the units of sampling rather than people, so probability sampling and sample size were not issues of concern for this grounded theory study. Theoretical sampling based on emergent concepts directed data collection as the analysis progressed (Glaser and Strauss, 1967). For example, the older people and caregivers initially interviewed emphasized the older person being mentally sound; "I have [not] gone off my rocker" and "her mind is good, you know," which caused the investigator to question how the decision-making process was affected when the older person was cognitively impaired. That question lead to contacting an Alzheimer's support group for possible participants.

The majority of older people initially interviewed were using a variety of resources. How the decision-making process was influenced when the older person had access to fewer resources was explored by sampling older persons without family in the local area and individuals living in an area of the county with fewer community services because of increasing distances.

Participants

Older Persons

Of the 32 participants, 14 were identified as the older person or care recipient; six women and eight men. Six of the older people were married while the remainder were widowed. All had from one to eight living children, but only two older people were currently living with adult children. The remaining 12 older people were living in their home with a spouse (*n* = 5) or alone. The distance from adult children to whom the older person would turn for help or advice ranged from next door to 3000 miles. The majority of older people (57%) had an adult child whom they would call living within the county or state, while the remainder were equally divided between having an adult child within a neighboring state or in a distant state.

The care recipients ranged in age from 70 to 94 years (*M* = 81 years). The majority were white but three were Native American Indians. Four older people had completed eighth grade or less while six had attended college. The remaining four had either attended high school, completed high school, or had received post high school vocational training. The average length of time the older people had lived in their current home was 20 years with a range from 2 to 54 years. Half had lived in a rural setting most of their lives. Compared to others their age, 57% of the older people considered themselves in excellent or good health. The least impaired older people (Mrs. B and Mrs. E) still needed assistance with three instrumental activities of daily living (IADL). A total of 43% (*n* = 6) of the older people were dependent in at least one activity of daily living (ADL). These six individuals included two people who were bedfast, five of whom had experienced strokes, one receiving continuous oxygen, one being treated for cancer and two being treated for other terminal illnesses. Most of the older people (64%) reported receiving hands-on care from family members. Two older people indicated that most of the help provided by family was arranging for others to help them.

While 36% of the older people indicated that they had a yearly household income of under $10,000, 57% reported an income between $10,000 but under $20,000. One older person's yearly income was between $50,000 but under $75,000. When asked about being able to get along on one's income, six older people (43%) indicated "I have just enough, no more," while seven (50%) answered "I have enough with a little extra sometimes." One indicated always having money left over. Table 2 contains a summary of demographic data for the older people.

Table 2

Demographic Data: Older People (*n* = 14)

Characteristics		*n*	Percent
Gender:	Women	6	43
	Men	8	57
Age (in years, *M* = 81)			
70-74		5	36
75-84		2	14
>84		7	50
Education			
Completed 8th grade or less		4	29
Attended high school		2	14
Completed high school		1	7
Post high school vocational		1	7
Attended college		6	43
Marital status:	Married	6	43
	Widowed	8	57
Living arrangements			
Alone		7	50
Living with spouse		5	36
Livine with adult child		2	14
Years lived in current home			
< or 10		2	14
10-19		8	57
20-29		0	0
30-39		1	7
40-49		1	7
50 or >		2	14
Self-assessed health status			
Excellent		2	14
Good		6	43
Fair		4	29
Poor		2	14
Types of help			
Hands-on care		9	64
Arranging care		2	14
An equal amount of both		3	21
Ability to manage on income			
Just enough; no more		6	43
Enough, with a little extra sometimes		7	50
Always have money left over		1	7

Note. Total may equal more or less than 100% as the result of rounding.

Caregivers

Spouse caregivers. Of the 18 informal caregivers, 7 were spouses (3 wives, 4 husbands) ranging in age from 62 to 80 years (*M* = 72 years). All were white and provided hands-on care to their partner. One had completed eighth grade or less, while two each had either attended high school, completed high school, or attended college. Most had lived the majority of their lives in a small city (more than 2500 but less than 50,000 people). All had living children ranging from one adult child to six adult children. Four of the caregiving spouses had an adult child living within the local area to whom they would turn most for help or advice. The other three had adult children whom they would ask for help but who lived hundreds of miles away. If help was needed right away, the majority (72%) would call on a friend, neighbor, or the ambulance service.

Two of the spouse caregivers considered themselves in excellent health compared to others their age, while the remaining five rated their health as good. One had recovered from a near fatal accident three years ago, another had major surgery, while a third required oxygen on an intermittent basis. All but one of the spouse caregivers reported a variety of health problems despite their perceptions of their health being good to excellent.

The majority of spouse caregivers (71%) reported a yearly household income of between $10,000 but under $20,000, and described their ability to get along on their income as having "just enough; no more." Demographic data regarding the caregiving spouses is found in Table 3.

Table 3

Demographic Data: Spouse Caregivers (n = 7)

Characteristics	*n*	Percent
Gender		
Women	3	43
Men	4	57
Age (in years, *M* = 72)		
60-64	2	29
65-69	1	14
70-79	3	43
80 or >	1	14
Education		
Completed 8th grade or less	1	14
Attended high school	2	29
Completed high school	2	29
Attended college	2	29
Self-assessed health status		
Excellent	2	29
Good	5	71
Fair	4	29
Poor	2	14
Sources of help other than older person		
Child(ren)	4	57
Other rleative	1	14
Friend	1	14
Misunderstood question	1	14
Emergency help		
Ambulance	2	29
Friend/neighbor	3	43
Family member	2	29
Ability to manage on income		
Just enough; no more	5	71
Enough, with a little extra sometimes	1	14
Always have money left over	1	14

Note. Total may equal more or less than 100% as the result of rounding.

Adult children caregivers. Of the 18 family caregivers, 10 were adult children (n = 8) or children-in-law (n = 2), and primarily women (70%). The caregiving children ranged in age from 44 to 66 years (M = 55 years); eight were white, two Native American Indian. All had completed high school, with six having attended college, and one completing college. Eight of the adult children caregivers were married and living with their spouses, two having been divorced or separated. Three of the adult children (one couple and one daughter-in-law) had their parent living with them. All but two of the adult children had living children of their own, but none had children under age 18 living with them. Three of the adult children had their own children living within a few miles of their home while the other five had children 90 to 3000 miles away. The adult children had lived in their current residences an average of 17 years with a range of one-half year to 32 years.

Six of the adult children judged their own health as good, with three reporting excellent health, and one indicating only fair health. If these adult children needed help caring for their parent, five would ask their spouse for help, three another relative and the remaining two would ask help from a friend or the home health agency. None indicated that they would ask their own children for help with the older person's care, although grandchildren were spontaneously mentioned in the interviews as helping in three of the families. Four of the caregiving children provided their parent hands-on care, while four arranged for care, and the other two provided an equal amount of both.

The majority of adult children (60%) in describing their income indicated they had enough with a little extra sometimes, with 30% always having money left over. One adult child indicated that "I can't make ends meet." The majority (60%) reported a yearly household income of under $30,000. Table 4 contains demographic data for the adult children caregivers.

Caregiving friend. One of the caregiving participants was the friend of the older person. In age he was actually older than the identified "older person." By the second interview he was also experiencing his own health problems. Because he so closely resembled the older people as a group, he was redesignated as a separate family himself when describing family background information in the analysis section. This caregiving friend was an 84 year old widower living alone in a home he had owned for about a year. He had no children. He had attended high school. Considering his health excellent, he provided the "older person" hands-on care (running errands, providing transportation, and companionship). When the older person needed help, this friend called 911. In describing his ability to get along on his income he said, "I always have money left over" with a total yearly household income under $10,000.

Analysis of Demographic Data

Demographic data was analyzed with the help of SPSS, a computer software statistical package for the social sciences. Frequencies, means, and percentages were the statistics used to describe the participants.

Table 4

Demographic Data: Adult Children Caregivers (*n* = 10)

Characteristics	*n*	Percent
Gender		
Women	7	70
Men	3	30
Relationship to older person		
Daughters	6	60
Sons	2	20
Children-in-law	2	20
Age (in years, *M* = 55)		
40-49	1	10
50-59	6	60
60-69	3	30
Education		
Completed high school	3	30
Attended college	6	60
Completed college	1	10
Marital status		
Married	8	80
Divorced or separated	2	20
Years lived in current home (*M* = 17)		
1 or <	2	20
2-9	1	10
10-19	2	20
20-29	4	40
30 or >	1	10
Self-assessed health status		
Excellent	3	30
Good	6	60
Fair	1	10

Table continues

Table 4 (Continued)

Demographic Data: Adult Children Caregivers (*n* = 10

Characteristics	*n*	Percent
Sources of help to care for older person		
Spouse	5	50
Child(ren)	0	0
Other relative	3	30
Friend	1	10
Home health agency	1	10
Who would you call for immediate help		
Family member	5	50
Friend/neighbor	3	30
Home health agency	2	20
Most help provided to older person		
Hands-on care	4	40
Arranging care	4	40
Equal amount of both	2	20
Ability to manage on income		
Can't make ends meet	1	10
Just enough; no more	0	0
Enough, with a little extra sometimes	6	60
Always have money left over	3	30
Annual income (in dollars)		
<1,000	0	0
10,000-19,999	4	40
20,000-29,999	2	20
30,000-39,999	1	10
40,000-49,999	1	10
50,000-74,999	2	20

Note. Total may equal more or less than 100% as the result of rounding.

Data Collection Guide

The interviews were conducted following two open-ended interview guides (Time 1, Time 2) each with the older person and family/friend caregivers (see Appendix F). The questions included in the interview guides were developed after review of past empirical studies and were designed to describe and analyze the process used by rural older people and family caregivers to decide whether and when the older person needs a more supportive living environment. The content of the interview questions was the same for the older person and the caregiver, but the question wording was adapted to the status of the informant (whether older person or caregiver).

The initial questions found in both the first and second interviews were designed to get acquainted and establish rapport with the participants while obtaining general information about the current situation. Establishing rapport is important to establishing internal validity in qualitative research (Lincoln & Guba, 1985). The individual also has a need to "talk," to have the investigator understand their situation (Archbold & Stewart, personal communication, 1990). These initial questions proved capable of eliciting many events and activities that were significant to the individuals. The ending questions were designed to give the participants an opening to share anything else that they considered important, a strategy described by Lofland & Lofland (1984) as useful for eliciting new material not mentioned in relation to previous questions. Also the investigator wanted the participants to feel comfortable asking any additional questions about the study, interview process, and the direction of the interviews. This helped to encourage an ongoing consent process. Many times the older participants asked about community resources available. Adult children used this opening to ask questions about what decisions other families were making.

Antecedent, concurrent, and contextual variables that were found to influence the decision-making process were mentioned in response to questions about what caused the participant to think about getting more help or changing where she/he lived. The influence of other people on the older person's decision-making was discovered by asking about who the older person talked with about getting more help and her/his perceptions about how others viewed the help she/he received. Symbolic interaction, the foundation of grounded theory, indicated that an individual's reality was influenced by the perceptions of other people's views, and thus the person's perceptions are driven by the social environment.

The first interview guide was shortened after the first two interviews with older participants by combining some of the questions (see Appendix F) because some older people became fatigued with the longer interview. The additional questions also proved to be unnecessary with the participants answering several of the original questions about decision-making (precipitating events, naming others they talked with about the need for help, choices available, how the decision will be/or was made) in connection with the introductory question and its probes.

Demographic data were collected through self-administered forms from the older person and caregivers at the end of the first interview (see Appendix G). For the older person the demographic data included age, gender, ethnic group membership, past and present living situation (location, size of community lived in for most of life and length of time in current residence), others within the household, level of education, occupation (most of working life), current marital status, children and their distance from parent's current home, subjective evaluation of health, who they would call if help was needed (relationship to contact person and how far away the contact person is), ability to get along on current income, and gross yearly income. For the caregivers the demographic data included the same as that collected from the older person with the following additions: how far he/she lives from the family member who is participating in this study, who do they call when they need help caring for their family member. This information had been found to be important in previous studies in understanding the nature of the caregiving situation. The self-administered format was chosen to help insure the information remained private and to decrease the effect of social desirability on the participant's responses to the questions about age, income, and income adequacy. Although the print was large, 10 of the older persons and 4 of the caregivers (3 were spouse caregivers) requested that the investigator read the questions for them. Fatigue and low reading comprehension abilities appeared to prompt these requests for help with completion of the demographic data information.

Procedures

Sample Access

The agencies and organizations that were thought to have contact with older persons who might be considering a move from their home were contacted. The county supervisor of Senior and Disabled Services Department (SDSD) agreed to have department staff (a) discuss the study with clients who met the study requirements, (b) provide them with a volunteer flyer (see Appendix H) describing the study, and (c) provide the investigator with names and phone numbers of those interested in a further explanation of the study. Other local agencies that agreed to help contact possible study participants included home health nursing agencies (HHA) and a private health clinic. The SDSD and HHA staff member had the older person sign a consent to release information (see Appendix I) prior to providing the investigator with their name, address, and phone number. Local clergy, a community volunteer, a senior dining site supported by the Area Agencies on Aging, a support group for Alzheimer's Disease, a provider of health care in the community, and referrals from other study participants were additional sources contacted by the investigator for possible study participants. Participants were obtained through all of these sources except the SDSD and the senior dining site. Table 5 summarizes the sources that referred participants to the study.

Table 5

Referral Sources Recommending Participants

Referral Source	# of Older People	# of Caregivers Without OP*
Home health agencies	6	
Private health clinic	1	
Health care practitioner	2	
Local clergy	1	
Community volunteer	2	1
Other study participants	2	
Alzheimer's Disease Support group		1

Note. OP — older person.

Data Collection

The older person informants. The older person was initially contacted by the investigator through a telephone call. After the study was explained briefly, eligibility to participate was determined, and verbal consent was obtained, arrangements for the first face-to-face interview were made. These were all conducted in the homes of the older people and lasted one to two hours. The need for a degree of privacy for the interview was mentioned during the initial telephone call, e.g., being alone in a room with the participant. In six of the families this ideal situation did not prove to be possible. One older person was so frail that the caregiver felt comfortable leaving her alone only for short periods of time. One spouse who was experiencing memory problems from a stroke requested that his wife help him answer the questions. Two of the couples were living in very compact homes and it would have been an inconvenience for the spouse to leave the living room while the interviews were being conducted. In the two families where two caregiving adult children (both spouses) were interviewed, three of the four interviews were done with the adult children together. Difficulties scheduling interviews around their work schedules made this necessary.

At the beginning of the interview, the consent form was reviewed (see Appendix J). If the older person could repeat in her/his own words the purposes, risks, and benefits of the study and signed the consent, the interview was conducted and tape recorded. In two cases the older person was determined by the investigator to be too cognitively impaired to sign the consent and also too impaired to understand the interview questions although the caregiver, as the responsible family member, had agreed to have the spouse participate. Although these two families did not meet the original criteria for inclusion in the study (older person was not able to participate), the results of data analysis up to that point had indicated that whether the older person was considered cognitively intact was an important concept in the family's decision-making process. Therefore these two families were included to develop the contrasting situation. This is an example of the theoretical sampling done in grounded theory (Glaser, 1978); sampling to densify the theory as it emerges.

Although the original procedures included contacting the older person first, in five families the caregiver was the initial contact. Contacting the caregiver first was requested by one of the home health agencies and one of the informal sources as a way to protect the frail older person. Having identified this protective mechanism, when the investigator called a couple, whoever initially answered the telephone was used as the initial contact person, whether caregiver or care receiver. In one case, both members of the couple listened to the original telephone contact and were invited to participate in the study.

In the original study design the older person was to be interviewed a second time approximately 6 weeks after the first interview. This timeline was followed in 5 of the 17 families. The remaining 12 families had a different timeline. For one family the older person was too ill for the second interview and the caregiver declined the interview for them both. Within a few weeks the older person's death notice was published in the local paper. Two families were leaving on extended trips so the second interview was done at 4 weeks for three of the four individuals (two care receivers and one caregiver) within these families. For the remaining nine families, the separation between the first and second interview ranged from 7 to 37 weeks with an average of 21 weeks (over 5 months) between interviews. This increased time interval between interviews proved necessary for some participants because of illnesses, trips planned, or to allow them time to get settled after a move. In six families the interviews were spaced further apart to allow the investigator time for analysis of the first interviews.

A telephone call midway between the two interviews was originally planned to check on the person's current status and discuss the arrangements for the second interview. It was quickly discovered that the families did not plan this far ahead and after the first two families were interviewed, the investigator changed the timing of this telephone contact to just prior to scheduling the second interview.

The second interview with the older person lasted approximately one and one-half hours. Because almost two-thirds of the second interviews (19 out of 30) were conducted an average of 21 weeks after the first, the event trajectories of the older people or couples proved to be a useful device to review with these participants. Their trajectories reflected what had been discussed at the first interview. Reviewing the trajectories with the participants also was a method used for establishing the credibility of the study. The participants clarified times and added events that they considered important that had been omitted at the first interview. The guide for the second interview contained questions about what had happened since the last visit with the investigator, what changes or decisions had been made, how others viewed these decisions, what advice they would give others, and what adjustments had to be made. The second interview captured how the participants' thoughts and feelings changed over time.

The original study procedures included a plan for a telephone call to each participant at the end of the analysis to review the individual's status, what had occurred since the last visit, and future plans. Due to the interview phase of the study spanning a year and the completion of the analysis requiring another year, the planned final telephone call seemed ill-timed and was not done for several reasons. For example, for the individuals interviewed at the start of the study, this would have meant a contact from the investigator almost two years after the second interview. The depth of information that would help expand the balancing model's conceptualization could not be obtained with a telephone call with this much time having elapsed since the last contact with these participants. Rapport would be doubtful. It was the investigator's judgment that this final telephone call would only be an intrusion on the family without having benefit for the participants or the study.

Family caregiver informants. The family member or friend contacted by the investigator to participate in the study was chosen by the older person and was either a spouse, an adult child, or friend. In the three cases that involved protecting the frail older person, the caregiver was first designated by the referral source but the older person agreed with this selection. The family member informants were considered to be caregivers regardless of whether they provided direct care to the older person and/or managed care and served as an adviser to the older person. The schedule of telephone contacts, interviews, and gathering demographic information followed the same pattern as described above for the older person. For the three adult children caregivers living outside the county, prearranged telephone interviews were substituted for the face-to-face interviews. These telephone interviews were 20 to 40 minutes in length. Consents were mailed with the participant keeping one and returning a signed one before the first interview was conducted.

Field notes describing what was observed during the interview were recorded immediately after the interviews. These field notes included the time, location, and description of the interview setting, the general appearance and behavior of the participants, the general tone of the interview, whether others were present during the interview, and what interruptions if any occurred during the interview. Notes were also jotted down on the interview guide during the visit.

Ethical Considerations

Protection of Human Subjects

The Oregon Health Sciences University institutional review board reviewed and approved the study (see Appendix K) and was given periodic updates on its progress during data collection and analysis. Participants were encouraged to ask questions about the study while the investigator reviewed the consent form (see Appendix J) with them reading aloud the purpose, time requirements, risks and benefits of the study. The participants were also given sufficient time to read the consent over by themselves before signing. A copy of the consent form was left with the participant in addition to the investigator keeping a signed copy.

In addition to reading and signing the formal consent form at the first interview, ongoing verbal consent occurred (Ramos, 1989). As the data collection and analysis continued and the focus of conceptual analysis emerged, the participants were kept informed of the direction of the questioning and potential risks. The right to withdraw from the study and to refuse to answer any questions at any time was part of the interviewing process throughout the study. The interview guides for the older person and caregiver contained the question, "Is there anything you would like to ask me?" This encouraged discussion of the study procedures and maintained an ongoing consent process (Lofland & Lofland, 1984; Archbold & Stewart, personal communication, 1990).

Data Management

The tape recorded interviews were transcribed with last names removed in the transcription process. A transcriptionist outside the local area was used and understood that the material transcribed was confidential. The coding sheets identifying the individuals with the numbered transcripts and demographic data forms were accessible only to the investigator, kept secure, and in a location separate from the transcripts. Data segments shared with seminar participants had additional information such as first names and place names blacked out.

Potential Risks and Benefits

Physical risks to participants in the study were minimal. However, discussing current situations (illnesses, damage to the home) that were going to require changes in the older person's routines proved to be emotionally sensitive. Some mild to moderate anxiety or sadness was expressed by a few of the older participants or spouses. The adult children's descriptions of the decline seen in their parents brought them tears and produced emotion laden pauses in the conversation. The investigator remained with the individual until she/he relaxed, was supportive by acknowledging the feelings expressed, and/or by a gentle touch on the hand or arm as appropriate. The interview would have been terminated if the emotional reaction was beyond the normal bounds. Referral to an appropriate service was planned if additional support was desired by the participant. Neither termination nor referral proved to be necessary.

Two of the older participants mentioned suicidal thoughts. These were explored with the participant until the investigator was sure that the individual was not planning to act on these thoughts and that others in the family were aware of this depression. One of these individuals was currently being treated with an anti-depressant.

Participation in the interviews allowed the participants to express their feelings, reflect on their thoughts about their living situation and needs, and declare appreciation for the help currently received or received in the past from caregivers, both informal and formal. Several older participants stated that they enjoyed the interviews and a few specifically indicated that the interview questions helped them think through the current choices they had. With all of the participants agreeing to be contacted for the second interview even after several months separated the interviews, the commitment of the participants to the study was evident. The only family that declined to participate in the second interview was experiencing the impending death of the older person.

Data Analysis

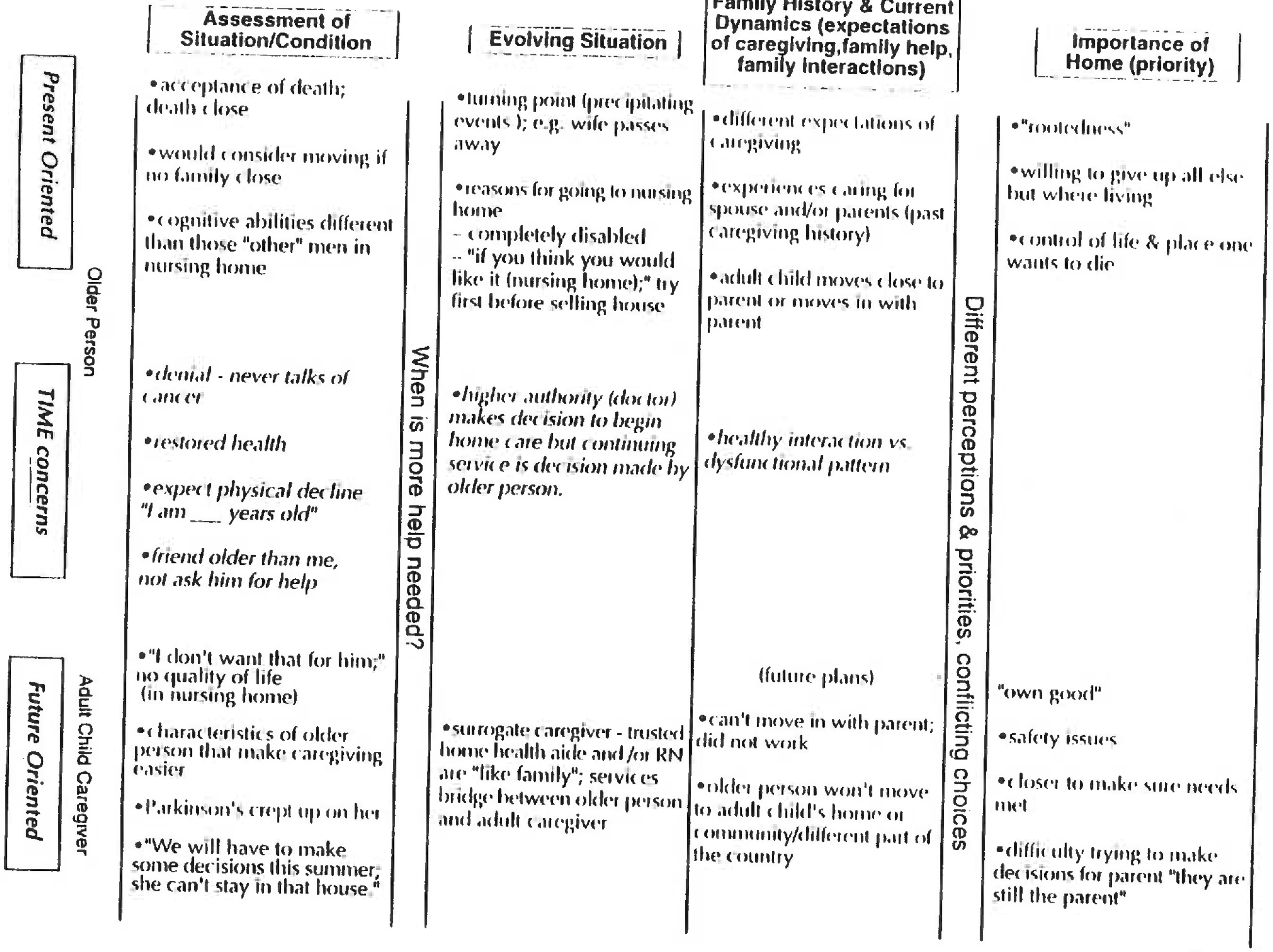
Analysis of Interviews

Analysis of the data began after the first interview with the recording of memos, initial impressions about themes noticed in the participant's statements. The transcribed interviews once verified with the tape recordings were read line by line identifying incidents and facts. These were recorded in the margin. As incidents were compared with each other, tentative concepts were discovered and coded, as an abstraction from the data. For example, a beginning code was labeled *PPT*, precipitating event. Incidents coded PPT from the interviews with older people included "they ballooned my legs (surgery for peripheral vascular disease)," "I had a blackout and I fractured my back," "I lost my wife," "my kids moved off from there and my brother moved away." The first codebook contained 12 categories with their definitions: *family help, services, family interactions, past caregiving history, facts/details, expectations of caregiving, priority, assessment, future plans, precipitating events, older person's characteristics, caregiver's characteristics.* Table 6 contains a summary of the analysis strategies used. A matrix strategy used to learn the relationships between categories was drawn and data bits that supported these interconnections were reviewed with a committee member. See Figure 1 for this "conceptual picture" of some of the categories and their relationships. Some categories are row and column headers and others are located in the cells of the matrix.

Comparisons also were made between the situations of the participants to discover additional categories and look for similarities and differences. An event trajectory was developed for each older person with the vertical axis being increasing dependency (independent to dependent) and the horizontal axis representing living situation (home to alternative other than home) over time. The line plotted between the two axes was labeled with the events that produced more or

Figure 1

Figure 1. Concept picture



		Assessment of Situation/Condition	Evolving Situation	Family History & Current Dynamics (expectations of caregiving, family help, family interactions)	Importance of Home (priority)
Present Oriented	Older Person	•acceptance of death; death close •would consider moving if no family close •cognitive abilities different than those "other" men in nursing home	•turning point (precipitating events); e.g. wife passes away •reasons for going to nursing home – completely disabled -- "if you think you would like it (nursing home);" try first before selling house	•different expectations of caregiving •experiences caring for spouse and/or parents (past caregiving history) •adult child moves close to parent or moves in with parent	•"rootedness" •willing to give up all else but where living •control of life & place one wants to die
TIME concerns		*•denial - never talks of cancer* *•restored health* *•expect physical decline "I am ___ years old"* *•friend older than me, not ask him for help*	*•higher authority (doctor) makes decision to begin home care but continuing service is decision made by older person.*	*•healthy interaction vs. dysfunctional pattern*	
Future Oriented	Adult Child Caregiver	•"I don't want that for him;" no quality of life (in nursing home) •characteristics of older person that make caregiving easier •Parkinson's crept up on her •"We will have to make some decisions this summer; she can't stay in that house."	•surrogate caregiver - trusted home health aide and/or RN are "like family"; services bridge between older person and adult caregiver	(future plans) •can't move in with parent; did not work •older person won't move to adult child's home or community/different part of the country	"own good" •safety issues •closer to make sure needs met •difficulty trying to make decisions for parent "they are still the parent"

When is more help needed?

Different perceptions & priorities, conflicting choices

Table 6

Summary of Analysis Strategies

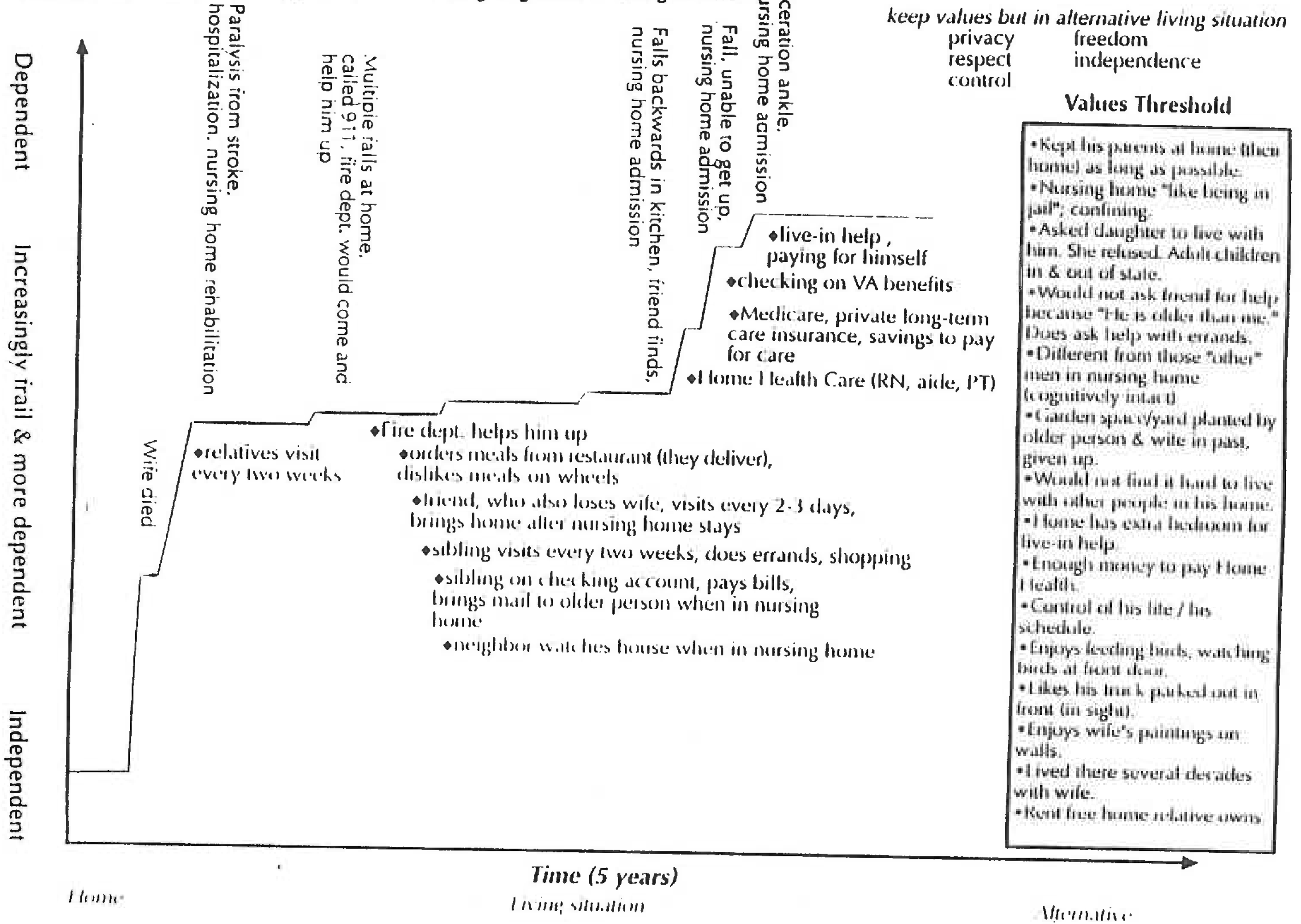
Method	Analysis Period Early (5 months)	Mid (7 months)	Late (7 months)
Substantive Codes	12	120	24
Conceptual Categories	Key themes	Key themes selected and refined, looked for BSP*.	Refine BSP
Strategies	Conceptual picture, early trajectories, forcefield diagrams	Trajectories, review literature	Compare general theories with balancing model
Feedback	Gerontological seminar, poster presentation	Qualitative seminar	Gerontological seminar

Note. BSP — Basic Social Process. Feedback from committee members was received throughout the analysis process.

less dependency over time and the family help and services which supported the older person in their living situation over time. A "values list" along the side of the graph highlighted the older person's values that influenced the decisions made as more events occurred that increased one's frailty. *Values*, as a conceptual category, had evolved after analysis of the matrix and development of the event trajectory. The investigator realized that many data bits contained within other codes, such as priority, future plans, and older person's characteristics, were not represented. The above information was presented to a graduate gerontological nursing seminar to obtain additional input on how the data could be conceptualized. Figure 2 depicts

Figure 2

Figure 2. Dependency trajectory: older man and a caregiving friend - "fishing buddies"

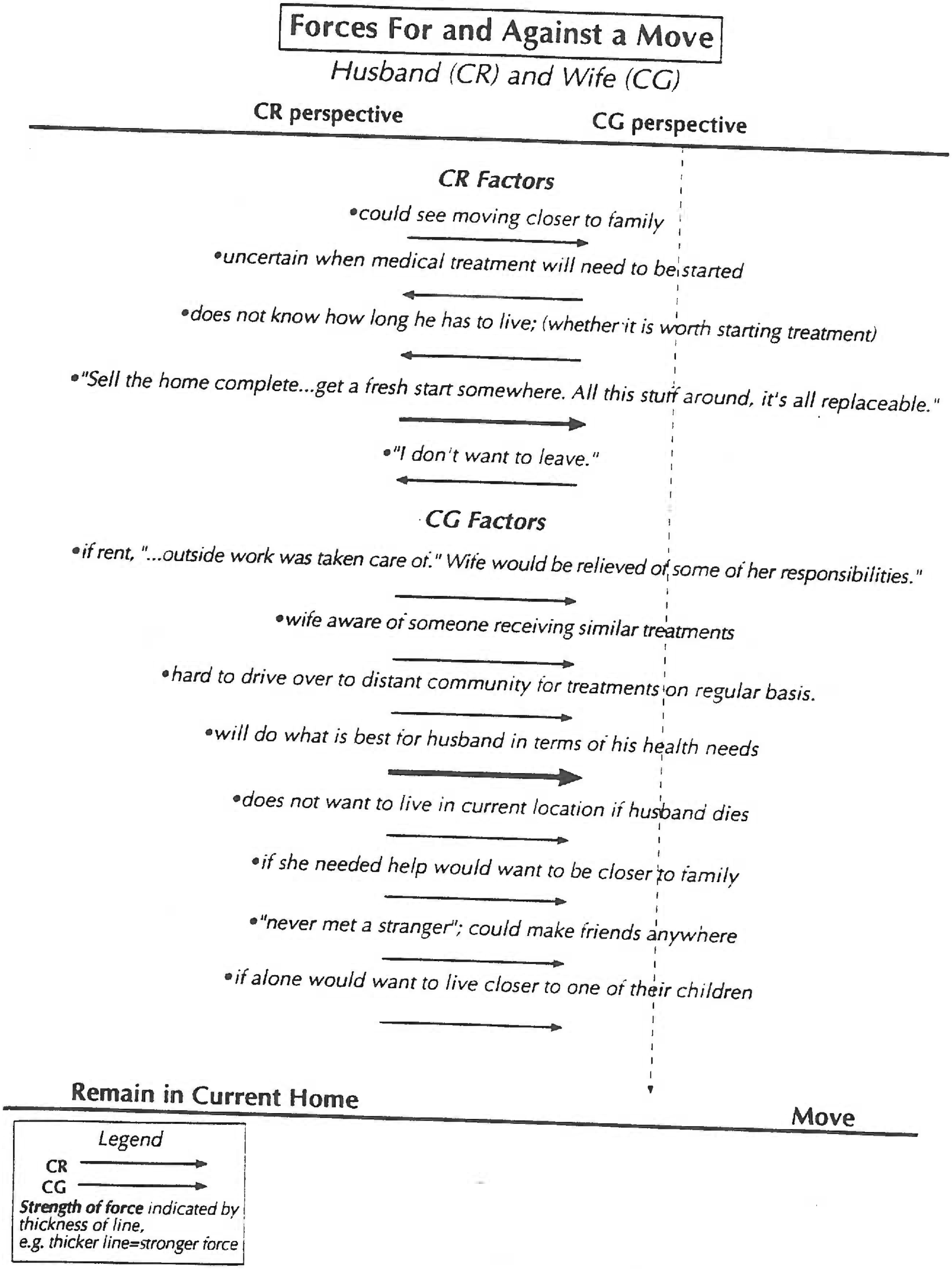


one of these early event trajectories. The siminar participatns agreed that values appeared to have an important influence on the decision-making process.

As the analysis progressed over time, several strategies were used to visualize and think about the data. Some of these strategies were the result of other nurse scholars' interaction with the data. A committee member reading transcribed interviews suggested viewing the data in terms of conflicting forces acting on the older person and family that either facilitate or oppose a move to a more protective environment. This conceptualization was patterned after Lewin's (1954) system for diagramming how human behavior is influenced by positive and negative forces and the direction of these forces. A living place/location continuum ranging from home to institutionalization formed the base of the model. Visually "adding up the forces" (older person, caregiver, family, home environment, and service system) for and against a move determined where on the living place continuum the older participant was placed. While analyzing the data, force field diagrams were developed for several of the families. Figure 3 illustrates a force field diagram for Mr. and Mrs. C after the first interview.

A poster describing the study and illustrating a revised event trajectory for two of the families was presented at the Third International Family Nursing Conference in Montreal, Quebec, on May 26, 1994. Critical events, decisions, informal caregiving, and formal services were illustrated across the event trajectory time line (horizontal axis) with dependency ranging from low to high (vertical axis). Figure 4 provides an example of a dependency trajectory for Mr. D developed for

Figure 3. Force field diagram: Mr. and Mrs. C



Forces For and Against a Move

Husband (CR) and Wife (CG)

CR perspective **CG perspective**

CR Factors

- *could see moving closer to family* →
- *uncertain when medical treatment will need to be started* ←
- *does not know how long he has to live; (whether it is worth starting treatment)* ←
- *"Sell the home complete...get a fresh start somewhere. All this stuff around, it's all replaceable."* →
- *"I don't want to leave."* ←

CG Factors

- *if rent, "...outside work was taken care of." Wife would be relieved of some of her responsibilities."* →
- *wife aware of someone receiving similar treatments* →
- *hard to drive over to distant community for treatments on regular basis.* →
- *will do what is best for husband in terms of his health needs* →
- *does not want to live in current location if husband dies* →
- *if she needed help would want to be closer to family* →
- *"never met a stranger"; could make friends anywhere* →
- *if alone would want to live closer to one of their children* →

Remain in Current Home **Move**

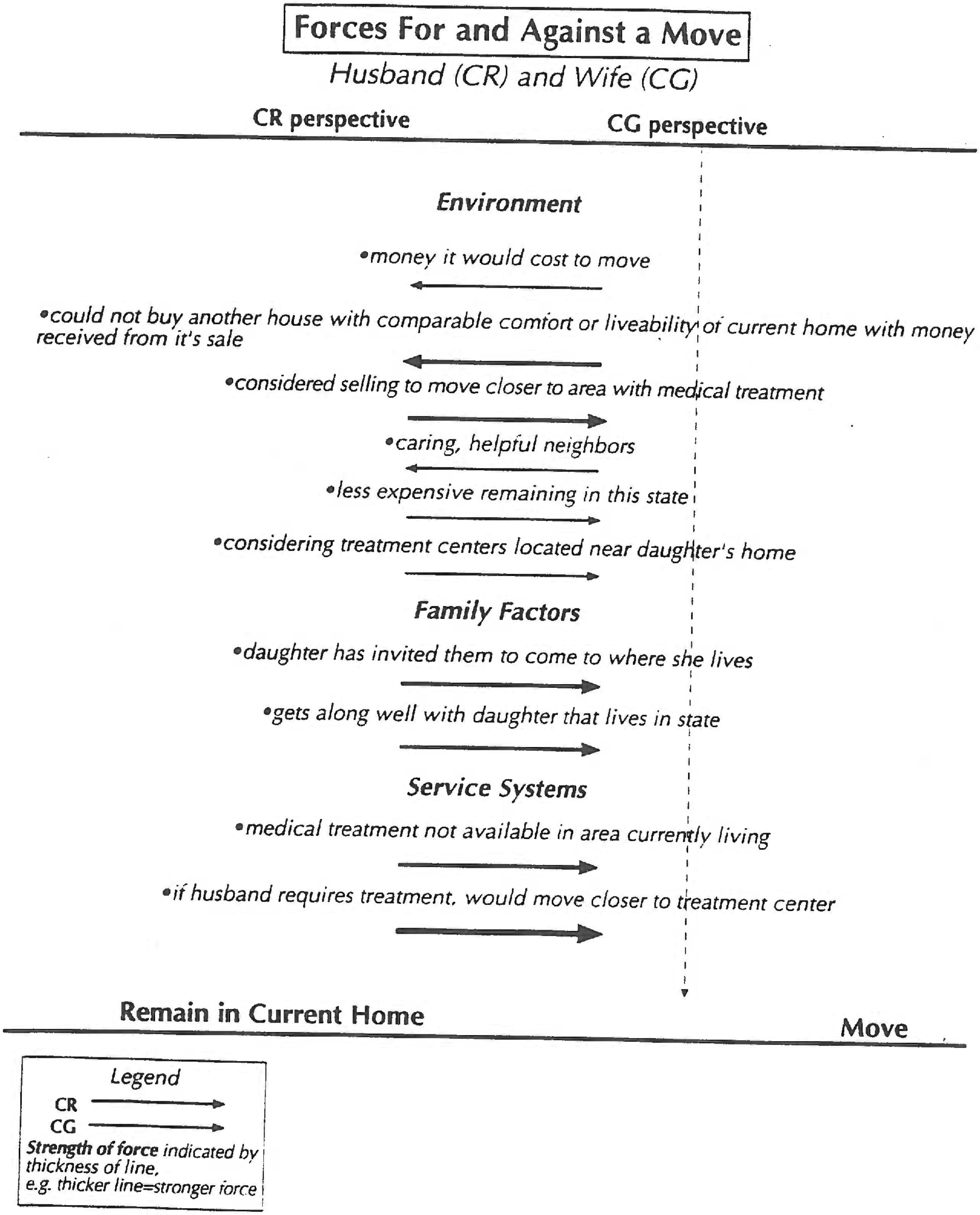
Legend

CR →

CG →

Strength of force *indicated by thickness of line, e.g. thicker line=stronger force*

Figure 3. Force field diagram: Mr. and Mrs. C (Continued)



Forces For and Against a Move

Husband (CR) and Wife (CG)

CR perspective **CG perspective**

Environment

- *money it would cost to move* ←
- *could not buy another house with comparable comfort or liveability of current home with money received from it's sale* ←
- *considered selling to move closer to area with medical treatment* →
- *caring, helpful neighbors* ←
- *less expensive remaining in this state* →
- *considering treatment centers located near daughter's home* →

Family Factors

- *daughter has invited them to come to where she lives* →
- *gets along well with daughter that lives in state* →

Service Systems

- *medical treatment not available in area currently living* →
- *if husband requires treatment, would move closer to treatment center* →

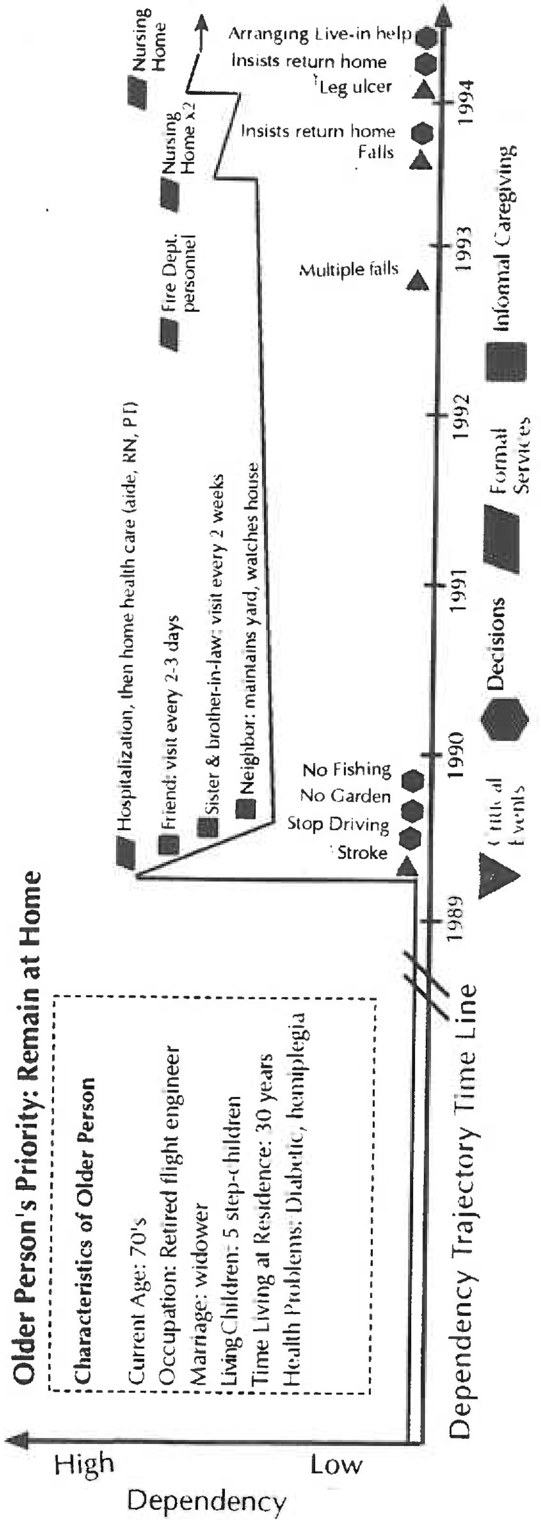
Remain in Current Home **Move**

Legend

CR →
CG →
Strength of force *indicated by thickness of line, e.g. thicker line=stronger force*

Figure 4

Figure 4. Dependency Trajectory Mr. D



the poster presentation. Feedback from conference participants was positive finding it helpful to visualize family situations with the dependency trajectory.

The substantive codes were increased as more interviews were analyzed and additional ways of conceptualizing the data were discovered. This continual open coding minimized the chances of forcing the data into a preconceived pattern. Two committee members reviewed some of the substantive coding of selected transcriptions for verification and suggested some additional codes.

At this point the investigator focused on the substantive coding of incidents without raising the level of analysis to theoretical codes, how the substantive codes interact. "Initially codes come very fast, and it is important to realize that these codes need correction by trimming and fitting" (Glaser, 1978, pp. 60-61). Although Glaser associated the "drugless trip" with the free flow of analysis memos, I experienced this "flow like crazy" with coding (p. 24). Before I came to the realization of the need to "trim," I had developed a codebook with over 120 codewords. Over time the work of data analysis became focused on the need to abstract theoretical codes from the substantive categories. Stern (1980, p. 22) described this need to cluster or connect the investigator's "overwhelming number" of codes as reduction. Committee members suggested ways to densify codes: (a) looking at a matrix of who does what (b) group codeword by parts of speech, e.g., nouns, pronouns, (c) look for codes that overlap the same data bits and how they interact (d) look for processes, (e) look for coding families (Glaser, 1978). My initial attempts at densifying codes were not very successful, resulting, for example, in categories such as caregiving activities and decision-making.

Theoretical sampling was one strategy used for densifying emergent categories. As the substantive codes were developed, data collection was directed to sample areas that needed deeper or broader elaboration and to find connections among categories. Two of the codes that appeared predominant were *caregiving* (formal) *services* and *family help*. Examples of data from Mr. J contained within these codes follow.

> They [home health care] just come out and check her with her pulse and her heart and her back, and checked her feet.
>
> He [son] goes there [rehabilitation center to visit his mother] regardless. He'll walk if he has to. That way, he likes his mother and she likes him. She remembers him well.

Six of the eight initial families interviewed were receiving home health services by the time of the first interview. These older participants were able to discuss retrospectively how they decided to receive this care, but a question remained, "How did families make this decision if they had not gone through the process previously?" Families that lived in more isolated areas of the county where services may not be as accessible or where families may not be as aware of what services are available were sought to sample their experiences and processes.

Of the first eight families, only two were couples. There were distinct differences identified between data from the widowed older person with an adult child caregiver and that from the members of a couple alternating the care receiver and caregiver role, depending on the condition of each older person at the time.

One thing that seemed different was that there was more agreement within couples regarding what was important when making decisions regarding future care needs than between the parent and adult child dyads. Three additional couples were recruited to increase saturation of categories emergent from couples' experiences.

The importance of the older person's mind or mental capabilities were identified in all of the first eight families interviewed whether couple or intergenerational. These references to the mental capabilities were coded within the categories SEASSESS (personal assessment of self, one's own abilities) or GASSESS (general evaluation of the current situation, needs, conditions of the older person and/or caregiver). Examples of statements by participants included "I feel like my mind's as good as it ever was," "I have [not] gone off my rocker (laugh)," "she's quite capable mentally," and "we don't want anyone to think she is not mentally all right, because we think she is." Because decision-making is considered a cognitive process, older participants that may be experiencing some decline in mental capabilities would add to the theoretical development.

As data analysis progressed, key passages were identified and coded in transcripts that were not yet coded line by line with the 120 codes. Themes that kept recurring in the previous coded interviews or that were mentioned in the literature were looked for specifically. Themes included in the key passages were *meaning of home, outlook, priority, philosophy of life, care, independence, importance of the day, accepting help, cope, decline in health, negatives of current* *living situation, protection of older person from others, and change in responsibilities for caregiver.*

As the analysis continued, a tentative core category (a variable relevant to the participants, Glaser, 1992) for the older person appeared to be *maintaining independence*. The core category *maintaining independence* was found in passages coded *independence, philosophy of life, priority, outlook, home*, and *cope*. In some cases the individual associated maintaining independence with living in one's home that has been her/his residence for many years. However for other people moving closer to family members that could be asked for help was a way to maintain independence. With family help these "moving" older people felt a degree of independence could be maintained. In either case the older person wished to control the environment "as long as [I] can." Accepting help from formal sources was permissible if the older person recognized the need for help, the help was provided in her/his own environment, and it was affordable. Help also was acceptable from family members or formal sources if it did not threaten one's independence too much or if it was considered to be only short term to recover from an immediate crisis.

Although *maintaining independence* seemed to be an important category much was left out of the theoretical framework when it focused on maintaining independence. To raise the analysis to a more conceptual level and to identify important concepts related to independence, the data were asked a set of questions outlined by Glaser (1978) that focus on the development of a core category: (a)

"What is this data a study of?" (b) "What category or property of a category, of what part of the emerging theory, does this incident indicate?" (c) "What is actually happening in the data?" (p. 57). The literature sources were reviewed looking for similarities and differences with the data and emerging categories.

Increasing the practice of theoretical memoing while re-reading the data with the above questions in mind began to raise the level of analysis to a higher conceptual level. Memoing captures the analyst's thoughts about the properties of categories and the nature of connections between categories and/or their properties (Glaser, 1978). While more theoretical memoing during the earlier development of substantive codes would have slowed down the generation of large numbers of codes and forced thinking about the relevance and fit of the categories for a theoretical framework, it may have placed premature restriction on category identification. An example of an early memo that indicated the linkage between a cluster of codes follows.

> The older person maintains the perception of independence while recognizing a decline in his/her physical abilities that requires accepting more help from others and changing one's priorities (such as giving up activities and/or possessions) in order to maintain this perception of independence. (Analysis, 2/11/95)

This memo arose from reviewing data coded *uncertainty* and *don't know.* Older people talked about uncertainty related to their health status, what priorities could be maintained, and vague possibilities about what could happen in the future. Feedback from members of a graduate qualitative seminar about the analysis of a sampling of data segments and their respective conceptualizations on *maintaining* *independence* and *uncertainty* lead to a review of data segments originally coded in the list of 120 codes *DECISION, CHOICE, MOVE, ASSESSMENT, PRIORITY, VALUES, INDEPENDENCE, CAREGIVING, SERVICE* (formal services), *PAST EXPERIENCE* (with caregiving), *STAY, UNCERTAINTY* (12 code words). The seminar members' critique prevented premature ending of open coding with resultant focusing on *maintaining independence* and *uncertainty* as core categories. These categories did not account for most of the variation in behavior found in the older people, a characteristic Glaser (1978) describes of a core category.

The older person's uncertainty was not generally about which alternatives would be picked when changes were needed but rather about the time when such changes would be needed in the older person's life. Reviewing the data segments identified with the twelve code words and the basic social process identified as uncertainty and memoing lead to the conceptualization of *confidence level*, defined as a feeling of assurance or certainty that one's routines can be maintained. A memo at the time included: "how vulnerable the person feels may be what tips the balance and results in a move" (Analysis, 3/14/95). This was one of the early references to *balancing*, the concept that later proved to be the core process for the theoretical framework.

Another early memo documented that older people talked about fear, being scared, feelings of isolation, and concerns for safety. The theoretical questioning, "Do these emotions precede decision making?" resulted in further exploration. This emotional aspect of the process first was identified as *recognizing imbalance* and later the older person's *emotional response of awareness.*

Other categories developed at this time included *routine disrupters, sustaining routines, relinquished routines, judgments regarding help*, and *home.* Definitions of these concepts and their relationships were presented to a graduate gerontological nursing seminar to identify gaps in the conceptualization and assist in development of a theoretical framework. This group was most excited by the category *sustaining routines*, defined as activities judged essential by the older person to maintain a sense of self. What the investigator had previously considered the tentative core category, *confidence level*, was not as enthusiastically received. The comment was made that the nurse may not want to build up the older person's confidence level if one assessed that the person was not safe to remain in the home.

In response to this feedback from the gerontological nursing seminar participants, interviews were recoded to identify more data segments that related to these concepts of sustaining routines and confidence level. The investigator recognized that an important concept reflecting the older person's perspective was contained within the data bits coded confidence level. As a strategy to identify properties of these categories, the questions Lofland and Lofland (1984) outlined to understand units of social life were used when analyzing *sustaining routines* and *confidence level.* An example of a Lofland and Lofland question included "what are its consequences?" (p. 94) or as applied to confidence level, what are the consequences of a lower confidence level? These categories focused on the older person's perspective and that of the caregiving spouse.

The adult child's perspective was reviewed looking for similarities and differences with the spouse caregivers and older people. Additional categories identified through this process included *consistency in parent's habits/behavior*, *number of parent's complaints*, and *parent's ability to manage finances*. Later in the analysis consistency in the parent's behavior and the parent being able of manage financial matters appeared to be a way the adult child assessed whether the parent was balancing. All of the transcripts were recoded with 24 codes, developed from the key themes and categories identified in memos related to confidence level and sustaining routines in order to capture data segments that could be compared. This was the beginning of selective coding; coding was limited to variables that related to the core variable in significant ways and that developed a parsimonious theory (Glaser, 1978).

Extensive memoing regarding the categories identified and their properties and relationships was done as the data segments were reviewed by category (e.g., all the segments coded *sustaining routines*) and by individual participant (e.g., all the segments coded for one participant regardless of the category). Each group of participants was compared with the other groups, e.g., an older person's data segments were compared with other older people and with the segments from spouses and adult child caregivers. Glaser's (1978, p. 78) six C's coding family (causes, contexts, contingencies, consequences, covariances, and conditions) was used as a beginning theoretical framework for the categories identified. "Family stories" were written showing how different families' data fit into this framework. Review of the theoretical memos and family stories by the committee chairwoman pointed out gaps in the theoretical framework and alternative ways to conceptualize the data. It was at this point in the analysis that *sustainability of routines*, the ability of the older person maintaining her/his priority routines was considered the core process. A triangle composed of routine *disrupters*, *resources*, and *recognizing/accepting limitations* was developed. *Decision-making* focused on choices to *maintain priority sustaining routines* and the importance of *values* in choosing sustaining routines resurfaced.

As more of the data segments were compared, the older person's values were discovered to influence how all of the other concepts were operationalized. What was being balanced were the older person's *routines*, *resources*, and *disrupters* (balancing triangle refined). *Recognizing imbalance* within the triangle lead to *decision-making*, reprioritizing one's routines and resources. *Recognizing imbalance*, which appeared in the data at first as an emotional response, was the concept linking the balancing triangle with the decision-making process. The names of the categories and the wording of their definitions were carefully selected based on the data and the meaning of the words from dictionaries and thesauruses (*The American Heritage Dictionary*, 1978; Seaton, 1986). Story boards were developed for each family placing data bits that fit within each category into the theoretical framework. *Decision-making* was expanded to *assessing and prioritizing one's disrupters*, *routines*, and *resources* and *taking action*. Strategies for taking action included *relinquishing routines, avoiding accidents, accepting help*, and/or *moving to gain resources*. This process of comparing family situations with the model pointed out further areas in the framework that were not clear.

Reviewing with two committee members a selection of the family descriptions that summarized the story boards and the definitions of the categories helped to refine the definitions and rework the theoretical framework. For example, *recognizing imbalance* continued to be the part of the model that needed more development. Recognizing imbalance involved both affective and cognitive parts; emotions expressed when an older person was out of balance and "armchair theorizing" when the older person considered potential imbalance. The committee members suggested other extant theories to compare with the emerging theory to provide additional perspectives on the conceptualization. Glaser (1978) recommends comparing the emerging theory with existing theory to find ways they may be linked and the theories broadened.

The perspective gained from reviewing Helson's adaptation (1964) and Festinger's dissonance (1957) theories helped to clarify how the contrasting data fit together with that related to *recognizing imbalance*. The dimension of *awareness* was identified as containing the emotional response of *recognition* and the cognitive processes of *realizing that sense of self no longer agreed with reality* and the *acknowledgement that a shift in one's sense of self was needed to correspond with reality*. Another example of existing theory lending support to the emerging theory's conceptualization involves the definition of disrupters. Whether an event is classified a disrupter is determined by the older person's assessment of the event and whether his/her balance was threatened. This component contains an aspect similar to Lazarus and Folkman's (1984) primary appraisal: "determining what was at stake" (p. 32).

The coding families outlined by Glaser (1978) were used to help further consideration of the data in abstract terms. Additional dimensions of balancing and the balancing continuum were developed. While rewriting the family stories in terms of the balancing model categories and continuum, the balancing model was further refined. How the adult children caregivers' viewed the process differently from their parents provided further density to the model. As the results were written, additional verification and reworking of the conceptual framework occurred. Data bits were reviewed selecting examples to illustrate the concepts and linkages between concepts. Hypotheses related to the linkages had to be modified. For example, *accepting that imbalance is present* was reintroduced into the outcomes of the balancing process. Accepting originally had been included in *recognition* and *acceptance* of imbalance but was lost to the framework when *recognizing imbalance* was centered on only the emotional response with the cognitive aspect being incorporated into *prioritizing*. Additional theories were compared with the balancing model lending support to the conceptualization. The balancing model contributed to the theories by focusing on the decision-making process from the older person's perspective and demonstrating how this process compared with that of the adult child caregiver.

Trustworthiness

Lincoln and Guba (1985) used the term trustworthiness of the study to refer to validity and reliability issues in qualitative research. They developed four constructs to evaluate trustworthiness that correspond to the assumptions of the qualitative paradigm: credibility, transferability, dependability, and confirmability. These constructs were used to guide the research process so that error might be minimized.

Credibility, to ensure that the process was accurately identified and described (Marshall & Rossman, 1989) was achieved in a number of ways. Prolonged engagement and persistent observation during the data collection was one strategy. Of the 32 participants, 30 were interviewed twice and at least one telephone call was made to the participant or family between interviews. The time period between interviews ranged from 4 weeks to 9 months. Interviews were primarily in the participant's home with the exception of adult children caregivers who lived out of the area. In these three cases all contacts occurred over the telephone. Data collection visits ranged in length from 20 minutes (telephone interview) to over two hours. Most of the interviews with the older participants lasted about 1 1/2 hours. In discussing their daily routines and how they managed, participants often showed the investigator areas of their home, possessions, and family pictures. They were sharing some tangible evidence about what really counted in their lives.

Triangulation, another strategy for achieving credibility, involves the use of multiple data collection sources and methods. Although the interview transcripts provided the main source of data used in the analysis, observations, telephone calls, field notes, and written correspondence added to the data sources and methods used. After each interview field notes recorded the setting, a summary of the main content and observations made during the interview. After the first interview the investigator's informal assessment of the ADL and IADL levels of the older person were noted. Field notes were recorded after telephone calls to the participants between interviews. The date and content of telephone calls made by the participants to the investigator were also documented. A letter from a participant was added as a data source. Being a sparsely populated rural area, information about participants sometimes became known from informal sources without the investigator seeking it out. This also was added to the field notes. Comparing the two groups, older people and adult children caregivers, also increased the credibility, scope, and depth of the model being developed.

Throughout the data collection and analysis process (a 2-year period), committee members were consulted at regular intervals for peer debriefing regarding methodological strategies, ethical and clinical questions, theoretical sampling, coding, and development of the model. Through their questions the investigator's assumptions and interpretations of data were clarified. Through their critiques the investigator was encouraged to raise the level of abstraction, densify the model, rework linkages that were incomplete, and not to limit the analysis by premature identification of a core variable. Discussions of the analysis at three separate doctoral seminars and the poster presentation at the Third International Family Nursing Conference provided opportunities to obtain feedback from peers and helped to broaden the investigator's conceptualization of the data. Negative cases were scrutinized and the emerging theory was reworked to account for this data that initially seemed contradictory. These strategies increased the model's credibility.

Member checking occurred during the interview and analysis phases of the study. During the interviews, the investigator asked the participants to clarify the meaning of their statements when this was in doubt. The investigator routinely summarized verbally the information provide by the participants to allow them to correct errors in the investigator's understanding and contribute further information. At the end of the second interview some of the participants asked about the findings of the study. This provided the opportunity to confirm aspects of the categories with these participants. A nurse, social service worker, and journalist who each were currently arranging care for their parents reviewed the emerging model at different points in its development. They indicated agreement with the salience of routines, resources, and disrupters for their parents and found the balancing model helpful in understanding their parents' positions related to accepting help. Anecdotes that illustrated the concepts were offered from their own experiences. As adult children they confirmed that their own lives were disrupted when their parents were experiencing imbalance. They each talked about time pressures trying to restore or maintain their parent's balance while continuing their own life routines.

A previous director of a geriatric assessment service and private consultant for adult children arranging care for their parents also reviewed the balancing model near the end of the analysis. She indicated that it appeared "simple" (parsimonious), a trait that reflected it fitting with the experiences of older people and their caregiving children. She felt it would be valuable as a tool used when counseling families about these decisions to seek help or move.

Hard copies of interview schedules, transcripts, field notes, memos, codebooks, analysis notes and minutes from dissertation committee meetings in addition to computer disk copies of much of this information were kept secure by the investigator. For confirmability two of the committee members reviewed parts of the audit trail tracing how concepts evolved as the analysis progressed. Transcripts and theoretical memos verifying the "fit" between data and conceptualizations were reviewed by different committee members at various points during the analysis. During the last six months of the analysis the investigator met with one or more of the committee members approximately every three weeks for guidance with and assessment of the analysis. These frequent contacts and feedback from committee members contributed to the dependability of the study, another criterion for trustworthiness.

To supplement the verbatim transcripts of the taped interviews, pauses, laughs, sighs, and nonverbal behaviors that were a part of the dialogue were added to the transcripts by the investigator when they were verified. This helped to capture the emotional tone of the conversation and triggered additional investigator memories of the actual interviews during analysis. The accompanying field notes also enriched the descriptions. These thick descriptions and the detailed accounts of the sample families should help others evaluate the transferability of the balancing model to other situations and groups.

CHAPTER IV

RESULTS

The balancing model, the process older people use when deciding whether to receive help in the home or move to receive the help needed, is described in this section. Information about how the family caregiver's perspective (spouse, adult child, or friend) may differ from that of the older person is also included. For the older person, the goal of balancing is to continue one's life routines. The older person considers this vital because their routines are a reflection of their values and sense of self. Preserving one's values and sense of self, described by Erikson, Erikson, and Kivnick (1986) as autonomy and identity, is the reason balancing is critical to the older person. In the current study, the values of importance to the older people were independence, control, and self-reliance. When deciding how to maintain one's balance, the older person's consideration is holistic and not only centered on the current circumstances. For the adult child, her/his perspective may be focused on the current situation which can lead to disagreements with the parent. Disagreements within the couple (older person and caregiving spouse) can also occur if their perceptions of their state of balance as a couple do not agree. Table 7 contains definitions of the concepts in the balancing model.

Balancing is the process of maintaining a dynamic sense of equilibrium among the older person's *routines*, *resources*, and *disrupters*; the three components of balancing. The balancing model was developed from older person's and spouse's

Table 7

Definitions of Concepts in the Balancing Model

Concept	Definition
Balancing	Process of maintaining a dynamic sense of equilibrium between the older person's routines, resources, and disrupters; everyday activities continue as usual; minimal awareness when one is in a state of equilibrium but feeling of comfort may be described. A person is not balancing when disequilibrium exists between one's routines, resources, and disrupters creating discomfort.
Values	Principles considered worthwhile that influence how the other concepts in the model are appraised. Statements made by the older participants about their routines, and what resources and routines were prioritized when making changes were considered a reflection of their valuing independence, control, and self-reliance. Remain independent in decision-making, such as choosing where they lived; control of routines; self-reliance in the use of resources, such as their finances.
	COMPONENTS
Routines	Ordinary activities that maintain a sense of self for the older person and are therefore judged important and meaningful for maintaining the sense of self.
Resources	Reserves that help maintain the older person's routines.
Disrupters	Events that are a perceived threat to the older person's ability to continue routines with a given set of resources.
	DIMENSIONS
Centrality	Individual's determination of which routines, resources, and disrupters are most important in maintaining the sense of self.
Urgency	The older person experiences some pressure to take action to restore balance by increasing resources and/or changing routines of central importance

Table continues

Table 7 (Continued)

Definitions of Concepts in the Balancing Model

Concept	Definition
Permanence	Individual's perception of whether balancing can continue indefinitely as is, whether it is temporarily upset, or whether lasting changes will need to be made to restore a state of balance.
Awareness	Affective and cognitive acknowledgement by the individual that some amount of disequilibrium is present; some threat to one's values.
Affective	Older person's emotional response to the sense of disequilibrium.
Cognitive	Realizing that one's sense of self is not consistent with reality and acknowledging that a shift in sense of self to agree with reality is needed.
	OUTCOMES
Accepting	Indicates a willingness to recognize that disequilibrium is present and changes are needed to restore balance (cognitive process).
Prioritizing	Considering alternatives and weighing priorities; assessing and choosing routines and resources that are most important to the older person's sense of self and that are consonant with her/his values (cognitive process).
Taking Action	Making changes in one's routines and/or resources to restore equilibrium or insure that equilibrium is maintained.
Strategies	Routines modified, increased caution, routines relinquished, help accepted, move to gain resources while maintaining priority routines.

perspective. The adult child provided a second perspective of the parent's balancing. The *balancing process* is described here as a continuum with a range from balance to imbalance with the individual determining their state of balance. Balance describes a state of equilibrium; everyday activities continue as usual. These everyday activities reflect what is most important to the individual; the sense of self. As described by Norris (1991), "We simply know that our daily round is how we live . . . how we hold the simplest of our tasks speaks loudly about how we hold life itself." *Imbalance* describes the state when the person acknowledges that a decision or change needs to be made because disequilibrium exists among one's *routines*, *resources*, and *disrupters* creating discomfort. Figure 5 illustrates the balancing model. Concepts contained in the balancing model at times will be in italics in the text to prevent these common terms from being overlooked.

The four dimensions of the balancing process include *centrality*, *urgency*, *permanence*, and *awareness*. These four dimensions interact with the three components (disrupters, resources, and routines) to determine the location of the older person on the *balancing continuum*. *Accepting*, *prioritizing*, and *taking action* are the outcomes of the balancing process. To maintain or restore balance, the older person *accepts* that changes need to be made, *prioritizes* routines and resources, and *takes action*; two cognitive processes and one behavioral process, respectively. Behaviors taken may include *modifying one's routines*, *increased caution*, *relinquishing routines*, *accepting help*, and *moving* to have help more accessible.

Although the balancing model is illustrated as a linear process in Figure 5 (to clearly show relationships between concepts) it should be thought of as cartwheeling triangles as drawn in Figure 6. Disrupters can lead to disequilibrium between one's routines and resources, and the older person attempts to restore balance. If changes

Figure 5

Figure 5. The Balancing Process

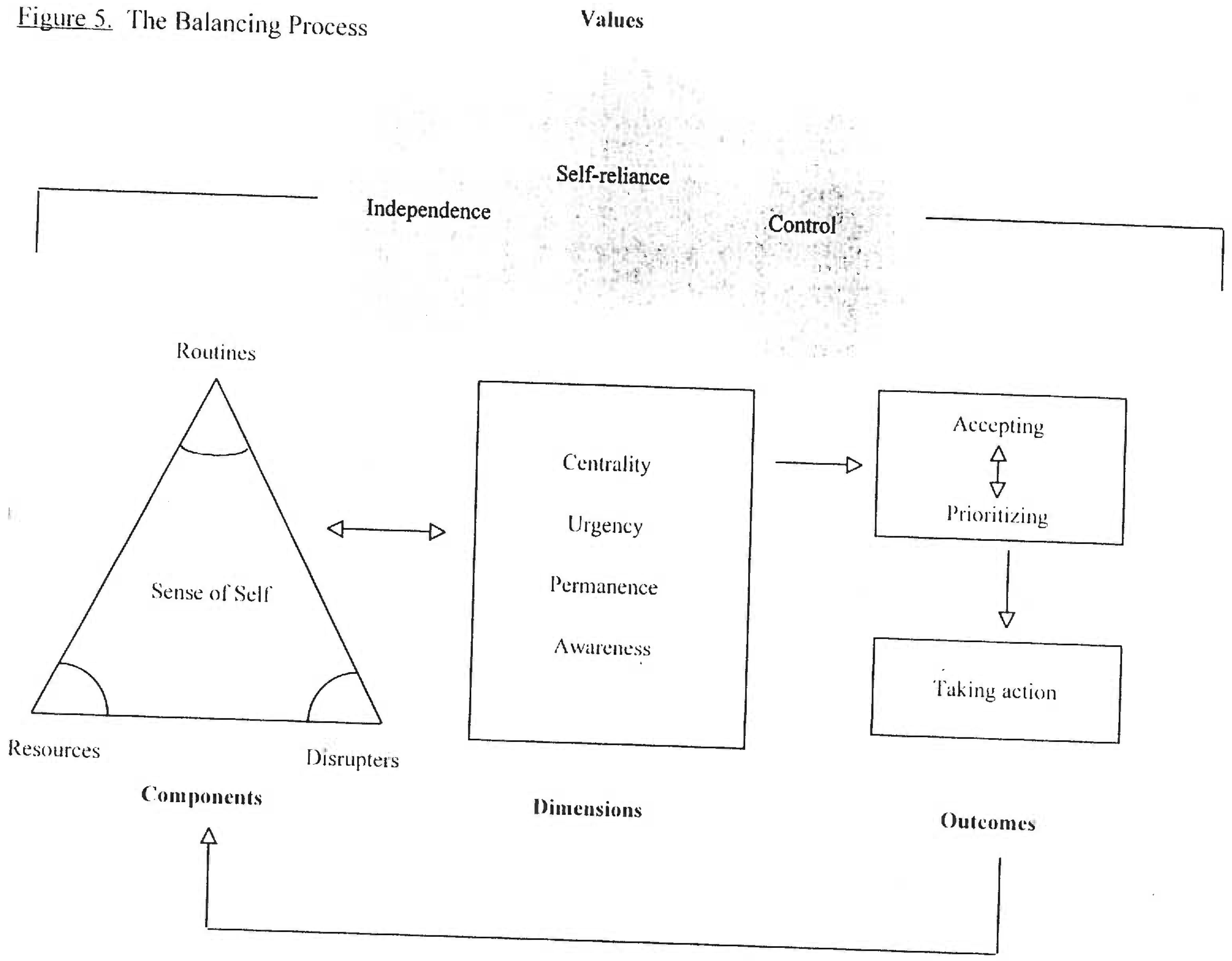
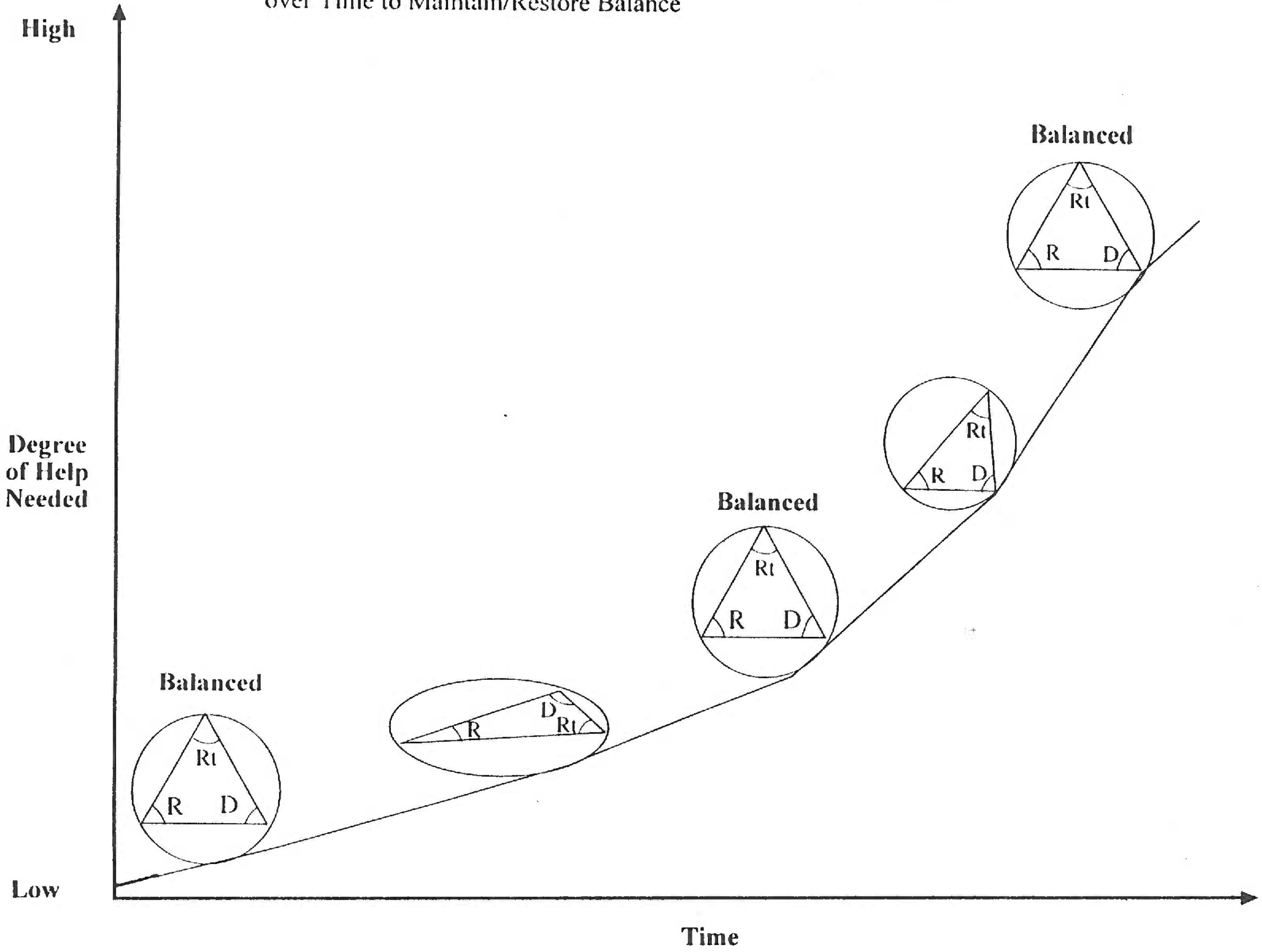


Figure 6

Figure 6. Changes among Routines (Rt), Resources (R), and Disrupters (D) over Time to Maintain/Restore Balance



in one's routines and/or resources or perception of disrupters occurs, a new balance may be restored. However, the balance is restored at a level indicating a greater need for assistance from others to maintain priority routines.

Before discussing the concepts of the balancing process in more detail, the families, their circumstances at the time of the interviews, and leading up to that time will be summarized. This will provide background information for the "family stories" and data bits that are later used to illustrate aspects of the balancing model and also provide the reader with a sense of participation in each older family's process. Each family though different and unique shared overt or tacit evidence of how they processed their own progressive dependency while maintaining their values of independence, control, and self-reliance. Then the *balancing model* will be described with its *three components*, *four dimensions*, *three outcomes*, and the influence of *values* on the entire process. Following that, the interactions among the components and dimensions that determine the older person's position on the *balancing continuum* will be discussed in more detail. Generally the members of a couple agreed on whether they were balancing or how to restore their balance. The cases in which the couple did not agree on their *state of balance* will be discussed in more detail. These more unusual circumstances for this group of participants helped to clarify the dimensions of the balancing model. How the adult child's perspective of the situation differs from that of their parent's will then be outlined.

Background Summaries of the Families

Seventeen families will be described. One friend, Mr. DF, first identified as a caregiver but in terms of age and health status more closely resembling the older participants, is included among these older family summaries. Two of the families included interviews with only the husband caregivers, the wives being too cognitively impaired to provide an informed consent. Included with each summary is a trajectory outlining some of the disrupters and decisions made by the older person and the resources used. When the caregiving dyad is a married couple, the balancing level represents the couple as a unit. The balancing level represents only the older person when the caregiver is an adult child or friend. To protect the families anonymity, they are identified by letters of the alphabet that do not correspond with their names. Other identifying information and details of the family situations also have been changed to protect their anonymity. The older person and spouse is identified by one letter and title (e.g., Mr. and Mrs. C) with other family members identified by the older person's letter and additional letters designating relationship, e.g., CD for daughter of Mr. and Mrs. C, CDL for daughter-in-law, CS for son, CF for friend.

Mrs. A: "It wouldn't be if I want to go, because I'd never want to go. It would be if I had to [go to a nursing home]."

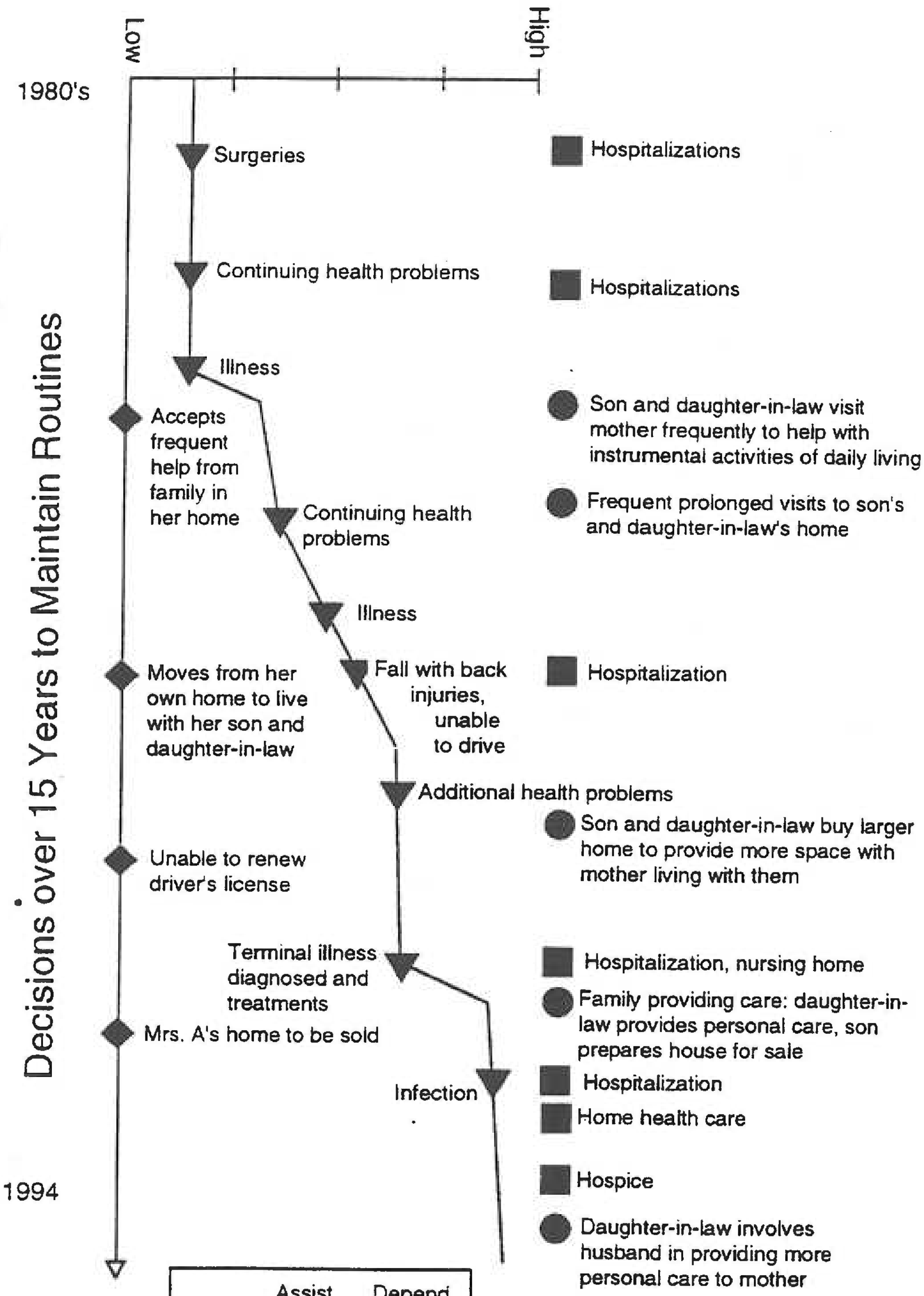
Mrs. A is a widow in her 80's living in the home of her son and daughter-in-law. She moved from her own home located in another state after repeated surgeries and illnesses, a fall with back injuries, and becoming unable to drive.

Since the move she has continued to have additional health problems and is now experiencing the physical decline associated with a terminal illness.

In addition to the care provided by her son, daughter-in-law, and granddaughters, Mrs. A has home health care and hospice services. When asked about the possibility of needing additional care, Mrs. A stated, "you can get one of those [hospital bed]" and "we'll just have to hire someone." "I'd rather die right here [at home]," was Mrs. A's wish. Mrs. A emphasized that she had made financial arrangements; "I carry my own insurance, so I have [a] supplement, [more than] Social Security. I better have because $500 is my drug bill last month."

Mrs. ADL (Mrs. A's daughter-in-law) was experiencing the "stress" of caregiving and the disruption it created in her and her husband's life; "Especially at this time of our lives. We probably have another 4 or 5 years, and then we will not be able to travel or do anything like we have been doing." Several months passed involving frequent trips to help their mother in her own home, before the couple decided that Mrs. A needed to live with them because of her declining health. The couple purchased a different home with more "breathing room" after Mrs. A had been living with them for a few years and when the couple decided this arrangement could continue for a number of years. Mrs. A's mother had lived to be in her 90's, so the son and daughter-in-law assumed Mrs. A also might live with them for a long time. Figure 7 depicts the trajectory for Mrs. A.

Interaction of Dependency Needs and Resources



	Assist	Depend
ADL	3	3
IADL	1	6

Figure 7. Trajectory for Mrs. A. at First Interview: "It wouldn't be if I want to go, because I'd never want to go. It would be if I had to [go to a nursing home]."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

Decisions over 15 Years to Maintain Routines

Mrs. B: "I don't know what I would do without them."

Mrs. B, a widow for over 40 years, is in her 80's living in her own home on rural property she has owned for decades. Over the last dozen years several falls, one of which resulted in a fractured leg, made Mrs. B realize that she needed to depend more on her daughter and sister for help. Her difficulty walking is also compounded by a progressive neurological disease that was diagnosed within the last few years.

Mrs. B talked about the importance of her home saying, "you get pretty well attached to it," but also emphasized the activities she continued to enjoy that living in her own house made possible; "I take care of my own house (cleaning). I cook my own meals most of the time. I do build a fire quite often." Mrs. B also looked forward to doing her own shopping, participating in an exercise class, and attending the weekly senior lunch; activities made possible through the transportation provided by her daughter or sister. "It takes away a lot of worry" knowing her daughter and sister live close to her home.

Mrs. B's daughter is also happy that she can help her mother as needed, and realizes that as her mother's neurological disease progresses, she will need to provide her mother help full-time. "Well, I think that at some point I'll probably have to either go live with her or have her live with me, you know, when she gets to the point where she won't be able to cook for herself. Or, you know, just can't do things as well." But until that time comes, Mrs. B's daughter feels that her mother living in her own home gives her mother "independence." At times, Mrs.

B's daughter admits that it requires being "very patient" to allow her mother to do as much for herself as possible. See Figure 8, Trajectory for Mrs. B.

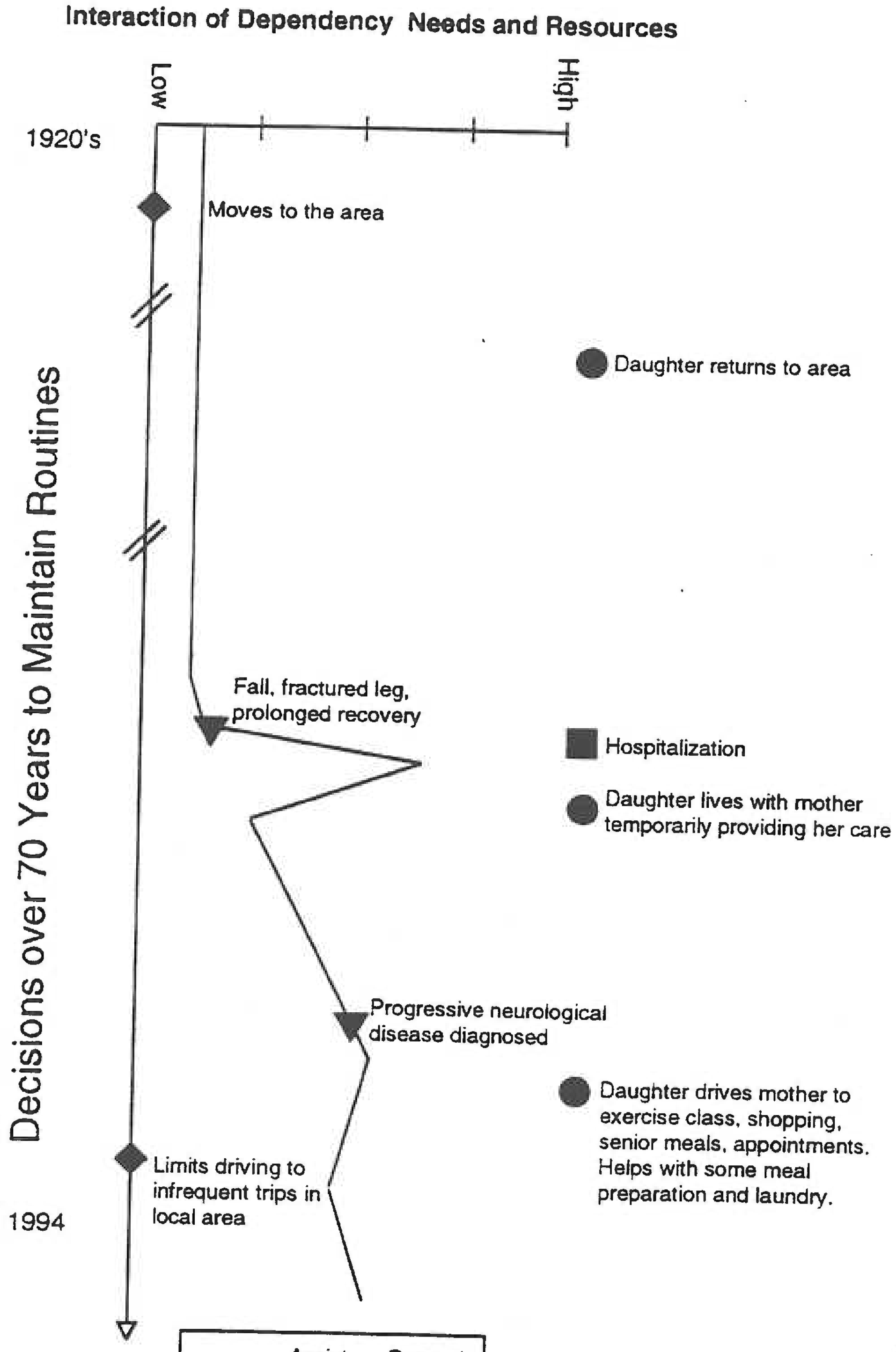
Mr. and Mrs. C: "Should we do **this**, should we do **that**, or what if, what if."

A couple in their 60's and 70's, Mr. and Mrs. C have been married over four decades. They moved to their current home located about 40 miles from a larger community after Mr. C retired several years ago. Their life was drastically changed a few years ago when Mr. C became disabled without warning. He had to give up his repair business and Mrs. C had to assume more of their household responsibilities. Mrs. C also has had health problems, experiencing a back injury that prevented her from driving for a few months. The couple was able to remain living at home while Mrs. C recovered from her injury helping each other with their daily needs, and having neighbors provide transportation.

More recently, Mr. C has been diagnosed with a chronic, progressive, terminal illness that will eventually require regular treatments that are not available in their local area. The couple was considering the housing options available at several alternative locations where Mr. C could receive medical care. The couple considered this a very uncertain period.

Mrs. C considered it a deficit not having family close during this period of "limbo." They had only one of their children living in the state, with the other children scattered around the West. All of the couple's siblings living on the opposite coast. "We're finding out that being away from family and relatives is about the roughest thing right now," was the way Mrs. C described this separation

Figure 8



	Assist	Depend
ADL	0	0
IADL	3	0

Figure 8. Trajectory for Mrs. B at First Interview: "I don't know what I would do without them."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

from family. They were thinking of moving closer to one of their daughter's once Mr. C began his treatments. The trajectory for Mr. and Mrs. C is represented in Figure 9.

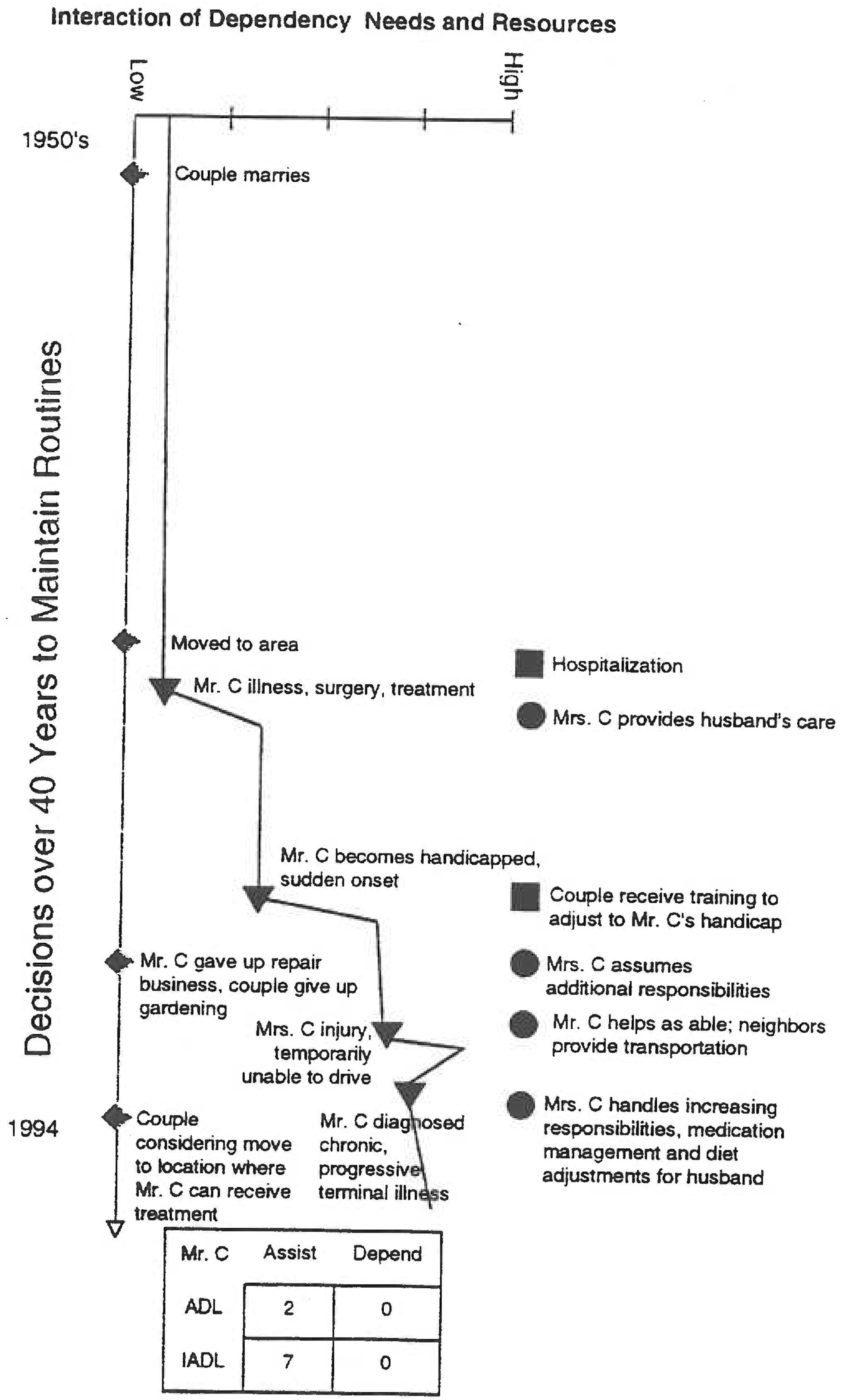
Mr. D: "I don't want to go to a damn nursing home."

Mr. D is in his 70's having lived alone for the last few years following his wife's death. Mr. D had a stroke with hemiparalysis shortly after losing his wife, and he had been "getting along all by myself" with the assistance of home health care, ordering meals from a local restaurant, neighbors and friends running errands and maintaining his yard, and relatives visiting every few weeks.

Mr. D was arranging live-in care at the time of the study interviews, so he would "never" have to return to a nursing home having had multiple admissions over the last 2 years. Repeated falls at home, being unable to get up after falling without calling the fire department for assistance, and skin ulcerations lead to these frequent admissions. With a couple living in his home, Mr. D indicated that "I got somebody to take care of me now, so I don't have to worry about going back [to a nursing home]."

Although Mr. D did not own his home, he had lived in the house for over three decades. In talking about the advantages of home, Mr. D stated, "I like to look at my pictures, oil paintings that my wife made. And I can watch television when I want to, what I want to look at. And I can go to the bathroom when I want to. I don't know, it's just home, that's all." The trajectory for Mr. D is found in Figure 10.

Figure 9

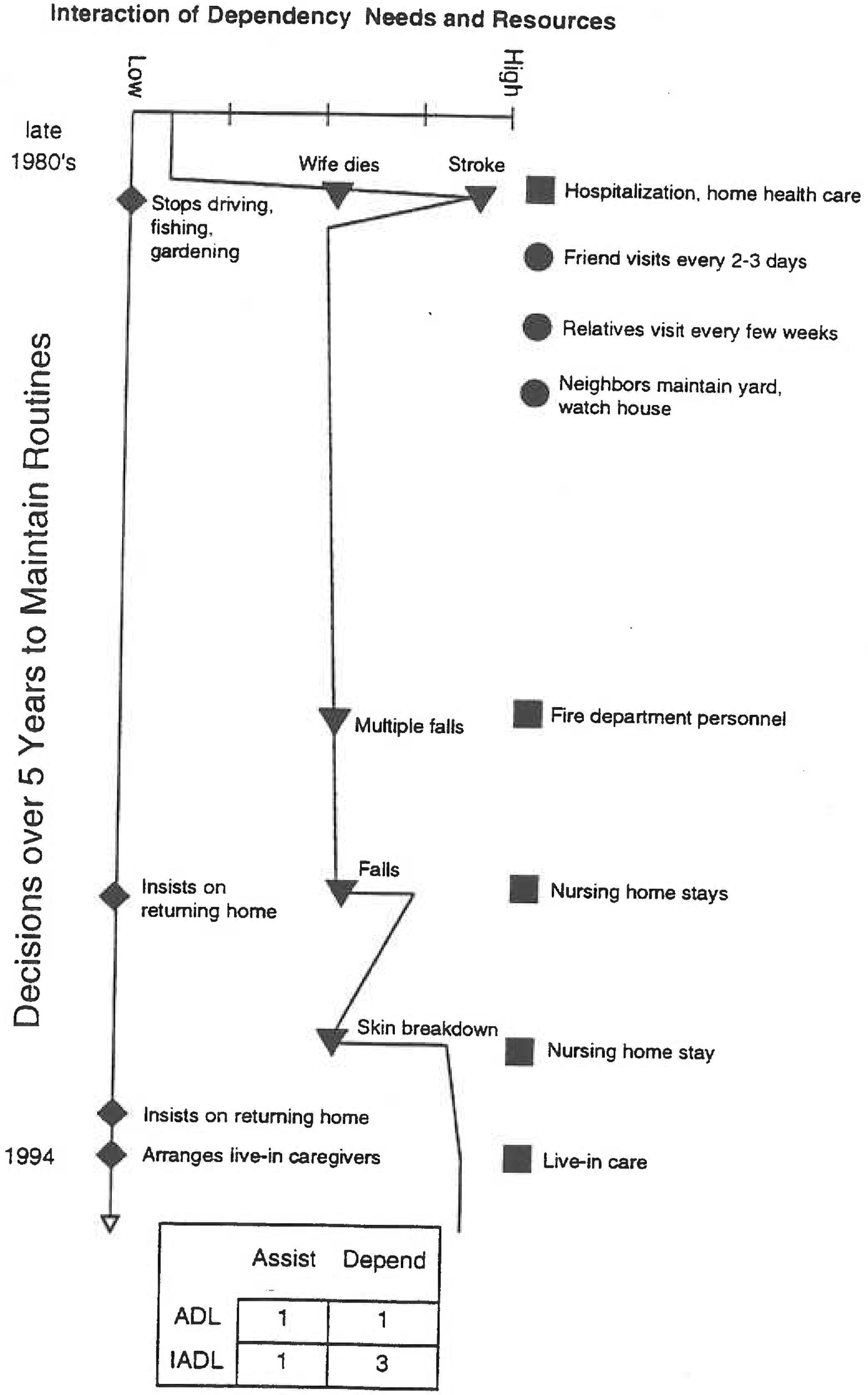


Mr. C	Assist	Depend
ADL	2	0
IADL	7	0

Figure 9. Trajectory for Mr. and Mrs. C at First Interview: "Should we do this, should we do that, or what if, what if."

▶ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

Figure 10



	Assist	Depend
ADL	1	1
IADL	1	3

Figure 10. Trajectory for Mr. D at First Interview: "I don't want to go to a damn nursing home."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

Mr. DF: "I've got to be **pretty bad** if I can't do it myself."

Mr. DF, a widower for a few years, is a friend of Mr. D's visiting him every few days. Mr. DF is also available to run errands for Mr. D and brought him home from the nursing home in the past. Mr. D indicated that he would not ask his friend for any greater level of help because Mr. DF is "pretty near 90 years old."

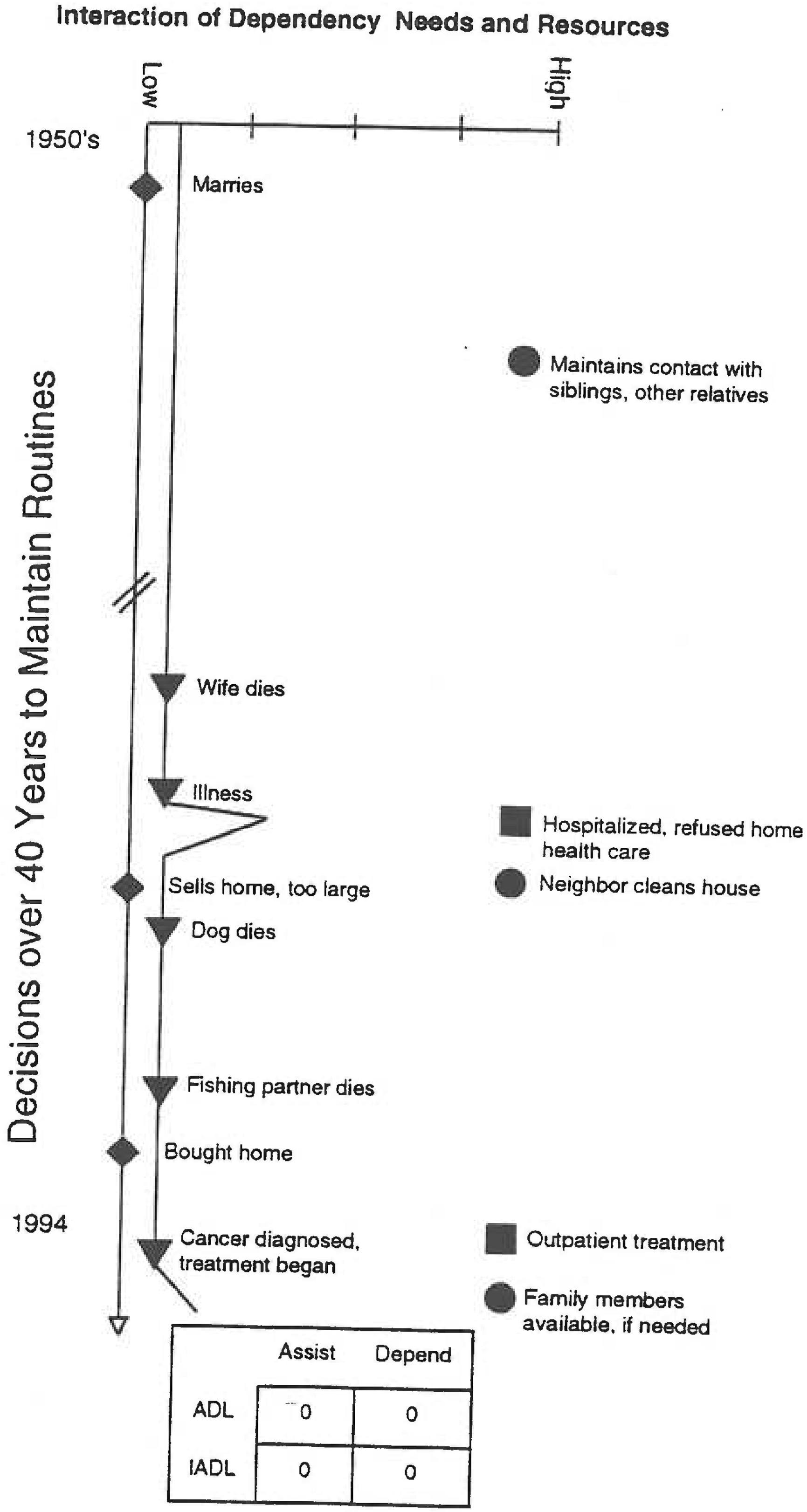
Mr. DF began treatment for cancer during the interval between interviews for the current study. He continued to feel well commenting that the only change he noted was the need to take a nap in the afternoon. Mr. DF continued living in his own home, doing his own house cleaning and cooking, gardening, fishing, visiting and helping his friends. A sister living in a neighboring state was available to come and stay with Mr. DF if he needed assistance, but so far this has not been necessary.

Mr. DF was looking forward to the future, talking about the new car and boat he planned on purchasing once his medical therapy was completed. He had already decided if further treatment was recommended, he was not going to pursue it. "I've been here a long time," indicating that he was ready to die. Mr. DF had a friend die in the hospital receiving cancer therapy, and did not want to have a similar experience. Figure 11 represents Mr. DF's trajectory.

Mrs. E: "I was **struggling** [before home health care started]."

Mrs. E, a widow for over 20 years, is a woman in her 80's living in a home she has owned for over 5 decades. She has received home health care for the last few years. This assistance began after Mrs. E fell, fracturing her arm a second time within a few months of the first fall and a heavy spring snow storm prevented her

Figure 11



	Assist	Depend
ADL	0	0
IADL	0	0

Figure 11. Trajectory for Mr. DF at First Interview: "I've got to be pretty bad if I can't do it myself."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

from driving into town to keep her doctor's appointment. Continuing illnesses and additional falls meant that home health visits also continued. Mrs. E's daughter who lives a few hundred miles away was pleased that the home health aide was visiting her mother frequently; "somebody beside the telephone . . . that she actually sees somebody." Mrs. E's adult children called her weekly and came to visit at least once a year to make repairs and clean her house.

During the study interviews Mrs. E's immediate concern was the damage caused to her home by an earthquake. At the first interview she talked about remaining in her current home "until it falls on me," but by the second interview Mrs. E was considering having a new house built or a manufactured home moved onto her land. This was an uncertain time for Mrs. E; "I never faced anything like this before. I had a home and it was mine and I could do as I please." The home and surroundings had special significance for Mrs. E raising her family and having her husband die in her arms in the house. "I said, 'No Dad, I'd never be sick of this place' . . . He was sleeping right there where that bed is now and he died in my arms . . . So I promised him I'd wait [here]." See Figure 12 for Mrs. E's trajectory.

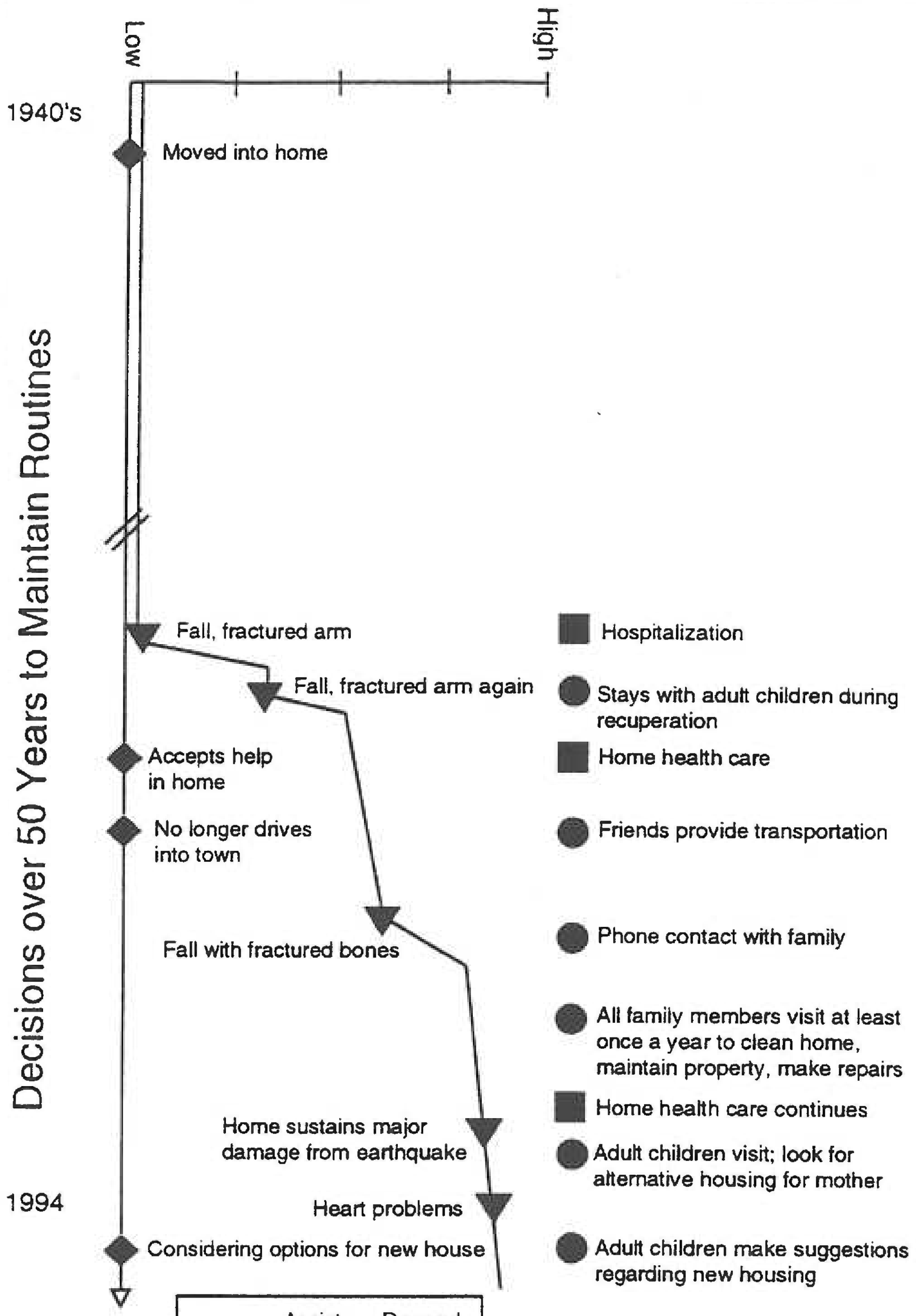
Mr. and Mrs. F: "I **try to go in there every day and see her.**"

Mr. and Mrs. F are in their 70's. Mrs. F was a patient in a rehabilitation unit recovering from a stroke during the first study interview. Mr. F was maintaining their home and learning to manage their finances, a task Mrs. F always had done in the past. Both Mr. and Mrs. F were looking forward to the day when Mrs. F would return home. Mr. F acknowledged that it was important that his wife be able to

Figure 12

Interaction of Dependency Needs and Resources

Decisions over 50 Years to Maintain Routines



	Assist	Depend
ADL	0	0
IADL	3	0

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

Figure 12. Trajectory for Mrs. E at First Interview: "I was struggling [before home health care started]."

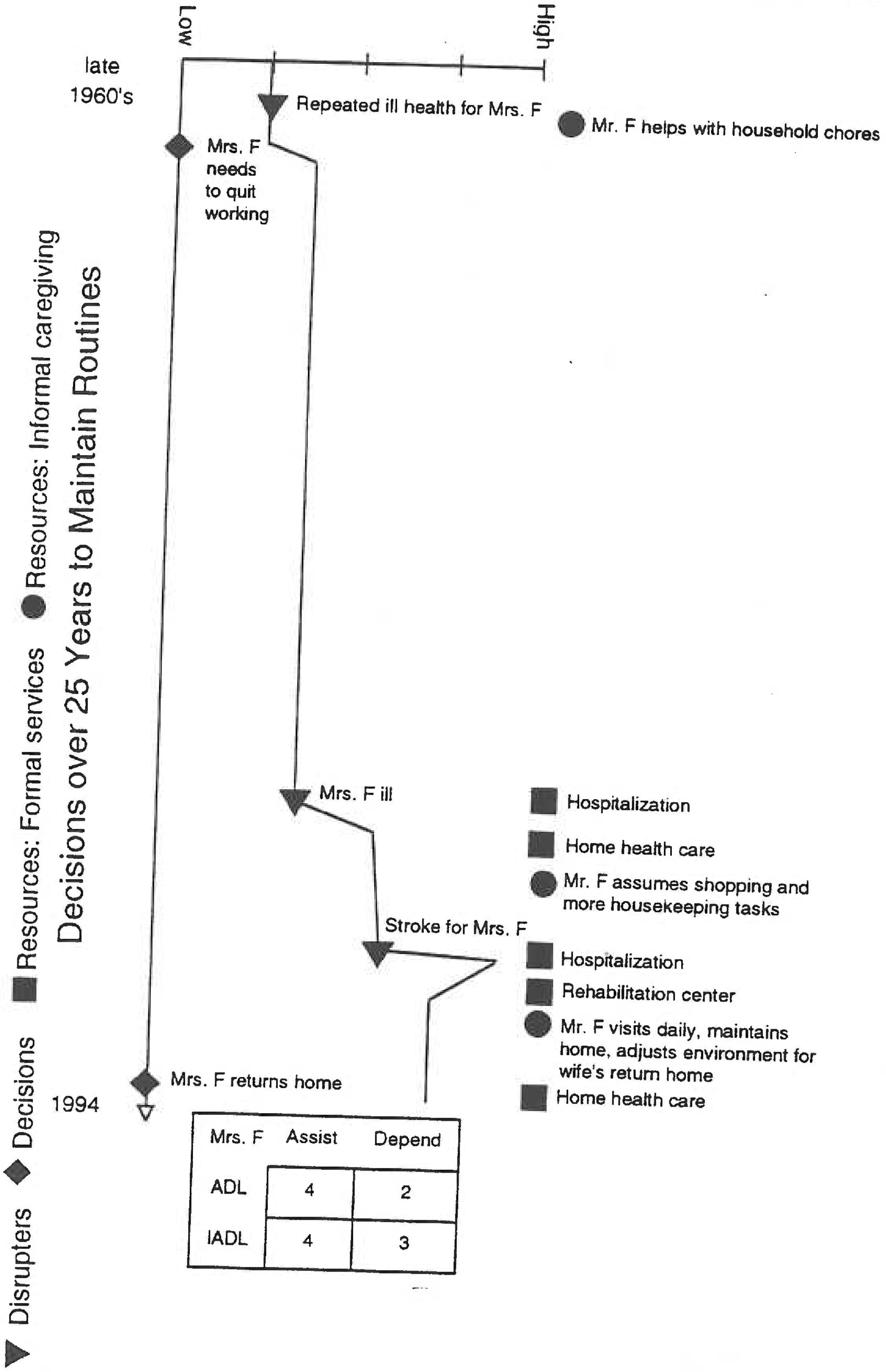
walk with "a cane" and have her "kidneys taken care of" (incontinence) before coming home if possible.

Mr. F's own medical problems were currently stable. At the present time his only concern was his wife's welfare. He was prepared to help his wife with her personal care and talked about ways to make their bathroom more accessible. Previously Mr. F had monitored his wife's medications. The couple was familiar with home health care services having visits in the past after Mrs. F had been discharged from the hospital. Family lived in the area and would visit, and Mr. F indicated that his wife would also accept care from them. There were not friends available that Mr. F would ask to stay with his wife if he had to run some errands. Mrs. F had been home for a day trial visit and Mr. F felt things had gone well. He stated his outlook for the future caring for his wife, "I just have to take it as it comes, that's all." The trajectory for Mr. and Mrs. F is portrayed in Figure 13. The balancing level as seen in the figure is a reflection of the couple's interaction and the support they provide each other.

Mr. G: "I'd rather die right here . . . I own this place."

Mr. G, married for over 50 years but currently living alone in his own home, is in his 80's. Mr. G has a chronic metabolic disease with associated vascular problems. He uses oxygen continuously for shortness of breath. At the first interview he said that he hoped that he would die soon but wanted to remain living at home until that occurred. He was depressed about no longer being physically

Figure 13 **Interaction of Dependency Needs and Resources**



Mrs. F	Assist	Depend
ADL	4	2
IADL	4	3

Decisions over 25 Years to Maintain Routines

Figure 13. Trajectory for Mr. and Mrs. F at First Interview: "I try to go in there every day and see her."

able to do any work or care for his wife. Mr. G, however, stated that his religious beliefs would stop him from ever committing suicide.

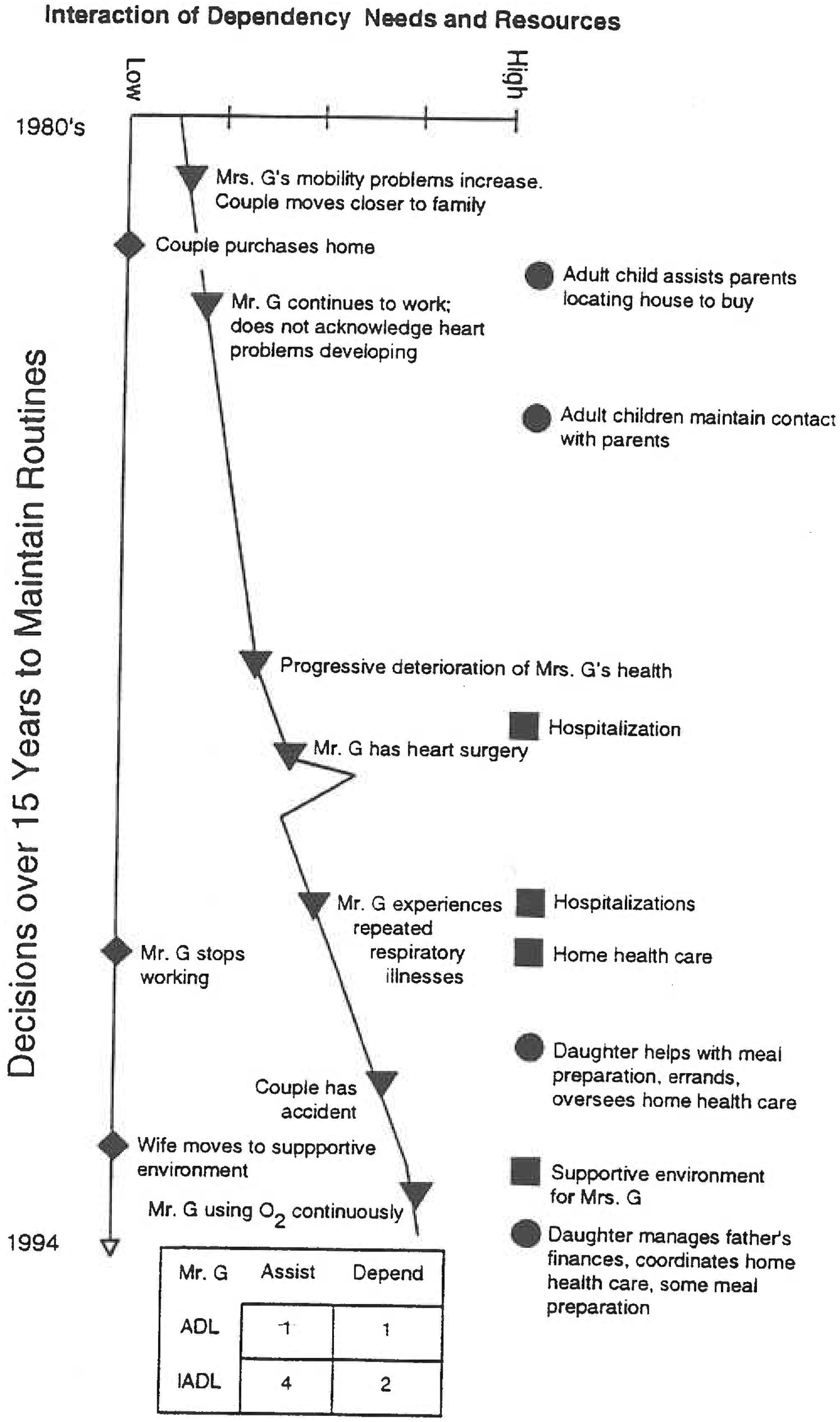
Mr. G's daughter arranged for Mr. G to have home health care. She also helped manage his business affairs, cooked occasional meals, and had frequent contact with him. Mr. G's daughter had also arranged for her mother's care outside the home. Mr. G's daughter thought he would have a better quality of life if he moved to a foster home, but was allowing him to make that decision. "He's capable of still making his own decisions . . . haven't taken that away from him." See Figure 14 for Mr. G's trajectory.

Mrs. H: "I got lonesome and I knew that if I came down here I could be with my family."

Mrs. H, a widow of almost 10 years, is close to 80 years old and moved to her current home a few years ago. She sold her home of over 30 years located in another state after other family members had left the area. Mrs. H has had a chronic neurological disease for several years and indicated that she wanted to be closer to family members "if I need them." She chose the current community because her grandson lived in the area and adult children were within a day's drive.

Since the move Mrs. H has needed the help of her children, grandchildren, and great grandchildren. She was hospitalized multiple times and required surgery. Home health care was arranged for her by a daughter after one of these hospitalizations and was continued since then. The aides help Mrs. H with her personal care, housekeeping, and shopping. In talking about adjusting to having

Figure 14



Mr. G	Assist	Depend
ADL	1	1
IADL	4	2

Figure 14. Trajectory for Mr. G at First Interview: "I'd rather die right here. . . I own this place."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

someone outside the family come into her home to provide this help Mrs. H stated, "It wasn't very hard for me because I realized I needed them."

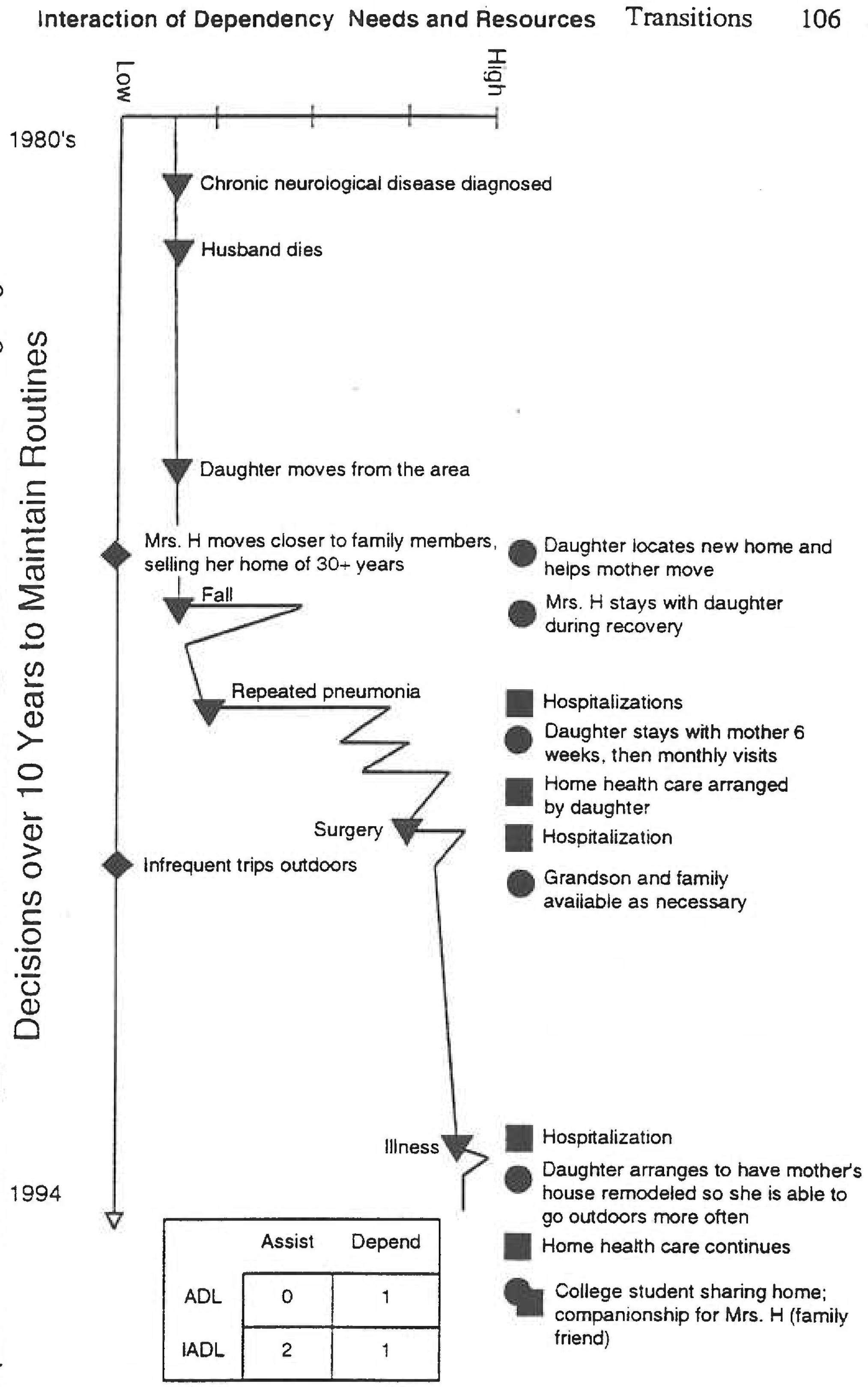
Family members and friends visit regularly and are available by telephone if needed. In describing what was special about living in her own home, Mrs. H said it was "comfort." "If I want to cook a dinner or something, I can invite people over." The home was picked out for Mrs. H while she was still living in her old home. Her daughter chose a large home for two reasons: (a) "having to get rid of all your possessions I didn't think was very fair to her," (b) "sometimes it helps to try to hedge your bets a little bit," indicating that there would be room for live-in help if her mother needed that additional assistance or companionship. Mrs. H's trajectory is depicted in Figure 15.

Mr. I: "I was chairman of the board and I had to give that up because **I couldn't read the menu** (laugh), what was on the agenda."

Mr. I, a widower for over 10 years, is in his 90's and recently had a car accident that resulted in blindness. No longer being able to drive and giving up his board position for a local corporation were not easy for Mr. I. "If I hadn't had that accident, I'd still be driving. My license lasts, I think two more years." "I was a director there for [several] years." But Mr. I was matter-of-fact about adjusting to these losses. "No use fussing about it. Or adding to your troubles. Accept it and go on your way."

Mr. I was "going on his way" with the help of home health aides, taxis, and a yard maintenance service. His son arrived from the East after his father's accident

Figure 15



	Assist	Depend
ADL	0	1
IADL	2	1

Figure 15. Trajectory for Mrs. H at First Interview:
"I got lonesome and I knew that if I come down here I could be with my family."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

Decisions over 10 Years to Maintain Routines

to return his father to his own home from a care facility. In describing this help from his son, Mr. I stated, "my son brought me [home], he said, 'You're familiar with the place, why don't you enjoy it.'" Mr. I had lived in the area for 7 decades.

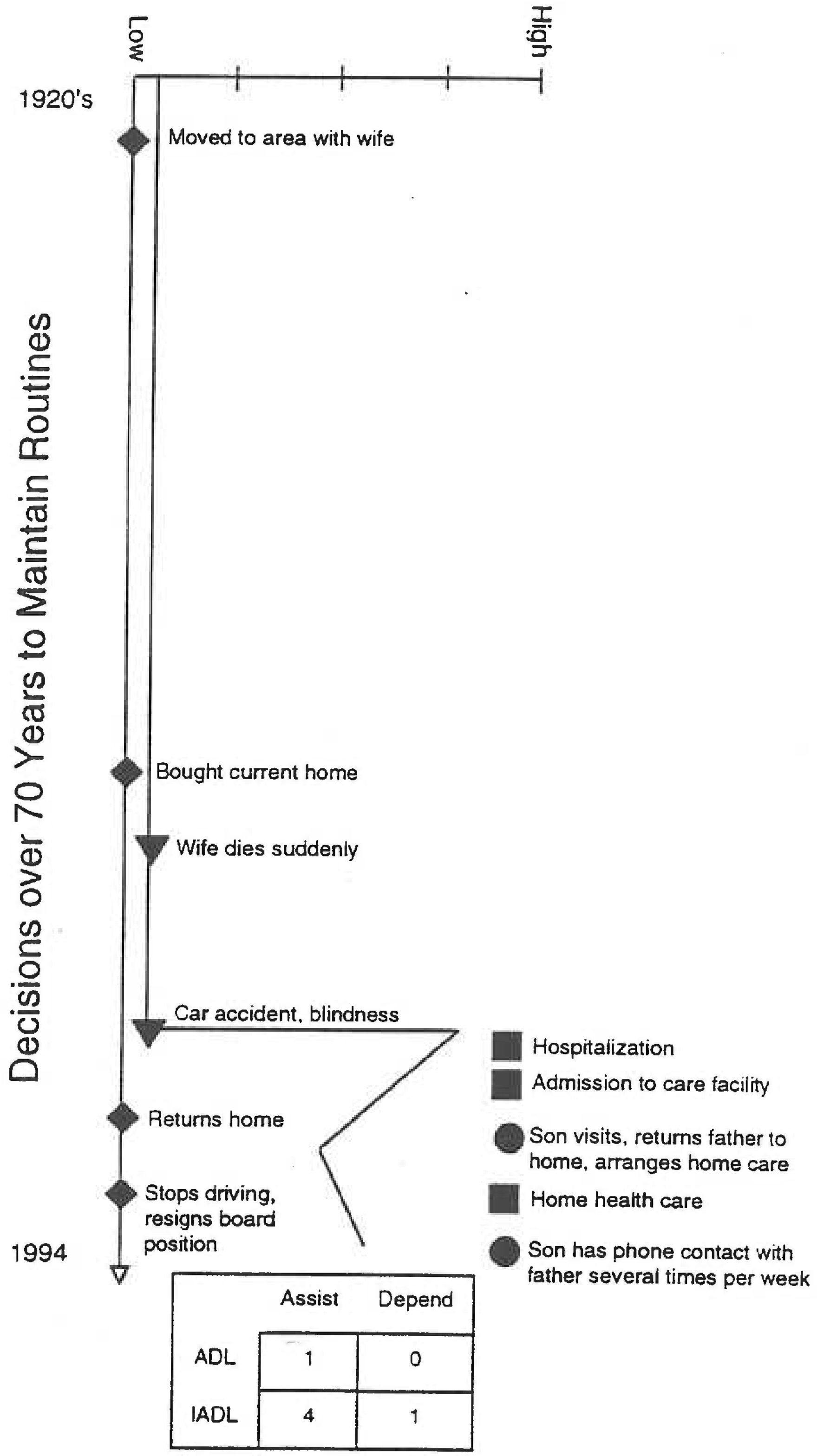
Mr. I's son mentioned that his father that visited him back East a few years before and looked into housing in that area. Mr. I had decided not to make the move because he was not familiar with his son's "surroundings" and still had friends back home. The son realized that his father's physical abilities were declining, but indicated that mentally his father was doing very well. Mr. I's son felt his father would loose these mental capabilities if he was in a care facility with "zombies." Mr. I's son was also matter-of-fact about arranging care for his father. "I wanted him to get back to his house . . . and find somebody who could look after him." However he admitted some problems in finding the care needed. "I had a lot of calls back home during the period of time that I was there . . . I was at my wit's end to know which way I was going to go . . . " Both father and son felt Mr. I was more "comfortable" in his own home. Figure 16 contains Mr. I's trajectory.

Mr. J: "so as far as entertaining myself, **get out the saw and hammer** . . . ."

Mr. J, a widower for about 5 years, is in his 70's living in his own home and has his son and daughter-in-law living with him and providing his care. Mr. J had two strokes resulting in hemiparalysis a few years ago. He is almost completely bedfast. He also has the services of home health care including physical therapy. This service started after his daughter-in-law, feeling she was "having a nervous breakdown," contacted the agency for help. Mr. J's son now provides his father

Figure 16

Interaction of Dependency Needs and Resources



	Assist	Depend
ADL	1	0
IADL	4	1

Figure 16. Trajectory for Mr. I at First Interview: "I was chairman of the board and I had to give that up because I couldn't read the menu (laugh), what was on the agenda."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

most of his daily care except for bathing, bowel and catheter care provided by home health. Mr. J's daughter-in-law works full-time and maintains the home.

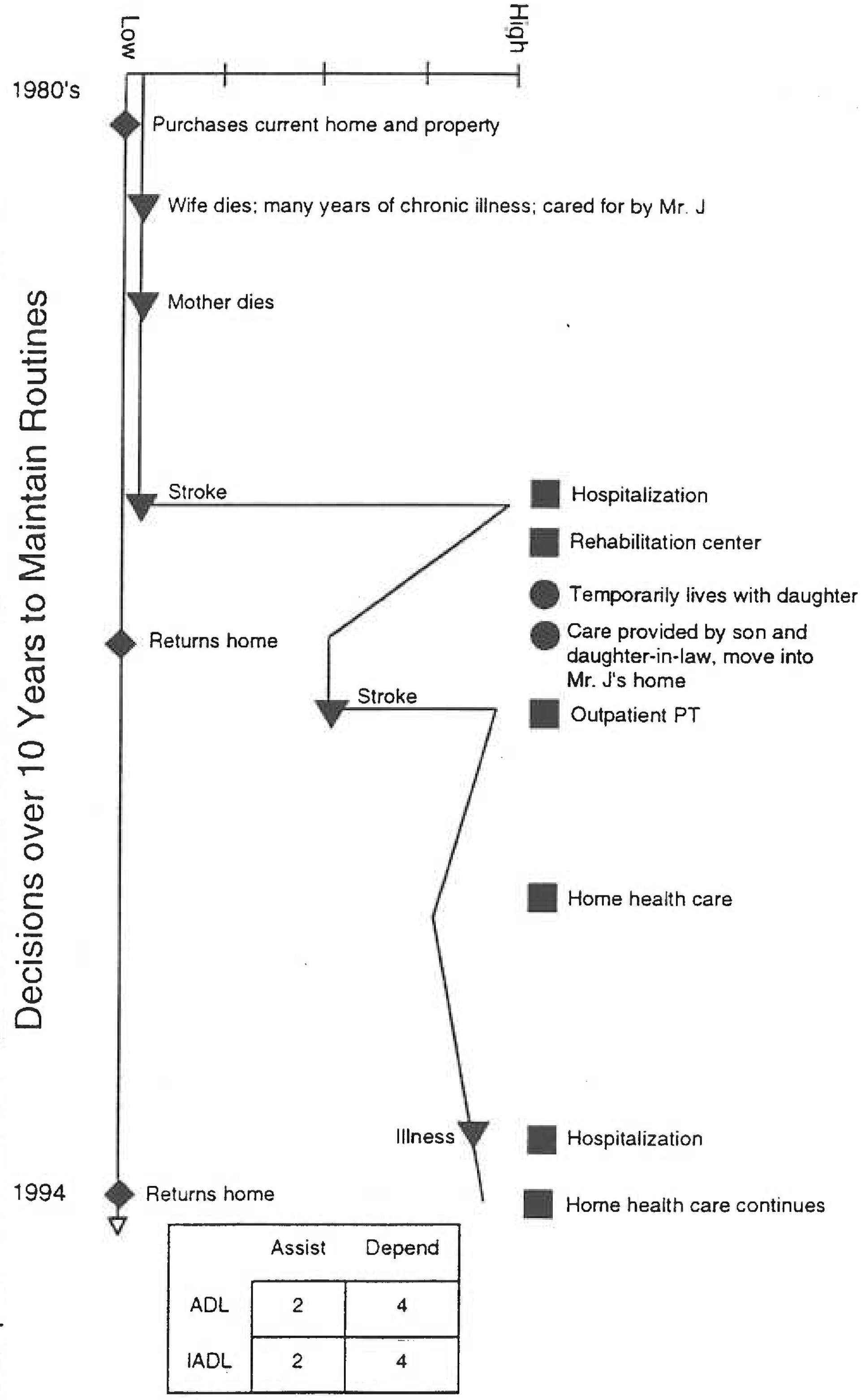
Mr. J is depressed about being physically dependent. He described himself as always remodeling his homes before he had his strokes. Now his primary activity is very different, watching television. He talked about having a spot picked out by the river where he would drive his car into the water, if he were able, to commit suicide. However, Mr. J has not been able to drive since the first stroke. In describing his wife, Mr. J said, "she chickened out and left me," having died first. Mr. J's daughter-in-law indicated that she thought Mr. J's depression was somewhat better since he was taking a new anti-depressant.

Mr. J's son and daughter-in-law anticipated caring for Mr. J in his home indefinitely with the assistance of home health care. That is what Mr. J wanted and financially, other alternatives were not considered possible. Mr. J's son also indicated that he felt that was the best situation; remaining in one's own home. He felt the only advantage of a nursing home would be increased socialization. Mr. J's son associated foster homes with substandard care. The trajectory for Mr. J is found in Figure 17.

Mr. and Mrs. K: "if Saint Peter's going to ring the bell" vs. "I want to go up to Montana now."

Mr. and Mrs. K, married over 20 years, are in their 70's living in their own home approximately 50 miles from a larger community. Mr. K has been experiencing transient ischemic attacks (TIAs) while Mrs. K had fractured her arm

Figure 17 **Interaction of Dependency Needs and Resources**



	Assist	Depend
ADL	2	4
IADL	2	4

Figure 17. Trajectory for Mr. J at First Interview:
"So as far as entertaining myself, why get out the saw and hammer. . . "

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

within the last year. Although Mrs. K was originally the identified "older person" having the more recent injury, Mr. K's more frequent TIAs had called Mrs. K into action. When Mr. K had "an attack," Mrs. K rubbing his neck helped the TIA symptoms resolve more quickly. Who the caregiver was depended on the day. As Mr. K described the situation, "Seems like either she don't feel well or I don't, or something, you know." Mr. K was no stranger to caregiving having cared for two previous wives through their prolonged illnesses.

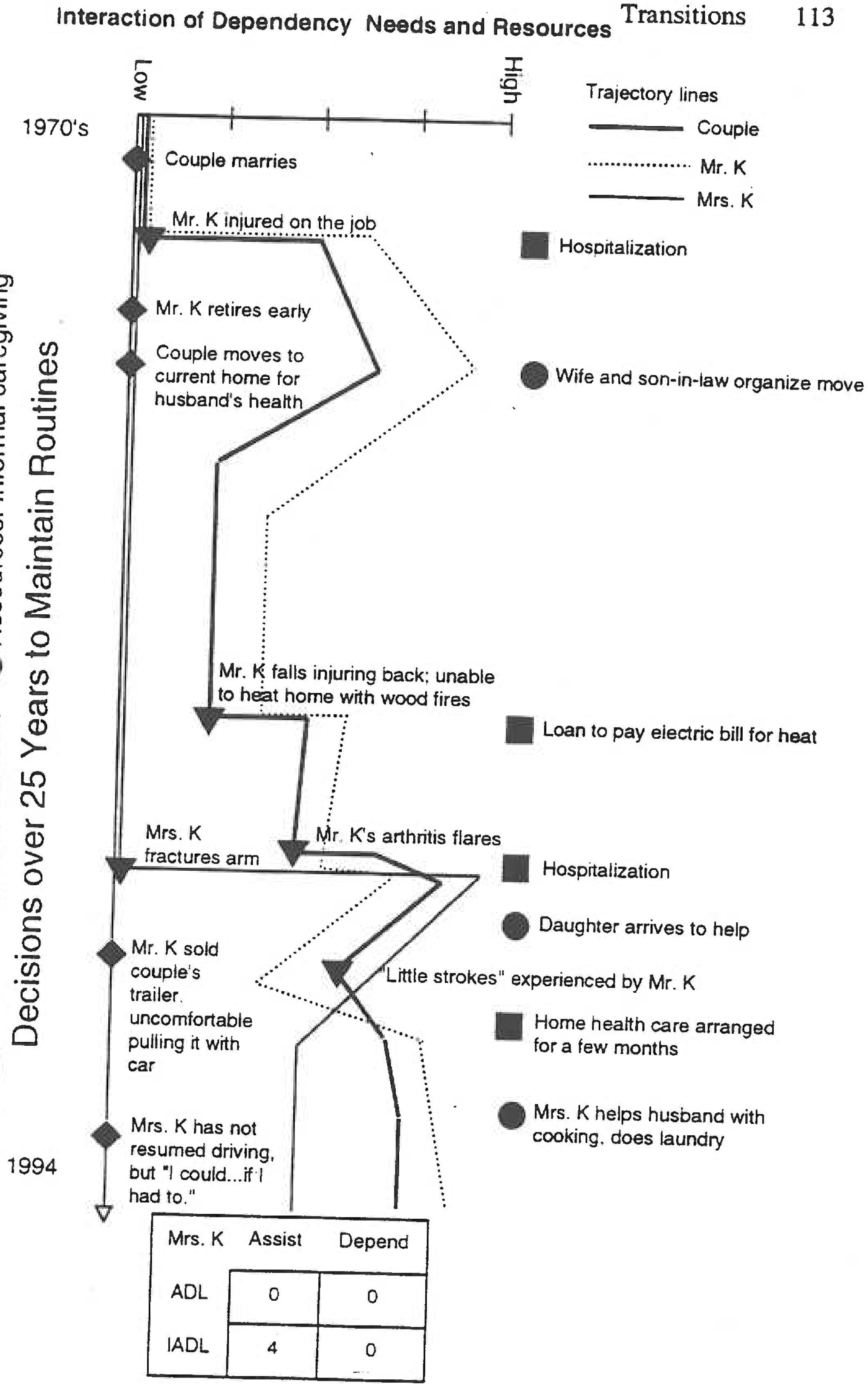
Mr. and Mrs. K moved to their current home several years ago after Mr. K retired early as a result of an on-the-job injury. The doctors gave him only a few years to live at the time, but he physically improved and was able to maintain their home and several acres of property until the last few years. Then he had fallen causing a back injury. This was the event he associated with the beginning of his physical decline. More recently Mr. K was experiencing "little strokes" that at times made him reluctant to drive. He felt they had the help of neighbors readily available, if needed in an emergency, but was of the philosophy that "if Saint Peter's going to ring the bell, it's time to go . . . but I don't worry about it." Mr. K does almost all the couple's cooking and cleaning. He provided Mrs. K total care the first 2 weeks after the fall fracturing her arm. Then Mrs. K's daughter visited and provided care. Home health services were also arranged that continued for several months. Although this injury occurred almost a year ago, Mrs. K had not yet attempted to drive the car, "but I could drive it if I had to." She still needs some help from her husband with dressing and bathing. In terms of household activities, Mrs. K does the couple's laundry.

When talking about the possibility of moving closer to a town, the couple indicated that they were unsure whether they could afford any place closer, and they were very comfortable in their current home. Mr. K indicated that he could not physically care for his wife again in the event of another accident, and if that occurred they would need to live closer to adult children or move to a nursing home. In contrast, Mrs. K was purchasing exercise equipment because "it would be good for us." She also said she would like to move to Montana although she mentioned going outdoors less because of the cold weather at their current location. Mrs. K did not want to discuss their thoughts of moving with their adult children indicating that her daughter was "too bossy." See Figure 18, trajectory for Mr. and Mrs. K individually and as a couple.

Mr. and Mrs. L: "As long as my hands and my legs are working, I'm going to stay in my own home and do what I have to do."

In their 80's, Mr. and Mrs. L have been married about 10 years. This is a second marriage for Mrs. L stating, "I think your second marriage is more for companionship and friendship." The couple are living in Mrs. L's home approximately 50 miles from a larger community. They do have neighbors close who can be called on as necessary. Mrs. L does not drive and needed to depend on these friends to provide her transportation the several years after her first husband died and before remarrying.

Figure 18



Mrs. K	Assist	Depend
ADL	0	0
IADL	4	0

Figure 18. Trajectory for Mr. and Mrs. K at First Interview: Mr. K, "if Saint Peter's going to ring the bell;" Mrs. K, "I want to go up to Montana now."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

Decisions over 25 Years to Maintain Routines

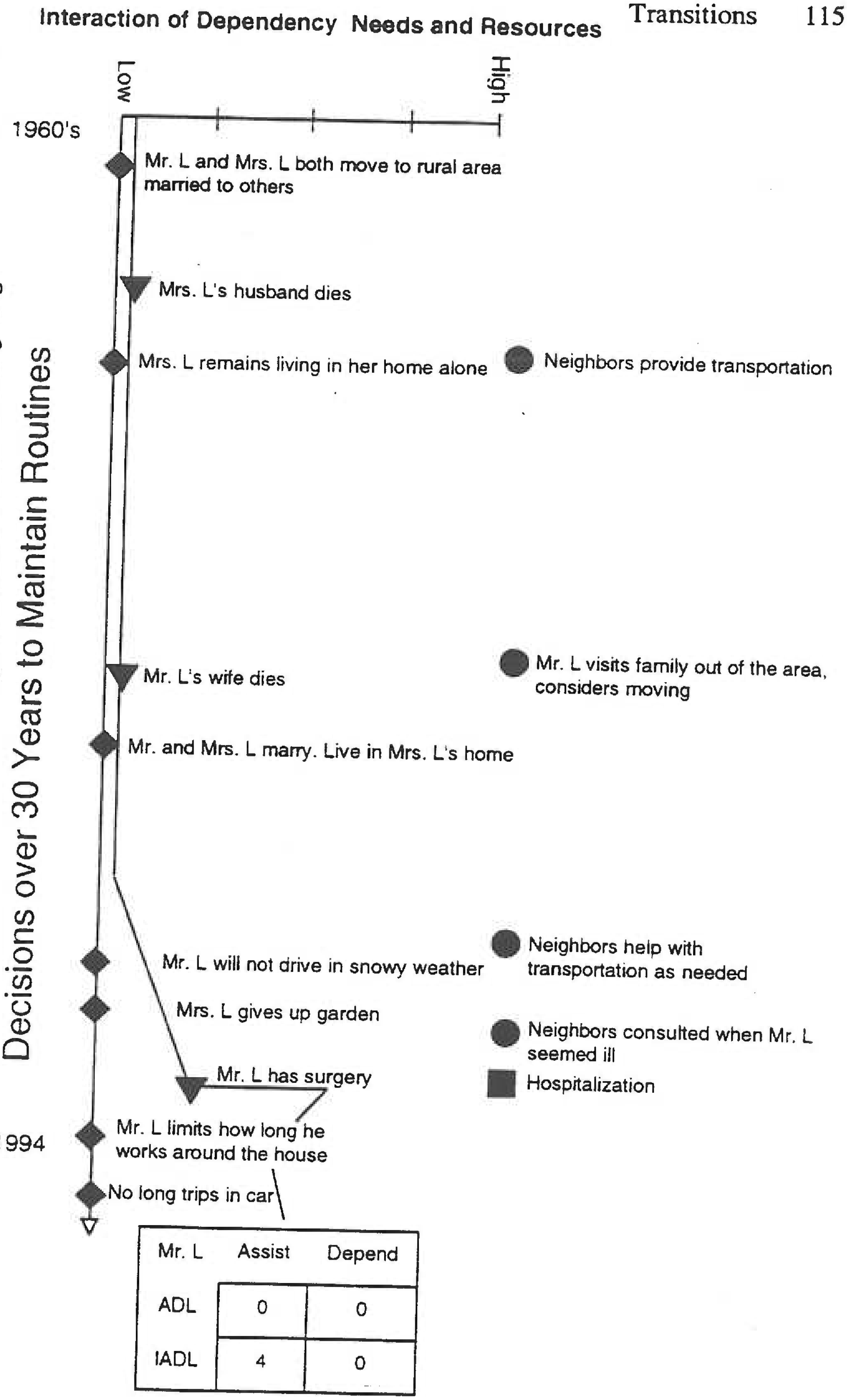
Mr. L had surgery just prior to the first study interview and was recovering. His vision was also failing. Mrs. L had vascular problems and found she was no longer able to walk very far. The couple carefully planned their trips into town. "I refuse to drive in snow," Mr. L stated referring to his snow blindness. Mrs. L mentioned, "but we know just what we want to do. I always have a grocery list and everything. . . . We go in the morning about 10:00 a.m. and we get home about 2:30 p.m. . . . Then we're bushed."

Mr. and Mrs. L both have family in the area. They would consider moving into town, but did not want to live with a family member "unless you really, really are down and out and can't take care of yourself" per Mrs. L. Moving into town would require selling their current home first, but for now they were "comfortable." The trajectory for Mr. and Mrs. L is represented in Figure 19.

Mr. M: "That's why **I'm so careful** about driving . . . because I know if something happens to me . . . well **that's it** [living in their own home]."

Mr. M and his wife have been married for over 5 decades and have been living in their current home for almost 30 years. A man in his 70's, Mr. M has had surgeries for cancer and vascular problems but remains active maintaining their home, assisting his wife, and volunteering in the community. Mrs. M has been experiencing a cognitive decline for a few years; a problem Mr. M was willing to acknowledge and discuss only at the second interview. He needs to supervise his wife while she cooks, help with the housework, and answer her questions about the day and time. Mr. M anticipates needing to give up his volunteer activities in the

Figure 19



Mr. L	Assist	Depend
ADL	0	0
IADL	4	0

Figure 19. Trajectory for Mr. and Mrs. L at First Interview: "As long as my hands and my legs are working, I'm going to stay in my own home and do what I have to do."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

Decisions over 30 Years to Maintain Routines

near future, no longer being able to leave his wife at home alone. This will be a real hardship for him; "then I'm going to be tied down where I can't (pause), can't do anything."

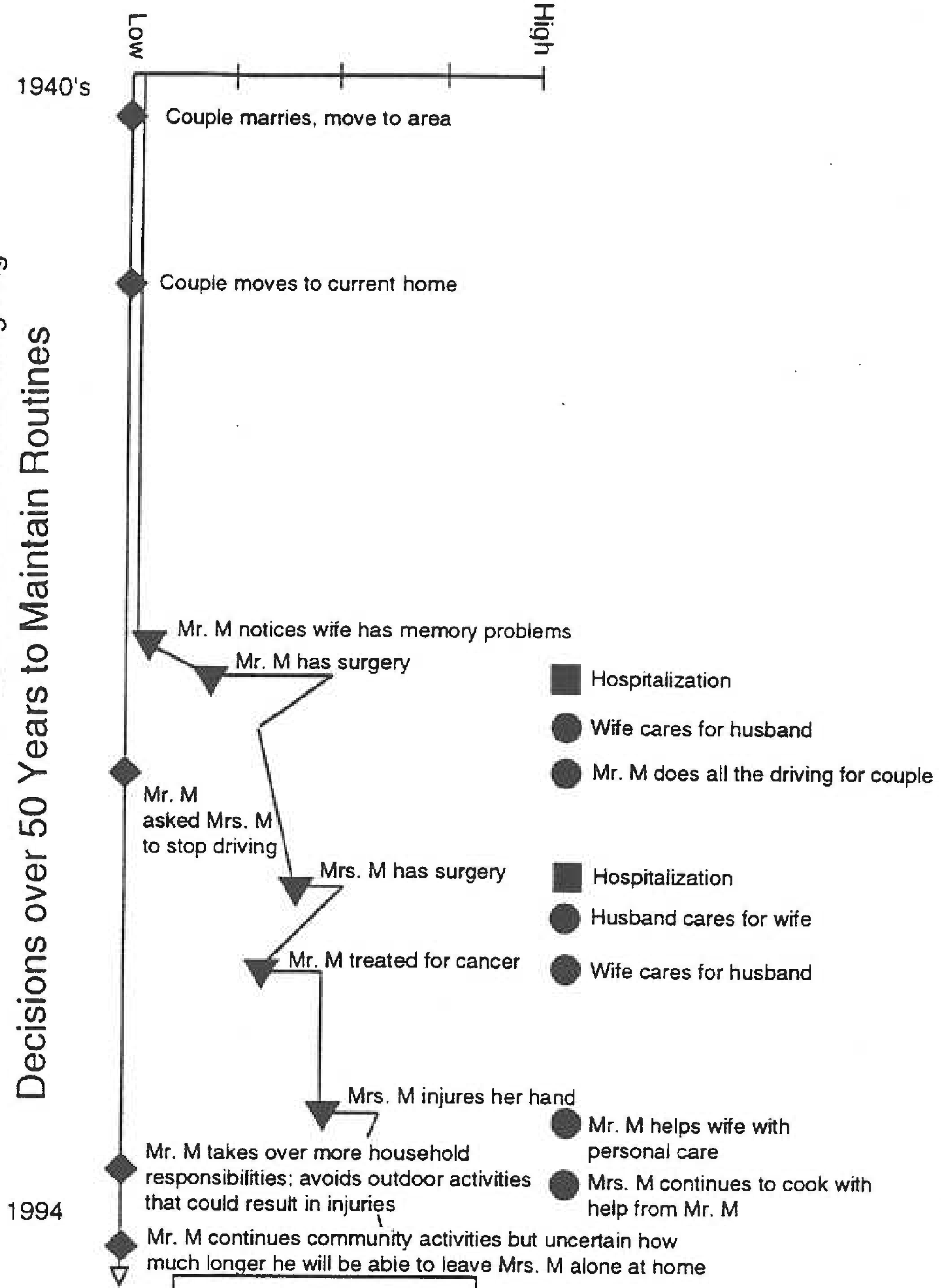
Mr. M acknowledged that he has already found it necessary to make adjustments in the couple's activities. He stopped his wife driving after she seemed to be easily distracted and ran a stop sign. He no longer climbs trees to trim branches or cuts his own firewood and avoids heavy lifting. These activities were eliminated to avoid injuries; "I'm really cautious." Mr. M feels his wife would like to die at home and considers it "no problems here" because his wife seems more oriented in their home maintaining their daily routines.

Mr. M has not talked extensively with this adult children about their mother's mental decline. "I don't know what the kids are really thinking. I don't ask them anything. But they realize that they have to come through me if it's going to be remembered because she won't remember." If the couple is unable to remain in their own home, Mr. M does not want to live with his children, but would move to a care facility. Figure 20 depicts Mr. M's trajectory taking into account the care Mrs. M requires.

Mr. and Mrs. N: "This isn't my fault . . . **I've got to think of me now** because I've been **thinking about her all these years.**"

Mr. and Mrs. N are in their 60's. Mrs. N was only recently diagnosed with a cognitive impairment, but Mr. N has been aware of his wife's memory problems for

Figure 20



Mrs. M	Assist	Depend
ADL	1	0
IADL	7	0

(Based on husband's description)

Figure 20. Trajectory for Mr. M at First Interview: "That's why I'm so careful about driving. . . because I know if something happens to me. . . well that's it [living in their own home]."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

Decisions over 50 Years to Maintain Routines

a number of years. For the last few years he has found it necessary to stay home with his wife and is now beginning to assist her with some of her personal care.

The couple have lived in their home for three decades. Mr. N would like to sell this home and purchase a newer house that would require less maintenance. However, he realizes that his wife may find it difficult adjusting to a new house and neighborhood. Mr. N is also unsure how long he can continue caring for his wife. His indecision about moving and financial concerns dominated Mr. N's conversation.

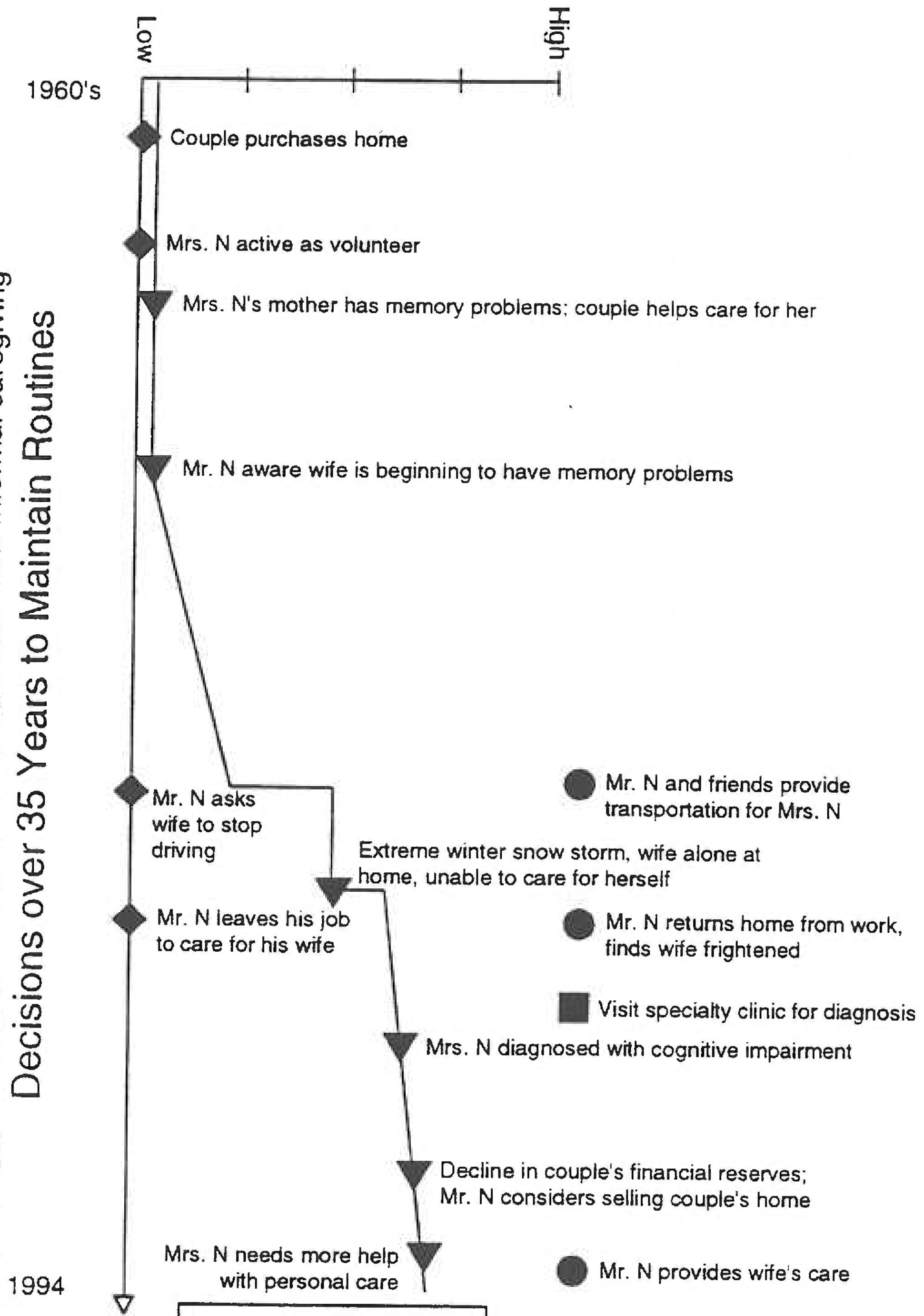
Mr. N anticipated that his wife would need the care of a foster home in the future. Until then "I want to stay with her as long as I can, you know. She's my little sweetie. She comes around and hugs me." Mr. and Mrs. N have been married for many years. Several family members live in the area and one has had nursing experience. Mr. N knows this relative with nursing experience will help him select a foster home for his wife when the time comes. Figure 21 contains Mrs. N's trajectory, which takes into account the care Mrs. N requires.

Mr. O: "It got so I **can't drive to town.** That is **I could, but I'm taking chances.**"

Mr. O, a widower for 10 years, is in his 90's and has lived in his home in a rural part of the county for over 5 decades.

No longer driving except to the post office and a local restaurant, he depends on family, friends, and the senior citizen bus for transportation. He made the decision to stop driving to town after having repeated strokes. "Because I'd never know when it's going to come back on again."

Figure 21



Mrs. N	Assist	Depend
ADL	1	0
IADL	6	6

(Based on husband's description)

Figure 21. Trajectory for Mr. N at First Interview: "This isn't my fault. . . I've got to think of me now because I've been thinking about her all these years."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

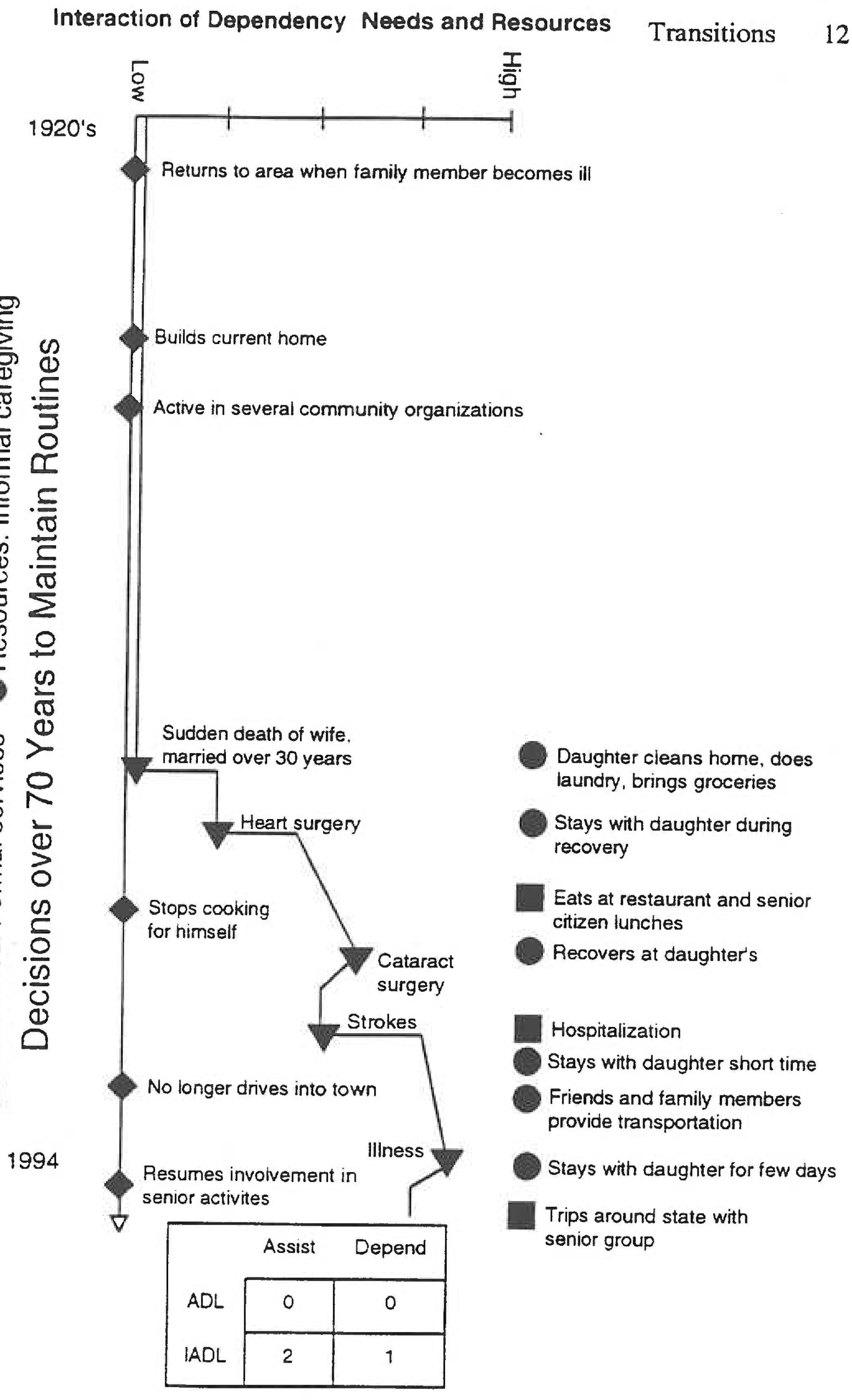
Decisions over 35 Years to Maintain Routines

Other health problems have included eye and heart surgery, equilibrium disturbances and falls. Although he no longer cooks for himself after starting a fire from forgetting a pan left on the stove, he continues to supplement his oil heat with wood fires. Family members bring him his wood and visit at least weekly to clean, do his laundry, and bring groceries. When ill or recovering after a hospitalization, Mr. O stays with his daughter for brief periods. His family knows he prefers to be at home. His daughter said, "he doesn't have to answer to anyone [at home]." However, she is reassured that he will ask if he needs help; "If he wants to come here he'll say, 'I need to come down and stay for a while. I don't feel good. I don't want to be alone.'" She anticipates that in a couple of years he will need to live with her permanently. But for the present, "he's gotten so involved right now [with senior activities] that it's keeping his mind off [not depressed] . . . he looks better and he's like happier again." Mr. O's trajectory is illustrated in Figure 22.

Mr. and Mrs. P: "I had had that **really bad accident** I suppose is what probably **cinched it.**"

Mr. and Mrs. P are in their 60's. Between the two study interviews they moved from their rural home to a city near two daughters and Mr. P's medical care. Mr. P had experienced at least two strokes and was receiving treatment for cancer. After the move Mrs. P developed additional heart problems. Although the second study interview was approximately 6 months after their move, Mrs. P was "just now getting things reorganized." If she had it to do over again, she would not have moved.

Figure 22



	Assist	Depend
ADL	0	0
IADL	2	1

Figure 22. Trajectory for Mr. O at First Interview:
"It got so I can't drive to town. That is I could, but I'm taking chances."

▶ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

Decisions over 70 Years to Maintain Routines

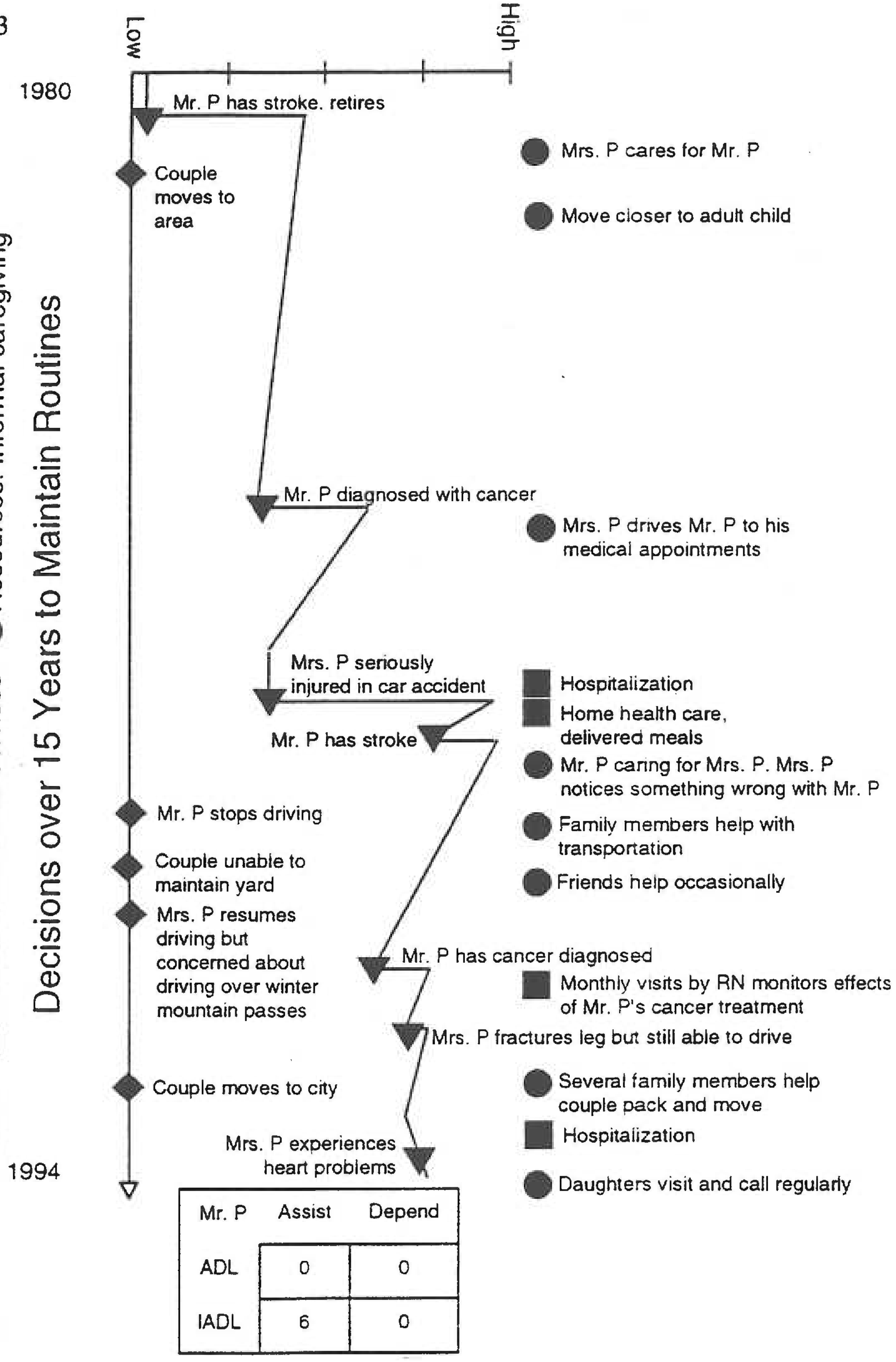
The couple first talked of moving after Mrs. P had a near fatal car accident and required several months to recover. Mr. P also had another stroke while caring for Mrs. P after her return home from the hospital. With this combination of problems Mrs. P felt isolated in their rural location and no longer felt confident driving hundreds of miles over winter mountain passes so Mr. P could keep his medical appointments. However, it took the couple a few years before they were able to sell their home and move.

Mr. P was glad they had moved "now that it's all over." He mentioned several advantages of their new home and location; "two daughters living here [in town]," "she can see a doctor much easier here," "we can get groceries," "enough room for two people . . . for all the energy I got." He appreciated the assistance all their adult children provided in helping them pack, move, and make repairs to the new home. Several adult children came from other parts of the country to help. What was most important to Mr. P was that their health problems appeared to be stabilizing and "us being together and being able to take care of each (other)." Mrs. P agreed, "Thank God, we have each other (laugh)." Figure 23 depicts Mr. and Mrs. P's trajectory.

Components of Balancing

Balancing may be visualized as a equilateral triangle with the components, *routines*, *resources*, and *disrupters*, one at each apex. Data contributing to the development of these components of balancing were discussed by the older person when responding to the questions, "Could you start by telling me a little bit about

Figure 23



Mr. P	Assist	Depend
ADL	0	0
IADL	6	0

Figure 23. Trajectory for Mr. and Mrs. P at First Interview:
"I had had that really bad accident I suppose is what probably cinched it."

▼ Disrupters ◆ Decisions ■ Resources: Formal services ● Resources: Informal caregiving

Decisions over 15 Years to Maintain Routines

yourself and what's been going on?" and "Could you use more help than you are getting now?" To visualize the three components of the triangle as balancing, think about a point in the center of the triangle as the balancing point. If each apex does not remain of equal weight, the triangle tips much as a three-legged stool would tip if one of the legs was not of equal length. This balance point is sense of self referred to in the definitions of the components but later described more fully with values.

Routines

Routines, ordinary activities that maintain a sense of self for the older person, often can be identified by "I" statements or personal pronouns. These are activities that the older person does for her/himself or over which she/he has control. The following are examples of routines identified by older participants as important. Each data bit is followed by an identifying code indicating the speaker, whether the quotation is from the first or second interview (P1 or P2), and line numbers from the numbered Ethnograph ^{R} version of the interview transcript.

> I take my own baths. Do most of my own cooking and I do my laundry. (Mrs. E, P1, 336-338)
>
> So far, they [home health aide] haven't had to build a fire yet. [You usually have that done before the home health aide arrives?] Yes. I get up and get that going before they get here most of the time. (Mrs. E, P1, 1044-1052)
>
> There are things you should know about him besides just the times he's been sick. What's kept him going. What, such as he has been writing [poems] since he was a little boy. (Mrs. P, P1, 1106-1114)

Living in one's own home can reinforce one's chosen routines that reflect one's values. Erikson, Erikson, and Kivnick (1986) considered living in one's own home an important symbol of autonomy (freedom, self-reliance). Living in familiar surroundings helped the older person face "encroaching inadequacies, limitations, humiliations [that] can seem potentially overwhelming" (Erikson, Erikson, & Kivnick, 1986, p. 201). Data bits follow that support the importance of home to the older person as an environment that supports their routines and therefore their values of independence.

> [What does it mean when you say: It's home?] I don't know. You can do what you want to I guess. I don't mind getting my own breakfast and lunch. In fact, I kind of enjoy it. (Mr. I, P1, 515-519)
>
> I'd rather be home. Then I can be more free. I can get around. Sometimes I feel like [I might] fall down, but I make up my mind to not do that and I'm alright. (Mr. O, P2, 848-853)

Resources

Resources, as reserves that help the older person maintain her/his routines, include the older person's assets and the assets of other people that the older person can access as needed. The older person's resources comprise physical and psychological abilities, one's belief system, and possessions. Other's reserves available to the older person include the informal caregiver's physical, psychological, or financial support for the older person in accomplishing her/his routines, in addition to formal services available to the older person. This component was examined for similarity to published literature. Lawton (1982), in the ecological model of adaptation and aging, used the term competence to describe the individual's characteristics: biological health, sensory-perceptual and cognitive capacities, motor skills, and ego strength. Inclusion of other's assets with the older person's resources in the present study's definition of this component is an expansion of Lawton's definition of competence which was restricted to the individual's attributes. Data examples of resources follow.

> We got a good, warm place. We got plenty of food. We can help others sometimes. (Mrs. P, P1, 1627-1629)
>
> And she [daughter] did a couple of things I needed done that I couldn't do. But . . . And then, of course, she got him to talk and say some things different. Came out with some things he hadn't expressed to me. So I think it was good all the way around. (Mrs. C, P2, 1232-1246)
>
> So, I wasn't, it wasn't as though we were isolated [in our rural home] because all we had to do was pick up the phone and call and there was people [friends and neighbors] that could come and do anything. (Mrs. C, P1, 742-747)
>
> [Daughter talking about conversation with her father] If you really don't want to go [move into a foster home] because you don't want to leave your home yet, then you shouldn't go. (Mrs. GD [Mr. G's daughter] P2, 374-377)

The belief system of the older person made her more resilient:

> We have to take what comes. And to do it gracefully. There's no need to fighting against things like that [needing help]. Whatever happens is probably for your good anyway. So whatever happens, I'll try to fit in and do whatever I have to do. (Mrs. H, P1, 872-880)

Disrupters

Disrupters are events that are a perceived threat to the older person's ability to continue routines with a given set of resources. When there is a disrupting event, resources could be lost or prove to be inadequate to allow the older person to continue routines. Routines could be lost if additional resources were not obtained. It may be the older person's assessment of an event, rather than the event itself, that determines whether it is classified a disrupter; whether the event is putting the balance at risk. Data bits illustrating this component follow.

> Well this earthquake is what decided me. Because I was alright until that came and shook the house apart. Then that heavy snow. If we get a heavy snow again. (Mrs. E, P2, 500-505)

> After I broke all those bones and come home and I couldn't take care of myself. But we got a snow storm here after I come home in March and I still couldn't use my arm. And my ribs, I had those four ribs broken that time. Well I broke it twice. I told you I broke it here and then a month later broke to my, my elbow. (Mrs. E, P2, 1170-1182)

Similarities and differences between this study's component *disrupters* and Lawton's (1982) term environmental press were explored. Environmental press was defined as an environmental stimulus or context having potential demand character for an individual leading to a behavior outcome. Both disrupters and environmental press share the idea of force being exerted on the older person. While Lawton's definition of environmental press expanded outward from the immediate physical environment to the macro level of institutions and norms of society, the present study's definition of disrupters allowed the older person to determine what was a threat to their resources and routines.

The concept of *balancing* is similar to Helson's (1964) use of adaptation: a dynamic equilibrium. In Helson's theory, equilibrium was the steady state that occurred when constant stimulation was no longer sensed or became neutral as a result of adaptation. On-going changes were made by the individual to maintain this steady state. Adaptation as an active process had the individual initiating action to restore equilibrium. In the present study, the older person considers it the normal state-of-affairs when routines, resources, and disrupters are in balance. Only when there is a disequilibrium or when the older person moves along the continuum toward imbalance is the individual increasingly aware of the processes involved in trying to remain in balance/equilibrium. *Routines*, *resources*, and *disrupters* are balanced by the older person to insure that one's life routines are maintained; a reflection of personal *values*.

Dimensions

Dimensions of the balancing process include *centrality*, *urgency*, *permanence*, and *awareness*. Each dimension will be defined below followed by data that illustrate the dimension.

Centrality

The centrality dimension is the individual's determination of what routines, resources, and disrupters are most important in maintaining the self. This evaluation of disrupters and priority routines and resources is based on the person's values or principles considered worthwhile.

Mrs. B's home and living in her home represented centrality for her.

> Well, you get pretty well attached to it. And it has been home for a good many years [approximately 50 years]. And the river out here has been kind of company too for me. And beaver and muskrats and different things out there. (Mrs. B, P1, 376-383)

Although most of the older people considered living in their current home of central importance, some recognized that *disrupters* influenced whether this *resource* and it is associated *routines* could remain *central*. Mr. F and Mrs. H talked about how centrality could be influenced.

> I don't [have] anything to consider other than her [wife's] welfare of being home here, why if they get her so she can walk, you know. I'm going to get, trying to get, her kidneys [incontinence] taken care of so that don't give her no problem. (Mr. F, P1, 1398-1405)

> Well, not as long as I can live (laugh) by myself. I want to live alone, I mean as long as I can. Can't never tell when that might come up . . . like if I had a stroke or if I had a heart attack or something like that. That'd make quite a bit of difference. But, as long as I'm able to go on my own, I like it this way. (Mrs. H, P1, 595-770)

Urgency

The urgency dimension indicates that the older person experiences some pressure to take action to restore balance by increasing resources and/or changing routines of central importance. Although the exact time limit may be unknown, some limit does exist by which time changes and action will be needed if balance is to be restored.

> And, I don't know, it was just sort of in my mind that I couldn't handle another winter driving down the mountain twice a month sometimes. After the accident. I just . . . I could have, but it would have been more stress. We never minded it as long as our health was good. (Mrs. P, P2, 1034-1047)

> I've seen tapes [on Alzheimer's Disease] of how they really get worse. In fact, I saw her mother . . . I can't, you know this isn't my fault. And I've got to think about me now because I've been thinking about her all these years. (Mr. N, P1, 1713-1727)

Permanence

The permanence dimension is the individual's perception of whether balancing can continue indefinitely as is, whether it is temporarily upset, or whether lasting changes will need to be made to restore a state of balance. None of the older participants completely denied the possibility of having to make changes in the future. They did indicate that while their current balance was as stable as possible, they were not going to make changes in routines or resources. Mr. O and Mrs. H both considered themselves in balance.

> No, I never even thought about leaving this place [current home]. Because I got [several hundred] acres up there in timber . . . I'd have to get pretty helpless before I'd go to a [nursing] home (laugh). I don't think, I don't think I'll ever get that way though. (Mr. O, P1, 936-939 and P2, 959-963)

> Everyday as it comes. Whenever a day comes where I have to make another decision, I'll do that, depending on how I am and what's happening to me, and all those things. (Mrs. H, P1, 845-850)

A disrupter may not produce a lasting imbalance. Without major changes in one's resources or routines, a temporary imbalance can be restored to balance by waiting for the disrupter to resolve and accepting short-term help (temporary increased resources) with one's routines. An example of this wait-and-see position included the time needed to heal after an injury.

When the disrupter will not go away or its impact on resources and routines will not diminish with time, changes in routines and resources are necessary to restore a state of balance. If the older person considers the current state of balance permanently affected (disequilibrium), new ways to restore the balance may be considered. In response to the interviewer's comment that people react to situations like his in many ways, Mr. C said:

> Helpless (laugh). [Name of doctor] said there is not hope [to recover his physical abilities]. (Mr. C, P1, 699-701)

In response to the disequilibrium created by his disabilities, Mr. C gave up his repair business, indicated that his wife assumed more of the household responsibilities and, as a couple, they socialized with friends more.

In discussing Mr. C's future need of medical treatment for a recently diagnosed terminal illness, Mrs. C indicated that their balance was permanently affected, and also indicated a sense of urgency developing.

> And once the [vacation] trip is over, then we may really have to face the real cruel reality of the situation. It's not going to go away. (Mrs. C, P1, 886-891)

Awareness

Awareness represents both an affective and cognitive acknowledgement by the individual that some amount of disequilibrium is present; some threat to one's values. Affective awareness involves the older person's emotional response to the sense of disequilibrium. The emotions indicate discomfort and are expressed by the older person or observed in the older person's behavior by others. Examples include feelings of fear, pressure, worry, uncertainty, and depression.

> Mrs. C and Mrs. E talked about their affective responses to disequilibrium. It's putting pressure on us. The uncertainty of it [husband needing medical treatment] is very nerve-wracking. I haven't given up hope. I'm not giving up hope I guess. (Mrs. C, P1, 782-786)
>
> So it all worries me, but what's the use of worrying. I can't, there's some things I can't do. (Mrs. E, P2, 178-182)

Mr. N's disjointed sentence structure when talking about whether or not to sell the couple's home was an indication of his affective response.

> Well as long as she's no worse than she is, I guess I can hang in there. But it's just, you know, I just want to know for sure about the,

> but that's what everybody says, you know, if I would get a good deal and just keep the place, it would be better to have a little modular [house]. (Mr. N, P1, 652-661)

Cognitive awareness contains two parts: realizing that one's sense of self is not consistent with reality and acknowledging that a shift in the sense of self to agree with reality is needed. However, this shifting of the sense of self is accomplished in such a way that values are not threatened. Shifting also entails a redefinition by the older person of what routines and resources are considered of central importance. This part of the theory was informed by Festinger's (1957) theory of cognitive dissonance as well as the data. Festinger's theory emphasized that the individual experienced psychological discomfort if pairs of cognitive elements did not agree. He said that reality would exert pressure on the individual to bring these cognitive elements into agreement with the impinging reality (p. 11). In the *balancing process*, the cognitive elements that need to agree are the individual's sense of self with the reality that *resources* have been lost or are no longer adequate to keep *disrupters* in balance in order to maintain one's *routines.*

Mr. O's statement indicated both the realization and acknowledgment of a shift in sense of self; *full cognitive awareness.*

> But I can't, it got so I can't drive to town. That is I could, but I'm taking chances. So I'd rather have somebody else come after me than to do it. (Mr. O, P2, 672-677)

At times, the statements by the older person reflect a realization of this dissonance between sense of self and reality, but do not indicate a complete acknowledgement of the need to shift one's sense of self. Behaviors that reflect the previous sense of self continue to a limited extent. Mrs. B's statements about driving reflect this *incomplete cognitive awareness.*

> Well, I'm not sure just when this disease [chronic degenerative neurological disease] started . . . from then on I haven't been doing quite so well. And, if it wasn't for [my daughter], I don't know what I would do sometimes. She drives, course I drive some, yet. I drive sometimes when I want to get my hair fixed . . . but she drives most of the time for me. (Mrs. B, P1, 78-94)

Outcomes

To maintain or restore balance, the older person uses cognitive and behavioral processes. They are *accepting*, *prioritizing*, and *taking action.* Accepting, a cognitive process, indicates a willingness to recognize that disequilibrium is present. Prioritizing is the cognitive process of considering alternatives and weighing priorities. It involves assessing and choosing routines and resources that are most important to the older person's sense of self and that are consonant with one's personal values. Taking action is the behavioral process that involves making changes in one's routines and/or resources to restore equilibrium or insure that equilibrium is maintained.

Accepting that disequilibrium is present can be difficult for the older person when this admission is considered a threat to one's sense of self and values. Mrs. K was not willing to accept that her ability to drive (a priority routine and resource) was permanently impaired following a fractured arm (disrupter).

> [You're not driving yet?] No. I haven't tried it. [So that's probably the biggest change for you?] Well like I say, I went out and checked it. I could reach everything. It would just be doing it. (Mrs. K, P2, 863-873)

Mr. K considered his wife's "arm is useless."

> This whole cup was away from the bone three, three and half inches, just shattered. She'll never ever regain full use of that arm. (Mr. K, P1, 255-260)

In the balancing model, *prioritizing* is a cognitive process similar to Lazarus and Folkman's secondary appraisal which asks "what might and can be done" (1986, p. 32). In the present theory, what might be done is compared with a set of personal standards, one's *values*, while Lazarus and Folkman refer to the personal factors of commitments and beliefs influencing appraisal.

Prioritizing is a process that traditionally has been considered part of decision making or problem solving. In this study the parts of prioritizing are named *considering alternatives* and *weighing priorities*. The process includes the person gathering information about alternative resources and comparing the pros and cons of each. The effect on *routines* of various *resources* chosen is evaluated; "if this . . . then . . . ." The older person considers the limitations and restrictions of resources, and may redefine priority routines to those that can be maintained with acceptable resources. Other possible resources that are considered *rule outs* are options that are considered unacceptable, unwanted, or producing effects that are not desired.

Mr. D provided examples of an older person prioritizing routines and resources and clearly stated what he would *rule out* or find unacceptable.

> [Advantages of live-in care] Well, for one thing it'll give me some company all the time that I can talk to. And it will save me money [not] having to go to the restaurant everyday, three times a day, to get

> my meals. And maybe I can get some of the things I want to eat. (Mr. D, P1, 1118-1126)

> Oh, the doctor and the people [at the nursing homes], . . . they all think I ought to go to a foster home. But I don't want to go to no foster home and live with somebody else. (Mr. D, P1, 1472-1478)

Taking action includes strategies used by the older person to restore equilibrium or insure equilibrium is maintained. *Routines* may be *modified* or *relinquished*, help may be *accepted*, or the older person may *move* to gain resources while maintaining priority routines. Mr. D provided an example of the older participant taking action to allow his routines (living at home) to continue by accepting help (the resource of a live-in couple). He modified his routine of living alone.

> They're [live-in help] going to move into that bedroom I got back there. I stay in this bedroom. (Mr. D, P1, 172-175)

The length of time required for the outcome to be accomplished may be short or longer. When the resources needed to continue priority routines are not readily available, the older person will delay taking action until those needed resources are obtained. Mr. and Mrs. P wanted to continue the priority routine (*centrality*) of living together in a home of their own, closer to Mr. P's medical care and two of their daughters. However, the couple considered this move contingent upon selling their current home. They waited 3 years until a buyer offered a price they considered acceptable.

Routines are *modified* over time to protect the balance as disrupters accumulate and/or resources are lost. Modifying routines may include increasing caution when carrying out a routine. Mr. M talked about being more cautious when using a chain saw and driving.

> It's one of those things that I wasn't never too cautious about before. I thought everything would be fine, but you're not as fast, you know, to grab yourself if something does happen. I'm really cautious with a chain saw, where I didn't used to be. (Mr. M, P2, 1089-1098)

> . . . careful about driving, stop signs and everything, because I know if something happens to me, pretty serious, well that's it [couple would have to move to care facility]. (Mr. M, P2, 1075-1080)

To insure one's balance, non-priority routines can be relinquished by the older person while continuing those judged more important. Baltes and Baltes (1990) in their psychological model of successful aging described this phenomenon as the selection process. Selection indicated that the individual chose high priority routines to continue when faced with declined functioning with age. Examples of data bits that illustrate the relinquishing of routines in response to decline and disequilibrium between routines, resources, and disrupters follow.

> Oh, no stamina at all . . . on my feet a little while, my back begins to ache and so forth. I stay away from things. Household chores, I guess you might say. Very much. Taking care of myself is about all, (laugh) I do. (Mr. C, P2, 601-608)

> And these little old girls [home health aides], they come and do all my heavy work, thank God. I can't even run my carpet sweeper very long at a time without just going heart [rapid heart rate] . . . because I'm just not strong enough. I don't have the strength any more. I can sit and think about it, but I don't get it done. (Mrs. E, P2, 775-785)

> I used to have a garden out here every year, but since the wife passed away I haven't had nothing. I haven't been able to do nothing. [Mr. D had a stroke with paralysis soon after his wife died.] (Mr. D, P1, 901-906)

Values

All of the concepts in the balancing model are operationalized through the older person's values, which act as a filter. Values are the principles considered worthwhile that influence how the other concepts in the model are appraised. The statements by the older participants about their routines, and what resources and routines were prioritized when making changes were considered a reflection of their valuing of *independence*, *control*, and *self-reliance*. No participants spontaneously labeled their values as such, however such tacit understandings can be inductively derived from the following theoretical literature and data statements/situations.

Erikson et al. (1986), Chenitz (1983), and Baltes and Baltes (1990) each referred to concepts in their theories that reflected the same or similar valuing of independence, control, and self-reliance. Erikson et al.'s definitions of identity and autonomy included activities that reflected the "I," and freedom, self-reliance, and control. Chenitz found that older people entering a nursing home wanted to maintain their control and independence and resisted the admission if it was not voluntary. Baltes and Baltes, in discussing their concept of selection, indicated that the individual chooses high priority domains when faced with declining personal functioning. High priority domains provided personal control, satisfaction, and preserved selfhood, all apparent values.

In this study the older participants desired to *remain independent* in decision making, such as choosing where they lived. They wanted *control* of their routines. They wanted to remain *self-reliant* in the use of resources, such as their finances.

Maintaining one's values reinforces one's sense of self. Situations and data bits that illustrate these values follow.

Several older people strongly expressed wanting to determine where they would live which included not living with their adult children. Mrs. K negatively responded to her daughter's suggestion that she could come and live with her in the event that Mr. K died. Mrs. L talked about agreeing with her own mother's philosophy that no two families can live in the same house. Mr. and Mrs. C did not want to live with their daughter's family, although they would consider moving closer to their daughter.

> But I remember what my mother said, and I think it's true. She said there's no home big enough for two families. Never. No matter how much you love your children, you don't want to go [live with them] unless you really, really are down and out and can't take [care of] yourself. (Mrs. L, P2, 365-374)

> I wouldn't want to live in her [daughter's] house. I want a place by myself, as long as I'm able to be independent. I'd like to stay independent some way or another. (Mrs. C, P1, 979-984)

Mrs. H and Mr. and Mrs. P illustrated the value of *remaining independent*. They moved closer to their daughters so they were nearer to help, although they purchased their own homes to live in. Mrs. E, in talking about her children, said, "they never buck me" concerning her decision to remain living in her current location. Mr. I and Mr. M both would choose living in a care facility over living in an adult child's home.

> If something happens to me, pretty serious, well that's it [living in their own home]. They're going to have to dissolve this . . . and get someplace to be taken care of . . . I don't think that would be a good

> deal, moving in with your family. Because they're both working over there . . . she [daughter] has a temperament. (Mr. M, P2, 1077-1157)

Controlling one's routines as a value of the older people was illustrated in their choosing what they continued to do for themselves and what they relinquished to others when receiving help in the home. Mrs. E's and Mrs. H's statements demonstrated choosing routines to continue and relinquish.

> Do my own laundry and my own cooking. And that's the way I want it. I mean, but I let them [home health aides] do things that are hard to do. Lifting. (Mrs. E, P2, 894-899)

> But I have to have help to take a bath because I'm weak and shaky enough that I can't be sure. So, they [home health aides] give me [a shower]. (Mrs. H, P1, 171-177)

> Oh, I can do the cooking yet. It's no trouble at all. I don't eat very fancy, but that's alright. (Mrs. H, P2, 333-336)

Mr. D who had been a nursing home patient in the past, and Mr. G who was refusing to move to a foster home both emphasized wanting to remain in control of their activities.

> Well, I don't like either one of them [nursing homes] because it's just like being in jail. You got to go to a certain place to smoke and you can't get out. Can't do anything you want to do. (Mr. D, P1, 493-498)

> [Giving advice to someone else] Go by your feelings. If they felt like they'd rather go to a foster home, then that's up to them. Felt like they'd rather sit here [in their own home] and die by themselves, that's up to them. That's the way I feel. (Mr. G, P1, 690-696)

The older person preferred to use personal resources before needing to draw on those of others. For example, being financially *self-reliant* played a predominate part in the decisions of the older people. Many felt that "we ought to stand on our own two feet and not ask the kids for things," expressed in the words of Mrs. E. Mr. D, Mrs. E, Mr. and Mrs. C, and Mr. and Mrs. K all agreed that they could not live any place else for "what it costs" to live in their current homes. Mrs. B stated that "I wouldn't have much to pay them" if she needed home health services. Mr. J did not feel he could afford living in a retirement center. Mrs. H was able to purchase her new home with the money from selling her previous home. The exchange of equity between homes influenced Mr. and Mrs. P's decision concerning the new home they purchased, and this financial consideration would enter into Mr. and Mrs. L's and Mr. M's decision-making when moving. Mr. D and Mr. I wanted to remain living in their homes and both paid privately for help provided at home, totally or partially.

Of the 17 older families, 15 owned the homes they were living in. This home ownership reinforced the older participants' *values* of *independence*, *control*, and *self-reliance*. The home was a *resource* that represented a financial reserve and an environment in which the older person had a sense of control and freedom. Mr. and Mrs. K expressed a sentiment common to the older participants about living at home, "we live at our own pace . . . when we feel like doing something we do it; we don't, we don't."

States of Balance

In this section, interactions among components and dimensions of the balancing model will be described in greater detail. These interactions determine the relative state of balance present for an older person in a given situation. From the investigator's participant observations in conjunction with the interview data itself, in addition to *balance* and *imbalance* being identified as the opposite ends of the balancing continuum, *potential imbalance*, *temporary imbalance*, and *precarious balance* were recognized and will be discussed. Table 8 contains definitions of the states of balance and Figure 24 illustrates the balancing continuum. In general a couple agreed on their state of balance and the adult children tried to support the parent's perceived state of balance. But cases did occur when the couple themselves or the different generations did not agree about where the older person may be on the balancing continuum. These differences in perceptions about the state of balance will be discussed. Two families will then be described showing variations in the state of balance over time.

Balancing

Balancing involves incremental adjustments to maintain relative equilibrium among the three components: *routines*, *resources*, and *disrupters*. There is minimal *awareness* of balancing when one is in a state of equilibrium. Yet this state of relative balance can be described as a fairly comfortable one by the older participants when outlining their every day routines. Mr. and Mrs. L's statements demonstrated their balancing in a rural setting.

> No, he doesn't like that at all [driving in snowy weather]. So I try to keep groceries ahead, you know. And I, if we catch cold or something, I always keep cold medicine, cough syrup, and everything in the medicine cabinet. I get that all in before the snow flies. So we're situated. And get chicken broth and all that done (laugh) . . . We keep warm, comfortable, that's it. We read a lot. (Mrs. L, P2, 413-434)

Table 8

Definitions of the States of Balance

Concept	Definition
Balancing	Centrality not threatened; no sense of urgency; if disequilibrium occurs among current routines, resources, disrupters, whether temporary or permanent, balance restored quickly with modification and/or relinquishing of routines and/or adding resources; affective awareness, if expressed, described as comfort; cognitive awareness present.
Imbalance	Centrality threatened; urgency to restore balance; permanent disequilibrium among current routines, resources, and disrupters; affective and cognitive awareness; accepting, prioritizing, and taking action occurs to restore balance.
Potential Imbalance	Past experiences making person consider the possibility that centrality and permanence could be threatened in the future; no urgency or affective awareness with balance not currently threatened; cognitive awareness only.
Temporary Imbalance	Centrality and permanence not initially imbalance threatened; no urgency; cognitive awareness but no affective response with balance not considered permanently threatened.
Precarious Balance	Centrality threatened; if the threat is recognized as permanent but resources can be used to maintain priority routines, no urgency; cognitive and affective awareness if permanence is recognized; if the threat to centrality and permanence is not recognized because no acceptable alternative routines and resources are considered available by the person, affective awareness is present but only partial cognitive awareness (person realizes that the sense of self does not currently agree with reality, but acknowledging the need to shift one's sense of self does not occur).

> It's pretty good. I can go out and work. The only thing that I've got to watch is take my time, and if I get tired, rest a little bit and I can go right back at it then. I can't continue very long, and I cannot get into a rush [since recovering from surgery]. (Mr. L, P2, 881-888)

Balancing, as a process, is continuously changing and varying in degree. What is most important is preserving one's *values*. The components of the balancing process are varied or modified by the older person to safeguard his/her values. To maintain one's balance, the older person needs to *prioritize* his/her *routines* and *resources* so the *centrality* dimension of balancing is not threatened by the events considered *disrupters*. When centrality is not threatened, no sense of *urgency* is present. The older person is cognitively *aware* of the threat to one's routines and resources, and the modification and/or the relinquishing of routines occurs and/or resources are added examples of *taking action*. When centrality is not threatened, the *affective response* part of the awareness dimension may not be expressed or expressed as comfort by the older person. The initial disequilibrium can be *permanent* or temporary, but if centrality is not threatened, routines, resources, and disrupters can be adjusted in a matter-of-fact way to maintain balance without being discussed in much detail by the older person.

Mr. M gave examples of *relinquishing* and *modifying* some *routines* so that the couple's balance was comfortably maintained. This was necessary because Mrs. M's personal resources had diminished over that last few years as a result of an Alzheimer's type condition. Mr. M considered his wife's cognitive decline a *disrupter*. Mr. M accepted that his wife's condition was *permanent* and therefore influenced their routines and resources permanently. He was cognitively aware of his need to assume more of the household routines that his wife had traditionally done and provide his wife more supervision while she cooked (*taking action*). These actions indicated that Mr. M had both realized dissonance and shifted his image of his wife and his own sense of self to agree with the current reality (*cognitive awareness*). Mr. M also relinquished activities that he thought could easily result in personal injury to himself such as climbing trees or cutting firewood (*using caution*), so that he could continue to assume more of the household routines. He was more cautious when driving. He had his wife stop driving and they stopped heating their home with wood fires fearing his wife might get burned, a realized possibility since his wife's mother had been burned after she experienced a cognitive decline. What was of central importance (*centrality*) for Mr. M was continuing to live in their own home which represented maintaining their *independence*. This was not currently threatened. No *affective response* or *urgency* existed in Mr. M's descriptions because what was of central importance (remaining independent at home) was not threatened. Even though the *disrupter* (Mrs. M's Alzheimer's Disease) was considered a permanent threat to the couple's *routines* and *resources*, *balance* was still currently maintained because *centrality* was not threatened. Mr. M felt relatively comfortable; they were *balancing*.

> If [wife] stay[s], like at home here and she seems to be well satisfied and everything, no problems here, except time and burning stuff, you know. But if I'm here then I try to watch and see what she's doing so it [burning food when cooking] doesn't happen. (Mr. M, P2, 1222-1230)

Imbalance

When all four dimensions (*centrality*, *urgency*, *permanence*, *awareness*) of the balancing process are involved as a result of a disrupter permanently threatening the older person's central routines and resources, a sense of urgency is created. The older person recognizes that disequilibrium has occurred between his/her *routines, resources*, and the *disrupter*. Current disequilibrium produces an emotional response (*affective awareness*). The individual is cognitively aware that his/her sense of self no longer agrees with reality and acknowledges that a shift in the sense of self is needed (*cognitive awareness*). *Acceptance* of this disequilibrium, *prioritizing* and *taking action* then restore balance.

Mr. and Mrs. C provided an example of experiencing this disequilibrium and then restoring their balance. Balancing was restored by Mr. C changing what he defined as a priority routine.

Recalling when he became disabled a few years ago, Mr. C talked about giving up his repair business. The loss of this *resource* (his physical abilities) was recognized as *permanent*, drastically influenced a *routine* Mr. C considered *central*, produced a sense of *urgency*, and an *awareness* of the need to shift his sense of self, and resulted in disequilibrium.

> [Name of doctor] said there is not hope [to recover his physical abilities] (Mr. C, P1, 699-701)
>
> Almost overnight. I was driving on Monday and [couldn't] on Tuesday. (Mr. C, P1, 145-147)
>
> [I'm sure the physical loss changed things, a lot.] Oh, it did. Oh, it spoiled everything. I had a [repair] business started, but I lost it. I

> had to give it up because I can't work. I sold all the tools. (Mr. C, P1, 71-85)

Mr. C relinquished his business, and redefined his definition of what was most important. Living in their own home continuing their daily routines as a couple assumed *central importance* once the repair business had been *relinquished.* Mrs. C, by being able to assume the driving responsibilities provided the *resources* the couple required to continue living in their home. Mr. C learned to find "pleasures" in life regardless of his physical disabilities and even now as he faced the need for medical treatment for a newly diagnosed life-threatening disease. Mrs. C's support and encouragement were some of the *resources* that helped the couple re-establish their balance.

> I have had no great pleasures. Well, I should not say that, no great pleasures. I have had my times. We have had people come and visit. (Mr. C, P1, 632-636)

> And a couple of times he's said, "I don't have anything to live for." And maybe half hour or an hour he'll hear something, a radio [program] or get a telephone call, and changes his mind. (Mrs. C, P2, 613-619)

> So I kind of joke with him at times when he gets real depressed or something. And I think it helps him a little bit. I go by and lean over and give him a kiss unexpectedly. (Mrs. C, P2, 1199-1205)

A state of imbalance occurs when all four dimensions of the balancing process are involved. A routine and/or resource of *central importance* to the older person is threatened or lost. A *permanent* impact on routines and resources that will not improve with time has occurred. The disrupter will not go away and cannot be overcome with resources. The older person experiences a sense of urgency or pressure to act. This sense of *urgency* may require time to develop. Although urgency does not indicate that the action has to be immediate, some time limit does exist, although unknown, about when changes and action will be needed to restore balance.

Awareness of an *emotional response* is a dimension that accompanies some degree of disequilibrium. Recognizing this imbalance also involves the *cognitive awareness* processes of realizing that one's sense of self no longer agrees with reality and acknowledging the shifting needed in one's sense of self to produce agreement with reality. In Festinger's (1957) terms the disagreement and agreement between cognitive elements were dissonance and consonance, respectively.

To restore balance, *accepting* the disequilibrium, *prioritizing* routines and resources, and then *taking action* must occur. Strategies for taking action can include modifying or relinquishing routines, accepting help (gaining resources), or moving from one's current home to gain resources.

Potential Imbalance

Past experiences made some of the older participants think about the possibility of having one's priority routines and resources (*centrality*) permanently threatened from future disrupters. These thoughts about the future indicated a *cognitive awareness.* No sense of *urgency* or *affective response* existed because this threat was not a current reality. This pattern of dimensions and components interacting is present in examples from Mr. M's and Mr. I's situations.

Mr. M recognized the potential disrupter from the lack of personal resources which would threaten priority routines. The couple's home of many years had been a resource for his wife suffering from a cognitive decline; "as long as she's in her own environment, she's pretty good." Mr. M was also a resource being able to help his wife with household tasks. He felt he was in good health, but acknowledged "I don't know how long that will last." If his health failed, he envisioned them having to move from their home. Living together in their home was of central importance at the time of the interviews. Mr. M said that he thought it was his wife's desire to die in their home.

Mr. I felt balancing would continue as long as he had home health care. However, recognizing that disrupters might potentially increase, Mr. I indicated that he had given the home health aide a key to his house. He told the home health aide:

> You might come sometime and ring the doorbell and can't get in. So if that happens, you know there's something wrong, you better come in. (Mr. I, P1, 853-858)

If Mr. I needed more help, he had thought of potential changes he would make; he would arrange for additional help in the home or consider moving to a nursing home. His previous experiences with nursing homes had been positive.

From the investigator's participant observations and understanding of the interview content this was considered potential imbalance for the couple/older person. Potential imbalance is alluded to by the participants when future permanent disrupters that could potentially threaten routines and resources of central importance are mentioned. "If" statements can identify the state of potential imbalance. This armchair theorizing about possible imbalance involved a *cognitive awareness*, a realization and acknowledgement that one's sense of self would need to shift if this potential became reality. It was not accompanied by an *affective response* because balance currently existed.

Temporary Imbalance

A *disrupter* that is considered temporary interferes with the older person's *routines* and can result in the loss of *resources*, but this imbalance is not considered *permanent*. Priority routines (*centrality*) are not initially threatened. Mr. and Mrs. C provided an example of a couple responding to a disrupter considered temporary.

When Mrs. C had an accident that resulted in back injuries (disrupter), the couple experienced a *temporary* disequilibrium of their routines and resources. They were able to restore balance after the wife's injuries by helping each other with necessary routines such as meal preparation and relinquishing other things, such as house cleaning that were less important. These temporary modifications and relinquishing of routines indicated a cognitive awareness of the need to make these temporary changes to restore balance. These changes lasted the several months required for Mrs. C's recovery. Their priority routine, continuing to live together in their own home, was not threatened because the resources of neighbors and friends provided the couple transportation and other needed assistance. With no threat to centrality, no sense of urgency existed.

> And then we have some lovely neighbors around and they'd come and take me into town if I needed to go to town or something. And

> [husband] ended up in the hospital and people were around. They'd come and get me and take me down to the hospital to stay with him and come back. And it was great. People were helping all the time. (Mrs. C, P1, 700-711)

Initially the *modification* and *relinquishing of routines*, and the need to *accept help* may be seen as temporary. When a temporary loss of resources becomes *permanent*, and/or as more disrupters accumulate interfering with routines, to restore balance the older person realizes that receiving this help needs to become permanent. Acceptance of this help indicates that *prioritizing* and *taking action* (outcomes) have occurred. Mrs. E illustrates this situation.

For Mrs. E initial piling up of disrupters included multiple falls with a broken arm, hand, and ribs. After falling twice within a month's time with different fractures of her arm each time, and a spring snow storm that made driving even more difficult, Mrs. E accepted home health care (taking action) when ordered by her doctor. Mrs. E did not know anything about this resource, but admitted that "I was struggling" before they started coming. "I never would have made it after I got all those bones broke . . . without help."

> I wasn't used to anybody helping me or doing anything. I was used to doing it myself. But I found out I can't do everything I want. And I want to all the time. But I've felt real lucky to keep doing as much as I do. I mean, so far, I have not gone off my rocker (laugh). (Mrs. E, P1, 991-1000)

> Yes, the girls [home health aides] kept coming and they said, "Well you can't do it." I said, "That's just what you think I can do and if I make up my mind, I can." "[Name of aide] don't make up your mind until you're strong enough to make it up." But they're awful nice to me, all the kids. And they do a lot for me. They carry my wood. I can't lift like I used to, and I can't use my arms like I did for a long time. (Mrs. E, P1, 940-954)

Mrs. E realized and acknowledged the need to shift her sense of self from being self-sufficient in caring for herself to one where it was acceptable to receive help (cognitive awareness). She also came to accept that to continue balancing this need for help (an outcome) was permanent if she was to continue her priority routine of living in her own house (centrality).

> Well, go ahead, have them [home health aides] help you. After all, when you're 80 years old, you're not, most people, not taking care of themselves. (Mrs. E, P1, 1291-1295)

By accepting help, *centrality* was not threatened, and therefore, no sense of *urgency* existed.

Whether the *disrupter* is considered temporary and resolves with time or becomes *permanent*, if the older person's *routines* and *resources* of *central importance* are not threatened, balance is restored. No *urgency* exists to make changes in these priority routines and resources. *Modifying* and/or *relinquishing routines* and shifting one's sense of self to *accept help* indicates both a *cognitive awareness*, a dimension, and behavioral outcomes. Clinically this might be considered temporary imbalance. The older person's state of balance is temporarily changed, and balance is restored when the temporary condition resolves. If the temporary condition becomes permanent and cognitive awareness of this change in the permanence dimension is present, accepting, prioritizing and taking action occur, and balance is restored.

Precarious Balance

As a result of the accumulation of *disrupters*, the older person's *routines* and *resources* that are of central importance are threatened. The disequilibrium and threat to *centrality* are accompanied by an affective response (*affective awareness*) identified in the older person's statements or/and by observing their behavior. Using the *resources* of others can maintain the older person's central routines, and therefore no sense of *urgency* to make further changes occurs. If the older person recognizes the threat to routines and resources as *permanent*, then he/she realizes how one's sense of self deviates from reality and is able to acknowledge the need to shift this sense of self to agree with reality (*cognitive awareness*). But if no other alternative resources that support the older person's values are considered available, these central routines and resources will not be relinquished. If *permanence* is not recognized, the older person can realize that one's sense of self does not currently agree with reality, but does not acknowledge the need to shift one's sense of self (*partial cognitive awareness*). The older person is not willing to redefine priority routines and/or resources. Disequilibrium remains and discomfort is felt (*affective response of awareness*). Mr. G's and Mr. and Mrs. K's experiences will be used to illustrate these patterns of interactions when *permanence* is or is not recognized, and *full cognitive awareness* is present or not. In the case of Mr. and Mrs. K, they did not agree on their current state of balance.

Mr. G. At the time of the first interview, Mr. G was using oxygen continuously. The inability to be physically active caused Mr. G to wish he would die soon. Working had been of central importance to Mr. G. What was important to Mr. G now was to remain living in his own home. When asked about the importance of remaining at home, he stated, "I own his place . . . nobody can take it away from you until I die." Also important to him was having his guns in his home, an issue of control. While having guns in the home of a depressed person would not normally be considered appropriate, Mr. G's strong religious beliefs prevented him from considering suicide. This had been a topic hotly debated by the family per his daughter's account.

> So my dad walks out and he says, "Where are my guns?" And my mom goes, "[two adult children] took them." So he goes, "Get my guns back." So I got on the phone . . . .My mom told me that he, both he and her, had talked about suicide. But they can't do that because both of them have the same religious beliefs. So no matter how bad it gets, they're not going to do that. (Mrs. GD [Mr. G's daughter], P1, 1036-1108)

Mr. G's daughter helped her father continue balancing by arranging the resource of home health care. Mr. G's emotional response to the loss of his physical abilities threatening his remaining at home was feelings of hopelessness, "I'm existing, not living." Permanence was present; "I don't have any hopes for getting better." No sense of urgency to change his central priority was present for Mr. G. while balancing continued. He knew of no other resources that he was not already using that supported his values of remaining independent and in control. Mr. G's priority routine of remaining at home to die was possible because of the home health care received. Although he did not feel he had any choice in the decision to receive home health care (a decision attributed to his doctor and daughter), he accepted it. This indicated a cognitive awareness of realizing and acknowledging that if he was to remain living at home, he needed to receive help. Home health care personnel provided housekeeping, some meal preparation, helped him bathe, and monitored his health problems. He had ruled out Meals on Wheels as a resource stating, "It sure tasted like crap." Mr. G also had ruled out a foster home although he indicated that the home health nurse, a son, and daughter all thought he should move to one, the only other resource being discussed. Mr. G felt that he still had the personal resource of "a clear mind," so he was not going to a foster home. Living in his own home allowed Mr. G to maintain his values.

From participant observation and interview data, the investigator interpreted Mr. G's behavior as indicating that he considered himself to be in precarious balance, a low state of balance. *Precarious balance* occurs when one's priority routines and resources are threatened, but the older person does not want to relinquish these routines of central importance, a decision supported by one's values. No additional resources that support these values are considered available. While emotional awareness is present and the individual realizes his/her sense of self no longer agrees with reality, the individual may acknowledge the need to shift his/her sense of self to agree with reality. If the permanence of the disequilibrium is recognized, this acknowledgement of the need to shift one's sense of self occurs. Mrs. K's situation illustrates the interaction pattern among dimensions and components when the older person does not recognize as *permanent* the threat to a central routine (*centrality*) and does not have complete *cognitive awareness.*

Mrs. K. Mrs. K did not concede that the decreased mobility of her arm, even after the fracture healed, was permanent. She did not acknowledge her need to shift her sense of self although she realized this sense of self no longer agreed with reality (partial cognitive awareness). Mrs. K felt she could still drive her car with a standard transmission if she had to, although she had not done so since her accident. Although Mr. K was still able to drive, Mrs. K was not willing to relinquish the idea that she could still drive herself, evidence of her independence.

> I mean, it's all shift on this side. It's not power steering exactly, but I could drive it if I had to. (Mrs. K, P1, 960-964)

In contrast, Mr. K in talking about his wife's use of her injured arm,

> Her arm's useless. . . . She'll never ever regain full use of that arm and shoulder. No way. (Mr. K, P1, 164-261)

Disagreement within the couple; precarious balance. Mr. and Mrs. K also illustrate a couple that were dissimilar in additional dimensions of the state of balance interfering with their decision-making to restore balance.

While Mr. K talked about his physical "deterioration" and needed to use his supplemental oxygen more often for shortness of breath, Mrs. K was buying exercise equipment saying she "thought it would be a help to us." Mr. K realized and acknowledged a need to shift his sense of self to agree with reality (cognitive awareness), while Mrs. K was hoping the dissonance between her sense of self and reality was only temporary and could be overcome with exercise. Although this indicates that Mrs. K is *taking action*, this action is not helping to restore their balance.

Another example that indicated the difference between husband and wife concerning their cognitive awareness and acknowledgement of the need to shift one's sense of self related to their trailer. Mrs. K continued to talk about taking their trailer to the coast for a vacation, when she knew Mr. K had sold the trailer. Mr. K had sold the trailer because he did not feel comfortable driving and pulling a trailer when he was experiencing more stroke-type episodes. The only statement Mrs. K made during the interviews that demonstrated her awareness of a need to shift her sense of self to correspond with reality was when she stated that she could not remain living in their current home if Mr. K died.

> I have reached the point now where I think, how would I manage by myself up here. And my daughter wouldn't want to leave me here 5 minutes by myself. So that's in the back of [my] mind. (Mrs. K, P1, 1655-1661)

"A little cloud" hung over their heads, per Mrs. K, indicating an emotional response (affective awareness) accompanying their disequilibrium. But as a couple they could not agree on where to move. Living in their current home remained of central importance (centrality) and could be continued for the present by pooling their remaining resources and receiving help.

> Well I figure we're lucky because at my age I can go to the market and do the shopping and stuff. (Mr. K, P1, 454-457)
>
> I don't fret about helping [wife] or her helping me. I pretty well plan the meals and get it going. (Mr. K, P1, 1017-1021)
>
> I do all the cleaning there is. Some of these are dusty, but tough luck, I can't help it. I do as much as I can. I keep my stove and my sink and my bathroom and everything clean, spotless. The rest of it I don't worry about (laugh). I vacuum when I can. (Mr. K, P1, 301-310)

> I used to do it myself [cut and split their firewood], but this last year I haven't been able to, so I hired a man to come. (Mr. K, P1, 1107-1110)

However, Mr. K's statements indicated he judged their balance as more threatened than his wife did. He felt his functioning had permanently deteriorated. If his wife were to require extensive care as she did after her fractured arm, Mr. K did not feel he could provide it again. He had acknowledged a shift in his sense of self was needed to be congruent with reality; he no longer could meet all of his wife's care needs.

> And then I'm just, deterioration. Your body, you know, you don't use your muscles, you get so you can't (laugh). [When you fell and hurt your back, that really put you down?] That put me on the skids. I had three herniated discs, and the top one here cracked . . . Oh, I lost the use of my left arm and hand for 4 months. Absolutely useless. And still I go to reach up there with my hand and I don't make it sometimes (laugh). (Mr. K, P2, 343-370)

> These more or less mild strokes about March, end of January I had one that crippled my left side for about, probably a week. (Mr. K, P1, 9-13)

> [Caring for his wife after her broken arm] That was rough. Day and night, man I'll tell . . . Oh well (laugh)." [You hope you don't have to do that again?] A hundred years from now you'd never know the difference. Oh no, I wouldn't want to go through that again. Particularly, well, as far as I'm concerned. Because I'm getting down where I couldn't do it much more, you know. (Mr. K, P2, 574-588)

To restore balance in the event of an accident or further decline in health, moving closer to family help or obtaining the services of a nursing home would be required.

> But if we got some serious ailment or something, we'd have to move that's all. There wouldn't be no two ways about it. [To be closer?] Well, you'd have to get closer to family or, depending on what

> happened to you, maybe even a rest home, who knows. Like when she broke her shoulder, her arm, well, boy that first 3 months was something else. (Mr. K, P2, 531-546)

He would also consider using home health services again, if they could afford the cost.

The investigator's interpretation of the observations and statements of Mr. and Mrs. K was that they considered themselves to have a low degree of balance: *precarious balance*. They acknowledged that *disrupters* were threatening *routines* and *resources* that were considered of central importance (*centrality*). These priorities were maintained by the use of additional resources and the modification and relinquishing of other routines. No strong sense of *urgency* to make further changes was experienced because no other resources were available that would support routines that reinforced their *values*. How long their current degree of balance would remain was in doubt. Mr. K had acknowledged the need to shift his sense of self and accepted that the couple's balance was *permanently* affected (*cognitive awareness*), but Mrs. K was not willing to make these concessions, perhaps due to incomplete cognitive awareness. The lack of *acceptance* on Mrs. K's part, in addition to the couple not seeing other resources available that supported their values, prevented the couple from moving on to productive *prioritizing* and *taking actions* that would restore their balance.

Mr. K recognized the couple's differences in awareness.

> You know, she just, she wants to travel and everything and get out and around. Seems like either she don't feel well or I don't, or something, you know. (Mr. K, P2, 856-861)

Mrs. and Mr. K both indicated their difficulty prioritizing.

> So we'd considered selling, we talked about it. And then we say, "Well, what else." Then we drop it again. (Mrs. K, P2, 1177-1180)

> We really don't know where else we want to be. We like it here. And as long as, of course, we're all a distance away from everything. (Mr. K, P2, 464-469)

Variations in Balance Over Time: Mrs. H and Mr. and Mrs. P

The stories of Mrs. H and Mr. and Mrs. P provide examples that exemplify one older participant and a couple experiencing a variety of *states of balance* over time. Interaction between components and dimensions of the balancing model will be illustrated.

Mrs. H. Mrs. H experienced imbalance, balance, and then potential imbalance. At the first interview, Mrs. H recalled that a piling up of disrupters had occurred over several years leading to a state of imbalance. Mrs. H had a chronic neurological disease that made her gait unstable. Having had the disease for several years, she realized it was permanent. Mrs. H no longer had help readily available since her youngest daughter had moved from her area. Mrs. H stated, "I got lonesome and I knew that if I come down here I could be with my family." Mrs. H recognized her state of imbalance. She was cognitively aware and accepted that at times she needed help, her lack of resources in her current location was permanent, and her daughter moving (loss of a resource) created a sense of urgency. Mrs. H decided to move from her home of over 30 years. What was of central importance (living in her "family" home) was redefined to living in a home of her own closer to family members whom she could call on for help, a resource. She relinquished her old home, but was able to continue the routines that supported her value of independence in her new home. Home was no longer defined as a specific house, but as a place where she could be independent while also physically closer to family.

> Well it [moving] was just something I knew I should do. Because I was up there really by myself [at her former home]. My brother lived about 40 miles. He had a sick wife and I just, I knew that if I got down here, [name of daughter] could come over and take care of me if she had to. And I just felt like it was the thing to do and I did it. (Mrs. H, P2, 710-719)

Because this imbalance occurred in the past and balance was restored, Mrs. H did not mention an affective response.

Since this move a few years ago, more disrupters including a prolonged, near-fatal illness had continued to accumulate. The resource of family help was not enough, so to maintain balance, home health care was arranged by her daughter. Accepting this new resource supported the central priority of living in her own home, but also meant acknowledging a shift in sense of self. Mrs. H was no longer able to be totally self-sufficient in her home. Mother and daughter agreed that this additional resource of home health care was needed for Mrs. H to remain living independently at home. Mrs. H was able to continue cooking, caring for her dog, visiting with family and friends, and attending church and a Bible study. Having control of these activities became Mrs. H's new definition of living independently.

> But I feel at home [here], and if I had to go somewhere [else to live], I wouldn't feel at home . . . So then I can have anybody, you know, like if I want to cook a dinner or something, I can invite people over. I can't do that if I was in a foster home. (Mrs. H, P1, 667-680)

Agreeing to home health care, Mrs. H had a cognitive awareness of the need to adjust her sense of self. Help from outside the family needed to be accepted.

> Very weak. And I would just get over it [illness] and it would come back on me. So actually, I probably didn't really get over it. I had it four times. So, I had to have some help. And [name of home health agency] girls did a very good job. I'm really happy with them. (Mrs. H, P1, 106-114)
>
> [Was it hard just getting used to having somebody come in and do stuff for you?] No. It wasn't very hard for me because I realized I needed them. (Mrs. H, P1, 252-258)

Mrs. H realized that she was going to continue needing this help (permanent) but no sense of urgency or affective response existed because she currently was in balance.

Mrs. H recognized the potential for future imbalance from disrupters (cognitive awareness and centrality threatened) and the permanent disequilibrium that could result: "a stroke or if I had a heart attack or something like that. That'd make quite a bit of difference." However, remaining in her home as long as she was able continued to be of central importance for now. She would accept the resources of having someone live with her or moving to a foster home, if that was necessary. She wanted to maintain her independence and control: values. "But as long as I'm able to go on my own, I like it this way." Mrs. H had no sense of urgency to make any additional changes now, feeling comfortable with her current balance, an indication of having the components in relative equilibrium with each other. Balancing meant no affective response of disequilibrium was expressed by Mrs. H.

> Everyday as it comes. Whenever a day comes where I have to make another decision, I'll do that, depending on how I am and what's happening to me, and all those things. (Mrs. H, P1, 845-850)

Balancing was maintained with the care of her daughters, the help of her grandson's family, and the visits from home health care.

Mr. and Mrs. P. Mr. and Mrs. P experienced imbalance, then moved in an attempt to restore balance with the addition of resources. While Mr. P indicated that balance had been restored after the move, Mrs. P still felt disequilibrium.

For Mr. and Mrs. P, living in a home of their own and caring for each other were priority routines. Their ability to help each other was also a resource. The added resource of adult children living in the state could be called on as necessary, but the couple's values of independence and self-reliance meant these resources were not called on except in an emergency. They felt they were balancing until a few years ago.

> He's done all the upkeep until the last, I'd say the last few years. Even after he had [name of cancer], he got alright for a year or two real good. And he'd keep the snow raked off, and he'd do the wood, the two of us. And we didn't ask much, because we were perfectly fine. (Mrs. P, P1, 1285-1295)

Mr. P had experienced previous disrupters including a stroke and treatment for cancer. But the couple felt they were balancing until the wife had a life-threatening accident and needed extensive care at home that she did not feel her husband was physically capable of providing.

> And then when [I] did come [home from hospital] . . . I had to be turned over at least twice a night . . . and [he would] turn me and get the bedpan in. And I knew he wasn't able to take care of me. I knew then something was wrong, but I really didn't know what. This was not like the stroke he had in

> [place name]. It was a seizure like stroke. This was not. He didn't let me see anything. Except I knew he was white as a ghost and I knew he wasn't able to do what he was doing. (Mrs. P, P1, 1771-1792)

Mrs. P realized and accepted that Mr. P could no longer fully participate in maintaining their routines; centrality was threatened. He no longer did home repairs or drove. The image Mrs. P had of her husband changed to reflect the current reality, but she was not ready to totally redefine her sense of self. After being told following the accident that she would never walk normally again, she made herself walk daily. She was proud of wearing high-heeled shoes at their wedding anniversary party.

> And they told me they said, "If you do walk, you'll walk like this" [demonstrates abducted leg with limping gait]. And they thought that, right up until I said, "There's no way. I trust God, there's no way I'm going to walk like that." And, but anyway, I wore those heels that day [anniversary party]. . . . I'm so short I always wore heels. And he was so tall, when we were going together. (Mrs. P, P1, 2191-2208).

The accident did make Mrs. P question her ability to continue driving over mountain passes in winter to take Mr. P to his medical appointments (cognitive awareness). Her prolonged, difficult recovery following the accident and Mr. P's having another stroke during this same period were disrupters that diminished their personal resources. These changes were seen as permanent; their health and abilities would never be as good again. A sense of urgency developed; an affective response was expressed.

> I don't know what kind of a fear it is. I still go down all the time [drive over mountain passes], but there's something about, I don't enjoy doing, driving over them. Anymore. (Mrs. P, P1, 1938-1943)

> I get a little bit scared sometimes when he has a real bad day or something. And I'd much rather be somewhere a lot, we're not isolated, but it's sort of a feeling of isolation. (Mrs. P, P1, 1992-1999)

> Sometimes it gets, [I] would get really heavy [depressed] because, after I had the accident and then we were taking care of each other and neither one of us could really even take care of ourselves. (Mrs. P, P2, 1571-1577)

Mrs. P summarized how a disrupter leads to imbalance with a sense of urgency to make changes, and to affective and cognitive awareness.

> I had had the really bad accident I suppose is what probably cinched it [decision to move]. And then this lady called us that works there for the ambulance in [town name] and she was looking for a place to rent [they purchased the P's house]. She had heard that we were thinking of moving. And, I don't know, it was just sort of in my mind that I couldn't handle another winter driving down the mountain twice a month sometimes. After the accident. I just . . . I could have, but it would have been more stress. We never minded it as long as our health was good. (Mrs. P, P2, 1026-1047)

The couple had been in the new location 4 to 5 months when the second interview was conducted. Although Mr. P felt balanced in the new home, Mrs. P did not. The piling up of more disrupters had occurred, and Mrs. P was not sure she would have moved if she had known the difficulties they would experience.

> Really, I suppose if we had known, could foresee into the future, we wouldn't have moved at all. At our age, and then my health kind of started to go. I've had heart problems ever since I've been here. And that's new. I didn't have anything like that. But I think we could have took, we take anything except stress with people, you know [trouble with neighbor at the P's new home]. (Mrs. P, P2, 495-506)

> [Water pipe broken in new home] Some of these things wouldn't have been so bad, when you're younger you can handle all that. And we've had a lot of pipes break, a lot of things like that and he always was able to fix all of it and we just went on with our lives. But in this case, [had to get help from neighbors and emergency plumbing services] it was kind of a . . . It's more stress as you get older. (Mrs. P, P2, 1447-1458)

While Mrs. P continued to feel disequilibrium several months after their move, Mr. P outlined several resources they gained and indicated that he was satisfied with the action taken. He was legitimating the decisions they made and indicated they were balancing in the new location.

> You know, we can get groceries. She can see a doctor much easier here. (Mr. P, P2, 21-23)
>
> But we have enough room for two people. We got. For all the energy I got, you know. (Mr. P, P2, 184-187)
>
> But we like [city name] because we do have daughters living here in [city name]. We can call them and they come by and check on us pretty regular. And we got in contact, that [medical provider] contacted the nurse to come out, you know, for me. And that saves going clear to the [hospital and city name], you know, for that blood check. (Mr. P, P2, 100-112)
>
> We're better off now that it's all over [the move]. (Mr. P, P2, 538-539)

Decision-Making

Both Chenitz's (1983) and Festinger's (1964) theories discussed what was needed for the individual to accept the decision after it was made. Chenitz indicated that the older person needed to find legitimate reasons why he/she did not fit the stereotype of the typical nursing home resident to accept the move to a nursing home. Festinger's theory indicated that some dissonance between the cognition of the action taken and the positive knowledge about the choices not selected was present after a decision was made. After the decision was made, to decrease this dissonance the alternatives not chosen would be considered less desirable. Mr. P, listing many advantages of their new location, emphasized why staying in their previous home in a more rural area was less desirable.

Comparisons and Contrasts Between the Different States of Balance

The older person's judgments regarding the dimensions of *centrality*, *urgency*, *permanence*, and *awareness* interacting among themselves and with the components of *routines*, *resources*, *disrupters* will determine the state of balance that is present and where on the balancing continuum she/he is at any point in time. From participant observations and the constant comparison of the interview data from the different older people and couples, the investigator identified five states of balance. These states of balance were considered to be theoretically and clinically relevant. Table 9 outlines the states of balance identified and whether the dimensions are YES, recognized as affected, NO, not recognized or not affected, PARTIAL, partially affected, or potentially affected (POT).

The *urgency* dimension, the pressure to take action to restore balance, is discussed by the older participants only when the degree of balance is at its lowest, when imbalance exists. The *permanence* dimension is mentioned in association with all degrees of balance from balancing to imbalance with disequilibrium being present until changes are made to restore or maintain balance. In balancing the incremental changes to maintain equilibrium occur with relative ease when *centrality* is not threatened, so permanence of balancing is also easily maintained. Full *cognitive awareness*, the acknowledgement of disequilibrium, results in the older person entering into the decision-making processes to maintain or restore balance as long as resources that support his/her values are considered available.

Table 9

States of Balance

	States of Balance				
Dimension	Balancing	Imbalance	Potential Imbalance	Temporary Imbalance	Precarious Balance
Centrality	NO	YES	YES POT	NO/YES	YES/NO
Urgency	NO	YES	NO	NO	NO
Permanence	YES/NO	YES	YES	NO/YES	YES/NO
Awareness					
Affect	NO	YES	NO	NO/YES	YES
Cognitive	YES	YES	YES	YES	YES/PART

When the *centrality* dimension is threatened, the older person will make changes to restore balance between *routines*, *resources*, *disrupters* unless no alternative resources are considered available that support his/her *values*. This lack of alternative resources that support his/her values means the older person will not relinquish priority routines even though they are currently threatened. *Urgency* is not experienced because no changes are going to be made by the older person as long as current resources can maintain the threatened priority routines. But with this disequilibrium present, an *affective response* that indicates some type of discomfort is present. *Full cognitive awareness* is also present if the *permanence* of the disequilibrium is recognized.

Cognitive awareness is present with any disequilibrium or state of imbalance. However, this cognitive awareness may only be partial, with the older person realizing the sense of self no longer corresponds to reality, but not acknowledging the need to shift one's sense of self to agree with reality. This partial *cognitive awareness* occurs when the older person does not accept the permanent effects of disrupters on one's resources and routines. When *centrality* is not threatened, changes in routines and resources occur with relative ease because major shifting in sense of self to agree with reality is not needed. The *cognitive* part of the *awareness* dimension is influenced but no *affective response* is expressed. When centrality is threatened, the disequilibrium experienced is of a greater magnitude, and an affective response is expressed by the older person or others can observe the affective response in the older person's behavior.

The Balancing Process and the Adult Child Caregiver

The balancing model can be used by the adult child caregiver to understand the parent's decision-making process when deciding whether to receive help in the home or move to receive the help needed. Another balancing model placed parallel with the parent's can be used to represent the adult child's perspective of the process when helping the parent make these decisions. The adult child and parent may disagree on what *routines* should be considered of *central importance* to the parent, what *resources* are available, and what events are considered *disrupters*. If the adult child decides that *permanent* disequilibrium is present in the parent's current balancing triangle, a sense of *urgency* to make changes in the parent's routines and resources may occur. *Acceptance* that these changes are needed to restore the parent's balance occurs. For the adult child *prioritizing* and *taking action* to correct the imbalance identified in the parent's situation may occur more quickly than it would for the parent, who looks at her/his balancing more holistically. Prioritizing and taking action can be a more difficult process when it is one's own routines and resources that are being assessed and weighed in relationship to one's *values*, considered for *modification* and *relinquishing*. Time may also be required to obtain resources that the older person considers acceptable to restoring the balance in one's life.

The balancing process will be discussed from the adult child's perspective. The adult child's viewpoint of the components of the balancing triangle and dimensions of the state of balance will be described. How the parent's perspective may differ will also be outlined.

Components: Routines, Resources, and Disrupters

Adult children and parents generally agree on what was identified by the parents as disrupters, i.e., accidents or illnesses that result in a decline in the older person's physical abilities or the loss of help in the form of informal or formal services. The adult children interviewed accepted that they were resources for their parents. Mr. D and Mr. G both mentioned adult children from whom help was asked but not provided. These adult children did not agree to be resources for their parents, however they were not interviewed.

> I don't even talk to my daughters about it. I called them up and wanted one of them to come down here and stay with me and at the time she had a job and she didn't want to come. My ex-wife, her mother, was living with her. And, I don't know, I just completely give it up. (Mr. D, P1, 1412-1421)

> [Mr. G describing a conversation between his daughters] Told her she'd [daughter currently helping Mr. G] come in and cook our

> breakfast and fix stuff for us to put in the microwave for lunch. She wanted [name of other daughter] to come in and cook our dinner and do up the dishes at night. [Daughter] said no. (Mr. G, P1, 581-588)

Whether and how the parents continued their routines appears to be used by the adult child to assess the parent's functioning. The parent's *relinquishing* or *modifying* a *routine* was not always recognized by the adult child as a conscious decision by the parent to maintain balance, but only as a sign of further decline in the parent's abilities (diminished resources). Examples of this assessment process by the adult child is illustrated by Mrs. E's daughter, compared to comments from Mrs. E demonstrating her conscious selection of routines. In these and future examples, the adult child is identified by the parent's initial plus an additional letter or letters indicating the family relationship; D for daughter, S for son, DL for daughter-in-law, and SL for son-in-law.

Mrs. E's daughter (Mrs. ED) noted that her mother liked her dishes "squeaky clean" and was immaculate with the care of her clothes, but that her housekeeping had declined. "I mean she is just a clutter bug . . . she will not throw a paper out or anything." Mrs. E views the situation differently. Although she accepted the help of home health aides, she was not willing to "turn it all over" to them.

> I could just sit and lay and sleep, I guess, and they'd [home health aides] just take care of things. But I'm not going to. It's not good for them to have to feel responsible for me. (Mrs. E, P1, 1336-1343)

She reported continuing her routines of cooking, cleaning her bathroom, building fires for heat, doing her laundry and personal care, and caring for her plants. Mrs. E stated, "but I let them do things that are hard to do. Lifting. I can't lift like I did.

And I do get ghastly tired and all that." Mrs. E also referred to her household accumulations in a way that gave them more meaning and significance than the daughter's assessment of "clutter." Mrs. E realized that she had her possessions of a lifetime contained in her home. If Mrs. E moved she knew with her decreasing physical endurance she would find it difficult to sort through her things, decide what to keep, and what to give away. She did not want to part with many of her things, which would be necessary when moving to a smaller house that she could afford. Mrs. E realized others would not consider her possessions valuable but "junk."

> And what am I going to do, look at all the junk that's piled up here. For (laugh) [several] years, it has been piling up in here. A lot of it can go in the trash I guess and a lot of it I wouldn't want to part with. Even the pictures on the wall my kids have made. (Mrs. E, P2, 785-794)

Mrs. ED also used her mother's ability to continue paying her bills and balancing her checkbook as methods she employed to assess her mother's *resource* of mental functioning, explaining, "And when she starts not being able to, then we are in trouble."

> Because she keeps her bank book balanced and she pays her bills on time. She, you know, she does everything the way she is suppose to . . . I know we are constantly checking her. I think it irritates her a little bit. . . . [Mother asks daughter] "What do you think, I am getting senile or something?" She is aware of what we are doing. (Mrs. ED, P1, 1011-1033)

Dimensions: Centrality, Urgency, Permanence, Awareness

For the adult child, physical safety of the parent is usually given central importance (*centrality*) when considering the parent's state of balance. As a responsible caregiver, the adult child wants to insure the parent has safe routines and resources. When the parent's safety is considered threatened, the adult child considers the parent to be in a state of imbalance. The adult child's goal is to restore the parent's balance with the parent's physical safety of central concern. But the adult child also attempts to protect the parent's dignity by honoring the parent's wishes (*value*) when restoring balance whenever possible. However, the meaning of the parent's *routines* and property may or may not be fully understood by the adult child. The parent's routines are usually given priority in decisions made by the adult child if safety is not threatened. Mrs. E's daughter and Mr. I's son provided examples of the adult child's concerns for safety surrounding their parents' living situation and respect for the parents' *priorities* in the decision-making process, especially once the issue of safety was taken care of.

> She insists on staying at home now . . . She wants to be where she's lived for the last [several] years . . . we had it checked and they said the house was OK. It will stand [although receiving major structural damage after the earthquake]. . . . We may have to take her out of the house. . . . We looked around for places to rent, you know, for her that would be comfortable and there isn't any. The important thing is to have a [safe] place to live. There are not apartments . . . I guess people live there until their house falls down and then they move on, because all the houses that are vacant, you know, are falling down. I'm concerned if another earthquake hit, what would happen. (Mrs. ED, P1, 162-585)
>
> [After his father's accident] I wanted him to get back to his house if at all possible and find somebody who could look after him. Which he has. And he seems to be perfectly happy. (Mr. IS, P1, 273-278)
>
> Are they capable mentally to handle where they are? That's a factor. And he seems to be able to. His only physical problem is his degenerated, you know, he's deteriorated muscular-wise. . . . They [home health care agency] were concerned that he might fall and hurt himself. And I guess, yes, that's the situation, but he seems to be very, very careful of what he does. (Mr. IS, P2, 366-384)

Mr. I's son felt his father was still mentally capable and, therefore, safe to remain in his home with the help of an aide for half a day assisting with meal preparation, shopping, and housekeeping. Mr. IS felt he would be sacrificing his father's "mental health" if he was living in a care facility with other individuals not as mentally alert as his father was.

Mr. G's daughter recognized the importance of the symbolic meaning of her father's truck to him and did not want him to give up this possession before he was ready. Safety was not an issue because he no longer attempted to drive his truck.

> He sold his car. He will sell his truck. He's already said, "Well when I move [to a foster home] I don't have car insurance any more." You know so, I mean he doesn't drive any more. I just left it there because I don't want it to go away. I mean I want him to be able to see it. I want him to still carry his pickup keys in his pocket. (Mrs. GD, P2, 595-609)

Of primary importance for the older person is maintaining his/her *routines*, however he/she does not ignore safety. The older person wants to remain safe, but is not willing to sacrifice priority routines (*centrality*) to insure safety if there can not be some modification consonant with their values. This means finding ways to remain in balance or restore balance that are in concert with the older person's values. The data of Mrs. E and her daughter illustrate both the older person's and adult child's concerns for safety but also shows the differences in their priorities.

Mrs. E's daughter had talked to her mother about her decreasing driving abilities. She was somewhat reassured by her mother's response. She said she was not driving to the town 35 miles away any more, just to the local post office.

> We [adult children] don't trust her driving. I don't think her reflexes are good enough to still be driving. But she still does [drive]. She takes her car out. She doesn't go very far. She just goes to the post office and around the block. She does not try to drive to [name of town] or anything like that. But she was. I talked to her about that. I said, "Mom do you remember when we were younger, and you would see these old people on the road and going too slow or way too fast, and you would say they should do something about that because they were going to hurt themselves or hurt somebody else? You are at that age now. How do you feel about it?" And she would say, "I know I am not, you know, good enough driver in traffic and such, like that. But I am real careful around town here." (Mrs. ED, P1, 1039-1066)

> I just want . . . I am not there and just wanted to know in my own mind, that she wasn't going to jump in the car and take off for [name of distant town]. So I talked to her about it. (Mrs. ED, P1, 1071-1077)

Mrs. E still wanted to be responsible for getting her own mail, but accepted rides into town to do her shopping while indicating that for this help she was exchanging the use of her car.

> But I go into town every month or two. Someone to go with me. I have a lot of sweet little young neighbors. They like to go. And they like to drive my car, so that's why. (Mrs. E, P1, 464-470)

Included in Mrs. E's daughter's statements are the adult child's recognition of the *urgent* need to restore the parent's balance. Mrs. ED agreed with her mother that a disrupter included the earthquake that damaged her mother's home. At the first interview Mrs. E's daughter indicated that the house was checked and "It will stand . . . it is . . . old. . . . That house is on a redwood log foundation." Safety was Mrs. ED's concern and she recognized that *permanent* imbalance had occurred with the damage to her mother's home. Concern for her mother's safety provided the daughter with a sense of *urgency*; "I'm concerned if another earthquake hit, what would happen." Mrs. E had strongly expressed to her daughter that she did not want to move, that "she wants to be where she's lived for the last [several] years" indicating that the routines associated with her home were of central importance (*centrality*) to Mrs. E.

The adult child's perception of the parent's *awareness* of disequilibrium is based on what the parent says and does. Mrs. E had indicated to her daughter that she was in a state of disequilibrium. Mrs. ED stated that "she [her mother] kind of frets and stews about that, too, because the place is so old," yet her mother wanted to continue living on her property. Mrs. ED had looked for other housing for her mother in the area and was not able to find any, providing no acceptable alternatives.

Permanence is also recognized as a dimension of balancing by the adult child. Mr. I's son (Mr. IS) depicted this dimension. Mr. IS believed his father's car accident that resulted in his father's blindness was the *disrupter* "that terminated everything." This created an imbalance after which permanent changes were required to restore Mr. I's balance. No longer being able to drive was seen as taking away some of his father's *independence*. Mr. I resigned his board position for a local business because he could no longer read the meeting agenda. Relinquishing these routine activities indicated that Mr. I was aware and accepted the need to shift his sense of self to correspond with the reality of his blindness. Mr. IS felt his father relinquished his board position because of wanting to maintain a sense of "pride." Mr. I's son also recognized that to make these changes, his father was *cognitively aware* of his imbalance; a part of the awareness dimension of the state of balance.

Mrs. OD provided examples of an adult child recognizing the awareness dimension in the parent's balancing process; in these situations the *affective response* part of *awareness*. Mrs. OD identified several periods of imbalance for her father, some resulting in the *relinquishment* of routines: when her father gave up his driving, when he was concerned about his failing vision, and again when he seemed depressed following a hospitalization. She acknowledged her father's affective awareness.

> That was his big worry at first was the driving. "What am I going to do and everything?" It bothered him for a long time. And then it was his sight bothered him. "What am I going to do when I go blind?" Well we said, "You're not going to go blind." And then finally got that taken care of [cataract surgery], so now he doesn't really complain about anything. (Mrs. OD, P2, 462-474)
>
> Well for a while I kept asking [her husband], "Do you think I should be asking him if he's ready to move down here [to live with them]?" Because he was seeming kind of depressed, you know. And then all of a sudden he . . . it has been about a month, that he's really gotten active [in senior activities], and they go and pick him up and everything, you know. (Mrs. OD, P2, 697-707)

Decision-Making as Part of the Balancing Process

Mrs. ED's statements graphically illustrated the adult child *accepting* that imbalance is present in the parent's life. The adult child then begins *prioritizing* while considering the parent's wishes (*values*). At the first interview, Mrs. ED's priorities included having her mother come live safely with her, but her mother did not agree. Mrs. E felt she was balancing and wanted to remain living in her home.

At the second interview, Mrs. ED talked about having a mobile home placed on her mother's property as Mrs. E's new home. This alternative housing was an easier and less expensive way to restore her mother's balance than repairing the earthquake damaged home. Mrs. E was considering this option. Mrs. E had, by then, accepted the need to move out of her damaged house; that she was experiencing disequilibrium.

> I never faced anything like this before; I had a home and it was mine and I could do as I please. Now I don't have a home (laugh). Go where I can dig me a hole I guess. (Mrs. E, P2, 69-75)

> I thought about these prefabs that you can get. I thought I'd check into that and see what they cost. (Mrs. E, P2, 730-732)

Imbalance for the Parent

Temporary imbalance. Temporary imbalance is recognized by the adult child after the parent has an acute illness or accident from which the parent can recover. The parent accepts the help offered by the adult child in these periods of temporary imbalance, although the parent still wants to maintain *control* of their balancing and decision-making. Mrs. E demonstrated this to her daughter. After Mrs. E's fractured arm had been set and she was still in the hospital, her family arrived to take her to their home. Mrs. E described the situation.

> So they said, "Well, we're going to (name of adult children's community)." And I said, "No we're not. We're going to (name of mother's town)." And they said, "No. You have to go, we're taking you to (their home)." "You think you are. I'm going home and get some clothes . . . ." So they brought me home. I [packed] a suitcase. (Mrs. E, P1, 80-97)

Potential imbalance. All of the adult children identified situations that were considered potential imbalance for their parents. Increasing mobility problems and falls were identified by Mrs. BD, Mr. IS, and Mrs. OD. Mrs. ED mentioned "we are in trouble" if her mother's mental abilities declined, she became disabled or needed to use a wheelchair. Mrs. HD talked about if her mother "had a massive stroke or something." Mrs. GD recognized potential imbalance, "if he loses a limb, if he loses a kidney, if his eyesight really starts." Several adult children reflected on how *resources* helped the parent *maintain balance* at her/his current level of need. However, the parent faced potential changes in priority routines if the parent's personal resources declined further. Mrs. ADL, who's mother-in-law was terminally ill, talked about the need to consider a nursing home "if she becomes bedridden." Mrs. JDL indicated that as long as Mr. J is "not sick" and home health services continued, they could continue caring for him at home.

The adult children envisioned situations that would create potential imbalance for their parents, and therefore could produce difficulties in their own lives. These visions were in the thoughts of the adult children as they anticipated decisions that might need to be made in the future regarding their parents. Mrs. OD would have her father live with her.

> If it ever comes to the point that he just falls down or does get hurt or anything. He will just come here [to live with her]. (Mrs. OD, P2, 316-320)

Mrs. BD discussed the eventual need to live with her mother.

> Well, I think that at some point I'll probably have to either go live with her or have her live with me, you know, when she gets to the

> point where she won't be able to cook for herself. Or, you know, just can't do things as well. But I think she's comfortable in her house. (Mrs. BD, P1, 242-251)

Mrs. ED talked about the possibility of her mother living in a nursing home.

> But if my mom has to go into a nursing home, I would want her here [in a nursing home located closer to daughter's home] . . . She is sound of mind. If something happens, if she was disabled, where she can't get around, and I would have to put her in a place [nursing home], ...because she could not take care of herself anymore. (Mrs. ED, P1, 693-1250)

Mrs. HD talked about she and her sister sharing the responsibility of caring for their mother.

> We [Mrs. H's daughters] would probably share the responsibility. We would probably take her into our own homes . . . .you can't say that because if they had [a] massive stroke or something, but if at all possible, that's what we would do. (Mrs. HD, P1, 274-282)

Although these contingency plans were being formulated in the minds of the adult children, they were not always specifically shared with the parent. Mrs. OD and Mr. OSL talked about having Mr. O live with them, but had not discussed this possibility specifically with him.

> Mrs. OD: If there's anything seriously wrong, they know they call me. The doctors call me, you know, if he goes to the hospital or something. They call me and I'm down there. And they just know that he's coming home with me.
>
> Mr. OD: This is his own life. He knows [if] there are some problems somewhere along the line, he just comes here. Basically. (Mrs. OD and Mr. OSL, P2, 818-830)

The Adult Child and Decision-Making

The adult children will *take action* if they feel their parent's safety is threatened, overriding what may still be a priority for the parent.

> If it ever comes to the point that he just falls down or does get hurt or anything, he will just come here. I mean we would never let him just stay there and not, you know. (Mrs. OD, P2, 316-322)

The adult child taking action also will occur if their personal disequilibrium has reached an intolerable point. The adult child's needs may take priority over that of the parent's balancing. This situation was mentioned by Mrs. ADL, caring for her terminally ill mother-in-law.

> And, as long as she is comfortable here. And, I see no reason why she can't. Although I will not undermine my own health because I probably still have 25 years and I would like them to be as healthy as possible. But as long as she can get up, and she may be up until she draws her last breath, be able to get up out of her chair and get to her bed with her walker, get to the bathroom. (Mrs. ADL, P1, 1155-1165)

The adult children realize and acknowledge that they may need to assume a more prominent role in the decision-making process of their parents. Conflict with the parent was anticipated if the adult child needed to take action that would be contrary to that chosen by the parent. Physical safety was the priority when the adult child became directive. Mrs. HD and Mrs. ED talked about the difficulty of being "firm" with a parent.

> So in one respect you have to be a little more firm [mother saving her mail from Medicare for the daughter to review] . . . .but you have to respect their wishes as much as you can as long as it doesn't endanger their lives. (Mrs. HD, P2, 852-857)

> Just to let them know that you love them, and you are only doing it [moving parent from their home] because you love them and want the best for them. (Mrs. ED, P1, 1196-1200)

Mrs. BD was not able to assume this more dominant position with her mother.

> I don't like to see her drive, but on the other hand, you can't just tell your mother, "No, you can't drive." (Mrs. BD, P1, 48-52)

> And I think she doesn't drive too much. I think she's okay with just driving with me. I hope (laugh). (Mrs. BD, P2, 1149-1153)

Mrs. BD found that as time passed, her mother (Mrs. B) recognized how she needed to shift her own sense of self (*cognitive awareness*) and take actions to maintain her balance. This recognition by the mother produced agreement between mother and daughter on how to maintain the mother's balance without the daughter having to be more directive. Also the mother's values were not threatened.

> And I think, like a couple of years ago, it would have been too much for her because she would have tried to do the work [hosting the family reunion], you know. But she's far enough along in her, in everything now, that she'll accept it and she'll let us do [prepare for the reunion] instead of trying to do herself. She'll say, no, I can't do it. (Mrs. BD, P1, 1128-1138)

The Adult Child's and Parent's Values

How the older person maintains her/his balance is a reflection of personal values. A critical aspect of the balancing process for the older person is maintaining a sense of self and control (*values*) as manifested by whether the determination of imbalance is made by her/himself or by the adult child. Chenitz (1983) discussed this concept when she referred to whether the nursing home admission was considered voluntary by the older person. Chenitz found that the older person wanted to be involved in this decision of whether to move to a nursing home or not. Involuntary admission was one of the conditions that caused the older person to resist the entry into a nursing home in that study.

During the current research study, no older person interviewed mentioned being pressured by others to make a permanent change in the *centrality* dimension of balancing. The centrality dimension (what is most important in maintaining the self) is a direct reflection of the older person's *values*. The statements of Mrs. ADL, Mrs. BD, Mr. IS and Mr. and Mrs. OD reflected the adult children's value that the parent should continue making his/her own decisions when mentally capable.

> She vacillated for several days there whether or not she would have the surgery or what she wanted us to say, "Do this, do that." We said, "No that's not our decision, that's yours." So she decided she would go for the surgery. (Mrs. ADL, P1, 130-136)
>
> [Does she drive?] She does occasionally and that is a concern for me because I don't think she should be. But she never drives to [larger city approximately 50 miles away]. But sometimes she'll drive into [local, smaller community] or if she has a hair appointment then she'll drive over there or to [senior] lunch if I'm not going for some reason. (Mrs. BD, P1, 35-48)
>
> He was back here [father visiting son's home in another part of the county a few years previously]. . . . And we went through many, many places that he might move to. And . . . he decided that this was not his place because he was not familiar with our area . . . No, that wouldn't be the thing for him to do. (Mr. IS, P1, 247-260)
>
> [After Mr. O had been hospitalized] Mrs. OD: He stayed here for a week and then . . . [went] home. It would be easier if he stayed here [at her home].
>
> Mr. OSL: But he likes his independence. And you can't take that away from somebody.
>
> Mrs. OD and Mr. OSL: As long as he is able to take care of himself, that's important . . . His mind is . . . [Mr. OSL completes wife's thought] his mind's very good. (Mr. OSL and Mrs. OD, P1, 55-84)

Mrs. GD's descriptions of her interactions with her father also emphasize the value of the adult child that the parents should continue making their own decisions.

Mrs. GD listed a variety of reasons why she felt her father would have a better quality of life moving to a foster home, but insisted that he would be the one making the decision: "He's capable of still making his own decisions." Mrs. GD told her father, "If you really don't want to leave your home yet, then you shouldn't go." By the second research visit, Mrs. GD and her father discovered that at a lower altitude he could breath easily without supplemental oxygen. He considered moving to a foster home located near sea level closer to another daughter to gain this resource. Mrs. GD thought he was in the process of making this decision. "He just hasn't said, 'Okay, I'm ready to go.' So, you know, I don't know when he is. This is, it's really hard."

Mrs. GD realized that her father was lonely living alone. From the past experiences of other family members, Mr. G realized that he would retain his freedom in a foster home. By renting his home and not selling it, Mr. G also retained the "option to come home. Because if he's really miserable, I want him to come back." Although Mrs. GD felt her father would be happier moving to the foster home, she admitted she could not be sure, "that's not reality."

Mrs. GD wanted her father to make his own decisions, because "they lose so much so fast," she did not want him to lose the opportunity to make his own decisions when he was still capable. This was a reflection of Mrs. GD's values. Her brother disagreed and felt Mr. G should be in a foster home. "My brother [who] would probably put him in foster care, it's not that he doesn't care, it's just that he is so busy." Mrs. GD, indicating the "it's really hard" waiting for her father to decide whether he would move to a foster home and being afraid her brother would make the decision for his father if he was providing the care, are examples of the adult child finding it difficult to manage their own affairs at the same time helping the parent maintain their own balance.

The older person is also aware that the adult child has a life of her/his own. The older participants talked about not wanting to ask for help from the adult child unless it was considered necessary to maintain their balance. Mrs. E, Mrs. H, and Mrs. K expressed the *values* that you use the help of adult children discriminately so as not to overtax the family and to insure that you maintained *control.*

> But like I said, they [adult children and grandchildren] all have responsibilities. Why should [I] have them running around doing things for me. I'm not hurting. I can't do what I want to, but I can behave myself and not make it hard for them. (Mrs. E, P2, 474-482)
>
> But they're [grandchildren's family] so busy. I don't expect them to stop so often. Unless I call and need them or something they would come. They have their own life. (Mrs. H. P2, 417-422)
>
> She [daughter] wanted to come the second day [after Mrs. K fractured her arm]. And, golly, it was going to cost them $700 I think to get immediate [flight] . . . So anyway, I said, "Well actually, I'll be honest with you, we'd [couple] rather be alone right now." Because the two of us work pretty good together and he [her husband] wasn't hurting. He was in good health. (Mrs. K, P1, 1403-1416)

The older person was faced with many *disrupters* that threatened her/his routines and personal *resources.* As Lustbader (1991) described the older person's position, the dilemmas of dependency, he/she was needing to accept additional help from other resources to maintain or restore balance. Shifting one's sense of self and redefining one's priority routines was needed. This is a difficult process for the older person. The adult child, on the other hand, is concerned with the managing of two families, their own and the parent's. This dual balancing by the adult child of their own affairs and the parent's balancing triangle made the process even more complex for the adult child, an example of role strain or burden. It could result in disagreements between adult children and parents over the parents' need for more help or the need to move to get more help.

Summary

The older person's balancing process includes the *components* of the balancing triangle (routines, resources, disrupters), the *dimensions* of the state of balance (centrality, urgency, permanence, and awareness), and the *outcomes* (accepting, prioritizing, taking action). The older person's *values* influence all of the concepts contained within the balancing process. The caregiver's perspective of the older person's balancing process was also discussed.

CHAPTER V

DISCUSSION

The overall purpose of this study was to describe and analyze the process used by rural older people and their family caregivers in deciding whether and when the older person needs a more supportive living environment. Decision-making theory had been reviewed and was found incomplete when clinically trying to understand the process used by families faced with deciding how to meet the needs of older members as they aged. In the investigator's clinical experience, the older people did not need help making a decision; they knew what they wanted to do. The caregivers (professionals and adult children) usually needed no help making a decision. They thought they knew what the older person should choose in terms of getting help. However many times the older person and caregiver chose different alternatives. Using grounded theory methodology to analyze qualitative data describing the older person's and caregiver's processes, reasons for the different perspectives were found and explicated in the generated theory, resulting in the balancing model.

The balancing model with three *components* (routines, resources, disrupters), four *dimensions* (centrality, urgency, permanence, awareness), *outcomes* (accepting, prioritizing, taking action), and the overriding influence of *values* (independence, control, self-reliance) displays the many elements the older person weighs when deciding whether one's balance is threatened and whether any changes in her/his chosen routines or resources are needed. Viewing the balancing process from the older person's perspective helps the caregivers discover how they can assist the older person maintain the balance.

While the balancing model shares some concepts found in traditional decision-making or problem-solving theories (accepting, prioritizing, taking action), it also emphasizes processes that precede decision-making and have an effect on the action taken. The current study's unique contribution to the knowledge base is identification of these pre-decision-making processes: the components and dimensions of balancing. How the individual's values and perceptions influence the process was also discovered and included in the model.

The overriding influence of the older person's *values* on the other concepts in the balancing model is apparent in many of the concept definitions. *Routines* maintain a sense of self, *disrupters* are a perceived threat to the older person's routines and resources, *centrality* represents what is most important in maintaining the self, *cognitive awareness* includes realizing one's sense of self is not consistent with reality and acknowledging a shift in one's sense of self is needed, *prioritizing* involves determining which routines and resources are most important to the older person's sense of self and consonant with her/his values. Balancing was important to the older person because maintaining one's routines represents what the person holds most dear: her/his values. One's daily routines contain meaning, and, some writers infer, sacredness to one's routines (Norris, 1991). This interweaving of one's daily routines with values is the reason *maintaining* the *balance* between one's routines, resources, and disrupters is so important.

A way to visually illustrate how the balancing process occurs over time is demonstrated by the trajectories developed for each older person or couple. The trajectory illustrates that a period of time may be required for the older person to make a decision when a non-crisis situation exists. Various states of balance being present at different points in time is also discussed and illustrated by the *balancing continuum*.

The Balancing Model and Other Theories

The balancing model was developed through category refinement and integration while checking with the trajectories developed for participants. After the balancing model was sufficiently grounded in and developed from the data, the investigator reviewed other theories that related to the balancing conceptualization (Glaser, 1978). Theories of gerontology, adaptation, stress and coping, decision-making, and crisis intervention were compared with the balancing model to help expand, as the data allowed, the conceptualization of the process and place the model within the existing theory base. These ideas increased the investigator's theoretical sensitivity, and provided a degree of support for the balancing conceptualization. A fuller perspective on how the balancing model "fit" with the existing literature was obtained. Appendix L contains summaries of the other theories compared with the balancing model. Six of the theories will be discussed to show how the balancing model compares with these conceptualizations.

Crisis situations and the accompanying emotional discomfort they generate can make a person aware of the need for change and decision-making. Crisis intervention theory (Aguilera, 1994) and the balancing model were similar in that both acknowledged this emotional disequilibrium that existed in a crisis or when change was needed. Both theories considered the non-crisis state of the individual to be the customary state of equilibrium. The theories agreed that the problem-solving process could be used to help restore the equilibrium. In the crisis intervention theory the factors that could affect the re-establishment of equilibrium were identified as perception of the event, available situational supports, and coping mechanisms. The balancing model identifies *disrupters* and *resources*, concepts similar to the equilibrium restoring factors of crisis intervention theory, but, in addition, emphasizes the individual's *routines* that reflect one's *values* as part of the balancing process.

Crisis intervention theory also drew from Lazarus and Folkman's (1984) conceptualization of psychological stress, appraisal, and coping. Cognitive appraisal was defined by Lazarus and Folkman as the process that determined why and to what extent a particular transaction was stressful. Cognitive appraisal shaped the individual's emotional reaction to the transaction. This connection between the cognitive process of appraisal and an emotional response was supported by the qualitative data from this study. The concept of *awareness* in the balancing process model contains the *affective response* to disequilibrium and the *cognitive processes* of realizing that one's sense of self no longer agrees with reality and acknowledgement that a shift in one's sense of self is needed to restore agreement with reality. Lazarus and Folkman's conceptualizations and the balancing model also agree in the sequencing of the process. Cognitive appraisal was identified as mediating subsequent thought, feeling, and action (1984, p. 45). This parallels the idea in the balancing model that *awareness* needs to occur before the person is willing to move on to *accepting* and *prioritizing*.

Festinger's (1957) discussion of the consonance or dissonance between pairs of cognitive elements that corresponded to behavior also assisted the investigator's understanding of the concept of *awareness* generated from the data. The *emotional responses* of awareness were initially identified, but the associated *cognitive processes* were not as obvious to the investigator until examining Festinger's theory of cognitive dissonance. The cognitive component of shifting one's sense of self to correspond with reality after realizing the sense of self no longer agreed with reality was a more subtle process embedded in the older person's descriptions of making changes.

While the balancing model defines *disrupters* as threatening the older person's routines and resources, Lawton's (1982) theory of environmental press provided greater understanding of the balancing process. Lawton discussed environmental press as the environmental stimulus or context having potential demand character for an individual leading to a behavior outcome. The individual became aware of the environment when the press increased or decreased. Lazarus and Folkman (1984) described a transaction as being appraised as a harm/loss, threat, or challenge. In contrast, the current study's findings demonstrate that awareness of imbalance in the routines-resources-disrupters triangle occurs only when there is an increase in disrupters (threat to ability to continue routines with given resources). A decrease in the accumulation of disrupters and a return to balancing at the former lower trajectory level did not occur in this group of older participants with a mean age of 81 years. The trajectories visually confirm that a return to a prior trajectory level was an event that seldom if ever occurred for this group of older people.

Selective optimization with compensation, as devised by Baltes and Baltes (1990) and confirmed by them with older people living in nursing homes, strongly supports the balancing model. Selection indicated that the individual chose high priority domains to continue when faced with the decline of functioning with age. Optimization referred to the individual choosing behaviors that would increase one's reserve capacity and achievement of one's chosen life course. Compensation involved using supports to offset losses in personal functioning. In the balancing model this is conceptualized as the participant *maintaining routines* with selected *resources* when the balance is threatened by *disrupters*. Personal *values* influence how routines, resources, and disrupters are *prioritized* by the individual.

The nursing model reported in the literature that most closely represented the decision-making process of older people faced with a move was based on a grounded theory study done by Chenitz (1983). Five basic conditions were identified by Chenitz as influencing the person's response to nursing home admission: importance, desirability, legitimation, voluntary nature, reversibility. These basic conditions found by Chenitz are very comparable to dimensions and concepts contained in the balancing model. The balancing model covers the broader area of receiving help in the home or moving to receive the help needed and not only the move to a nursing home.

In the balancing model, *routines*, meaningful activities of the older person, and *centrality*, the older person's determination of what is most important in maintaining the self when restoring balance, both reflected the older person's sense of self and values. Chenitz's (1983) basic condition of importance, how much the nursing home admission disrupted the older person's maintaining control and independence, also reflected values. The older person *prioritizing* was described by Chenitz in the concepts of desirability and voluntary, the older person's assessment of the advantages and disadvantages of the move to the nursing home and making the decision to move, respectively. Another dimension of the balancing model, *permanence* is defined as the older person's perception of whether balancing can continue indefinitely as is, whether it is temporarily upset, or whether lasting changes will need to be made to restore a state of balance. The older person's perception that the imbalance is a temporary disruption and balance will be restored in time without significant changes in one's routines and resources, is similar to Chenitz's condition of reversibility, the older person's hope that the nursing home stay was not permanent.

Legitimation, finding acceptable reasons for the move to the nursing home without fitting the stereotype of the typical nursing home resident, was Chenitz's (1983) fifth basic condition. In the balancing model this legitimation could be seen as a way to reduce the dissonance between the older person's previous sense of self and their sense of self as a nursing home resident, *cognitive awareness*.

The element of time surfaced throughout the analysis: (a) present versus future orientation of the older person and adult child, (b) visualizing the changes in the dependency trajectory over time, (c) uncertainty, (d) changes in confidence level over time, (e) balancing as a continuum. Conceptualizing the move to the nursing home as a transition (Chenitz, 1983) also focused on the element of time.

Implications for Nursing Theory

Although decision-making models specifically developed for working with older people in clinical settings have been found in the literature since this study was initiated, they are broad systems models and focus on the ideal decision-making process or crisis situations (Beckingham & Baumann, 1990). The balancing model based on grounded theory analysis of empirical data both expanded these problem identification conceptualizations and dealt with a substantive area; the older person's decision-making process related to receiving help and deciding whether moving from one's home was required to obtain these needed resources. The conceptualization of *balancing* one's *routines*, *resources*, and *disrupters* expands the problem identification phase of the ideal decision-making models. From the investigator's clinical experience problem identification was a major area of disagreement between the older person and adult child caregiver, and, therefore, affected the remainder of the process.

Comparison and Contrast of the Balancing Model
with Clinical and Gerontological Literature

Older Person's Perspective

Many of the initial caregiving studies were motivated by the hope that ways to decrease the caregiver's burden, stress or role strain could be found (Archbold, Stewart, Greenlick, & Harvath, 1990; Deimling & Bass, 1986; Montgomery, Gonyea, & Hooyman, 1985; Zarit, Todd, & Zarit, 1986). Several of these studies focused on the difficulties caring for an individual with Alzheimer's Disease or related cognitive impairment (Pruchno & Resch, 1989; Zarit, Ory, & Zarit, 1985). This made the inclusion of the care recipients more difficult for ethical and practical reasons. The older person's perspective only was discussed in a limited way in the literature concerning decision-making, whether in terms of hospital discharge planning decisions or decisions made in the home regarding care. These gaps lead to the current study focusing on the care recipient (older person) in addition to the family caregiver. As stated by Pellegrino (1985) caregiving "must be square with what the patient thinks is 'worthwhile' given the circumstances and choices forced by illness" (p. 21) if the caring ethic is honored.

Adult Child Caregiver's Perspective

The adult child caregiver may experience increasing burden, stress, or caregiver role strain while helping the parent balance because the adult child also may be attempting to maintain her/his own balance. Although a category of "joint balancing," the adult child balancing her/his own routines, resources, and disrupters while helping the parent balance, was not completely developed in the current study, the existing caregiver literature seems to support this conceptualization. The adult child having to juggle a variety of roles was discussed almost 15 years ago by Brody (1981) when describing the "women in the middle," women caring for their own families and children while helping an aging parent. Bowers' (1987) grounded theory study of intergenerational caregiving demonstrated that caregiving involves hands-on tasks, but also mental activities, including planning and decision-making.

Mr. I's son recognized joint disruption of his father's balance and his own life when describing the situations after his father's accident resulting in blindness and again when home health care terminated services to his father. When Mr. IS, who lives in a different part of the county from Mr. I, came to see his father after the accident, he recognized the imbalance and described his own reaction, "I was at my wit's end" trying to decide how to help: son's affective response. A sense of urgency existed for Mr. IS: "I had to go out and take care of the situation." Mr. IS felt balance was restored for his father after arranging home health care, so his father was able to return living in his own home. Mr. IS was able to return to his own home in the East knowing his father was where he wanted to be.

Home health services provided a resource for awhile and balance returned for Mr. I. But then the home health agency produced imbalance for both father and son by not giving Mr. IS adequate advanced notice that their services would be terminated. Mr. IS stated, "So it didn't make my visit (laugh) very pleasant." His father, Mr. I, needed the resource of home care to continue living in his own home. Living at home continued to be the priority routine for both Mr. I and his son showing their agreement on the centrality dimension.

> Then they [home health agency] got a hold of me a day or so before I was to leave [return home from visiting his father] and told me all of these things. That they didn't feel comfortable with continuing the service . . . I had no forewarning. My visit was not for that particular purpose [arranging new home care for his father], but it degenerated into that situation and I felt that it would have been nicer to have known. I could have arranged my travel so that I could have spent more time had I known that this is what they were going to do. (Mr. IS, P2, 187-219)

Balancing was maintained by Mr. IS arranging private home care for his father. This insured the priority routine of his father which was living in his own home maintaining his daily activities. Mr. IS used the fact that his father was able to handle his finances "extremely well" as a way to assess his father's personal resource of mental abilities. His father's mental alertness was Mr. IS's justification for why his father did not need to leave his home for a care facility.

> I think you put somebody, a person who's fairly mentally active in with a group of people who are just zombies, and eventually, he's going to be in the same apple barrel, you know. He's going to turn into one of them. And so that was one of the considerations that we wanted to keep him away from. Not that they don't get good care [in a care facility]. They do . . . he's just not ready for that. (Mr. IS, P2, 416-433)

The other adult children in the present study mentioned having to juggle their personal balance with their parent's balance. Of these families, Mrs. ADL and Mrs. JDL seemed to be having the most difficulty with this juggling of their balance.

While the other parents remained living in their own homes, both the A and J families shared homes with their care receiver. Mrs. A was living in the home of her son and daughter-in-law (Mrs. ADL) and Mrs. JDL and her husband were living in the home of her father-in-law (Mr. J). Mrs. A was in the final stages of a terminal illness requiring extensive personal care from both family and formal caregivers.

> [Mrs. A's son] and I have put our lives on hold until, because we know that this is not going to be for a long time. Although, if I'd known it was going to be from (the later 1980s) until now, . . . I probably would have done something different [son and daughter-in-law had Mrs. A move into their home in 1980s] when she first started. . . . (Mrs. ADL, P1, 882-889)

> Mr. J, who experienced paralysis following a stroke, needed extensive care. Someday we'll have our life back, maybe. (Mrs. JDL, P1, 237-239)

> I get flustered, you know. Think sometimes, why can't we just go to McDonald's tonight or something. Well we can't leave for that long (sigh). [McDonald's is 50 miles away.] (Mrs. JDL, P2, 1266-1272)

Mr. J's son (Mr. JS) also recognized the imbalance his father's stroke created in his and his wife's life.

> I still have to be here all the time. I mean, you know, like I'm tied to this house. And, that's not good. (Mr. JS, P1, 1759-1762)

> [Wife] and I, we don't see each other. Because, now I'm home and she's gone [working out of the area 3 weeks per month]. (Mr. JS, P2, 1227-1233)

In the A and J families, the adult children and parents had many more overlapping *routines* and *resources* living in the same households and with the parents requiring a great deal of assistance from the adult children. *Disrupters* in either the parent's or adult children's lives appeared to have an immediate impact on the *state of balance* in each generation.

Although not expressed in such strong terms, the adult children living in households separate from their parents also indicated that they were juggling their needs with that of their parents' balance. Some examples from these adult children follow.

> I bought an apartment in town, that if we needed to be in town or if the winter was bad that we'd [mother and daughter] have a place to go. [Currently mother and daughter live in their own homes in a rural area of the county.] (Mrs. BD, P1, 1002-1005)
>
> I'm going to have, I'm taking a week off this week because I have my grandson. He's on school, spring break, but I can take another week later on. I'll go up [to visit her mother and help her get ready for a move] myself maybe just for a week. (Mrs. ED, P2, 219-225)
>
> When he [father] waits until the last day and he's out of this medication and he says, "Oh, by the way." You know, then I get a little frustrated with him. You know, I would rather he give me a couple of days, just in case I'm busy. (Mrs. GD, P1, 1866-1873)
>
> [Mother's and daughter's homes separated by several hundred miles] Usually when I go over I try to spend a week. And sometimes to get her caught up. With the building going on [mother's home remodeled] I was there a little bit more maybe. But in the winter with the weather bad, usually unless she doesn't feel well I don't go over there but maybe once a month for a couple of days. (Mrs. HD, P2, 653-663)
>
> Once or twice a week there's somebody up there to see him, really more than that. (Mr. OSL, P1, 173-175)
>
> Someone to keep the house up and I told him that I would do it. (Mrs. OD, P1, 332-334)

Continuum of Long-term Care

Financial resources being available influenced the thinking of the participants and helped determine what were considered viable long-term care choices. Near the end of the decision-making process the participants considered what supportive environments were available, but these options only were considered as "the last resort" as described by Smallegen (1985) while remaining in their own homes with needed help as the first choice. Nursing home care was the alternative discussed most frequently, but was the general term used by the participants to identify all the options available outside the home. Foster homes, residential care facilities, rehabilitation centers were often clumped under the term nursing home. For the participants they were similar because they all represented "not being home."

The older people and adult children were glad that alternatives were available. They did not indicate that they thought there was a lack of services in this rural area contrasting with Greene's (1984) speculation that the lack of community services in rural areas of Arizona was the reason rural older people were admitted to nursing homes at younger ages and with less functional impairment than their urban counterparts. Some of the out-of-state adult children commented that they felt fortunate that their parents had access to a variety of services in Oregon. However, these choices did not influence the balancing process except near its conclusion (prioritizing) and were considered "last resort" options. Three statements by participants (one older person and two adult daughters) describe their priorities.

> It wouldn't be if I want to go, because I'd never want to go. It would be if I had to [go to a nursing home]. (Mrs. A, P1, 747-749)

> It is not like I will just put her [mother] someplace [nursing home] and go on with my life. I will make her as comfortable as I can [in the nursing home]. . . . When we put my mother [in-law] in a rest home, we did not have a choice. No, if she could [have gotten] people, and she could have taken care of herself, then I would have felt guilty. Then I could have taken care of her myself. In the situations she was in, I couldn't take care of her. There is no way I could have taken care of her [post-stroke, blind]. (Mrs. ED, P1, 1161-1223)

> We [daughters] would probably take her into our own homes. If we, you know you can't say that because if they [parent] had a massive stroke or something, but if at all possible, that's what we would do. (Mrs. HD, P1, 274-282)

An alternative considered by the older participants and some of the adult children as more acceptable than care in a facility was living with family, if the older person could not remain in their own home. However, living with adult children was also an alternative that the older people did not want to choose over remaining in their own home unless forced into this decision by declining health. As expressed by one of the older participants, but representing the position of many older people:

> No matter how much you love your children, you don't want to go [live with them] unless you really, really are down and out and can't take care of your self. As long as my hands and my legs are working, I'm going to stay in my own home and do what I have to do. And I think you're a lot better off that way. Then there's no complications. (Mrs. L, P2, 368-382)

Although the continuum of long-term care options provide a range of less restrictive environments from the clinician's perspective, these alternatives are generally considered lacking when compared to a "home"; a value shared by the older people and family caregivers. This is supported by the literature that describes the decision of moving to a nursing home as the "the last resort" (Smallegan, 1985) and the guilt experienced by the caregiver after the older person is moved to a more supportive environment (Kammer, 1994). Fleck (1987) described the decisions regarding the funding of health care programs as political and moral problems: whether, as a society, we will make home health care services more available so older people can remain at home versus needing to move to a different environment to receive the care needed. Fleck felt these issues should not be considered economic or technical or organizational problems exclusively. He advocated public debate on these issues so fair and cost-effective polices for financing health care for older people could be developed. The quantitative study by McAuley and Blieszner (1985; n = 1,240) indicated that when non-institutionalized people 60 years of age and older were asked to select the type of care/living arrangement they would prefer "if you became sick or disabled for a long time," 70% of the sample chose paid in-home care.

A lack of resources leading the older person to decide that moving from her/his home was needed was supported by the literature. Brody (1978) found that urban people who applied for the Community Housing for the Elderly did so primarily because they felt lonely and isolated, their current house was in poor condition, and they feared crime in their neighborhoods. Béland (1984) looking at why older urban French speaking Canadians applied for admission to a residence of some kind, found that older people wanted to leave their homes because they did not have sufficient resources to stay in them. In the current study, the older participants often mentioned being lonely, but were not fearful of remaining in their rural homes.

They would have enjoyed more frequent visits from family members, but generally realized that their adult children had their own responsibilities and lives to live. As stated by Mrs. H and Mrs. E:

> But they're [grandson's family] so busy. I don't expect them to stop so often. Unless I call and need them or something they would come. They have they're own life. (Mrs. H, P2, 417-422)

> They [adult children and grandchildren] all have responsibilities. Why should [I] have them running around doing things for me. I'm not hurting. I can't do what I want to, but I can behave myself and not make it hard for them. (Mrs. E, P2, 475-482)

Remaining at home maintains the values of independence, control, and self-reliance identified by participants in the current study. A study by Coulton et al. (1989) had a similar finding in that older patients who went home after being hospitalized were less anxious about the decision regarding post-hospital care and felt more control over the decision than the older patients who went to a nursing home. The older patients at home were more satisfied with their surroundings 30 days post-hospital discharge.

A number of researchers (Kahneman, Slovic, & Tversky, 1982; Steinbruner, 1974; Gardner, 1985) identified the framing of a problem as important to its solution. In the current study the problem was framed by the older person as she/he wanted to remain at home, whether "home" was her/his long-term home, more recent home, or a relative's home. This choice supported the older person's values of maintaining independence, control, and self-reliance. The home allows the older person to continue priority routines that are an extension of her/his values that reflect a sense of self. The adult child supported this choice as long as the older person was considered safe at home. Horwitz and Tognoli's (1982) qualitative study found similar results; "home is a term used to link a state of being and a sense of self with a place" (p. 340). Rowles' (1980) and Rubinstein's (1989) studies demonstrated that place and self are interrelated. Therefore a rapid change in place can cause disorientation and a loss of self. We as a society should continue to support programs that allow the older person to stay at home.

The family caregivers in the Sims, Boland, and O'Neill (1992) study felt that they did not have any options when making the initial decision to provide home care. A few of the adult children in the current study recognized that there were alternatives for their parents other than the adult child providing the care. Mrs. GD and Mr. IS realized home care and foster home care were acceptable options to provide their fathers' the care they needed. However, the majority of adult children (*N* = 6) in the current study considered nursing home care a last resort if they were unable to provide their parents the needed care at home.

Meaning of Home

Three psychosocial processes as described by Rubinstein (1989) were used by older people to endow the home environment with meaning. These psychosocial processes were easily identified in the current study's data and helped to explain how home and one's daily routines become so embedded with meaning. The person "orders" the environment putting "into practice . . . his/her vision . . . of what is proper and what it means to be a person" (p. S48). Mr. J's vision of ordering his environment was not having a bed in the living room, and not being around other people with his "old bag of pee." Mr. J was paralyzed and had a urinary catheter.

> Everybody's always giving me [heck], because I don't want to go out and set in the living room. And I just feel embarrassed to go riding around other people with an old bag of pee sitting there. (Mr. J, P1, 651-657)

His personal ordering of the environment meant that Mr. J seldom left his bedroom.

For some individuals environmental features become an extension of the self. As described by Rubinstein (1989) these environmental features "carry the load of personal meaning and therefore aid in the maintenance of self, when it is threatened" (p. S50) Mrs. B had lived in this rural area for over 65 years and in the current home 50 years. In describing her home, Mrs. B said:

> Well, you get pretty well attached to it. And it has been home for a good many years. And the river out here has been kind of company, too, for me. And beaver and muskrats and different things out there. Fish. We have fish out there that's been jumping . . . It's nice to watch them. (Mrs. B, P1, 376-389)

Mr. O felt it was important for him to return home after a hospitalization and short stay at his daughter's home so he could continue building fires to heat his home. Maintaining his fire carried "personal meaning" and aided in the "maintenance of self" in Rubinstein's words (1989, p. S50).

> I should go home where I can get out and would have to, carry wood for myself, you know. (Mr. O, P2, 215-218)

> But I can't carry it in from out there [in yard]. My son-in-law, he carries it [wood] in and puts it on the porch then I can carry a stick in here. (Mr. O, P2, 537-540)

While Mr. I had only lived in his current home about 15 years, it was the last home in which he and his wife (now deceased) had lived. The home also contained furniture items from his ancestors.

> It's a nice little house. In fact, it's a good little house. Well laid out. (Mr. I, P1, 438-440)
>
> My oldest sister bought that [lamp] in Canada. [That table looks pretty special, too.] It is. My mother's oldest brother gave her that for a wedding present in 1884. That marble top was part of their bedroom set they bought when they were married. You don't see marble tops like that any more. (Mr. I, P1, 552-568)

Rubinstein (1989) described "entexturing, the fine-tuning of the extra body environment around the person" (p. S51). This fine-turning of the environment allowed the older person to continue his/her chosen routines. Mr. O recognized that he had problems walking and at times needed the use of two canes. However he continued to carry in wood to build his fire. This was not just for physical warmth because his oil heater was working well. It was a routine that Mr. O had done all his life and, although now modified, he continued.

> And I said I should go home [after staying with a daughter following a hospitalization] where I can get out and would have to carry wood for myself, you know . . . I try to get around here [at home] without a cane, you know, more than anything. . . . (Mr. O, P2, 215-218)

For Mr. O carrying in his wood and building his fire meant he was not "helpless." This familiarity with the physical environment of the home that permitted the continuation of activities that would not be possible outside this home environment was called "physical insideness" by Rowles (1980).

As the older person's physical capabilities declined, Rubinstein (1989) described how the individual began living in "central zones" closing off areas of the house considered peripheral. Energy was saved for routines considered necessary for personhood, a concept paralleling Baltes and Baltes' (1990) selection, the choosing of high priority routines when faced with declining functioning. After having his stroke, Mr. D restricted his activities to his chair in the living room. A cabinet next to his chair contained stereo equipment, controls for the television, important papers, his medications, and telephone. On the other side of his chair was a table with his mail, medical equipment, and urinal. Two trash containers were beside his chair. The oil paintings that his wife had done and his television faced his chair. This was where Mr. D spent his time when not in bed. Even the mail carrier recognized Mr. D's centralization, knocking, coming in to place Mr. D's mail on his table because Mr. D no longer was able to go outdoors to the mailbox.

The fine-tuning of the environment done by the older person is a concept sharing commonalities with the fine tuning of caregiving done by the caregiver for the care receiver (Cartwright, 1993). The fine tuning of the caregiver was defined as "the efforts by the caregiver to accommodate changing frailty trajectories with personal histories" (p. 31). This fine tuning done by caregivers was necessary for enrichment in family caregiving to older people. Enrichment was defined "as the process of endowing caregiving with meaning or pleasure for both caregiver and care recipient" (p. 6). The older person has been fine-tuning her/his environment over the years to accommodate to her/his declining personal capabilities so routines judged meaningful can be continued.

Methodological Issues

Key aspects of what the investigator learned from "doing" this study and gaps found in the analysis methods will be described: (a) the difficultly arranging but the value of interviews with multiple family members, (b) telephone contact as an interviewing approach, (c) problems with maintaining confidentiality, (d) the lack of methods for analyzing joint interviews, and (e) the value of other colleagues' input during analysis. The content of the study will be elaborated with the rural setting's influence compared with previous urban studies.

Family as the Unit of Research

Although looking at the family as the unit of research is becoming more popular as evidenced by the development of family nursing models (Beckingham & Baumann, 1990; O'Neill & Sorensen, 1991), family nursing conferences, and the new *Journal of Family Nursing*, the "doing" of family research is complex. Although Tilden, Tolle, and Garland (1993) in their research found interviewing two family members proved most valuable when describing the end-of-life decisions made by these families, it was difficult to arrange interviews with more than one informal caregiver in this study. Work schedules, family activities, and caregiving functions monopolized the time of these families. The distances that the investigator needed to travel to permit face-to-face interviews with rural participants and poor weather conditions also hindered data collection from more than one caregiver.

Acknowledging the above difficulties, having both the older person's and caregiver's assessment of the older person's current balance and seeing the older person functioning in her/his home environment was essential for evaluation of the decision-making process: (a) many of the older people seemed to have difficulty admitting to changes in activities that reflected a shifting in one's sense of self and (b) the adult child may be overwhelmed by the losses identified in the parent's functioning and not recognize the strengths of the parent that remain. For example, several of the older people had cars and trucks in working order and fully insured although these vehicles were driven infrequently or not at all. The car in the garage or the truck outside the front door symbolized *independence* and *control.* Information from the adult children often gave the investigator a clearer picture of how much the parent was actually driving. The older people themselves concerned with issues of safety would gradually decrease how far they drove and how often and depended more on family members and friends for transportation.

The adult child may describe the parent's needs and capabilities in terms that made the parent sound more dependent than was the actual case. In comparison to the parent known as the "all powerful, independent person" (Mrs. BD) of the adult child's youth, the older parent was dependent in ever expanding areas. The personal resources and strengths that the parent continued to retain were overshadowed in the adult child's perception by the parent's dependencies. The investigator's observations of the older person within his/her home which supported the older person's functioning added a great deal of information to the adult child's assessment of the parent.

Interviewing Methods

Telephone interviews were another concern going into the study. Being most accustomed to face-to-face interviews with patients, the investigator initially questioned the depth of information that would be gained from the telephone interviews with caregivers living outside the county. Grounded theory, as a qualitative method, depends on rapport and prolonged engagement with the participants to establish the credibility of the data. The investigator feared that it would be more difficult to develop this rapport and, therefore, the data from the telephone interviews would be compromised. This fear was unfounded. The data from the six telephone interviews with three long-distance adult children caregivers were very valuable to the development of the balancing model. Although the contextual dimensions of the setting were lost, telephone interviews make collecting data in rural areas and in a society with intergenerational families separated by hundreds (if not thousands) of miles one of the few qualitative methods available to gather this information. The use of the telephone has been suggested as a cost-effective intervention strategy (Skipwith, 1994) to provide counseling services to caregivers of older people.

Maintaining Confidentiality

The investigator found it very difficult to maintain confidentially and, at times, may have inadvertently breached these confidences when interviewing members of the same family. When discussing the same situation with different family members, the investigator found that her questions and comments would naturally refer to information obtained from another family member if she was not constantly on guard. Confidentially was also more difficult to maintain when different family members were interviewed one after the other to make a data collection trip more productive. With the information still fresh in the investigator's mind from the first interview, it was difficult not to make references to the first individual's perspective in the questions asked of the second family member. At times the investigator was not aware of this breach in confidence until reviewing the tape recordings. This need to "be on guard" took away some of the spontaneity from the interviews and was exhausting for the investigator.

Analysis Methods

Methods to analyze interviews done with more than one informant at the same time are also needed. Although the original study design indicated that participants would be interviewed separately, this proved impossible at times. These joint interviews provided valuable insights into how the older couples or adult children caregiving spouses each contributed to the decisions made. Their give and take more accurately reflected the reality of the family decision-making process. Although the investigator intuitively knew that this would be the case, these combined interviews were discouraged by more experienced researchers because of the lack of guidelines for the analysis of these combined interviews. Analysis of family interpersonal and intrapersonal interactions is complex and made more so when adding the intergenerational dimension. How to deal with this level of analysis has not been adequately addressed in the literature.

Analysis with the Input of Others

This research product is of better quality having had the feedback and insights of a variety of sources: dissertation committee members, graduate qualitative and gerontological nursing colleagues, caregiving experts (formal and informal), and participants. The investigator's understanding of the decision-making process was expanded in breadth and depth. Their guidance prevented premature restrictions on category identification, increased my theoretical sensitivity, and prevented the theory from being "thin." These individuals served much as would a revolving collaboration seminar as discussed by Glaser (1978, p. 33), a seminar of members each helping the others analyze data throughout the grounded theory process. For the beginning researcher this feedback seems vital for the development of emergent theory.

Context

The data originated from older people living in a rural area of the Pacific Northwest. The adult children interviewed were selected by their parents and were scattered throughout the United States. The rural influence on the older participants was clearly evident in aspects of the data from which the model emerged. For example routines that were important to several of the older people involved building a fire to heat their home. Even participants that no longer had to depend on wood heat, because of having alternative heating sources installed in their homes, continued to build fires and preferred wood heat.

Driving was another routine mentioned by all but one of the older people as an activity they had limited or relinquished. Driving is a symbol of independence for all adults (and teenagers) in this society, but in a rural area where public transportation is limited or does not exist, being able to drive is almost a necessity. The disrupters included physical or mental declines that interfered with one's ability to drive. Resources in the form of neighbors, friends, family members, taxis, or the senior van had to be found to provide transportation when the older people had to drastically limit or completely relinquish driving themselves.

The majority of the older participants had lived in their homes for many years. During this time they had developed relationships with their neighbors that now proved to be resources—individuals that helped with more than driving. The adult children who no longer lived in the area were reassured knowing that these neighbors were monitoring their parents. In one case, a daughter was surprised that this relationship had developed. Mrs. ED stated, "And everybody checks on her, I am sure. When I go home, her neighbors are in the house. People that when I was younger she didn't get along with as well are now their best friends."

The rural influence was also evident in the trust expressed by the older people in the home health staff that visited. Doors were kept unlocked so the aide could come in without knocking. The home health aide was given a key to let him/herself in if the older person was unable to answer the knock. This complete trust in the staff that was emphasized by several of the older people receiving this care was best expressed by Mrs. E, "I'm not worried about any of the girls that have come in. They all, I don't think a one of them would take anything that does not belong to them."

A characteristic identified by Dietz (1991) associated with older rural woman was their use of inner resources and prayer as a coping strategy. Her participants talked about trust or faith in God's will that provided a deep sense of hope that things would work out. Similar references to a belief and trust in God were made by both older men and women participants in the present study. Examples from three of the participants follow.

> I think that if I wasn't a Christian and didn't believe in prayer and depending on the Lord the way I do as much, I think it would be harder to handle. (Mrs. C, P2, 1389-1394)
>
> Well I just think whatever happens is probably God's will. Whatever it is, I'm going to try to fit in. (Mrs. H, P1, 829-833)
>
> I know one thing. One day here I had, I was so heavy [depressed] I just broke down and cried. I couldn't, I said, "I can't go on without her [his wife was in the hospital]." And you know, with God, you can, you can go ahead. (Mr. P, P2, 1590-1596)

Dietz (1991) also mentioned the women in her study found the rural setting calm and tranquil. Being away from the "watchful 'eyes' of a neighbor" represented freedom (p. 269). The older women in Dietz's study did not find the rural setting as isolating as younger woman had (Catalano & Dooley, 1977). In the current study although some of the older participants talked about the eventual need to move closer of a town, they hoped to remain in the rural home as long as possible. The older people that had lived in the area for 10 to 20 years, had specifically chosen the setting for retirement when health was more vigorous and driving was not a problem.

> He needs to be around that [the land]. Like we've rent[ed] a park or something [living on their property]. (Mrs. K, P1, 1160-1162)
>
> I'd retired and I did a lot of it [hunting and fishing]. I wish I could do it again (laugh). (Mr. L, P2, 1058-1060)

With the mean age of the older people being 81 years and the youngest older person 70 years of age, these were individuals that remembered the Great Depression. This cohort effect was demonstrated in the values they expressed related to paying one's own way and not owing money to another person. Mrs. E's statements capture these values.

> I feel like I owe all of them [neighbors who help her] something, if I could just pay it . . . He [neighbor] come took care of my cat. He takes care of the pump [for water]. I don't have to worry about that . . . So I made him a loaf of bread . . . it's the first time I've baked bread since way last fall. (Mrs. E, P2, 358-380)
>
> But then I worked hard all my life and I just, well [what] I've got, I've earned. Or I feel I have. (Mrs. E, P1, 741-744)

As one daughter described her mother:

> These are Depression people. I mean, my mom, she's paid [medical and hospital] bills she should never have paid. I don't know if we'll ever get [it straightened out] just because she's afraid of being on their black list, as she puts it. (Mrs. HD, P1, 1037-1044)
>
> And Mom is real conscientious. She wants all her bills paid. And she paid a lot out of her own pocket instead of waiting for Medicare and her insurance to pay just because it bothered her so much. (Mrs. HD, P2, 348-355)

The older participants did not do a great deal of spontaneous reminiscing during the open-ended interviews although the opportunity was available. Past events were discussed in responding to the investigator's questions. Perhaps reminiscing, reminding oneself of the past, was not needed when daily the older person was reminded of the past and his/her place in it by one's surroundings and the flow of one's routines.

Limitations

Although grounded theory methodology allowed the investigator to develop the balancing model from empirical data of older people and family caregivers considering how to get more help or the need to move, some limitations exist. A discussion of these methodological issues follows.

Only one family moved between the first and second interview. Their decision to move had been made three to four years previously and the investigator was just fortunate to have contacted the couple at this moving time. In a study by Colsher and Wallace (1990) that looked at the anticipated and actual relocation of a geographically-defined rural older population (N = 3097), two elements of their study that related to the present study involved immediacy of the move and destination of the move. Of those responding one year later 4.8% or 140 older people actually moved; 85 to a non-institutional setting and 55 to an institution. Of the participants that indicated they were planning to move, 32% actually moved to a non-institutionalized setting compared to 2% of those individuals who said they did not plan to move. More than 90% of the older people who moved to an institution in the year had not anticipated the move. Having found this information since beginning the current study, the investigator thought that being able to interview one family in the transition of interest was fortunate. The timing of when a decision needs to be made regarding a move is uncertain; therefore a process difficult to study.

The balancing model's final form with concepts defined and linkages determined occurred after the final interviews had been completed. Member checks of the balancing model with the original participants were not done. How accurately the model represented the participants' position has to be judged by the reader by how well the concepts "fit" the quotations from which they were developed.

To allow the reader to judge whether the investigator's interpretation of the data seemed valid and "fit," concepts and linkages within the balancing model were illustrated with multiple quotations from the data. However, with the limited number of participants and the rural setting of the study, the risk existed that the participants could be identified from the family background descriptions, the trajectories, and the quotations. To protect the families' anonymity, the data were modified by the investigator and the depth of detail limited. These modifications of the data could appear to produce some inconsistencies in the analysis and potentially limit the transferability of the model to other situations.

As documented for a number of years (Brody 1981; Shanas, 1979) family members and friends provide a great deal of assistance to older people in meeting their daily needs. The older people interviewed in the current study depended on family members for advice in making decisions, in addition to hands-on care provided at regular or irregular intervals based on the physical distance apart they lived. Distant adult children were called in emergencies and provided assistance to parents in these times of crisis, in addition to regular telephone contact at non-crisis times. The older person who had never married and/or had no living relatives was not theoretically sampled in this study. Therefore, how well the balancing model portrays or does not portray their situation can not be discussed. In addition, the participants of each generation interviewed were in agreement that the older person made their own decisions when cognitively able to do so. These were not relationships that contained extreme conflict or abuse.

No older persons who were identified as mildly cognitively impaired were participants. With mental capability almost universally mentioned by both older people and adult children caregivers, a person experiencing a cognitive decline may identify other dimensions of balancing not currently included. The adult children caregivers indicated that they would become the decision-maker for the parent if they identified a loss of the parent's mental capabilities. This is considered an appropriate ethical position when the individual is no longer capable of rational thought or self-governance (Hogstel & Gaul, 1991).

No older people were interviewed at the point of disequilibrium, a crisis; therefore, how adequately the balancing model conceptualizes decision-making at this critical time is unknown. The investigator speculates from clinical experience and Chenitz's (1983) model of older people's responses to nursing home admission, that the older person's balancing triangle priorities would be discounted, as least temporarily, if others were in control of the decision. As soon as the older person was again physically and mentally capable of making her/his own decisions, the older person expects her/his preferences to be honored, but if other permanent decisions have been made this may not be possible (e.g., if the home and possessions were sold).

Among the families interviewed for the present study, the investigator found relative agreement between older people and their caregivers regarding alternative resources that would be considered when more help was needed. During the interviews no adult children overruled decisions made by their parents. How effectively the balancing model conceptualizes the process when conflict occurs is unknown. From clinical experience, the investigator felt that visualizing two balancing models running parallel to each other might help capture and demonstrate areas of conflict intergenerationally; how the parent's and adult child's perceptions of the balancing process agreed and disagreed. The balancing model was useful in helping to identify the difference in the awareness dimensions when two people appeared to perceive their balance differently.

The cultural context in which the balancing model was developed needs to be taken into account along with the fact that the only non-white ethnic group represented among the sample was Native American Indian. The concepts in the theory are embedded in cultural traditions that make its application to other cultures and groups questionable (Fisek, 1991).

Implications for Nursing Research

Through the informal "grapevine" of the rural community, the investigator is aware that of the original 14 older participants of the present study 2 have died and 4 have moved. The current location and functioning status of the remaining eight is unknown. A proposed study could involve contacting the families and asking if they would agree to a series of interviews over the next year to continue to trace their decision-making process as additional disrupters occur. The balancing model could be strengthened by more member checking for credibility, and given more depth to the dimensions. The complexity of awareness and acceptance could benefit from further development of their properties. The influence of the adult child managing personal life routines and how these routines are interwoven with that of the parent's to insure "joint balancing" could be described. What strategies by the older person and family members seem to influence successful outcomes? Saturation of the dimensions of balancing and exploration of other dimension could be achieved. What would be a "wish list" for these families: services that would meet the older person's values of remaining independence, in control, and self-reliant. Theoretical sampling for the older person without family caregivers could be done. A companion study could also involve interviewing older people anticipating a move from their home to a senior residence. This would provide another comparison group to expand the generalizability from which the balancing model comes.

Developing a scale that would help the individuals involved in the balancing process determine their placement on the balancing continuum could prove to be a valuable counseling tool. However, when using qualitative data to develop a quantitative instrument the investigator must attempt to capture the best of both worlds: qualitative validity and quantitative validity and reliability (Imle & Atwood, 1988). A quantitative instrument for measuring the state of balance could be useful for nurses working with families with an older member facing increasing disrupters and the need for additional resources to maintain meaningful routines. Research into family and older person satisfaction with changes made after use of the balancing model as a clinical counseling tool would be of value.

Implications for Nursing Practice

The Older Person's Perspective

With the "piling up of disrupters" and the accompanying frailty, attempts are made to balance. One way balancing can be achieved is to maintain routines by adding to the older person's resources (formal and informal caregiving). The older person accepts the help of these resources to maintain routines considered most important in maintaining the self (centrality). Visualizing the family's decisions in this way helps everyone involved in the process appreciate the complexity of the situation. Weighing safety or autonomy, the ethical issue of who should make the decisions (Hogstel & Gaul, 1991) is not lost sight of when the balancing triangle (routines, resources, disrupters) is viewed from the older person's perspective.

The Balancing Model: A Counseling Tool

The balancing model can potentially be used as a tool for counseling families dealing with the multiple complex issues related to the older person receiving help and/or moving. The balancing model as a way to visualize the components, dimensions, and outcomes of the decision-making process used by the older person and family caregivers proved helpful to three adult caregivers who were asked to review parts of the model. The investigator is anxious to share the model with other families facing decisions about what help is needed and when a move to a more supportive environment should be considered by the older person, to both add to and clarify the conceptualization, and to more fully assess its value as a counseling tool.

Prior to starting this study, the investigator had spent two years working as a team member of a geriatric assessment service. Older persons often were referred to the assessment service because the family members or formal service providers were unsure what help the older person might need or wanted to know whether alternative housing arrangements were required to maintain the older person's safety. In my interventions with these families, I now recognize that I, like the families concerned, was focusing on the prioritizing and taking action aspects of the balancing model and trying to devise approaches to help the older person accept these plans. This attention to the selecting and choosing between alternatives also has been the focus of theory development and research studies on decision-making (Beckingham & Baumann, 1990; Dellasega & Mastrian, 1995; McCaslin, 1988; Sims, Boland, & O'Neill, 1992). While I intuitively knew that this approach did not meet the needs of the older person and experienced the older person's resistance to the process, I was unable to find in the literature a basis for changing this clinical approach. Decision-making theories that focused on mathematical models of probabilities or that were developed from data about choices made by subjects in the experimental laboratory did not help me understand the decisions made by these families in the naturalistic setting.

The balancing model emphasizes that the major processes essential to the decision-making occur before prioritizing alternatives and taking action. This provides an expanded view of the decision-making process, which partly reflected my clinical experience of the older people who did not want to discuss moving but were usually willing to accept additional help (resources) in the home. They had already decided what routines and resources were priorities, reflected their values, and were needed to maintain their balance. Resources that would restore the older person's balance were acceptable.

The grounded theory method allowed the investigator to understand more fully the older person's perspective. As a clinician, I had asked the older person about social support networks, past work and recreational interests, religious affiliations, in addition to health and medical history information, but did not understand the all-pervasive influence of her/his values on all of these areas. As a non-older person, and as a clinician, the view from within the older person's experience was impossible to have without spending time talking with older people and finding out what they considered important. During previous home visits with older people as a clinician having to consider what immediate interventions were necessary, I had not adequately "listened" to what was important to the older people. How the clinical information gathered during the home visit interconnected, was reflected in the older person's routines, and influenced the decisions to get more help was not understood by the investigator prior to the current study.

The model also begins to explain why the adult child and nurse may view the situation and decision differently than the older person does. The decisions to be made are often the focus for the caregivers (informal and formal). The importance for the older person of maintaining one's balance and therefore one's values, may not be fully appreciated by others. The older person is not "just being stubborn" when he/she does not want to give up routines that symbolically define his/her sense of self and represent one's values. Conversely, the adult child may not only "want to keep the parent safe" when arranging to move the parent to an alternative living situation, but also may be trying to maintain his/her own life routines. The popular literature contains articles that advise adult children, who are themselves reaching the "young-old" stage, about the "balancing act" with a focus on retirement financial planning (Kollath, 1995). The adult children are trying to make plans for their retirement, while realizing that parent may need help financially to meet their increasing needs that accompany living to "old old" age.

Another decision-making situation that documented the older person, family, and nurse having different perspectives involved whether the older person was ready for discharge from the hospital. A grounded theory study by Congdon (1994) interviewing all three groups found that each group reported different "discharge readiness" (p. 126). Older people were ready to go home, family members did not think the parents were ready, and nurses were uncertain. Looking at the discharge planning decision through the lens of the balancing model may help explain some of these different perceptions regarding discharge readiness. It is the investigator's experience that the balancing model proves helpful to the adult child trying to understand the parent's perspective when decisions regarding help for the parent are being made.

Policy Implications

With the evolution of environmental psychology of later life over the last 30 years and its focus on decreasing the environmental press experienced by older people (Lawton, 1982), more gerontology research centers are developing senior service centers in connection with housing units (Wayne State University, 1995). With the cuts proposed by the Republican Congress in Medicare and Medicaid, and the states determining where the diminishing federal dollars will be spent through block grants, it is projected that fewer dollars will be available for all programs designed for low income citizens including the five million older people who are poor (*New York Times*, November 5, 1995). Patterned after the university housing programs, delivering initial health care services at the senior apartment site may be one way to tap into funds available for both housing and health care. For example, a nurse could be available to see residents at the housing center. This is an example of a community-based nursing model for the delivery of services to older people and caregivers that is considered needed today in the environment of health care reform (Weiner, 1995).

The literature contains several articles on decision-making, discharge planning, and transitional care from the hospital (Congdon, 1994; Coulton, Dunkle, Goode, & MacKintosh, 1982). Some of this planning and decision-making could move into the community by having a nurse available to residents at the senior housing center. Individualized adjustments of the environment could be devised for the residents based on their functional abilities. Interventions for health problems could be identified and started earlier. Potentially fewer hospitalizations and moves to other more costly housing alternatives may be prevented or delayed. The nurse could be working with the residents who desired to maintain their balance in the current setting and also preparing the older person and family for the possible move to a more supportive environment. The older person cared for by a spouse has been identified as an individual less likely to have help from other caregivers and use fewer, if any, formal services (Tennstedt, McKinlay, & Sullivan, 1989). Many families also do not consider alternative housing needs before a crisis situation (Johnson, 1990) and may benefit from earlier intervention (Pruchno, Michaels, & Potashnik, 1991). With a nurse located at the housing site, rapport with the family can be established over time that allows for more sustained interventions. As identified by Pruchno, Michaels, and Potashnik factors leading to institutionalization of older people occur over time and therefore nursing home placement should be thought of as a process, not a single event. Nursing interventions that are available to the families over time should prove to be more effective. Systematic evaluation of outcomes of nursing-focused services are needed (Weinert, 1995). The effects of the nurse assisting older residents to make decisions earlier in their disequilibrium process could be measured partly with service utilization and cost analysis (Naylor, 1990). If long-term care services are to be provided by nurses in the community, a setting preferred by families (Greene, 1984; Johnson, 1990; Sims, Boland, & O'Neill, 1992), funds will need to be allocated from the current priority of high technology health care (Anderson, 1990; Fleck, 1987). Over the next few years, as a group nurses need to influence policy decisions to insure justice care for vulnerable populations, to shape the institutional order, and to insure an environment where professional nursing practice can occur (Anderson, 1990; Oregon League for Nursing, 1995).

The public housing administration (HUD) could benefit if more tenants could "age in place" lowering expenses involved with resident turnover. The resident manager who questioned the abilities of an older person to remain living safely in the facility without help could call on the nurse to assess a resident as an alternative to eviction. The concept of assisted living developed by the private sector could be more widely available to the public low income housing setting potentially reducing some of Medicaid's nursing home expenses.

Summary

Two interviews separated by an average of 21 weeks with 17 families (14 older people and 18 informal caregivers) were completed about the decision-making process used by the family when deciding whether and when the older person needed to leave the home for a more supportive living environment. Grounded theory methodology was used to analyze the transcribed interviews and develop the balancing model.

The older person is trying to maintain balance between his/her *routines*, *resources*, and *disrupters*. When imbalance between these three components occurs, the disequilibrium results in feelings of discomfort. The imbalance can lead to a recognition that his/her sense of self no longer agrees with reality and a shift in this sense of self will need to occur to restore consonance. This affective response and acknowledgement of cognitive dissonance and the need to restore consonance is conceptualized as *awareness*. When disequilibrium occurs the individual determines what routines, resources, and disrupters are most important in maintaining the self (*centrality*). The individual experiences some pressure (*urgency*) to take action to restore balance by increasing resources and/or changing routines of central importance. Whether the balancing is temporarily upset or whether lasting changes will need to be made to restore a state of balance (*permanence*) is also a determination made by the individual whose balance is threatened.

If the person accepts that disequilibrium is present, prioritizing and taking action occurs to restore the balance with routines and resources consistent with the person's *values*. Understanding the person's values and respecting these in the decision-making process is key to finding ways to restore the balance. However, values are taken for granted and can be difficult to identify because they are assumed by the person: a part of the self. The routines that the individual finds most meaningful help to identify these values. If the individual's values can be maintained, he/she is more willing to modify or relinquish routines that are more peripheral to the values of central importance. Families can use the balancing model to help understand the decision-making process used by the older person when needing to obtain help in the home or considering a move to obtain the help needed.

The model concepts were compared with existing theoretical and clinical literature. The implications for future research and practice were discussed within limitations of the study methods and context. Nurses are urged to take a more active role politically so they can influence the resources available to families in the long-term care continuum including nursing care.

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APPENDICES

APPENDIX A

Research Studies Related to Family's Perspective of LTC

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Branch & Jette, 1982
Purpose	To identify risk factors for LTC institutionalization.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Prospective, correlational study. (S) Massachusetts probability sample of 1,625 non-institutionalized individuals 65 years of age and older. (M) Six year study with interviews year one, two, and six, and annual mailed surveys the other three years. (I) Face-to-face interviews and mailed surveys. *Assistance in Basic ADL* designates CRs who use mechanical or human assistance in performing one or more of six basic activities of daily living: bathing, dressing, transferring, eating, and grooming. *Assistance in Instrumental ADL* identifies those who use assistance in performing housekeeping, transportation, food preparation, or grocery shopping. The remaining two LTC indices are components of Branch's Vulnerable Elders Index. The *Number of Unmet Instrumental Activity Needs* index CRs who have unmet needs in one or more of seven instrumental activities: transportation, personal care, housekeeping, social activities, grocery shopping, food preparation, and emergency assistance (i.e., support available during an illness or crisis). A need is categorized as unmet for CRs who are both not self-sufficient in an area of functional activity and are not using the assistance they need. The index is constructed by dividing the number of areas in which an elder has an unmet need by the number of areas in which valid information is available; values range from 0 to 1. The last LTC needs variable is an index which operationalizes *Areas of Extensive Health Care Utilization*. This index focuses on use of seven health and social services: receiving meal services at home, receiving homemaker services, contacting a physician monthly or more frequently, hospitalized 31 days or more during the previous 12 months, admitted to a nursing home during the previous 12 months, receiving nursing services at home, or receiving special care (e.g., wound dressing). The index is constructed by dividing the number of areas in which the elder has extensive utilization by the number of areas in which valid information is available; index values range from 0 to 1.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Branch & Jette, 1982
Design (Cont.)	There are five physical disability variables: *Perceived Health; Sight Deficit* (CRs' reports of whether they see well enough to read newspaper or magazine print, with corrective lenses if necessary); *Hearing Acuity* (CRs' perceptions of the quality of their hearing, with hearing aids if necessary); *Functional Disability* (CRs who report having a physical health problem which bothers them or who are unable to do heavy work, climb stairs, or walk a half mile); *Ambulation Aid* (CRs who use a walker or wheelchair). *Mental Orientation*: interviewer's subjective judgment of the CR's degree of orientation at the time of the initial interview. Systematic training for these judgments was not attempted: judgments were based on 45 minutes of interaction. *Morale*: summated rating index constructed from responses to four questionnaire items: satisfaction with the way a CR spends his/her time; the extent to which little things bother a CR; the extent to which a CR perceives things as better, the same, or worse than he/she thought they would be as he/she ages; and satisfaction with one's present life. 4-point scale from 1 (high morale) to 4 (low morale). (A) Multivariate analysis was used to estimate the predictive power of 19 independent variables on subsequent institutionalization.
Concepts	The independent variables measured could be grouped into six categories: demographic characteristics, attitude, social context, LTC needs, physical disability, mental/emotional disability. Demographic characteristics (age, gender, education, Medicaid eligible); attitudinal factor (willingness to enter a nursing home); social context (lives alone, widowed, relatives nearby); LTC needs (uses assistance in basic ADL, uses assistance in instrumental ADL, number unmet instrumental activity needs, areas of extensive health care utilization); physical disability (perceived health, sight deficit, hearing acuity, functional disability, uses ambulation aid); mental/emotional disability (mental orientation, morale).

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Branch & Jette, 1982
Findings	Five variables were significantly related to institutionalization: advancing age (80+ years), using ambulatory aids, mental disorientation, living alone, and using assistance to perform instrumental activities of daily living. These five variables explained 9% of the variance in LTD institutionalization. Only 2% of the sample indicated a willingness to enter a nursing home during the initial interview. 147 elders, 9% of the original cohort, entered a LTC institutional at some time during the six-year study.
Comments	The LTC institution was considered the nursing home and chronic disease hospital. Events or conditions that occurred between the first interview and institutionalization were not considered in the analysis. Demonstrates that many more CRs enter a LTC institution than are initially willing to do so.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Deimling & Poulshock, 1985
Purpose	To examine the transition to LTC and to determine the relative impact of different types of CR impairment, CG health characteristics, and CG attitudes concerning nursing home placement on the decision to institutionalize.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Longitudinal. (S) Purposive sample derived using randomization procedures. *N* = 589 (selected from 2000 families). *N* = 64 CG (families who did experience crisis related to the CR's health, divided into *N* = 26 families who placed CR in an institution during follow-up period (between first and second interview). *N* = 38 families did not place CR in institution following crisis in first six months between interviews. *N* = 525 families did not experience CR-related crisis. Metropolitan and non-metropolitan counties contiguous with the Cleveland SMSA. (M) Separate interview sessions with CR, CG, and any available third generation family members. Six month telephone screening interview. In-person follow-up interviews with CG (*n* = 64) in families that experienced crisis related to care giving. (I) CG's attitude toward nursing home placement: How would CG feel about putting the CR in a nursing home? What type of care does CG feel that CR would receive in a nursing home? (A) Predisposing characteristics at interval level, analysis of variance, and F statistic to test significance of mean score differences across family categories. Predisposing characteristics categorical in nature, chi-square statistic used to test statistical significance of obtained cell frequencies. Discriminating power of predisposing characteristics in multivariate context using discriminant function analysis.
Concepts	See Instruments and Findings

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Deimling & Poulshock, 1985
Findings	CG's attitude regarding acceptability of nursing home placement among CGs where CR institutionalized. Nearly 50% expressed positive response to nursing home in initial interview. Among CGs in which CR placed in nursing home, 50% CGs felt that they would receive good care. Families where CR experienced health crisis and was subsequently placed in nursing home, CG reported also twice as many health problems as CGs where CR was not institutionalized. CGs in families where CR institutionalized reported significantly higher levels of CG task burden (subjective measure of CG tasks as upsetting, tiring, difficult. Restrictions in CG's social attitudes — CGs reporting greater restrictions in social and recreational activities were more likely to institutionalize the elder during the follow-up period. Factor's *not* significantly different between (*n* = 64) two groups (institutionalized vs. non-institutionalized related to crisis): CR ADL limitations, CR symptoms of mental impairment, CR disruptive behaviors; CG mental health (depression); negative changes in elder/caregiver/family relationships; total stress effects.
Comments	Demonstrated that the attitudes CGs have regarding the suitability of nursing home care prior to CR health crisis are important factors in predicting the placement of CR during a crisis.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Dick, Friedsam, & Margin, 1964
Purpose	To determine the residential mobility and living arrangement history of CRs who currently chose to live in a home for the aged.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Retrospective, descriptive study. (S) A convenience sample of 211 residents of two voluntary, nonprofit homes for the aged (Protestant and Jewish). (M) Interviewing residents about their moving and living arrangements during the 15 years prior to moving to the home for the aged. (I) Closed-ended questionnaire. Further description not given except health measured with five-item Guttman-type scale. (A) Frequencies.
Concepts	Living arrangements, health.
Findings	Two thirds of the changes in living arrangements and moves occurred during the five-year period just before moving into the home for the aged. Crs in poorer health at the time of admission had experienced more changes in residence and living arrangements. There was an increase in CRs living with or adjacent to relatives and non-relatives within the five years before admission, with most of changes involving the CRs moving in with children.
Comments	No description of services provided to the residents of the home for the aged. Sample limits generalizability of findings. One of the earliest studies looking at some of the characteristics of CRs living in an institutional setting other than a nursing home.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Christ, Visscher, & Bates, 1988
Purpose	To examine, describe, and determine variables used in Adult Congregate Living Facility (ACLF) admission decision process.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Exploratory/descriptive. (S) *N* = 114, random selection of one-third of all clients completing application process for ACLF placement in Miami. 64 admitted (56%). 50 not admitted (44%): 41 (82%) living independently at 6 months; (five people (10%) not found for follow-up. Requirements for admission: 65 years or older; residing in one of two adjacent counties; able to function independently; completing comprehensive pre-admission multidimensional assess, including PE. Most females (86), all Caucasian, average age = 83. Of total sample, 95% (110) not using social support (household help, mental health counseling, day care, home delivered meals). (M) Examined records of clients applied for admission retrospectively. Chart review of the admission placement decisions. Based on this information, three groups: (I) 64 accepted offer for admission; (II) 10 (9%) denied admission; (III) 40 (35%) declined admission also interviewed. Six months after completion, follow-up and retrospective chart review. (I) Self-report for alcohol intake, injuries, food allergies, telephone, drug allergies, requiring help when ill. Orientation: Goldfarb Orientation Checklist. Physical exam, integrative functions: reflexes, sensory perception, muscle strength, associated functions, capacity of cranial nerves and cerebellum, gait/station. (A) ANOVA, examine significant differences between study groups. Chi-square test, determine significant differences within a variable across study groups.
Concepts	See Instruments. (OARS Multi-Dimensional Assessment Tool. Standard history and physical exam form.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Christ, Visscher, & Bates, 1988
Findings	Group III (declined adm.) — finances played major role in not moving into ACLF. Had to sell homes or condominiums or time their admission with release from rental leases. Group III significantly more support from neighbors/friends than groups I and II (also reported family). Group I and III did not differ on orientation, integrative function, or abnormal pulse rate.No significant difference across groups in patterns of illness, medical diagnoses, taking of medications, results of lab tests, indicators of social integration, EKG results. Eight factors differentiating accepted (I) from rejected groups (II): impaired orientation [(group II double impairment level in integrative functions)]; impaired integrative function; abnormal pulse rate; alcohol intake; injuries; food allergies; drug allergies; requiring help when ill. Drug allergies and requiring help when ill did not influence admission recommendation (group III had these present).
Comments	Appeared as if study only looked at formal services for social support. Mean age of Group II five years greater than other two groups.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Greenberg & Ginn, 1979
Purpose	To determine the predictors of LTC placement.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Correlational-comparative design. (S) 266 clients 60 years or older who had begun LTC services from either a skilled nursing home or in-home agency during a three-month period. A random sample of 10 nursing homes and seven in-home agencies in an urban area were selected to draw the client sample from. (M) Questionnaires completed by agency staff to obtain client information. (I) The questionnaires developed for study covered variables in four categories: socioeconomic status, support system, family and client preferences, major medical conditions and functional abilities. The questions that dealt with family and client attitudes towards institutionalization were constructed as five-point Likert scales. Functional abilities were measured by the scale developed by Katz et al. (1963). In addition to the six ADL measured on the original Katz scale, the client's ability to walk, to take medication, to prepare meals, and to make decisions were assessed. (A) Logistic regression analysis used to estimate a multivariate placement model.
Concepts	See Instruments.
Findings	The variables most highly related to nursing home/in-home placement were the client's ability to take medication, index of ADL dependencies, client preferences, index of medical conditions, and family preferences. The placement model regression equation containing 20 variables explained 68% of the variance.
Comments	Authors stress the importance of learning more about the placement process before making causal inferences about the cost-effectiveness of alternative LTC settings. Data collected from agency staff, not CRs.

RESEARCH STUDIES RELATED TO FAMILY'S PERSEPCTIVE OF LTC	
Author/Date	Liu & Manton, 1983
Purpose	To describe the population of people who enter nursing homes each year.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Descriptive study. (S) Secondary analysis of data from 1977 National Nursing Home Survey (NNHS). Synthetic admission cohort restricted to those individuals admitted to nursing homes from January to December of 1976, and the sample of 1977 current residents to represent nursing home patients who were not discharged as of the last day of 1976 (surrogate "retained" patients). The surrogate "retained" patients combined with the sample of discharged patients from the 1976 Survey of Discharged Residents (DRS) to comprise all possible users of nursing homes in 1976 (the two sets are mutually exclusive and collectively exhaustive of all users in 1976). (M) Derived 1976 admission cohort by extracting new admissions in 1976 from a hypothetical population of everyone who used nursing homes at some point during that year. The data base for the hypothetical population is the 1977 NNHS which was designed to provide national estimates of nursing homes and their patients. (I) See Subjects (A) Frequencies.
Concepts	Age, sex, marital status, primary payment source, primary diagnosis (cancer, chronic brain syndrome, hip fracture), disability (bedfast, chairfast, incontinent bowel, incontinent bladder).

RESEARCH STUDIES RELATED TO FAMILY'S PERSEPCTIVE OF LTC	
Author/Date	Liu & Manton, 1983
Findings	Estimated that 1.1 million people admitted to nursing homes in 1976, 40% of the approximately 2.4 million total users of homes over the 12-month period. Demographic and payment source characteristics: over 75 years of age (67%); female (63%); unmarried (77%); 50% of the patients were supported primarily by public payment sources (Medicare or Medicaid). Approximately 40% of the admissions were either bedfast or chairfast; 16% had difficulties controlling bowels or bladder. Contrasted to the sample of current residents, relatively higher proportions of persons in the admission cohort with characteristics associated with short durations of stay, such as being male or married. Lower proportions of bedfast patients were admitted than were discharged over the 12-month period. Higher proportions of patients with bowel incontinence were admitted than were discharged. Greater lengths of stay of the 85+ group reflect the higher proportion of these "old-old" patients entering nursing homes for long-term residential care. 40% of admissions remained in nursing home more than 12 months. New admissions contributed only 22% of total nursing home days in the year. The subset of admissions who were also discharged during the year used only 7% of total nursing home days, despite the fact that they constituted 60% of the total number of admissions (1.16 million) and 28% of the total number of nursing home patients (2.4 million).
Comments	Large proportion of patients who were admitted in 1976 were also discharged in the same year. Nursing homes extensively used for short-term rehabilitative purposes as well as long-term residential care.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Newman, Struyk, Wright, & Rice, 1990
Purpose	To determine if National Long-Term Care Survey (NLTC) disproportionately represent those successful in remaining out of institutions.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Secondary data analysis. (S) Sampled CRs with at least some LTC needs (*N* = 5,580). Nationally representative sample, chronically impaired individuals 65 and older. 8% sample (*n* = 446) at-risk group (institutionalization for at least 90 days or death in an institution). 20% of sample members who indicated they used informal assistance also purchased some CG services. (M) Data linkage (statistical) of American Housing Survey (AHS) and NLTCS (not unified data set). (I) 1982 and 1984 NLTCS; 1978 AHS; 1984 determine whether 1982 sample member had become institutionalized by 1984. (A) Logit models for multivariate estimation. Technique for four of the five hypotheses (equation) path analytic model for intervening effects hypothesis.
Concepts	Dependent variable — risk of institutionalization. Informal care (if spouse CG or CG lived within 10 minutes); formal support (use of paid CGs). Functional incapacities (IADL assistance needed).
Findings	Reduce risk of institutionalization: if spouse CG or CG lived within 10 minutes of CR; if only informal care; if CG spouse and housing has special modifications (i.e., grabbars, raised toilet seat); if receive formal care giving and live in dwelling with six or more rooms; home ownership which leads to use of formal support.
Comments	Very broad definitions of formal and informal CG, paid vs. unpaid.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Nocks, Learner, Blackman, & Brown, 1986
Purpose	To determine if nursing home admission can be avoided with increased community services.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Longitudinal experimental research design. (S) South Carolina Community LTC Project: Medicaid-eligible and nursing home eligible patients (individuals sought nursing home placement under Medicaid). Three counties representative of state as a whole. Approximately 11% of project area residents age 65 or older. 284 experimental clients and 340 control clients for a total of 624. Participants in program between 7/80 and 6/81, data collected during first 18 months of each client's participation. Average age of control participants = 74.3 years; average age of experimental participants = 73.2 years. Sample age criteria: 18 years and older. (M) Random assignment of patients into experimental and control groups. Mandatory pre-admission screening policy. Determine medical eligibility for nursing home admission (functional deficit criteria). Experimental patients, eligible to receive neutral case management and variety of new community services under Medicaid that were not offered in other parts of the state. New community services (in addition to case management offered experimental group patients): personal care, medical day care, home-delivered therapeutic meals, home-based therapies, medical social services, respite care. (I) See Analysis. (A) Univariate analyses: examine outcomes (percent participants admitted to nursing homes and percent total participant days spent in nursing homes by all group members) by initial level of care (SNF vs. ICF) and initial Medicaid eligibility level (SSI-eligible vs. non-SSI-eligible). Logistic regression: examine outcomes in the context of predictors of nursing home use. Analysis of covariance model used to test effects of experimental intervention on total nursing home days, while controlling for variables that might affect nursing home use.
Concepts	See Analysis and Findings.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Nocks, Learner, Blackman, & Brown, 1986
Findings	Fewer experimental clients entered a nursing home at some time during the first 18 months following initial assessment than control group clients (43% vs. 59%). Experimental group clients used significantly fewer nursing home days than control group clients (120 vs. 184 days; 30% vs. 49% of their total participation days). Being hospitalized at intake, living alone, having higher ADL and IADL impairment scores, and surviving past the first 60 days in the project had significant relationships with entering a nursing home within 18 months.
Comments	18% experimental group and 16% control group 64 years or younger. Models accounted for only small/modest proportions of total variable in nursing home entry and total nursing home days (8.6% and 13.6%). Lost approximately 25% of possible participants between pre-screening and Medicaid eligibility certification (28% control, 22% experimental). All experimental group participants given same benefits. All experimental group participants given same benefits. Did away with institutional bias in two-tiered eligibility system for experimental group only. Control group: two different benefit packages based on SSI vs. non-SSI eligible.

RESEARCH STUDIES RELATED TO FAMILY'S PERSEPCTIVE OF LTC	
Author/Date	Scannell, 1987
Purpose	To explore some of the dimensions of LTC selection as experienced by adult children.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Exploratory descriptive. (S) Non-probability sample of adult daughters, sons, and daughters-in-law (*n* = 32) who had played a significant role in selecting a LTC setting for a parent. CR was living either in congregate care (*n* = 7); adult foster care (*n* = 6); assisted living (*n* = 10); SNF, ICF, or RCF (*n* = 9). (M) Closed-ended questionnaire administered in face-to-face contact. (I) Structured in-person interviews. (A) Rests of association between selected variables and outcome variables.
Concepts	CR: LTC housing history, reasons for home, health status, mental status, diagnosis of cognitive decline or depression, chronic illness, hospitalizations or doctor visits in past year. Search process: how was it done, options, attributes sought, how judge quality of the attributes, ease of finding information, did CG discuss search process with CR, did CR visit options, did CR influence choice, timing appropriate, what would have made the search process easier. Deciding on the need for LTC: circumstances leading to move, number of CGs involved, emotional drain, guilt, sense of support from CR, experience of duty, sadness, rejection by CR, fatigue, anxiety, relief, loneliness. Outcome variables: CG satisfaction with LTC choice, present LTC setting "ideal choice" if money were no object, CG burden, amount of most guilt felt during the overall process, amount of guilt felt at the time of the interview. Rau's (1986) adaptation of Zarit's Caregiver Burden Scale.

RESEARCH STUDIES RELATED TO FAMILY'S PERSEPCTIVE OF LTC	
Author/Date	Scannell, 1987
Findings	Congregate care with minimal service is the type of facility most often chosen for entry into the LTC system. Nursing homes are also an entry level for CR recovering from acute health condition. CRs who enter the continuum of care at the nursing home level leave a period of months to move to LTC arrangement with lower levels of care. Foster care was more often chosen as a second, third, or fourth LTC arrangement than first. First entry due to mental decline, death, or institutionalization of spouse, need for convalescence from acute health crisis, or the desire for a secure living arrangement near an only child. CG satisfaction with the present facility was associated with factors which indicated a good match between the services provided by the facility and perceived needs of CR. Emotional experience of LTC selection and helping CR accomplish move is draining, guilt producing, burdensome, fatiguing, and often lonely.
Comments	Sample selected from the universe of 147 CGs who participated in a telephone survey about selecting LTC for CR from a universe of 300 CGs who had contacted an assisted living facility over one year regarding services provided.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Smallegan, 1985
Purpose	To determine what problems existed that led to the family decision that the CR needed to move to a nursing home.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Retrospective, descriptive study. (S) Family CGs of 288 persons recently admitted to 27 nursing homes (both intermediate and skilled facilities) located in two states, representing both rural, small cities/towns, and mid-sized cities. (M) Interviewed family CGs. Nursing home staff assessed ADL needs. Interviews covered the time from the onset of problems until the decision for admission to a nursing home. (I) Questions about the problems of the individual admitted and the family, the needs for help, helpers, the length of time for which help was given, and the frequency and intensity of help given. (A) Frequencies, nonparametric test of associations and correlations. Stepwise multiple regression to determine the relative ability of a series of factors to predict the time that individuals remained in the last mode of care before entering a nursing home.
Concepts	Support: assistance with shopping, occasional provision of meals, laundry, or lawn mowing. Serious care: ranging from frequent checks and regular provision of meals to living together. Substantial help: serious care as well as general support. Net for help: summary ADL — frequency with which help was given (occasionally, frequently, daily, more than daily, or living together). Intensity of help given: support/errands, general help/prepared some food, prepared almost all food/total care.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Smallegan, 1985
Findings	Almost half of the CRs received help by CGs for eight months to five years before nursing home admission. 33% of the CRs were living with an adult child or other kin. At the time of admission, 66% of the CGs thought CR needed 24-hour assistance, 64% reported CRs became less well shortly before admission. Two-thirds of the CRs were admitted directly from a hospital. The major precipitating causes for admission were frequent falls, general debility, confusion, fractures, strokes, incontinence, difficult behavior.
Comments	Sample unusual with men providing care for two-thirds of the sample. Again, community services were used rarely. The statement was made that somewhat greater care was provided in rural areas, but the data that would support this conclusion was not provided. Supports the position that the family chooses nursing home care for their older relative when 24-hour assistance is considered needed.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Tobin & Lieberman, 1976
Purpose	To determine if something other than institutionalization causes the psychological characteristics labeled "institutional effects."
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Longitudinal study. (S) A convenience sample of 100 CRs on the waiting list for the homes for the aged (three homes). A community sample (*n* = 35) and institutional sample (*n* = 37) that matched the waiting list sample in terms of self-care and mental functioning. The homes for the aged did not accept applicants who had psychiatric disorders or were terminally ill. (M) Intensive interviews and psychological testing were done at least three times: while on the waiting list, two months after admission to the home, at the end of the first year living in the home. (I) See Concepts. (A) Comparisons were made between waiting list group and two other groups: community residents and institutional residents.
Concepts	Four areas of psychological functioning were assessed (cognitive functioning, affective responsiveness, emotional states, self-perception) using a variety of established measures, measures developed for this study, and interviews.
Findings	The waiting list sample was more like the institutionalized sample and both were very different from the community sample. Residents-to-be were described as having a moderate degree of cognitive disorganization, constriction of affective responsiveness, feelings of anxiety, and depression. Most of the psychological qualities attributed to the adverse effects of entering and living in an institution were already present in people on the waiting list.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Tobin & Lieberman, 1976
Comments	Demonstrates that negative psychological effects occur even before the CR moves to the institution, while on the waiting list for admission. Outlines identifiable periods of the process: CR and CG considers the fact that institutionalization may become necessary in the future; following the decision to seek institutional care; CR waiting institutionalization; actually being admitted and living in the new environment. The situation seemed unusually in that the period between application and admission to the homes was typically seven months. The sample was unique, being composed of mostly Eastern European immigrants to the U.S. Because of the lengthy interviews, individuals with severe vision, hearing, communication or cognitive problems were excluded from the study. The samples were also comprised of individuals described as being in good mental and physical health for their age. This is not usually considered the description of people needing a LTC setting.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Townsend, 1965
Purpose	To determine reasons for CR admission to residential homes and other institutions.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Descriptive study. (S) Random sample of 173 public and private institutions and residential homes visited in England and Wales. Statistical information obtained on 7,689 pensionable age residents with questionnaires completed on 530 of these residents (489 were interviewed). 136 individuals were in the sample of residents who were admitted to one of the facilities during the four-month study period but who had died, been transferred to the hospitals, or returned home. (M) Interview questionnaires completed on residents who had been admitted in the previous four months. Also, questionnaires wee completed on a sample of residents who had been admitted during this four-month period but who had since died, been transferred to the hospital, or gone home. When information could not be obtained directly from the resident, personal observations, information from staff, and records were used. (I) Specifics of interview questions not discussed. (A) Frequencies.
Concepts	Family composition, structure, and organization, incapacity homelessness, lack of socioeconomic resources.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	Townsend, 1965
Findings	By contrast with the general population of 65 and over, the CRs living in institutions were much older (many 80+), in relative numbers more women than men 70 and older were living in institutions but proportionately as many women as men aged 65 and over were in institutions. Although there tended to be more men than women of each particular marital status, there were several times more unmarried and widowed than married persons, and also married persons without children. The death or sudden illness of close relatives were the most common events precipitating admission. Persons who were admitted to the institution who had been living alone were significantly less infirm than persons living with their children or with others. And among the persons living alone, persons with no relative living nearby tended to be less infirm than the rest. Reasons given for CRs who had been living with other people being admitted to an institution: overcrowding of CG home; financial difficulties; relatives they were living with were themselves ill, infirm, or of advanced age; friction with a son-in-law or daughter-in-law.
Comments	No details about questionnaire in discussion; only information regarding specific variable categories obtained from tables. No information about whether some of the demographic information reported was on all of the residents in the 173 selected facilities, how the 530 residents were chosen for the interview/questionnaire, how the 136 residents who left the facilities were selected, and the informed consent procedures. It was not always clear in the discussion of findings whether *home* referred to all institutions for CRs or just residential homes. The differences between the types of institutions were not defined. It is never specifically stated that individuals of pensionable age were 65 years or older, but this appeared to be the correct assumption with the data reported. When counting surviving children, no category for unmarried CR having a child. No specific information given on socioeconomic or educational status of sample.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	York & Calsyn, 1977
Purpose	To look at the interrelationship between variables related to the resident-family interactions before and after nursing home admission.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Retrospective, descriptive correlational study. (S) 76 CRs living in one of three urban nursing homes. 76 CGs identified as the person to contact in an emergency. (M) Nurse observational rating scales to assess the CR plus open and closed-ended interview questions for CG. Observation assessed on CR's physical capacities, cognitive, psychological, and behavioral functioning. Open and closed-ended interview questions asked about CG involvement before and after CR moved to nursing home and the problems leading to the move. (I) Behavior of Older Patient Checklist (nurse observation rating scale) — cognitive functioning-sensorium, social interaction, verbal hostility, physical hostility, depression, psychotic behavior, personal appearance); Physical Capabilities Checklist (nurse-rated) — self-care, sensory capability, ambulation, activity level. (A) Frequencies, correlations.
Concepts	Behavior of Older Patient Checklist (7 dimensions); Physical Capabilities Checklist (4 dimensions). Both developed for this study.
Findings	A large proportion of the CGs provided help to the CR on a variety of household and personal tasks and maintained frequent phone contact prior to nursing home admission. CGs were aware of community services available to help the CR, but few CGs used these services. Also, less than half of the CGs visited the nursing home prior to CR moving there. Bed availability and location were the main reasons given by CGs for choosing a particular nursing home. 59% of the CRs were admitted to the nursing home from the hospital. Only 19% of the CGs indicated that the CR had input in deciding to move to the nursing home.

RESEARCH STUDIES RELATED TO FAMILY'S PERSPECTIVE OF LTC	
Author/Date	York & Calsyn, 1977
Comments	Did not interview the CRs regarding the decision to move to the nursing home. This had not been a recent move with the mean length of stay in the nursing home being almost three years. No psychometric information on measures provided. Does not describe how the decision to move to the nursing home may be different for the CR and CG when hospitalization does not precede this decision.

APPENDIX B

Research Studies Related to the Older Person's Perspective

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Bear, 1990
Purpose	To determine the effects of the CR's health status and social networks on their likelihood of returning home from a residential care facility.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Longitudinal, correlational study. (S) 85 new residents (within two months) of 47 residential care facilities located in two Florida counties, and 75 persons loving locally identified by residents to be their closest others. (M) Face-to-face interviews at time of residential care facility entry on CRs primary network characteristics and on their functional and cognitive status (when CRs were mentally or physically unable to respond to the interview [*N* = 32], network data from their closest others were used), paired T-tests showed no differences between responses from interviewed residents (*N* = 49) and their closest others. Six-month follow-up interviews established CR's location and functional and cognitive status. (I) Measurement of network density, reciprocity, and intensity based on CR's primary network during the year before entry. At the time of these initial interviews, functional and cognitive status were also measured. Follow-up interviews six months later determined the CR's location and functional and cognitive status (Katz's ADL Questionnaire; Pfeiffer's Short Portable Mental Status Questionnaire). Network intensity obtained by averaging CR's Emotional Bondedness Scale with that of their network member's (Snow & Crapo, 1982). (A) Logistic regression analysis. Analyze the effects of each of the independent variables on returning home. Effect of CR's physical and cognitive abilities on returning home analyzed separately (minimizing effects of multi-collinearity).
Concepts	Network density, reciprocity, and intensity; ADL; mental status; emotional bondedness.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Bear, 1990
Findings	Although being non-white, paying for their own care, and having less intense network ties increased the CR's probability of going home (own home or home of network member) from residential care facility, the CR's high functional status at six months was the variable most important in explaining this return home. Twelve CRs out of 80 returned home.
Comments	Psychometric adequacy of measures not given. One of the few studies that looks at the move to a LTC residence other than a nursing home. Explanation of inverse relationship between network intensity and CR returning home from residential care facility: the highly supportive networks use the residential care facility as a last alternative for meeting the CR's needs.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Béland, 1984
Purpose	To determine whether the factors underlying the desire for different forms of housing correspond to those usually assumed in proposing the establishment of home aid and care services.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Comparative Study (S) Three simple random samples drawn from the records of the universal old age pension scheme of the Canadian government for one working-class neighborhood in a metropolitan area and two medium-size cities. The three samples contain 556 records for persons 65 and over in three Montréal working-class neighborhoods. Loss of 31% of the initial sample drawn (9 months lag between time samples drawn and interviews) yielded 301 valid questionnaires. (M)/(I) Data collected divided into 10 broad observational sectors: (1) socio-demographic variables (8 items); (2) housing conditions (11 items); (3) state of physical and mental health, measured by disability and chronic illness indicators and psychological well-being indicators (6 items); (4) functional incapacity using Katz's ADL and an indicator of difficulty of pursuing activities outside the home in winter; (5) means of social integration in the neighborhood, with relatives, and with friends, in addition to participation in community organizations and formal relations with various social agents such as merchants (14 items); (6) use of medical, hospital, and pharmaceutical services (8 items); (7) the responsibility of those interviewed for domestic tasks; (8) help received from various social agents (8 items); (9) wish to live with persons other than those sharing home, wish for a given type of dwelling. (A) A discriminant analysis of the wish to leave home.
Concepts	Contextual variables (socio-demographic, housing conditions, state of health, functional disability, social integration), action variables (use of services, responsibility for tasks, assistance received, congruence of choices and social arrangements), impact variable (choices of dwelling).

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Béland, 1984
Findings	Persons wished to leave their homes because they did not have sufficient resources to stay in them. The principal indicators of resources affecting desires for housing were occupation before retirement (Blishen scale—in French), sex (female), widowhood, rental of dwelling, cohabitation, number of chronic diseases, and subjective estimation of health. Help given in the home by social agents had only marginal effect on desires for lodging, but the use of many medical services was correlated with the desire to leave the home. The frequency of formal and informal social relations was related to an increase in the desire for different housing. Functional disabilities generally did not explain desires for housing, but ability to function in winter increased the desire.
Comments	Canadian sample. Housing conditions, cohabitation with children, and sickness explain part of the variance of the wishes of elderly persons to leave home whereas functional impairment is not related to them. A lag of nine months occurred between the time the samples were drawn and the time of the interviews. At the time of the interviews, approximately 9% of the sample populations had died and another 9% could not be found. No variations between samples in the proportions lost were noted. Another 2-5% of the respondents refused to participate, and 4-8% were absent after three interviewer visits.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Brody, 1969
Purpose	To follow-up individuals who had applied and not applied to a voluntary home for the aged at least one year later.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Descriptive study. (S) Randomly selected sample of 50 applicants and 50 non-applicants (mean age 78 years for both groups) and family members who had inquired about admission to the Home for the Jewish Aged located in an urban setting and associated with a geriatric center. (M) Interviews or records reviewed. The mean time interval between initial inquiry about admission and follow-up interview was 16½ months. (I) Using interviews, case records, and death records to compare two groups to a home for the aged over one year after initial inquiry about the facility. (A) Frequencies.
Concepts	Survival, health status, current living arrangements, number of living arrangements changes, reasons for non-application, reasons for withdrawal of applications, reasons for subsequent application by former non-applicants. The formation of attitude was considered a process and was composed of the personality of aged individuals, quality and structure of family relationships capacities and resources of family members; individual and family tolerance for stress; psychological and socially-determined perception of the meaning of institutionalization; availability of alternative resources.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Brody, 1969
Findings	More than 80% of the sample moved during the time interval. The overall direction of change for both groups was away from living alone or with another person and toward congregate housing (institutions and intermediate facilities). The number of reasons offered initially for requesting institutional care and the attitude of the CR toward institutionalization were both strongly related to living in institutions at follow-up. Attitudes toward institutionalization could change as a result of emotional, physical, and financial stress and by the lack of availability of adequate supportive resources.
Comments	Supports the position that the attitude of the CR was a significant variable in determining whether institutionalization occurred. What is characterized as attitude could be considered factors influencing the decision-making process. Sample including only individuals inquiry about one specific LTC setting limits generalizability of findings. Around a quarter of the inquiries came from older individuals already living in institutions.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Brody, 1978
Purpose	To compare people who moved in and those who only applied to Philadelphia Geriatric Center's innovative project Community Housing for the Elderly.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Project evaluation descriptive research. (S) 87 older people who applied for tenancy in Community Housing and who met the eligibility criteria: (1) age 62 and over and income as specified by HUD, and (2) functional health such that the tenants could manage in Community Housing (e.g., able to climb stairs and manage the minimal housekeeping and cooking). (M) While about 300 older people initially inquired about admission, the 87 subjects included in the research were those who completed application forms, interviews, and other procedures. Those in the experimental group of tenants (*N* = 24) were selected by a table of random numbers from the pool of those who passed the clinical evaluation and met the other eligibility criteria. The random procedure was used to eliminate possible biases in the selection of tenants; final decisions on acceptance rested with the older people themselves. Assignment could not be made to the two control conditions; rather, natural events (moving or not moving) determined the group assignment of each individual. The experimental group was comprised of those who accepted the offer and moved in. All subjects received evaluations on instruments and questionnaires administered at baseline (time of application) and at six-month follow-up. Social workers also provide evaluations of subjects as part of data. (I) There were 144 variables covering demographics; contacts with family and friends; recent interpersonal losses; types of living arrangements and satisfactions and dissatisfactions with those arrangements; social participation; physical, cognitive, social, and behavioral functioning; self-reported health; morale; and self-concept. Influential Factors Inventory, 75 possible reasons in favor of or against the potential move. (A) Frequencies

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Brody, 1978
Concepts	See Instruments.
Findings	At baseline, the three groups were equivalent on all but eight of the 144 variables. There were no significant differences in age (mean about 74, range 63-94), in family status (80% widowed, the remainder single, divorced, or separated; mean number of children 1.45), and in having similar histories of extreme stability in previous living arrangements. Eight variables indicated that the control movers were experiencing more health problems, though their functional capacities were similar to those of the other two groups. By six-month follow-up, health problems continued to differentiate the group of control movers and those difficulties had begun to be evidenced by declines in functional capacities. The nonmovers were similar to the experimentals at baseline, but by six-month follow-up, five had died and the survivors showed differences in the direction of somewhat poorer health. Reasons offered by subjects at baseline for wish to move to Community Housing: Fear and crime (52.9%), poor condition of current dwelling (57.5%), loneliness and isolation (60.9%), accessibility to services and facilities (41.4%). As with the reasons offered in favor of moving, the reasons offered by the subjects at baseline against moving did not prove predictive of who would have moved by the time of the six-month follow-up. A very strong predictor of moving/not moving by follow-up emerged from the social worker's baseline rating on the influential factors inventory of factors operating against moving for each subject. Social worker rating (based on the interview) that the subject was reluctant to leave familiar surroundings or that the subject would find the prospect of moving too hard psychologically was extremely significant. More than 70% of the nonmovers, but only 9% of the control movers and 25% of the experimentals were judged to have such resistance.
Comments	One of the early studies looking at move to LTC facility other than a nursing home.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Chenitz, 1983
Purpose	To generate a theory related to the CR's responses to nursing home admission.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Retrospective, exploratory study used grounded theory. (S) 30 CRs admitted to two urban nursing homes, family members visiting the CR, staff, physicians who visited CR in nursing homes. (M) Observation, formal and informal interviews, and medical record review. Open-ended interviews with CR six to nine months after admission several times per week. Observations were also made of the resident's care and informal interviews with families, staff, and physicians. Comparative data were collected on 30 CRs receiving home care from visiting nurses. (I) Open-ended interview questions. (A) Grounded theory.
Concepts	See findings.
Findings	Five basic conditions were identified that influenced the CRs' responses to the nursing home in spite of individual differences: importance, legitimation, desirability, voluntary nature, reversibility. Intervening factors included timing, CR's health, family relationships. Response to the nursing home admission included acceptance (strategic submitting or submitting by default) and resistance (resigned resisting or forceful resisting).
Comments	Outlines some of the factors that may be important in determining the CR's response to a move. Limited by only focusing on the move to a nursing home. Not clear where the residents were living prior to their entry into the nursing home, but Chenitz commented that a common route into the nursing home was by way of the acute care hospital. All of the CRs were alert and oriented on admission.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Coulton, Dunkle, Goode, & MacKintosh, 1982
Purpose	To describe decision-making post-hospitalization.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Exploratory-descriptive study. (S) 40 hospitalized patients over 60 years of age (mean age 74 years) who would need post-hospital care. (M) Face-to-face interviews shortly before discharge and medical record review. (I) Used open-ended questions: information about patients and families involved in the decisions about post-hospital care; the amount of information the patient had about alternative choices; the degree family members and professionals influenced the decision; the gains and losses considered by the patient; and the patient's acceptance of the plan were obtained. (A) Content analysis.
Concepts	See Instruments
Findings	Factors that affect the degree of involvement the patients had in the decision-making that were identified: level of mental impairment; information patient had about LTC resources; patient's perceived freedom of choice of several alternatives for LTC; time available to make choice; degree of hope that plan would lead to an acceptable outcome; family power structure; commonality of family/patient goals; social support; patient's assertiveness.
Comments	Focus on decision-making at the time of hospital discharge with less than half of the patients going to an institutional setting. Need to look for the factors affecting the patient's involvement in this decision-making process in the situation of the CR considering the move from home.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Coulton, Dunkle, Chow, Haug, & Vielhaber, 1988
Purpose	To determine whether there are multiple dimensions of the process that are relevant to planning for post-hospital care.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Instrument Development. (S) Large, urban, university-affiliated hospital. Elderly patients who were expected to require post-hospital care for more than 30 days interviewed just prior to discharge. All patients older than 60 years in hospital during 18 month period eligible. Not interviewed if requested not to participate or high level of confusion revealed by mental status exam. Twenty respondents excluded because they were judged as unreliable informants. *N* = 314; mean age = 75.2. (M) Interview done a day prior to scheduled discharge. (I) 29 items. Patient's perceptions of process of making decisions about post-hospital care. Five-point visual analog scale (not at all true, somewhat true, half true and half false, mostly true, completely true). Two observer measures of patient decision-making: (a) rating of patient's overall involvement in decision-making (patients asked to describe, in own words, how post-hospital care plan came about); responses recorded by interviewer; two raters judged degree to which patient was actively involved in the planning process—no involvement to high level of involvement; (b) degree to which patient actually acknowledged more than single option for post-hospital care; interviewer judgment based on review medical record and questioning patient's medical social worker; availability of post-hospital care alternatives rated 1 = least to 5 = most. (A) Exploratory factor analysis of 29 decision-making items.
Concepts	Functional ADL — needs assistance in one or more areas (32%). Totally dependent in one or more areas (59%). Also see Findings.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Coulton, Dunkle, Chow, Haug, & Vielhaber, 1988
Findings	•Hypervigilance: 7 items reflect generalized feelings of fear, anxiety, agitation, pressure regarding the decision. ∝ = .75. Correlated with judgment of patient's involvement, r = -.22. •Family support: 3 items referring to the involvement of patients' families in the decision-making. ∝ = .70. •Restriction of choice: 3 items that seemed to reflect patients' perceptions that their options for post-hospital care were limited. ∝ = .60. Correlated with perceived alternatives, r = -.29. •Certainty of outcomes: 4 items referring to whether outcome of decision is knowable and understandable. ∝ = .51. Correlated with observer judgments of patient's involvement in decision-making, r = .15. •Control: 2 items pertaining to how much control patient had over the decision. ∝ = .62. Correlated with observer judgments of patient's involvement in decision-making, r = .25. •Rushed: 2 items reflecting a feeling of being rushed and pressured by time. ∝ = .51. Correlated with observer judgments of patient's involvement in decision-making, r = -.20.
Comments	47% discharge to own home. 20% discharge to other's home (relative's). Majority not currently married (69%); females (72%). 46% education less than high school.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Hartwigsen, 1987
Purpose	To explore how and why housing decisions were reached.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Retrospective exploratory-descriptive design. (S) 25 older Caucasian widows (mean age 77.4 years) who had moved to a life care facility in Arizona. Education level averaged 12.3 years with 13 having college degrees. 96% had been employed in career-oriented professions, 40% were childless. Average income range $15,000 to $19,999. (M) An interview schedule and open-ended questions. Interviews took place in the respondents' homes at the life care facility (variety from studio apartment to two-bedroom cottage), and lasted a minimum of two hours. (I) Open-ended questions asked about past life, widowhood, and housing choices. (A) Content analysis consisted of looking for commonalities in answers and identifying steps in the relocation pattern.
Concepts	Past-life experiences in marriage, as family and as professional-career woman; widowhood; housing choices.
Findings	Decisions to relocate were often initiated by crises experienced vicariously by respondent, health or financial problems experienced by family and friends. Steps in the relocation pattern identified: inertia to remain in the family home; changes over time influencing decision to leave family home; inertia break (vicarious crises inciting relocation); relocation to life care facility; and re-establishment of home.
Comments	Focused on the move from family home. Demonstrated that a vicarious crises may precipitate the move from home to a more supportive environment. Sample of women not representative of age cohort.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Kane, Kane, Illston, Nyman, & Finch, 1991
Purpose	To compare CRs using adult foster homes (AFH) with those using nursing homes, and to see if disabled Medicaid residents were being inappropriately channeled to AFH because of decreased cost of AFH.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Cross-sectional comparative study. (S) Sample included 402 nursing home residents and 405 foster home residents in four geographic areas in Oregon, representing both rural and urban areas. Facilities were selected randomly in each area. 108 foster homes and 39 nursing homes participated in the study. (I) Developed by authors. (M) In-person structured interviews with respondents or family member proxies and care facility staff members. Patient records were also used. (A) Correlations.
Concepts	Questions covered the areas of functional abilities, ADL/IADL, cognitive status, health, mood, activities, recent relationships, satisfaction, factors related to choice of care setting.
Findings	Foster home residents were less likely to come from acute care hospitals. In choosing a care setting, foster home residents were more concerned about a home-like atmosphere and privacy, while nursing home residents wanted more organized activities and physical rehabilitation. In choosing a care setting, 60% of foster care residents and 36% of nursing home residents (or their family proxy) believed that they had some control over the choice. Variables which were significant in identifying residents of a foster home included being female, having previously lived in relative's home or adult foster home, being able to transfer, toilet, and take medicines. Variables that were associated with being a nursing home resident included having a hip fracture and being a Medicaid recipient. On average, nursing home residents are more disabled (more help need with ADLs).

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Kane, Kane, Illston, Nyman, & Finch, 1991
Comments	No information about how long residents had been living in each setting and the number who were admitted from home. Psychometric adequacy of measures not given. Raises the concern that with many of the residents having poor cognitive functioning this would limit their involvement in the decision-making process if present at the time when considering the move to the care setting. Supports the position that adult foster homes are an important alternative to nursing home care in Oregon.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	McAuley & Bleiszner, 1985
Purpose	To determine the preference of a community sample of CRs for five long-term care options and the factors associated with various choices.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Correlational study. (S) Representative sample of noninstitutionalized, relatively healthy people 60 years of age and older living in Virginia (*N* = 1,240). (M) Face-to-face interviews. (I) Interview questions based on OARS multidimensional functional assessment plus questions related to attitudes about LTC arrangements. (A) Frequencies, regression.
Concepts	Attitudes about LTC arrangements: Respondents were asked to express their agreement or disagreement with each of the following arrangements: If you become sick or disabled for a long time: (a) have a housekeeper or nurse (who you pay or an agency pays for) take care of you in your home; (b) have a relative (such as your husband/wife, child, or other relative) care for you in your own home; (c) go to live in a home of a relative; (d) go to a nursing home; and (e) go to a place during the day, such as an adult day care center, where care, rehabilitation, and social activities take place, and return home in the evening.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	McAuley & Bleiszner, 1985
Findings	The two most frequently selected LTC arrangements involved receiving care in the respondent's own home either by a relative (66%) or paid help (70%). Of the two choices requiring a change in residence, moving to a nursing home was selected more often (28%) than moving into the home of a relative (15%). Adult day care was chosen by 32% of the respondents. A total of 25% of the sample selected only one of the five choices. 10% would only choose care in their own home from a relative. 57% of the respondents selected a mix of formal and informal care arrangements. 57% selected only care arrangements that did not require a range of residence. Demographics also influence choices, i.e., younger chose adult day care and care from relative in own home; married chose care in own home by relative (assume spouse); more money chose nursing home option; whites, paid in-home care; non-whites, adult day care and nursing home.
Comments	Demographic characteristics of sample not outlined. Whether these preferred LTC arrangements would be selected when the CR was actually needing care is unknown. Demonstrates that CRs have definite ideas about the LTC arrangements they prefer with care in their own home most desired. But we have no information from this study about why certain care arrangements were preferred. Although a majority of CRs selected both formal and informal care, other studies indicated that formal care services were rarely used.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Rowles, 1983
Purpose	To understand the attachment to place of older people.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Exploratory study. (S) Strong interpersonal relationships were developed over a four-year period with 15 older residents (age range 62-91) living in a rural northern Appalachian community. Reported on five of these 15 residents that moved from the community. (M) Participant observation and in-depth interviews. (I) See Method. (A) Content analysis.
Concepts	See Findings.
Findings	A relocation dilemma for the CR was between the physical, social, and emotional support provided by the familiar environment and the desire to be close to family who had moved from the area. Over a period of years, the CRs decided to relocate and eventually sever ties with the community. Factors that encouraged relocation were deteriorating health and consequently reduced ability to maintain independent living. Anticipating the need to move accompanied the presence of chronic health conditions. Phases of the process that occur over time and as the CR's health declined were: children relocate; accommodation; season migration to visit children; crisis; relocation; holding on by maintaining house in community and returning to visit; severance.

RESEARCH STUDIES RELATED TO OLDER PERSON'S PERSPECTIVE	
Author/Date	Rowles, 1983
Findings (Cont.)	Reluctance to leave home despite the deteriorating contemporary physical setting. In part, this expresses attachment to a familiar house. Rootedness in place; bonding with environment outside the house reinforces reluctance to relocate (more than a manifestation of inertia). "On being inside": *Physical insideness* — functional existence with the setting manifest in the immediacy of everyday activity. Body awareness derives from and is enhanced through familiarity with a setting, through the very process of living within a place. *Social insidedness* — People and relationships, among them are essential components of the place (community and local). Spatial proximity also fosters intimately linked support networks with high levels of functional and social reciprocity among neighbors. *Autobiographical insideness* — a series of remembered places, of which the drab contemporary physical setting is but a remnant "lived in" place conveying a sense of ongoing affinity and forming a repository of personal identity. Acknowledging different levels of insideness is a key to understanding how place can affect well-being in old age. *Autobiographical insideness as a factor in accommodation to aging* — as people grow older, physiological and psychological capabilities become progressively impaired; physical participation in environment becomes increasingly supplemented and gradually supplanted, by emotional and vicarious participation in place. Autobiographical insideness assumes increasing importance. *Autobiographical insideness can rarely be created within a new setting.*
Comments	One of the few studies that described the decision-making process of CRs moving from their homes. Four of the five CRs moved into the home of an adult child. Supports the conceptualization of the older person considering the need to move prior to a crisis situation.

APPENDIX C

Research Studies Related to Rural Older People

RESEARCH STUDIES RELATED TO RURAL OLDER PEOPLE	
Author/Date	Dwyer & Miller, 1990
Purpose	To compare characteristics of CRs, CGs informal networks, and formal networks likely to impact primary CG stress and burden by area of residence, and test conceptual model explaining CG stress and burden in rural, small city, and urban samples.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Correlational study. (S) Matched sample of 1,388 noninstitutionalized CRs and their CGs drawn from the 1982 National Long-Term Care Survey (LTC) and the National Survey of Informal Caregivers (ICS). Rural *n* = 283, small city *n* = 536, urban *n* = 569. (M) Unpaid CGs from the ICS were matched to CRs from the LTC for whom they provided care. Primary CG identified as the individual who reported the greatest number of hours per day spent providing caregiving services. (I) CR: ADL indicator — Six ADL limitations summed (eating, getting in/out of bed, moving around inside, dressing, bathing, toilet use), IADL indicator — 9 IADL impairments summed (heavy work, light work, laundry, meals, shopping, moving outside, walking, managing money, telephoning). Mental functioning summing incorrect responses to a 10-item memory test. Six tasks accomplished by CR that denote their ability to assist the CG (chores, babysitting, money gifts, keeps company, feel useful, other) summed. CG: ADL impairments — six ADL limitations summed. ADL tasks — summed CR's ADL limitations for which CG provides help, IADL tasks — summed CR's IADL limitations for which CG provides help. Informal helping network: resources total number of unpaid helpers; the number of unpaid helpers who assist with at least one ADL limitation; summed total of the number of IADL tasks with which CR received some assistance from informal helpers; the number of relatives' visits and telephone calls; number of friends' visits and telephone calls.

RESEARCH STUDIES RELATED TO RURAL OLDER PEOPLE	
Author/Date	Dwyer & Miller, 1990
Design (Cont.)	Formal helping resources: total number of formal helpers; number of formal helpers that assist with at least one ADL limitation; number of IADL tasks performed by paid helpers. Stress: measured by single question: "If bathing the CR causes you stress that is represented by 100 points, how many points would you give to show how much stress it causes you to do all of the things you do to help?" CG burden: summing unweighted positive responses to nine problems experienced by CGs as result of caring for CG. These nine problems are Cr forgets, gets confused, or is uncooperative; CR sometimes embarrasses CG; CR sometimes lapses into senility; CR sometimes yells at CG; CG does not have enough privacy; CG has a limited social life; CR requires constant attention; caring for CR has worsened CG's health; providing care for CR costs more than CG can afford. Residence: Six categories that range from country/nonfarm to large city and denotes place of residence of CR. (A) Comparison of means, probabilities of t.
Concepts	See Instruments.
Findings	Significant rural urban differences: 49.8% of CGs were spouses in rural areas compared to 42.5% in urban areas. Rural CGs had significantly lower incomes ($12,400 vs. $16,100) and were less likely to experience a negative employment effect due to caregiving (24.0% vs. 31.3%). Self-perceived health of urban primary caregivers was greater than for rural residents. No significant residential differences in the gender, age, length of caregiving, ADL impairments, or ADL tasks of the primary CG. There does not appear to be a consistently more extensive informal caregiving network available to CRs in rural areas. Rural CRs have fewer paid helpers (.19), the least number of paid helpers assisting with at least one ADL task (.09), and receive help with the fewest number of IADL tasks (.30). In all three instances, values for rural samples are significantly less than small city sample, while the urban CRs represent a middle category.

RESEARCH STUDIES RELATED TO RURAL OLDER PEOPLE	
Author/Date	Dwyer & Miller, 1990
Findings (Cont.)	Primary CGs who resided in small cities were more likely to be an adult child than rural residents. Small city CGs provided the fewest hours of care and helped with the fewer number of IADL tasks, but differences are significant only when compared to urban dwellers. They were also less likely than their rural counterparts to share a residence with the CR (78.9% vs. 84.8%), but just as likely to experience a negative impact on employment as a result of being a CG. Small city CGs had incomes between those of rural and urban residents and perceived their health to be significantly better than rural dwellers. Rural CGs had highest mean stress levels (4.81), but lowest average burden levels (2.69). With the exception of significant higher level of burden in urban compared to the rural sample (*P* = .05), none of the differences are significant.
Comments	Large sample size permitted data analysis not compatible with the small samples typical of research on urban/rural caregiving. Because stress responses are highly right-skewed, a log transformation was performed.

RESEARCH STUDIES RELATED TO RURAL OLDER PEOPLE	
Author/Date	Lee, 1990
Purpose	To examine the physical, mental, and social health perceptions of rural persons engaged in agriculture at three different adult developmental levels: middle age (30 to 50 years), new middle (51 to 70), and older (over 71 years).
Design (S) Sample (M) Method (I) Instruments (A) Analysis	(S) 162 farms and ranchers who responded to a questionnaire. (M) Mail questionnaire to random sample of 300 members of a state agricultural organization having 3,000 members. (I) Health perception: Engel's (1984) Perceived Health Status instrument which contains physical, mental, and social measures of health. (A) Descriptive statistics and analysis of variance.
Concepts	See Instruments.
Findings	Entire rural sample indicate lower concern/worry regarding physical health and a greater rejection of the sick role than that found among national normative samples; mean mental health score for the study sample was similar to that obtained for national samples; social health perception subscale, respondents scored highest on positive marital relationship and satisfaction with place of residence.
Comments	Knowledge of health perceptions with differing adult developmental levels and for particular geographic community samples. Nurses more realistically assess the specific health needs and health care preferences of persons in these groups, and thus design appropriate intervention.

RESEARCH STUDIES RELATED TO RURAL OLDER PEOPLE	
Author/Date	Long & Weinert, 1989
Purpose	To develop an integrated theory base for rural nursing.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Retroductive approach, building upon both qualitative and quantitative research data. QUALITATIVE DATA (S) Data gathered primarily from persons in ranching/farming areas and from towns of less than 2,500 persons. (M) Data collected through ethnographic study by Montana State University College of Nursing graduate students. Interview sites selected by students based on specific interest and convenience. During a six-year period, data gathered from approximately 25 locations. In general, each student worked in depth in one community, collecting data from 10 to 20 informants over a period of at least one year. (I) Open-ended interview questions using Spradley's (1979) guidelines. Opening question in the interview: "What is health to you . . . from your viewpoint? . . . your definition? (A) Content analysis based on ethnography. QUANTITATIVE DATA (S) Convenience sample (*N* = 62) of survey participants was located through the Agricultural Extension Service, social groups, and informal networks. All lived in Montana, completed the questionnaires in their homes, and returned them by mail. (M) Mail questionnaire to middle-class whites, with an average of 13.5 years of education and a mean age of 61.3 years, who had lived in Montana an average of 45.6 years. (I) Beck Depression Inventory (Beck, 1967); Trait Anxiety Scale (Spielberger, Gorsuch, & Lushene, 1970, to tap mental health status; General Health Perception Scale (Davies & Ware, 1981), to measure physical health status and health beliefs; Personal Resource Questionnaire (Brandt & Weinert, 1981), use of informal systems for support and health care.

RESEARCH STUDIES RELATED TO RURAL OLDER PEOPLE	
Author/Date	Long & Weinert, 1989
Concepts	Rural, sparsely populated. States such as Montana, which are sparsely populated overall, are viewed as rural throughout, despite the existence of some population centers within them. Health status and health beliefs, isolation and distance, self-reliance, and informal health care systems.
Findings	Work, or the fulfilling of one's usual functions, is of primary importance. Health is assessed by rural people in relation to work role and work activities, and health needs are usually secondary to work needs. Rural informants who lived outside of towns traveled a distance of almost 23 miles on average for emergency health care, and over 50 miles for routine health care. Despite these distances, rural dwellers tended to see health services as accessible and did not view themselves as isolated. Desire to do for oneself and care for oneself was strong among the rural persons interviewed. Informants who had lived in Montana over 10 years but less than 20 still considered themselves to be *newcomers* and expected to be viewed as such by those in their community. Rural dwellers are self-reliant and resist accepting help or services from those seen as *outsiders* or from agencies seen as national or regional *welfare* programs. Help is usually sought through an informal rather than a formal system. Health care providers in rural areas must deal with a lack of anonymity and much greater role diffusion than providers in urban or suburban settings.
Comments	Health care services must be tailored to suit the preferences of rural persons for family and community help during periods of illness. Nurses can provide instruction, support, and relieve to family members and neighbors, who are often the primary-care providers for sick and disabled persons.

RESEARCH STUDIES RELATED TO RURAL OLDER PEOPLE	
Author/Date	Long & Weinert, 1990
Purpose	To describe health as it is perceived by chronically ill persons; to measure their physical health, mental health, and disability level; to contrast the health perceptions and health measures of chronically ill persons in urban and rural areas.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Descriptive-comparative study. (S) 358 persons with multiple sclerosis. Participants lived in 42 states in both urban and rural locales. The urban sample of 167 women and 59 men, and the rural sample of 93 women and 39 men were white, well educated, with an average age of 44.8 years. (M) Mail questionnaire. Also open-ended statement, "What does it mean to be healthy?" (I) General Health Index (Davies & Ware, 1981); CES-D (Devine & Orem, 1985); Enforced Social Dependency Scale (Benoliel et al., 1980); Sickness Impact Profile-Dimension II (Gilson et al., 1975). (A) Quantitative data analyzed using descriptive statistics. T-tests used to contrast the mean scores of urban versus rural persons on measures of physical health, mental health, and disability. Content analysis for descriptions of health.
Concepts	See Instruments.
Findings	Rural sample indicating higher levels of disability in the level of psychological disability as measured by the Sickness Impact Profile. No significant differences in the other measures lending evidence that for those with a long-term illness, place of residence does not appear to make a significant difference in level of physical health, mental health, or physical disability.
Comments	Results of content analysis not reported. Average age of 44.8 years. Only significant difference between the samples was that the urban group had a higher family income.

APPENDIX D

Research Studies Related to Decision-Making Process

RESEARCH STUDIES RELATED TO DECISION-MAKING PROCESS	
Author/Date	Beaver, 1979
Purpose	To identify the components of the decision-making process engaged in by the elderly mover prior to relocation.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Descriptive-correlational. (S) Non-probability sample consisted of 108 community-based elderly residents (66 years of age and over) who were living in a retirement apartment located near the downtown section of Los Angeles. Two groups, successful and unsuccessful adjustors, based on three apartment staff ratings. All CRs interviewed described by their doctors as physically and psychologically well. (M) Personal interviews. (I) Only instrument discussed: Successful/unsuccessful adjusters (CR) — 7 point scale (7 = excellent, 1 = fair). (A) Hypothesis testing: the chi-square test and difference-of-means tests. Discriminant analysis to obtain maximum difference between the two groups.
Concepts	Precipitating event; information received; reaction to the event; exploration of what to do; selective organization (framing); participation; preparation and choice; outcome (What has been the result of the person's choice? Was the final decision the actual decision of choice? To what extent did the individual participate in the decision-making process?).
Findings	CR did participate in the decision-making process. Self-reliance of CR who relocates; selectiveness with which CR sought out specific others for support (No significant difference between successful/unsuccessful adjusters). Tendency of the CR to consider only a few options when moving. CR stressed the practice of having a definite choice from the beginning about where he/she wanted to live. Two significant findings: Successful adjusters (52%) felt that it was important to consider the activities available at the setting prior to relocating; successful adjusters considered more choices.
Comments	Sample only extreme group of successful and unsuccessful adjusters included; limited or no discussion of instruments or question whether method was combination open-ended and closed-ended questions.

RESEARCH STUDIES RELATED TO DECISION-MAKING PROCESS	
Author/Date	Chadwick & Russell, 1989
Purpose	To explore the decisions confronting care professionals when discharging frail elderly people from hospital.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Exploratory study. (S) Ward meetings are held weekly, are chaired by a consultant geriatrician, and attended by those individuals involved with patients' care and discharge. This could include medical and nursing staff, physiotherapists, occupational therapists, social workers, pharmacists, dieticians, and representatives from the Hospital Discharge Service. Interviews were also conducted with a sample of consultants, social workers, ward sisters, and elderly patients. (M) Participant observation of 10 geriatric (acute and rehabilitation) ward meetings in two hospitals in England. Ward meetings provide the *formal* setting for decision-making. (I) Observations, transcriptions of ward meetings. (A) Content analysis.
Concepts	See Findings
Findings	The dilemma of discharging a vulnerable old person home: issues of risk, paternalism, and autonomy. The dilemma of allocating residential care for the "partly sick and partly well." Principle of autonomy is double-edged. It may be used to support individual choice, within the context of current political ideology; but it may also be interpreted as encouraging self-reliance, and as a way of denying collective responsibility for an elderly person's care needs, contributing to a view of society which sees itself as a "community of limited liability." Definitions of health and illness to be inextricably linked to issues of resource-management. In caring for frail older people, professionals are confronted with conceptual ambiguities, and with the limitations of a welfare system that has artificially categorized old people's needs.
Comments	British study.

RESEARCH STUDIES RELATED TO DECISION-MAKING PROCESS.	
Author/Date	Coulton, Dunkle, Haug, Chow, & Vielhaber, 1989
Purpose	To characterize decision-making process, obtain information regarding nature of LTC placement, and assess CR's affective adjustment to LTC arrangement.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Correlational study. (S) Non-random sample of medical-surgical hospitalized patients over 60 years of age referred for post-hospital care (*N* = 290); major Midwestern metropolitan area. (M) Interviews with patients at time discharge plans being made and 30 days after discharge. (I) At discharge (a) anxiety about decision-making experience: 7 items reflecting patient's fear, anxiety, panic regarding planning for care; $\propto = .75$. (b) Decision control: 2 items — who made the final decision; degree to which choice actually belonged to patient, $\propto = .62$. (c) Expectations regarding control. Modification of Rotter's internal-external locus of control scale: 15 items (7 external, 8 internal) randomly selected from original scale. *30 days after discharge:* (a) Psychological distress: Brief Symptom Inventory (BSI), symptom check list yields total psychological distress score. (b) Patient satisfaction: 4 items, satisfaction with immediate surroundings, neighborhood, building or residence, interest in relocating. *Other variables:* Patient age, education, discharge destination, functional status: 5 item Katz Index of ADL. (A) Multiple regression.
Concepts	Care choices: skilled care, intermediate care or rehabilitation facility, care from home care agency in patient's or relative's home, planned care at home provided by family or other non-professional providers.

RESEARCH STUDIES RELATED TO DECISION-MAKING PROCESS.	
Author/Date	Coulton, Dunkle, Haug, Chow, & Vielhaber, 1989
Findings	Psychological distress skewed toward little distress. Sample displayed relatively high mean levels of internal control and low mean levels of external control. Patients varied in perceptions of decision control: 50% feeling they had control over discharge plan, 10% feeling they had no control, 40% expressing some degree of partial control. Decision anxiety scores normally distributed; satisfaction was nearly normally distributed. Anxiety about decision-making process increases psychological distress. Perceived lack of control over the decision is associated with post-hospital psychological distress for patients with high levels of internal locus of control, but not for those whose expectations for internal control are low. Patients who went home more satisfied than those who went to institution. More decision, anxiety less satisfaction. More decision control, higher satisfaction. Decision anxiety higher among individuals with more ADL limitations. Patients with greater expectation of external control experience less decision anxiety.
Comments	Information about the total number of patients discharged home versus to an institution not included. Small R^2 values (seven independent variables). Psychological distress = .13. Satisfaction = .21. Patient satisfaction a measure of satisfaction with physical environment only. Did not reflect satisfaction with care patient receiving.

RESEARCH STUDIES RELATED TO DECISION-MAKING PROCESS	
Author/Date	Simms, Boland, & O'Neill, 1992
Purpose	To describe the experiences of families caring for an ill family member in the home; to elicit descriptions of decision-making and problem-framing from the perspective of the CG.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Grounded theory approach. (S) 17 CGs of CRs at home within a metropolitan Intermountain West area; all but three were women. (M) Open-ended questions, observations. (I) Open-ended questions were designed to construct an understanding of CGs' experiences in all aspects of home care, including decision-making. (A) Grounded theory.
Concepts	See Findings. The frame of the problem develops as people consider (1) how the problem is presented; (2) their present mood; (3) ability to imagine alternatives; (4) experience with a similar situation; (5) perceived effect of the problem on current lifestyle; and (6) sense of whether the decision outcome will be a win or a loss for the decider.
Findings	Decision-making processes are difficult to study because individuals cannot easily or directly describe what they thought about prior to deciding. People often remember decisions they made but cannot recall the exact process used to arrive at decisions. Decision-making is not a static process. Progression from passive to active decision-making. For most CGs, decision to home care seemed simple. They did not think they had other options. Decision was structured to consider a single value rather than to integrate several competing values (non-analytical decision-making). CG try to maintain past roles in decision-making whenever possible by continuing to consult with CR. Loss of mutual decision-making was seen as significant and contributed to the sense of isolation and burden felt by CG. A different kind of family stress emerged as siblings negotiated among themselves for decision-making rights and roles as CGs.
Comments	Authors suggest that nurses need communication skills, ability to assess family behavior patterns, and skills in negotiating conflict situations.

RESEARCH STUDIES RELATED TO DECISION-MAKING PROCESS	
Author/Date	Weaver & Bryant, 1990
Purpose	To examine medical professionals' discharge planning strategies.
Design (S) Sample (M) Method (I) Instruments (A) Analysis	(S) 91 professionals, representing nurses, social workers, physicians, and residents employed at a Veterans Administration hospital. (M) Physicians, residents, nurses, and social workers were presented with 16 hypothetical case scenarios and asked to: (1) rate the appropriateness of four discharge options (nursing home, community nursing, adult day, and outpatient clinic care), and (2) select the most appropriate discharge plan for each case. (I) Discharge planning questionnaire. Four within-group variables were included in the scenarios: physical impairment, caregiver availability, follow-up required, and patient compliance. (A) Multivariate analysis.
Concepts	Factors most important when planning follow-up care: (a) degree of physical impairment; (b) availability of a caregiver; (c) amount of medical follow-up care required; and (d) degree of patient compliance. Physical impairment: patient was either impaired in bathing and dressing or was impaired in bathing, dressing, transferring, and urinary continence. Availability of a CG: either she did not work and was in good health or she worked full-time at an easily recognized job and had some minor medical problems. Patients required little follow-up care or a great deal of care, including dressing changes, physical therapy, and urinary catheter care, in addition to supervision of medication and monitoring of vital signs. The patient was compliant with the medical treatment regime or noncompliant with his medications, diet, and therapy.

RESEARCH STUDIES RELATED TO DECISION-MAKING PROCESS	
Author/Date	Weaver & Bryant, 1990
Findings	Decisions were greatly influenced by CG available. When a CG was available, respondents preferred community-based options (i.e., community nursing care or outpatient clinic); if the case involved complications (i.e., severe physical impairment, heavy follow-up, noncompliant patient), they considered community nursing care more appropriate than outpatient clinic. When a CG was unavailable, respondents preferred institution-based options (i.e., nursing home or adult daycare); if there were complications, they considered nursing home more appropriate than adult daycare.
Comments	Generalizability very limited: VA hospital with predominantly older men with low income. Poor response rate (63% nurses, 65% social workers, 50% physicians, 28% residents); asked to respond to hypothetical patient situations.

APPENDIX E

Research Studies Related to Meaning of Home

RESEARCH STUDIES RELATED TO MEANING OF HOME	
Author/Date	Horwitz & Tognoli, 1982
Purpose	To explore the question: "Does a concept and sense of home change across time, and in relation to psychological and environmental changes?"
Design (S) Sample (M) Method (I) Instruments (A) Analysis	Qualitative study. (S) 10 women and men living alone, all but one younger than 65 years. (M) 45-minute interviews. (I) Open-ended questions. (A) Content analysis.
Concepts	See Findings
Findings	Sequence of environmental and psychological changes participants experienced after leaving their parental home: an initial phase of feeling "not at home"; an incipient awareness of their need for a home; the psychological and physical arrival at a place that felt like home. Home as varying environmental and psychological dimensions across people's lives and does not seem to depend upon traditional family structure for its meaning.
Comments	Participants acquainted with one of the interviewers, but not known to the person interviewing them. Participants were white, urban sample.

APPENDIX F

Interview Guides

OLDER PERSON
Interview Guide
Phase 1

OP 1. Could you start by telling me a little bit about yourself, how you would describe yourself, your interests, likes and dislikes, what is important to you?

> What help do you get now and by whom?
> How has this changed over time?
> Who else has helped you in the past?
> What help do you give others?

OP 2. What has lead up to you considing getting more help or changing where you live?

> **PROBE**: When did all this start, change, come about? What happened?

OP 3a. What is (CG's) view of the situation?

> **PROBE**: What does (CG) think and feel about this?

OP 3b. Who else have you talked to about this?

> **PROBES**: Who has been helping you at home or helped you with things you have needed, or helping you make decisions, manage your affairs?
>
> Who would you call if you had an emergency?
> Have you talked with (people named above) about getting more help or changing your living situation?

OP 4. What choices do you have about how to get more help or where to live?

> **PROBES**: What information have you gotten?
> What information have you asked for?
> From whom?
> What do others think you should do?
> What do you think about that?

OP 5. How are you going to decide what to do?

> **PROBES**: What kinds of things do you consider important in deciding (to get more help or changing living situation--adjusted by above conversation)?
> What would you like to happen?
> If you choose (the option mentioned by OP), what would be different from now?
> What would be the same?
> Will anything be better? Any thing worse?

OP 6. What do you think your family and friends would like to happen?

PROBES: What do you think will happen?
What do you want to make sure happens?
What would you like to happen?
Will further changes need to be made?
If (change mentioned), what would be different from now?
What would be the same?
Will anything be better? Anything worse?
How long do you think you will need help?

OP 7. There are many ways people react to these situations. Some feel overwhelmed by what is happening (PAUSE), pressured (PAUSE), helpless (PAUSE), hopeless (PAUSE), or relieved (PAUSE). (NOTE Non-Verbal Responses.) How did you feel about this? How did you react to (events mentioned)?

What has been helpful in thinking this through?
What has not been helpful?
What would have been helpful?

<u>We are almost done. I just have 3 more short questions.</u>

OP 8. What advice would you have for others in this situation or having to make these decisions?

OP 9. Is there anything else you think is important for me to know?

OP 10. Is there anything you would like to ask me?

Thank you for meeting with me and answering my questions. If it is OK, I will be calling you on the phone in 3 weeks to see how things are going, and again in about 6 weeks to arrange the second interview.

(NO) Why?

(YES) Great. Then I will be phoning you about (time in the month i.e. the end of February).

Thank you, again.

CAREGIVER
Interview Guide
Phase 1

CG 1. Could you start by telling me a little bit about yourself and (OP), your relationship, (how long you have known each other, if not family)?

How often you see each other or talk on the phone?
How do you help each other?
When did you start helping (OP)?
What do you think about (OP) getting more help or changing living situations?

CG 2. What has lead up to you considering getting more help for (OP) or (OP) changing (his/her) living situation?

When did all this start, change, come about? What happened?
What does (OP) think about this need... (for more help or moving?)
What does (OP) think and feel about this?

PROBE: What events triggered this need for more help?

CG 3a. What does (OP) think about this need (for more help or moving?)

PROBES: The person may want to deny that anything is different or put off thinking about what to do. (PAUSE) Some feel overwhelmed by what is happening. (PAUSE) Some feel relieved. (PAUSE) How do you think (OP) is feeling?

CG 3b. Who have you talked to about these suggestions?

PROBES: Who has been helping (OP) at home?
Who would you call if (OP) needed immediate help?
Have you talked with (persons named above) about (OP's) increasing needs for help?

CG 4. What choices do you think (OP) has?

What information have you gotten?
What information have you asked for? From whom?
What do others think (OP) should do?
What do you think about that?

CG 5. How are you going to decide what to do?

PROBES: What kings of things do you consider important in deciding whether to get more help for (OP) or having (OP) move? What would you like to happen?
If (change mentioned), what would be different from now?

What would be the same?
Will anything be better?
Anything worse?

CG 6. What do you think (OP) would like to happen?

What do you think will happen?
Will further changes need to be made?

CG 7. There are many ways people react to these situations. Some feel overwhelmed by what is happening (PAUSE), pressured (PAUSE), helpless (PAUSE), hopeless (PAUSE), or relieved (PAUSE). (NOTE Non-verbal Responses.) How did you feel about this? How did you react to (events mentioned)?

What has been helpful in thinking this through?
What has not been helpful?
What would have been helpful?

<u>We are almost done. I just have three more short questions.</u>

CG 8. What advice would you have for others in this situation or having to make these decisions?

CG 9. Is there anything else that you think I should know?

CG 10. Is there anything you would like to ask me?

Thank you for meeting with me and answering my questions. If it is OK, I will be calling you in 3 weeks to see how things are going, and to set up the second interview.

YES

NO Why?

OLDER PERSON
Interview Guide
Revision 3/4/94

OP 1R. Could we start by you telling me a little bit about yourself and what's been going on?

How did you happened to start with people coming in to help?

OP 2R. Could you use more help than you are getting now?

How much family do you have?
When you were making the decision, did you talk to anybody else about what was available?

Did you ever think about moving to a retirement community or something like that?
Did you ever think about trying to find somebody to live in full-time?

What is special about being able to stay home?
What do you think your family or friends think about the help you have?
How long did your parents live? Did they stay at home until the end?

OP 3R. There are many ways people react to these situations; needing to get help. Some feel overwhelmed by what is happening, pressured, hopeless, helpless, or relieved.

[Pause]
[Pause]
[Pause]
How do you feel?

OP 4R. What advice would you have for others in this situation or having to make these decisions?

OP 5R. Is there anything else you think is important for me to know?

OP 6R. Is there anything you would like to ask me?

Thank you for meeting with me and answering my questions. I have one last thing, completion of some short answer questions, such as your birth year, how much school you completed, things like that. This information will be combined with similar information from the other people I have interview to give a general description of the group of people who have talked with me.

If it is OK, I will be calling you on the phone in 3 weeks to see how things are going, and again in about 6 weeks to arrange the second interview.

Revision
3/7/94

OLDER PERSON
Interview Guide
Phase 2

OP 11. Could you start by telling me what has happened since we last talked?

PROBE: How has your situation or condition changed?
Have you come to any conclusions or decisions?
How do you feel about that?
(If a move as occurred) How did that change come about?
Are you satisfied with that decision?
Do things need to be changed?
What do you want to have happen?

OP 12. How does your family view these decisions and changes?

What do they think you should do?
How do you feel about that?

OP 13. What advice would you give someone in this situation, having to make these decisions?

PROBE: What has been most helpful?
What has not been helpful?

OP 14. What adjustments have you had to make? How is that going?

OP 15. Some (OP family relationship) have found that having to depend on their (CG) more since their illness or decline in health has affected their (~~relationship~~ interactions).
[Pause]

How do you feel?

OP 16. Is there anything else you would like to share with me?

OP 17. Is there anything you would like to ask me?

If it is OK, I would like to call you again after I have finished my study, and just see how things are going and whether anything has changed. I am interested in what you are thinking about all this, then, which will be in about _________ weeks from now.

YES

NO

Revision
3/7/94

CAREGIVER
Interview Guide
Phase 2

CG 11. Could you start by telling me what has happened since we last talked?

PROBE: How has the situation or condition changed?
Have any decisions been reached?
How do you feel about that?
(If a move as occurred) How did that change come about?
Are you satisfied with that decision?
Do things need to be changed?
What do you want to have happen?

CG 12. What does (OP) think and feel about these decisions and changes?
What does (OP) want to do?
How do you feel about that?

CG 13. What advice would you give another family working through this situation; having to make these decisions?
PROBE: What has been most helpful?
What has not been helpful?

CG 14. What adjustments have you had to make? How is that going?

CG 15. Some (family relationship of CG to OP) have found having to do more for their (OP) since her/his illness or decline in health has affected their ~~(relationship).~~ interactions.
[Pause]

How do you feel?

CG 16. Is there anything else you would like to share with me?

CG 17. Is there anything you would like to ask me?

If it is OK, I would like to call you again after I have finished my study, and just see how things are going and whether anything has changed. I am interested in what you are thinking about all this, then, which will be in about __________ weeks from now.

YES

NO

Thank you again for being willing to spend your time talking with me.

APPENDIX G

Demographic Data Forms: Tell Us About You

TELL US ABOUT YOU

Fill in the blank or CIRCLE the answer that describes you.

1. In what year were you born? 19____

2. What is your sex?

Female	1
Male	2

3. What is your race?

African American/Black	1
Asian/Pacific Islander	2
Hispanic	3
Native American Indian	4
White	5
Other	6

4. What is the highest grade in school that you completed?

Completed 8th grade or less	1
Attended high school	2
Completed high school	3
Post high school vocational training	4
Attended college	5
Completed college	6

5. What kind of work have you done most of your working life?

____

____

6. What is your current marital status?

Married	1
Widowed	2
Divorced or Separated	3
Never married	4

7. How many living children do you have?
______________ children

8. How far away do you live from your children? (Provide answers for up to three children, choosing those three whom you turn to the most for help or advice.)

8a.

We live together	0
Less than one mile	1
Number of miles (Write in)	__________

8b.

We live together	0
Less than one mile	1
Number of miles (Write in)	__________

8c.

We live together	0
Less than one mile	1
Number of miles (Write in)	__________

9. Do you have children under age 18 living in your household or for whom you have caregiving responsibilities?

0 No
1 Yes

If *YES*,
9a. How many? _____
9b. Approximately how many hours per week do you spend in caring for or supervising these children?
_____hrs/wk?

10. Where has your place of residence been located most of your life?

Open country/non–farm	1
Farm setting of less than 2500 people	2
Small city (city/town/village with more than 2500 but less than 50,000 people)	3
City of 50,000-250,000 people	4
Suburb of large city	5
Large city over 250,000 people	6

11. Approximately how many years have you lived in your current house/apartment?
_____________years

12. Besides yourself, who lives in your household? CIRCLE ALL that apply.
Spouse 1
Child(ren) 2
Other relative(s) 3
(Write-In relationship)____________
Friend(s) 4

13. Compared to other persons your age, would you say that your health is:

Excellent 1
Good 2
Fair 3
Poor 4

14c. Thinking about the person who helps you the most with your current every day needs, what kind of help does this family member/ friend provide more of?

Hands-on care (preparing meals, doing laundry, chores, help with bathing, etc.) ... 1
Arranging care (arranges for others to help you) 2
About an equal amount of both 3
Advice but no actual hands-on or arranged care provided 4

14d. Who would you call if you needed help right away?

Spouse 1
Child(ren) 2
Other relative 3
Write-In relationship____________
Friend 4

14e. How far away does this person live from you?

We live together 0
Less than one mile 1
Number of miles (Write-In)__________

15. Which of the following four statements describes your ability to get along on your income?

I can't make ends meet 1
I have just enough; no more 2
I have enough with a little extra sometimes 3
I always have money left over 4

16. Which category represents the total amount of your yearly household income? In answering this question, please consider money from jobs, net income from a business or farm, dividends, interest, net income from rent, social security, and any other money income.

Under $10,000 1
$10,000–$19,999 2
$20,000–$29,999 3
$30,000–$39,999 4
$40,000–$49,999 5
$50,000–$74,999 6
$75,000–$99,000 7
$100,000 or more 8

APPENDIX H

Volunteer Flyer

Study Seeks Volunteers

Transitions in Frail Rural Older People

A doctoral student who is a nurse, Kathy Wood, RN, is seeking volunteers for a study about older people deciding to get more help. The purpose of the study is to learn about this decision from the older person's and family/friend's view and learn about what choices they feel are available. The long-term goal of the study is to learn how nurses might help older people and their caregivers during this time of deciding to get more help. To qualify for the study individuals need to be:

65 years of age or older,
speak English, and
considering the need for more help with every day tasks because of decreasing health.

The older person will also choose up to 2 family members and/or friends who will be asked to give their views about the choices available. Persons who agree to be part of the study will be interviewed twice, six weeks apart. All information will be kept confidential. Interested persons are invited to let ________ ____________ (Agency Representative) know of their willingness to talk with Kathy Wood, RN, MN, FNP, or contact Kathy direct at (503) 885-8276.

APPENDIX I

Consent to Release Information

Consent to Release Information

I give____________________________ (Agency Name) permission to give Kathy Wood, RN my name, address, and phone number. I understand that she will be calling me to talk about being interviewed for her study of older epole choosing what help to get with every day activities.

____

Signature Date

____

Printed Name

APPENDIX J

Consent Forms

1/24/94

OREGON HEALTH SCIENCES UNIVERSITY
Consent Form
Older Person

TITLE: Transitions for Frail Rural Older People: Thinking about a move from home to a more supportive environment

PRINCIPAL INVESTIGATOR: Kathy Wood, RN MN FNP, 503-885-8276

FACULTY ADVISOR: Patricia Archbold, RN, DNSc

PURPOSE: This research study will be used to:

(1) learn how rural older people and their families decide whether and when the older person needs to move to a more structured setting; and,

(2) learn what affects the decision to move or not to move.

Your part in this research study could last up to 4 months.

PROCEDURES: I will be interviewing you twice, 6 weeks apart, where you choose. Each interview will last about 1 to 1 1/2 hours. I will ask you questions about your health, the kinds of help you receive from family members or friends, what added help you feel you need, and whether you can get that help at home or have thought about a move from home to get that help. I will tape record the interviews. I will also be talking with one to two family members or friends you choose, who help you, and who you talk to about your care needs. At the end of our first interview, I will ask you to fill out a form made up of questions about things like your age and education. I will leave with you a set of questions at the end of our second interview that I will ask you to complete and return to me by mail in an enclosed stamped envelope I will give you. At the end of the study I will call you to see how things are going and talk to you about what I found out from doing the interviews.

<u>RISKS AND DISCOMFORTS</u>: Some parts of the interview may touch on sensitive topics that may upset you. If you feel uncomfortable at any time, you may choose not to answer any questions.

<u>BENEFITS</u>: You may not personally benefit from being part of this study, but some people report feeling good because they may be providing information that may help others in the future. In addition, some people report that talking to someone is helpful.

<u>CONFIDENTIALITY</u>: The tape recordings of our meetings will be kept confidential. If, during our interview, I become aware of child abuse or elder abuse, I am required by Oregon state laws to report the abuse to the appropriate agencies. Our conversations will be written out with your name and other identifying information removed. The tape recordings will only be listened to by myself and the woman typing them out. Only the teachers working with me and other nursing students will be allowed to read the records of our conversations. Neither your name nor your identity will be used for publication or publicity purposes. At the completion of the study, all identifying material will be destroyed.

<u>COSTS</u>: There are no costs for being part of this study. There will be no payment to you as a result of being part of this study. You will be giving your time by agreeing to talk with me.

<u>LIABILITY</u>: The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

<u>PARTICIPATION</u>: Being a part of this research project is completely voluntary. You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with or

treatment at the Oregon Health Sciences. You may refuse to answer individual questions, you may discontinue the interview at any time, or you may choose not to be interviewed a second time.

If you have any questions about this research study, you can first contact Kathy Wood at (503) 885-8276. If you have further questions, you may contact Patricia Archbold, RN, DNSc at (503) 494-3840. If you have questions about your rights as a research subject, you may contact the OHSU Institutional Review Board at (503) 494-7887. If you sign, you will receive a copy of this consent form.

Your signature below indicates that:

_____ I have read what is written above and agree to be part of this study.

_____ I have had read to me what is written above and agree to be part of this study.

Date______________________

Name______________________ Signature__________________

Signature of witness__________________________

1/24/94

OREGON HEALTH SCIENCES UNIVERSITY
Consent Form
Caregiver

TITLE: Transitions for Frail Rural Older People: Thinking about a move from home to a more supportive environment

PRINCIPAL INVESTIGATOR: Kathy Wood, RN MN FNP, 503-885-8276

FACULTY ADVISOR: Patricia Archbold, RN, DNSc

PURPOSE: This research study will be used to:

(1) learn how rural older people and their families decide whether and when the older person needs to move to a more structured setting; and,

(2) learn what affects the decision to move or not to move.

Your part in this research study could last up to 4 months.

PROCEDURES: I will be interviewing you twice, 6 weeks apart, where you choose. Each interview will last about 1 to 1 1/2 hours. I will ask you questions about your family member/friend, what added help you feel she/he needs, and whether you feel she/he can get that help at home or needs to think about a move from home to get that help. I will also ask you about what has been helpful in thinking through these decisions. At the end of our first interview, I will ask you to fill out a form made up of questions about things like your age and education. I will leave with you a set of questions at the end of our second interview that I will ask you to complete and return to me by mail in an enclosed stamped envelope I will give you. At the end of the study I will call you to see how things are going and talk to you about what I found out from doing the interviews.

RISKS AND DISCOMFORTS: Some parts of the interview may touch on sensitive topics that may upset you. If you feel uncomfortable at any time, you may choose not to answer any questions.

BENEFITS: You may not personally benefit from being part of this study, but some people report feeling good because they may be providing information that may help others in the future. In addition, some people report that talking to someone is helpful.

CONFIDENTIALITY: The tape recordings of our meetings will be kept confidential. If, during our interview, I become aware of child abuse or elder abuse, I am required by Oregon state laws to report the abuse to the appropriate agencies. Our conversations will be written out with your name and other identifying information removed. The tape recordings will only be listened to by myself and the woman typing them out. Only the teachers working with me and other nursing students will be allowed to read the records of our conversations. Neither your name nor your identity will be used for publication or publicity purposes. At the completion of the study, all identifying material will be destroyed.

COSTS: There are no costs for being part of this study. There will be no payment to you as a result of being part of this study. You will be giving your time by agreeing to talk with me.

LIABILITY: The Oregon Health Sciences University, as an agency of the State, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

PARTICIPATION: Being a part of this research project is completely voluntary. You may refuse to participate, or you may withdraw from this study at any time without affecting your relationship with or treatment at the Oregon Health Sciences. You may refuse to answer individual questions, you may discontinue the interview at any time, or you may choose not to be interviewed a second time.

If you have any questions about this research study, you can first contact Kathy Wood at (503) 885-8276. If you have further questions, you may contact Patricia Archbold, RN, DNSc at (503) 494-3840. If you have questions about your rights as a research subject, you may contact the OHSU Institutional Review Board at (503) 494-7887. If you sign, you will receive a copy of this consent form.

Your signature below indicates that:

_____ I have read what is written above and agree to be part of this study.

_____ I have had read to me what is written above and agree to be part of this study.

Date____________________

Name____________________ Signature________________________

Signature of witness_____________________________

APPENDIX K

OHSU Institutional Review Board Approval

OREGON
HEALTH SCIENCES UNIVERSITY
3181 S.W. Sam Jackson Park Road, Portland, OR 97201-3098
Mail Code L106, (503) 494-7887   Fax (503) 494-7787
Institutional Review Board/Committee on Human Research

DATE: January 24, 1994

TO: Kathryn Wood, MN
Patricia Archbold, DNSc

FROM: The Committee on Human Research

SUBJECT: ORS#: 3489
TITLE: Transitions in Frail Rural Older People: Thinking About a Move from Home to a More Supportive Living Environment.

This confirms receipt from you of the revised consent form(s), and/or answers to questions, assurances, etc., for the above-referenced study.

It satisfactorily meets the recommendations made by the Committee on Human Research at its recent review. The proposal to use human subjects is herewith approved. It is requested that the date of this memo be placed on the top right corner of the first page of the consent form. This is the approval date of this revised consent form.

Investigators must provide subjects with a copy of the consent form, keep a copy of the signed consent form with the research records, and place a signed copy in the patient's hospital/clinic medical record (if applicable).

Approval by the Committee on Human Research does not, in and of itself, constitute approval for implementation of this project. Other levels of review and approval may be required, and the project should not be started until all required approvals have been obtained. Also, studies funded by external sources must be covered by an agreement signed by the sponsor and the Oregon Board of Higher Education.

If this project involves the use of an Investigational New Drug, a copy of the protocol must be forwarded to the Pharmacy and Therapeutics Committee (Pharmacy Services - Investigational Drugs, OP-16A).

Thank you for your cooperation.

wp:rcfapp 3/92

APPENDIX L

Summaries of Other Theories

SUMMARIES OF OTHER THEORIES

Selective Optimization with Compensation

Baltes and Baltes (1990) outlined a psychological model for successful aging. Their developmental approach emphasized selection, optimization, and compensation as the key components of a process of adaptation.

Selection indicated that the individual chose high priority domains to continue when faced with the decline of functioning with age. This selection process facilitated "adjustments to 'objective' reality without loss of selfhood" (1990, p. 20). This was accomplished by the individual adjusting his/her expectations so satisfaction and personal control was still experienced.

Optimization referred to the individual choosing behaviors that would increase one's reserve capacity and achievement of one's chosen life course. Compensation involved using supports to offset losses in personal functioning. Baltes and Baltes (1990) highlighted psychological strategies to improve memory and devices created by technology such as hearing aides as examples of compensation.

Selective optimization with compensation was considered by Baltes and Baltes (1990) as an adaptive way older people were able to continue important life tasks despite reductions in physical and mental reserves. Society was also seen as being able to provide opportunities and supports (age-friendly environments) that insured increased selection, optimization, and compensation.

Chenitz's Theory of Entry into a Nursing Home

Chenitz's (1983) nursing practice theory of entry into a nursing home as status passage, was developed from a grounded theory study of the responses of older persons admitted to a nursing home. Five basic conditions were identified by Chenitz as influencing the person's response to nursing home admission: importance, desirability, legitimation, voluntary nature, reversibility. Intervening factors included timing, the older person's health, and family relationships. The person's response to nursing home admission was acceptance or resistance; both further subdivided into strategic submitting or submitting by default and resigned resisting or forceful resisting.

Importance involved how much the nursing home admission disrupted the older person's maintaining control and independence. Desirability included the older person's perceptions regarding the advantages or disadvantages of moving to a nursing home. Legitimation was needed to have the older person accept the move. Reasons why they did not fit the stereotype of the typical nursing home resident needed to be found. They also needed to be involved in making this decision which meant it was voluntary. Reversibility indicated that the older person hoped the nursing home stay was not permanent.

Chenitz found (1993) that when irreversibility was combined with undesirability, involuntary admission, and no legitimation, the older person resisted the admission. Acceptance could result when any of these conditions that produced resistance were changed.

Entry into a nursing home was considered a status passage (movement from one resting place or status to another) by Chenitz (1993), and when it overwhelmed all other passages was classified a crisis. In addition to the influence of the basic conditions, acceptance of the move to the nursing home was determined by the older person's ability to cope with this passage. When the move can not be handled with the individual's usual coping skills, resistance and a clinical crisis was present. Using crisis theory, nursing intervention was focused on understanding the individual's experience, reinforcing past coping skills, and helping the older person develop new coping skills to resolve the crisis.

Crisis Intervention Theory

Crisis intervention theory as outlined by Aguilera (1994) involved a psychological crisis or emotional disequilibrium that resulted from the inability to solve a problem. The person was usually in a state of equilibrium, and when the equilibrium was disrupted by a change or loss, the emotional discomfort of disequilibrium resulted. A crisis resulted when an individual's usual coping mechanisms (problem-solving skills) did not help re-establish equilibrium and the individual's tension and anxiety continued increasing. This could lead to feelings of helplessness and inaction. Crisis intervention as therapy helped the individual reestablish equilibrium by concentrating on helping the individual solve the immediate problem.

Problem solving involved following a structured, logical order of steps to find the answer to a problem for which no dependable source of information was available (Aguilera, 1994, p. 26). Anxiety increased if finding a solution was very important for the person's well-being. Anxiety above tolerable levels caused the individual to concentrate on the discomfort and not problem solving. The therapeutic approach involved assessment of the individual and the problem, and helping determine ways the individual could solve the problem and reduce the symptoms of stress.

When a stressful event occurred, the presence or absence of balancing factors could affect the re-establishment of equilibrium. Balancing factors included perception of the event, available situational supports, and coping mechanisms. Perception of the event was equivalent to Lazarus and Folkman's (1984) cognitive appraisal, the meaning of the event in relation to the individual's life goals. Situational supports included others in the environment that provided the individual with nurturance and appraisals of the situation. Coping included individual strategies to reduce emotional discomfort and solve the problematic situation.

Stress, Appraisal, and Coping

Lazarus and Folkman (1984) considered their model of psychological stress, appraisal, and coping a boarder conceptualization of the decision making process as outlined by Janis and Mann (1977). Lazarus and Folkman focused on the individual coping and the cognitive approaches to handle psychological stress. Stress was not determined by the stimulus alone, but also by the individual's susceptibility to the stressor. With psychological stress, Lazarus and Folkman were concerned with any event the person felt or appraised as taxing his or her resources and endangering his or her well-being.

Cognitive appraisal was defined as the "evaluative process that determines why and to what extent a particular transaction or series of transactions between the person and environment is stressful" (Lazarus & Folkman, 1984, p. 19). Cognitive appraisal determined an encounter's significance for one's well-being and included two parts. Primary appraisal was deciding what was at stake and included harm/loss, threat, and challenge as conceptualized by Lazarus and Folkman. Secondary appraisal was determining "what might and can be done" (p. 35). Primary and secondary appraisal were occurring together, interacting, and shaping the emotional reaction and degree of stress. Lazarus and Folkman talked about the connection between emotions with cognitive appraisal as the cognitive-affective response.

Coping was defined as the "process through which the individual manages the demands of the person-environment relationship that are appraised as stressful and the emotions they generate" (Lazarus & Folkman, 1984, p. 19).

Different appraisals would affect coping and emotions, both outcomes of the stressful transaction. Coping was focused on regulating emotions or solving the problem based, respectively, on an appraisal that the situation had to be accepted or one could do something about it.

Lazarus and Folkman (1984) considered cognitive appraisal as central in mediating subsequent thought, feeling, and action (p. 45). Person and situation variables were seen as interdependent and factors that influenced appraisal. A person factor highlighted by Lazarus and Folkman was commitment. Commitments determined what had importance for the person and influenced choices made to maintain valued ideals and desired goals. When the person had a greater commitment to some area, he/she was more vulnerable to psychological stress in that area. Commitments provided a motivating force for coping.

Some situational factors that influence appraisal include event uncertainty (likelihood of an event's occurrence), duration (how long a stressful event persists), temporal uncertainty (not knowing when the event will happen), timing of stressful events in the life cycle and whether this has special meaning to the person. Conflicting thoughts, feelings, and behaviors can result from a prolonged process of appraisal and reappraisal when one does not know whether an event will occur. Lazarus and Folkman (1984) saw event uncertainty as creating feelings of helplessness and confusion. People also have a concept of the normal life cycle and anticipate events occurring at certain times. Anticipated events become a crisis only if they occur at a time other than that the person anticipated.

Situation control appraisal as defined by Lazarus and Folkman (1984) was the "products of the individual's evaluations of the demands of the situation . . . his or her coping resources and options and ability to implement the needed coping strategies" (p. 69). This appraisal reflected whether the person believed he/she could influence the stressful person-environment relationship. These appraisal and coping processes were significant because they affected what Lazarus and Folkman called adaptational outcomes. Adaptational outcomes included one's functioning in society, life satisfaction, and physical health. The relationships between these outcomes was considered complex, with a positive outcome in one area not necessarily meaning a positive outcome in another.

Continuity Theory

Continuity theory as developed by Neugarten, Havighurst, and Tobin (1968) was specifying the continuity of personality. This underlying identity of the self throughout life was used to predict one's adjustment in aging. Neugarten, Havighurst, Tobin described patterns of aging in people based on personality type, extent of social role activity, and degree of life-satisfaction.

Social role activity was the extent of activity in 11 different social roles (i.e. spouse, parent, neighbor, church member). Life satisfaction was a measure of psychological well-being and included pleasure in everyday activities, seeing one's life as meaningful, feeling that one accomplished major goals, having a positive self-image, and having an optimistic mood. Personality type was measured using both cognitive and affective personality attributes based on an ego-psychology model of needs and desires.

Continuity theory stated that in "normal" individuals, with age personality became more consistent. Values that had been important became even more so. The person continued to make choices, and was not seen as controlled by the social environment or biological changes. Personality was seen as the pivotal dimension in predicting the relationship between level of social role activity and life satisfaction.

Maddox's (1968) research with older people showing a persistence in role activity and life satisfaction scores over years supported that of Neugarten, Havighurst, and Tobin. But Maddox called this persistence behavioral pattern as the individual grew older as a continuity of life style instead of personality.

Erikson's Autonomy and Identity

Erikson, Erikson, and Kivnick (1986) reviewed the eight stages of psychosocial development and how these produced the strengths necessary for a vital involvement in old age. The stages of autonomy and identity will be reviewed.

Identity included beliefs, attitudes, enduring personal characteristics, commitments and activities that reflect the "I" (Erikson, Erikson, & Kivnick, 1986, p. 130). The way one has lived life reflected an underlying sense of self. With age, physical decline, loss of interpersonal relationships through deaths, and other societal circumstances, the person's activities that exhibit the self may become limited.

To maintain this sense of self, a variety of ways were used. The older person may have emphasized lifelong continuity of certain characteristics: "We've both been quite independent" (Mrs. C, P1, 634). This may have included continuing to identify with the status of social and financial privilege. "We always had help around the house" (Mr. J, P1, 408-409). Other people were involved in helping to maintain a sense of identity. One's personal image as reflected from others was balanced with one's internal image, and presented the way the individual would be remembered after death.

For some older people, to maintain identity required considering themselves better than the "others." They were not like other old people: "After all, when you're 80 years old, you're not, most people, not taking care of themselves [living in own home]" (Mrs. E, P1, 1292-1295). To indicate past beliefs, the older person may have talked about family members used as role models: "But she was just a very strong determined person [Mrs. K's mother] (Mrs. K, P1, 713-715). Personal belongings may have been used as reminders of past life experiences and relationships, and therefore one's sense of self.

> And what am I going to do, look at all the junk that's piled up here. For [laugh] 54 years, it's been piling up in here. A lot of it can go in the trash I guess, and a lot of it I wouldn't want to part with. Even the pictures on the wall my kids have made. (Mrs. E, P2, 785-794)

Autonomy represented freedom, self-reliance, and control. And important symbol of autonomy was living independently. Living in familiar surroundings and continuing established routines provided a supportive environment that helped the older person face declines in physical and/or mental abilities and societal stereotyping.

This self-determination had to be balanced with the increasing need for assistance. Autonomy was insured by the older person deciding what activities were important for autonomy and then accepting help as a part of facilitating this autonomy. If the older person had a more rigid definition of autonomy, no assistance may be considered acceptable. Accomplishing the activity without assistance became an end in itself, rather than a means to a goal (Erikson, Erikson, & Klunick, 1986, p. 203).

Hiring the assistance needed could be seen as a self-controlled activity maintaining autonomy while accepting help from family may not. But care from adult children helped keep the older person "safe" from institutional care that was more threatening to personal autonomy. Knowing adult children were available as a backup system, allowed the older person to continue activities that would have been otherwise been restricted because of anticipatory worry (Erikson, Erikson, & Klunick, 1986, p. 206).

Being able to live on the money available was important to one's sense of independence. Accepting financial assistance from adult children could be seen as representing expressions of love and concern while advice from a child was considered an impingement on autonomy.

Cognitive Dissonance Theory

Festinger's theory (1957) focused on the individual's cognition or knowledge, opinion, or belief about oneself, one's behavior, and the environment. Behavior was considered actions or feelings. The person desired to have consistency (consonance) between his or her knowledge or beliefs and actions. When inconsistencies did exist, the person tried to eliminate them. If this was not successful, the person experienced psychological discomfort.

Dissonance was defined as the "nonfitting relations among cognitions" (Festinger, 1957, p. 3). Festinger was concerned with the consonance or dissonance between pairs of cognitive elements that corresponded to behavior. Cognitive dissonance was seen as producing behavior that would decrease this dissonance; the motivation being the removal of the psychological discomfort that accompanied dissonance. The magnitude of the dissonance would be a function of the importance of the cognitive elements involved. If dissonance of sufficient magnitude was not reduced, symptoms of psychological discomfort would be observed (Festinger, 1957, p. 24).

Festinger emphasized that cognitions were responsive to reality. If a person's cognitions deviated from reality, reality would exert pressure on the individual to bring these cognitive elements into agreement with the impinging reality (Festinger, 1957, p. 11). Dissonance occurred if this agreement was not present.

Cognitive elements could be difficult to change and therefore made it difficult to reduce dissonance. Festinger (1957) outlined conditions that made behavior, and therefore behavioral cognitive elements, resistant to change: change that was painful or represented a loss; behavior that was satisfying in other ways; change that was not possible.

Festinger (1964) has applied cognitive dissonance theory to the decision-making process. To comprehend decision-making, he outlined the problem as understanding the process by which the individual evaluated the alternatives and made the choice. Whenever a decision had to be made, Festinger felt some dissonance was present between the cognition of the action taken and the positive knowledge about other choices not selected. Festinger suggested that during the pre-decision period the individual considered the information about the alternatives impartially, but after the decision to decrease dissonance between the action taken and the choices not selected, the alternatives not chosen would be considered less desirable.

Adaptation-Level Theory

Helson (1964) first studied adaptation of the senses to stimulation, but felt that certain characteristics of this form of adaptation were also present in more complex behaviors. Components of the theory included stimuli, adaptation-level of behavior, equilibrium. The adaptation-level of behavior was defined as the combined effect of all stimuli (focal, background, residual) impinging upon the organism both from without and within and included residuals from past experience. The individual's attitudes, values, judgments, ways of framing personal experience, intellectual and emotional behavior, learning, and interpersonal relations all represented adaptation to environmental and organismic forces (Helson, 1964, p. 37). Forces and stimuli were used interchangeably.

Helson (1964) pointed out that adapt meant to adjust. Adaptation made us aware of changes in the environment. Equilibrium or steady state were the terms used when the constant stimulation was no longer sensed or became neutral as a result of adaptation. Therefore the course of adaptation went from the initial sensitivity and activity in response to a change in stimulation to adjustment to this stimulation, if unchanged. Also when there was diminished response in some receptors to a stimulus that was continued, other receptors were found to have a heightened response.

Helson (1964) emphasized that the equilibrium was dynamic; ongoing changes were made by the individual to maintain the steady state. The individual responded to both changes in external conditions and internal processes. Adaptation as an active process had the individual initiating action based on internal stimuli, and not just responding to the environment. Helson emphasized that individuals could change their environment.

Helson (1964) pointed out that individuals also may seek out and strive for higher levels of adaptation, not only the maintenance of equilibrium, when they desired change and variety in life. Helson stated that "the adaptation level represents the zero or origin to which gradients of stimulation are referable. The steeper the gradient is, the greater the impact of the stimulus on the organism and the greater the response to it" (Helson, 1964, p. 50). Awareness of the stimulation was decreased if the level of stimulation did not change, while very intense or very weak stimuli were not completely adapted to or negated. Helson considered the continuing awareness of these high and low thresholds of stimuli as having survival value.

Person-Environment Model

Lawton (1982) described his ecological model of adaptation and aging in *Aging and the Environment: Theoretical Approaches.*

The model was originally developed "to link the physical environment to the behaving older person" (1982, p. 33). Components of the theory were competence, environmental press, and adaptive or nonadaptive behavior.

Competence was defined as a characteristic of the individual composed of the theoretical upper limit of biological health, sensory-perceptual capacity, cognitive capacity, motor skills, and ego strength. Competence ranged from low to high, and was assumed to lower as one aged.

Environmental press was defined as an environmental stimulus or context having potential demand character for any individual leading to a behavior outcome. Included in the environment were physical aspects of the individual's environment; significant others; characteristics of others living in the neighborhood; norms, values, institutions of the society or culture. Environmental press ranged from weak to strong.

Adaptive or nonadaptive behavior in the individual depended upon their competence and environmental press. The behavior included outwardly observable actions or inner affective responses and was placed on a continuum from positive to negative. Lawton (1986) stated that "adaptive behavior and/or positive affect may result from a wide variety of combinations of individual competence and environmental press . . . the level of demand is in balance with the person's ability to respond to that demand" (p. 11-12). Adaptation level was a line drawn between the competence and environmental press axis indicating where the environmental press was "average" for that individual's level of competence.

When an individual was able to respond to environmental press with behavior that was adaptive and an affect that was neutral, the individual was not very aware of this steady state. Lawton (1986) considered this situation as representing most of everyday behavior. Helson's (1964) conceptualizations of equilibrium and adaptation were cited by Lawton as the foundation for these statements.

The individual became aware of the environment when the press increased or decreased from the adaptation level. If the press was only moderate, behavior could be adaptive and affect positive. When the press exceeded the limits set by the individual's competence, behavioral and affective outcomes were no longer considered positive. A person of low competence would have their adaptation upset by only a small change in environmental press. With high competence, the individual was able to response in a positive way to a wider range of environmental press. But everyone had a breaking point, when behavior and affect deteriorated regardless of how high the individual's competence level.