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CAREGIVER CHARACTERISTICS CONTRIBUTING TO PERSON-ENVIRONMENT FIT FOR OLDER STROKE SURVIVORS: A QUALITATIVE, EXPLORATORY STUDY

By

Deborah Lynn deLaski-Smith

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ABSTRACT

CAREGIVER CHARACTERISTICS CONTRIBUTING TO PERSON-ENVIRONMENT FIT FOR OLDER STROKE SURVIVORS: A QUALITATIVE, EXPLORATORY STUDY

By

Deborah Lynn deLaski-Smith

A qualitative, case study methodology was used to explore caregiver characteristics that enhanced or inhibited person-environment fit in households where a person over age 55 had recently suffered a stroke. Research questions addressed the relationship between person-environment fit and the physical and demographic characteristics of the stroke survivor, caregiver characteristics and caregiver strain.

A person-environment fit scale was developed to assess the congruence of fit for the stroke survivor within the home setting. The scale incorporated the following variables: pre and post-stroke health; Activities of Daily Living; use of aids or devices for ambulation; housing features supporting ambulation; and the physical capabilities of the caregiver for providing care.

Secondary data analysis from The Experience of Stroke as a Critical Life Event: Supportive Ecosystems for Older Persons and Their Families, funded by the American Association of Retired Persons, Andrus Foundation, was

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completed. The major study involved a three part series of interviews with 20 stroke survivors, their designated informants and primary caregivers. Stroke survivors were over age 55 and recuperating from a recent stroke. Case studies were prepared for ten families. The stroke survivor in these families had problems with Activities of Daily Living, particularly ambulation, and the person-environment fit score was zero or a negative score indicating a problem fit.

Findings showed caregiver characteristics that support person-environment fit. Common characteristics included: good physical health, good emotional health, feeling prepared for caregiving, and exhibiting healthy caregiving behaviors. Caregivers in the negative person-environment fit group reported being less prepared in general for providing care, for making environmental changes, and knowing who to contact for making these changes. Higher caregiver strain was associated with negative person-environment fit.

Negative person-environment fit was associated with more pre and post stroke ailments, more problems with Activities of Daily Living and the use of wheelchairs in homes that did not accommodate passage. Ironically, stroke survivors and caregivers reported housing satisfaction in spite of negative person-environment fit. Implications for public policy are discussed, and future research endeavors are proposed.

DEDICATION

To my loving and patient husband, Gene,
whose support will always be treasured.

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Thank you to my entire family, immediate and extended. Your love and positive inspiration kept me motivated to press on toward completion. A final special thanks to my parents, who always told me I could do anything I put my mind to. Problems are the challenges that make life exciting and their positive attitude has given me great strength.

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CHAPTER ONE

INTRODUCTION

For any individual, young or old, healthy or disabled, a supportive physical environment can allow independence and the performance of needed tasks. Hiatt (1982) summarized literature suggesting that the environment serves as a releaser of intelligence, giving humans the capacity to master their surroundings. Positive interactions between humans and their environment can elicit intelligent coping behavior with a reduction in frustration and improved life satisfaction (Ittelson, 1975). The congruence between a person's capabilities and an environment that supports those capabilities is known as person-environment fit (Lawton, 1983).

Person-environment fit has fueled a design movement known as the universal design movement; so named by architect, Ron Mace (Neubacher, 1988). Universal design supports construction of all buildings to be accessible for 99% of the population, including the young, the old, the able bodied and the disabled. This concept has slowly become accepted for new commercial buildings and some apartment complexes, as dictated by Barrier-Free Construction Codes. In August 1988, President Reagan signed the update to the Fair Housing Act. One part of the bill requires all newly constructed apartments and condominiums to be constructed to be accessible to the old and handicapped by the end of the 1990's. Existing apartments or condominiums will be required to make structural modifications upon request of the disabled or elderly tenant (Downey, 1988). This legislation will broaden the housing opportunities for these populations.

A problem remains, however, with the handicapper accessibility of existing and new single family dwellings. The barrier-free construction codes and the recent legislation do not apply to these housing units. This is a major issue when 75% of the elderly and disabled populations are owners of single family dwellings. Thirty-six percent (in 1983) owned homes built prior to 1942 and have physical barriers (AARP, 1987).

Financial and psychological costs in making housing changes also impede person-environment fit. As one ages or becomes disabled, making physical changes to dwellings can be prohibitively expensive, thus discouraging adaptations. Additionally, many handicappers feel the need to be "normal", and struggle to cope with the existing physical environment rather than change it to ease functioning (Neubacher 1988). These financial and psychological costs are felt by all disabled individuals and many elderly persons including stroke survivors.

Older (over age 55) stroke survivors frequently have physical and psychological adjustments with which to cope. Many physical limitations are temporary, while others remain permanent disabilities. A supportive home environment, both psychologically and physically, could enhance completion of Activities of Daily Living (Katz, Ford, Moskowitz, Jackson, Jaffe, Cleveland,

1963) for those with permanent limitations. A tailored environment designed to personally fit physical needs can greatly enhance overall life satisfaction.

PURPOSE OF THE STUDY

Assessing environments for a disabled older person for person-environment fit has been tackled in varying dimensions by many researchers (Hiatt, 1982; Kahana, Liang, & Felton, 1980; Kiyak 1980; Lawton 1981; Lawton, Moss, Fulcomer & Kleban. 1982; Lawton & Nahemow 1983; Wohlwill, 1974). One avenue not yet explored is the role of caregivers in creating or inhibiting person-environment fit for the persons in their charge. Creating an appropriate fit would serve both patient and caregiver while improving the ability to perform tasks and reduce stress and strain.

The purpose of this study is to analyze case studies of elderly (over age 55) stroke survivors and examine characteristics about their caregivers that tend to support or inhibit achievement of person-environment fit. The relationship between person-environment fit and caregiver strain will be assessed.

The research is qualitative and exploratory in nature. It reviews ten case studies of older stroke survivors and their caregivers. Since the caregiver's role in providing a supportive physical environment is a research concept not yet explored in the person-environment literature, it is hoped that the characteristics of caregivers will provide insights for service providers to effectively promote person-environment fit.

RELATIONSHIP OF THIS STUDY TO MAJOR PROJECT

This study involves analysis of data from a larger project entitled, "The

Experience of Stroke as a Critical Life Event: Supportive Ecosystems for Older Persons and Their Families, Phase I". The project was funded by the American Association of Retired Persons, Andrus Foundation. The purpose of the study was to develop a more comprehensive knowledge of the older person experiencing a stroke, the family response to the stroke and the role supportive ecosystems assume in the enhancement of wellbeing for older persons, their families and society (Ames, Bond, Borland, Chenoweth, 1986). Changes in daily living as a result of stroke were explored for both the stroke survivor and the caregiver. The study also identified needs, adaptations and resources used by the stroke survivor and family. Application of this knowledge would enable older persons, their families, professionals and those who influence public policy to more effectively allocate and use resources to enhance the wellbeing of the individual, family and society.

The major study involved a three part series of interviews with 20 stroke survivors, their designated informants and primary caregivers. Stroke survivors were 55 years of age and older, and they had suffered their first stroke or had few residual limitations from a prior stroke. Patients were living in private residences and had left institutional care within 30 days to six months prior to the interview.

SIGNIFICANCE OF THE RESEARCH

Stroke is the third leading cause of death in the United States. Approximately 500,000 Americans suffer strokes each year. In 1985, 152,700 (down from 210,000 in 1974) in the U.S. (American Heart Association, 1987) and 5,528 (7% of the population) in Michigan died from cerebrovascular disease (stroke)

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(Michigan Health Statistics, 1987). There are approximately 1,990,000 stroke victims across the country who are alive today. Due to the progressive treatment of high blood pressure, deaths from stroke have declined by 50% between 1973 and 1987 (Ubell, 1987). Deaths overall from stroke are becoming more concentrated in the over 65 age bracket, particularly over 85 (Posner, Gorman, Woldow, 1984). The incidence of stroke may be declining, but for those afflicted older persons many disabilities remain.

The population of the United States is aging. There were 29.2 million (12.1%) persons over 65 in 1986 (American Association of Retired Persons, 1987). Similarly, Michigan's over 65 population was 12% in 1986 (Michigan Statistical Abstract, 1987), and the over 85 group is the fastest growing population. Across the country, the over 65 age group is expected to reach 32 million by the year 2000. The number of disabled persons will rise proportionately with the increase in the elderly individuals. Their projected total could reach 10% or roughly 25 million by the year 2000 (Raschko, 1982). Schilling, Combs, and Schwab (1982) project a 15% or 35 million disabled population requiring tailored housing needs or person-environment fit.

Of the elderly population, a very small percentage (5%) live in customized institutional housing. Percentages of nursing home residents in Michigan, based upon age, are as follows: 1% for persons 65-74 years, 6% for those 75-84 years, and 22% for individuals over 85 (AARP, 1987). On the average, older persons in nursing homes live there for five years, and the majority reach financial depletion before the end of the first year (Newman, 1976). The majority of disabled elderly persons live in private homes, with 80% of care being provided by family members (Hirshorn, 1988). Memory loss, dementia or Alzheimers, and loss of bladder or bowel control seem to be conditions that promote nursing home placement. Some of these conditions are not uncommon outcomes of disability due to stroke.

It is generally accepted that it is financially more expeditious for public or private insurance agencies to provide support systems for families to care for the disabled elderly in private housing. Unfortunately, the bulk of the housing stock in the United States does not accommodate the needs of disabled individuals. Stairs inside and outside the home, narrow door openings, narrow bathrooms and passageways inhibit person-environment fit for individuals using a walker or wheelchair. Ambulation is a critical problem.

The unique component of this study, as compared with other person-environment studies, is the assessment of person-environment fit and the analysis of the caregiver role in creating the fit. With stroke survivors in varying states of physical disability, the patient may not have much input in developing a person-environment fit. It is therefore important to attend to other individuals in the family who interact with the stroke survivor and may ultimately make these environmental decisions. Through identification of caregiver characteristics of those who are encouraging or inhibiting person-environment fit, the information can be shared with service providers for the tailoring of resource materials to address this population.

THEORETICAL APPROACH

HUMAN ECOLOGICAL APPROACH

The human ecological(ecosystems) framework provides the foundation for this qualitative family study. The approach explores the interactions and interdependencies of humans and their environments. Through observation of the holistic family system, one can then establish an understanding of the family culture, perceptions, functioning and decision making capabilities.

The human ecological approach is based upon the principles of ecology, which is the interrelations of organisms (humans) and their environments (Andrews, Bubolz & Paolucci, 1980; Bubolz, Eicher, Sontag, 1979; Sprout, 1965). The ecosystem framework progressed beyond biological ecology when systems theory and cybernetics were incorporated (Wright & Herrin, 1988). It is the openness of the system that allows dynamic interactions between the organism and each of the environments plus interactions between the varying environments.

Many environments comprise the ecosystem. Environments include the physical, biological, social, economic, political, aesthetic and structural systems (Bubolz, Eicher, & Sontag, 1979). These have been combined into three major categories: the natural or biological environment, the behavioral or psycho-social environment and the human constructed environment (Morrison, 1974) The environments interact either independently, multidimensionally, or in a uni-directional fashion with the organism.

The ecosystem framework allows humans to be examined within their context (Wright & Herrin, 1988). Understanding cultural and familial nuances based upon this context lends deeper meaning to qualitative research methodology. Bubolz and Whiren (1984) applied an ecosystems model to families of the handicapped. The framework identified the human component as the family unit with a systems approach to the flow of resources and energy into and through the system. It noted the impact of stressors on the family unit. Having a handicapped family member was a source of stress requiring intense energy demands and utilization of resources. Demands upon time, psychic energies and continual decision making, among other variables, were family stressors for their study. Caregivers played a key role in the family ecosystem, emphasizing their need to network with all available resources (human and non-human) in order to cope with the care-providing role.

Ward, LaGory and Sherman (1988) approached the study of environments for the elderly population from an ecological perspective. They indicated that in order to fully understand the relationship of the aging individual and the housing environment, one must view it from a contextual perspective. The relationships are multifaceted and complex. Understanding the concept of environmental satisfaction, for example, requires analysis of ecological, biological, psychological and social components. The environment is symbolically constructed and involves continual interpretation, since it is a mental construct in addition to being a physical reality. The older person's meaning of home varies from individual to individual. The impact the environment makes on the individual is unique to that individual. Contextual interpretation requires exploration of all interconnecting environments.

An ecological model will be used for this study of stroke survivors, caregivers and person-environment fit. The model includes the stroke survivor's physical health and abilities to perform Activities of Daily Living, and the interaction and interdependency with the human behavioral environment (the caregiver) and the human constructed environment (aids/devices and the home setting) to achieve optimum fit. Figure 1 illustrates the ecosystem relationship of human to environments.

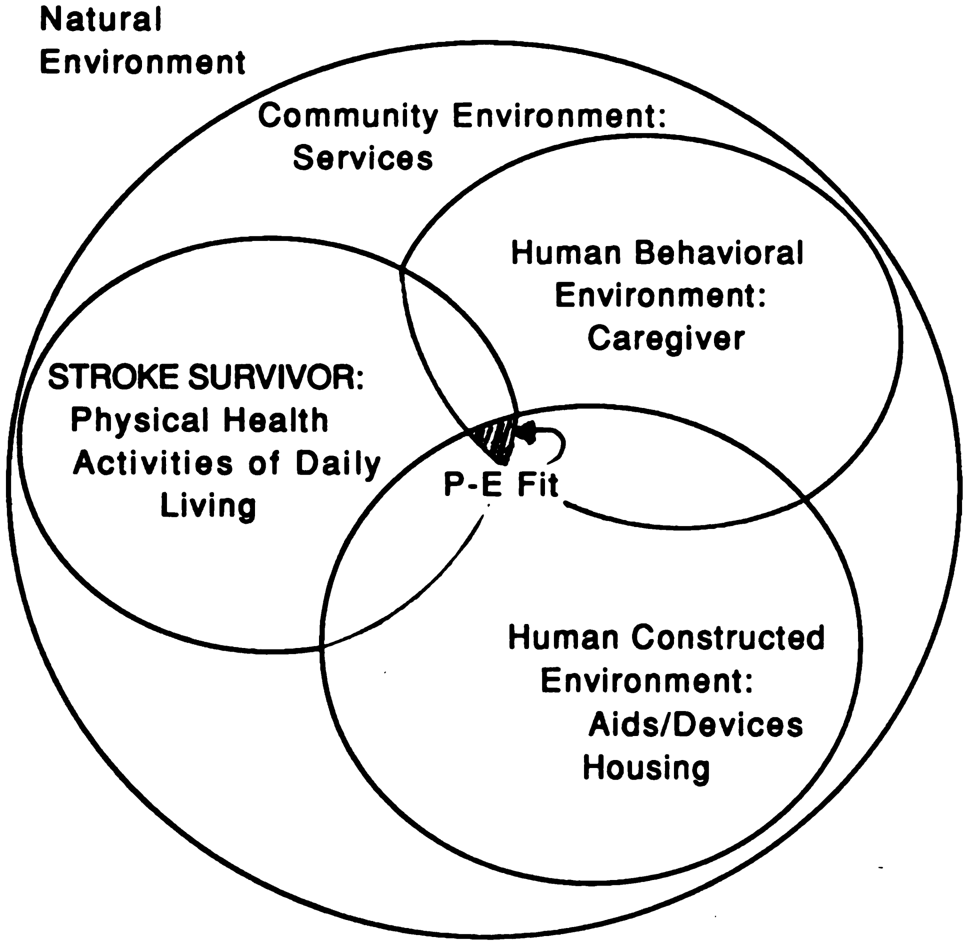

Figure 1: Stroke Survivor's Ecological Model

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PERSON-ENVIRONMENT FIT

The human ecological model encompasses the human and its interaction and interdependencies with the environment. Person-Environment Fit theory similarly addresses both the human component and the environment, focusing on the fit between the two. Lewin (1935) first theorized about person-environment fit but concentrated on the interpersonal environment. He developed the formula B = f(P-E), meaning that behavior is a function of the person-environment fit.

Expanding this concept to the physical environment, Lawton and Nahemow (1973) observed that the level of human competence paired with the appropriate amount of environmental press would result in adaptive behavior or culturally appropriate behavior given the situation. A mismatch would render maladaptive behavior or the inability to perform the appropriate behavior or task. Human competence included the individual's physical and psychological capabilities. Environmental press involved the social, psychological, behavioral, natural and human constructed environments; which is consistent with Lewin's concept and the Human Ecological perspective.

Person-environment fit theory has been applied to housing for the elderly (Altman, Lawton & Wohlwill, 1984; Hiatt, 1982;Kahana, Liang & Felton, 1980; Kiyak, 1980; Lawton, 1980, 1981, 1982, 1983; Lawton, Greenbaum & Leibowitz, 1980; Lawton, Moss, Fulcomer & Kleban, 1982; Rowles & Ohta, 1983). The literature hypothesized the application of person-environment fit theory to private residences (Lawton, 1980,1981, 1982, 1983). However, most of the research focuses on varying housing types for the elderly (eg. nursing homes, age congregated housing or apartment complexes for independent living) (Kahana, Liang & Felton, 1980; Kiyak, 1980).

A Multilevel Assessment Instrument (MAI) was developed to assess person-environment fit for 590 elderly persons either living independently in the community, receiving in-home services, or awaiting admission to a nursing home (Lawton, Moss, Fulcomer & Kleban, 1982). The instrument measured physical health, cognition, Activities of Daily Living, time use, social interaction, psychological well-being, family economics, and perceptions of the physical environment. Variables addressing the physical environment focused on perceptions of housing quality, neighborhood quality and personal security. The older person's perceptions of these items were compared with those of the interviewer to assess person-environment fit. The objective environment (eg. plumbing, steps, grab bars) was originally included in the study, but abandoned because of the difficulties in scaling relevant components. The researchers acknowledged the importance of the objective environment for overall wellbeing of the elderly individual.

DeJong and Branch (1982) developed a research model for predicting a stroke patient's ability to live independently. The model was based on the following equation: O = f(S,D,E.I). Components of the model incorporate: O for independent living outcome; S for socio-demographic characteristics of the stroke patient; D for disability related variables; E for environmental barriers; and I for an interface variable indicating the use of assistive devices, such as a wheelchair, to bridge the gap between functional limitations and environmental barriers. The study analyzed data from medical center computer files for 84 stroke patients.

Findings identified variables that could explain 56-80 percent of the variance in a patient's ability to live independently. These variables were: marital status, age, Bartel score, communication impairments and ability to drive. The components of their formula lent insight into the factors used in this study for measuring person-environment fit.

Parr (1980) developed a person-environmental interaction model. The basic assumption asserts that behavior in environments is the primary interest of both theoreticians and practitioners. Complex systems can be explored by selecting behaviors or functions and noting environmental interaction. His theory identifies person characteristics, environmental characteristics and mediators of behavior. The mediator of behavior can be a person. In the case of stroke survivors, their caregivers can be the mediators of behavior.

For this study, many components will comprise the person-environment fit model. These components are stroke survivor pre and post stroke physical characteristics, their ability to perform Activities of Daily Living, physical environmental changes, and the mediator role of the caregiver for enhancing or detracting from person-environment fit. Each of these component variables are defined in the Methodology Chapter (Chapter 3), and their path of interaction is illustrated in Figure 2.

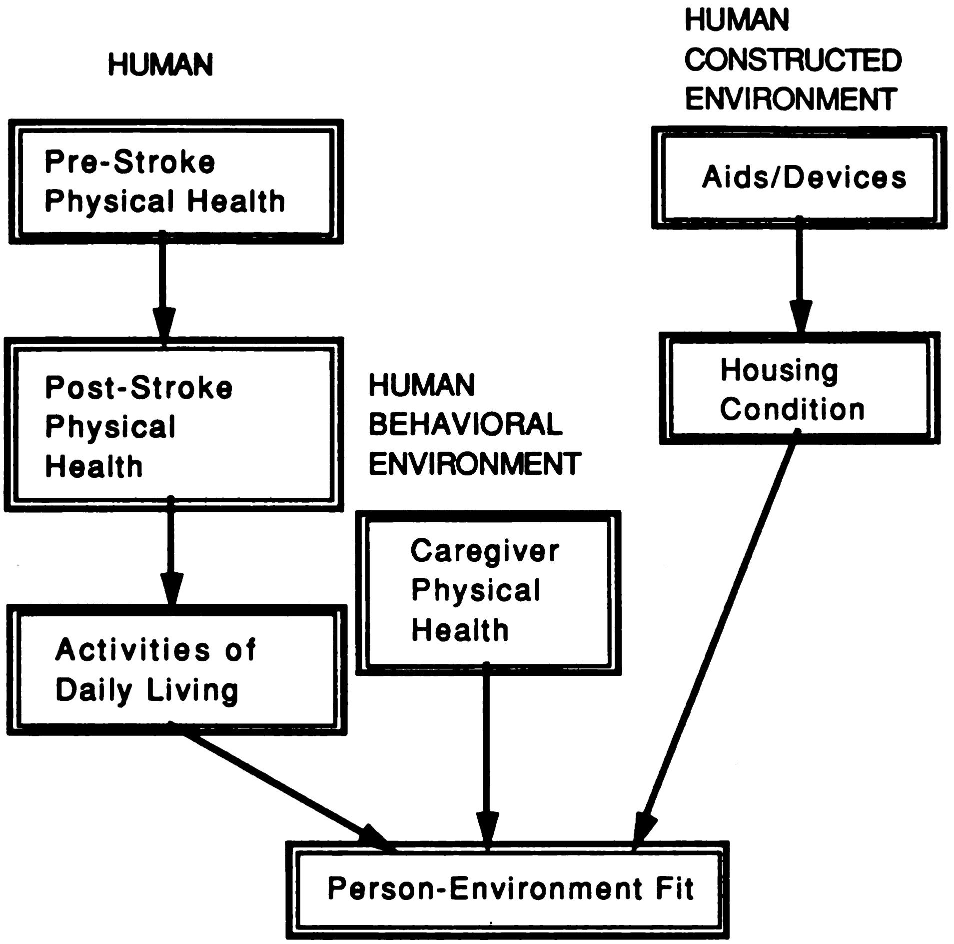

Figure 2: Factors Comprising Person-Environment Fit

STUDY LIMITATIONS

Since person-environment fit is an individualized proposition, the generalization of this study to all disabled, elderly, stroke survivors is limited. Additionally, qualitative studies provide rich in-depth content, but the limited sample size (n=10) prevents statistical testing of the significance of caregiver characteristics and person-environment fit. However, the sharing of this case

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study process and assessment of person-environment fit would benefit service providers in performing similar tasks for both patients with varying disabilities and their families.

Other research format limitations include the use of secondary data. Questions from one study do not always address the required information needed for another study that has a different purpose. Additional questions could have been added to create a more in depth five point person-environment fit scale versus the three point scale, used for this analysis, that was created from the existing survey instruments.

Limitations of the original data include the sample selection and interview responses. The stroke survivors and families agreed to be interviewed for the study, which may in itself indicate a level of coping with stroke as a critical life event. Persons who refused to be interviewed may have had different experiences to report. Information gathered from the interviews included objective plus open-ended reporting and interviewer observations. Reporting by the respondents may have been minimalized or exaggerated. At times inconsistencies could be found in the data between objective questions and open ended responses. Additionally, some questions required retrospective reporting, which sometimes can be influenced by memory capabilities of both the younger and older respondents. Interviewer observations, of such things as the housing environment, also may vary in detail from interviewer to interviewer. A complete description of the research procedures used for the major study is explained in the Methodology Chapter (Chapter 3).

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CHAPTER TWO

REVIEW OF LITERATURE

The review of literature chapter will cover relevant documentation for the following topics: the components of the person- environment fit scale for this study (physical pre and post stroke characteristics, Activities of Daily Living, use of aids or devices, physical characteristics of the housing environment), and characteristics about caregivers. Caregiver preparedness, help-seeking behavior and Caregiver Strain Index also will be covered. Literature relative to the theoretical framework of ecosystem theory and person-environment fit theory was addressed in Chapter One.

COMPONENTS OF PERSON-ENVIRONMENT FIT SCALE FOR THIS STUDY

STROKE

Cerebrovascular Accident (CVA or stroke) has been defined as a disruption of the blood supply to any portion of the brain (National Stroke Association, 1988). Strokes are the third leading cause of death in the United States (American Heart Association, 1987), even though deaths have dropped by 50% between 1973 and 1987 (Ubell, 1987). Although usually considered an affliction of the over 65 age group, stroke can take place at any age. In fact, one in seven deaths from stroke affect persons under age 65. Approximately 500,000 persons

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persons suffer strokes annually, and almost two million Americans are living victims of stroke. In 1985, 152,700 deaths were contributed to stroke (American Heart Association, 1987). Stroke is the leading cause of adult disability in the United States (Ford & Katz, 1965; National Stroke Association, 1988).

The average age of onset for stroke is 60 years (Finnery Fried, Myers & Barry, 1986). The average age for stroke survivors at the time of stroke was 71 years for men and 74.6 years for women. Over age 85, the incidence of stroke is similar for the two genders, and prognosis for mortality from stroke increases with age (Ford & Katz, 1965). Below age 70 the incidence of stroke is greater among men than women (Ford & Katz, 1965).

The three types of stroke include Thrombotic Stroke (cerebral thrombosis), Embolic Stroke and Hemmorrhagic Stroke. Thrombotic Stroke is the most common type of stroke and occurs when blood supply is blocked in a cerebral artery by a clot. Thickening of the arteries (atherosclerosis) frequently narrows the artery passages to the point where the blood supply tends to form clots, thus closing off the passageway. About one quarter of patients who survive a thrombotic stroke experience a recurrence within the next five years (Ford & Katz, 1965). Embolic Stroke occurs when a clot originating from another source in the body other than the brain dislodges and is carried in the blood stream to the brain. When the small vessels no longer will allow the clot to pass through, it plugs off the blood supply. This blockage is known as an embolism. An embolism may reoccur twice as frequently as thrombosis (Ford & Katz, 1965). Hemorrhagic Stroke occurs when a cerebral vessel breaks, leaking blood into brain tissue or areas surrounding the brain. Vessels can break if there is a weakened portion strained by degeneration of artery walls, hypertension, high blood pressure, head injury, or a bulge in the artery wall, known as an aneurysm (American Heart Association, 1987; Lavin, 1985; National Stroke Association, 1988; Posner, Gorman & Woldow, 1984; Stolov & Clowers, 1981).

PRE-STROKE HEALTH

Persons noted to be at greater risk of suffering a stroke frequently suffer from coronary disease, congestive heart failure, hypertension, high blood pressure, or may have experienced minor, intermediate stroke episodes (Ford & Katz, 1965). Atherosclerosis (hardening of the arteries) is frequently present, and individuals with diabetes also are at risk. Other common pre- stroke physical conditions may include high cholesterol levels, other fats present in the blood stream, heart irregularities, blood clot disorders, gout and heavy smoking (American Heart Association, 1987).

SYMPTOMS OF STROKE

Warning signs of an oncoming stroke may vary in type, strength and duration. Sudden weakness or numbness in the side of the face, arm or leg are indicative of lack of blood flow in the brain. Other symptoms may include: sudden headache, blurred vision, loss of speech or difficulty in speaking or understanding the spoken word; difficulty swallowing; sudden personality, emotional or cognitive changes; or changes in level of consciousness. Dizziness and unsteadiness also may occur. Many of these symptoms may be short in duration (several minutes to several hours). If recovery occurs within 24 hours, then a mini-stroke or transient ischemic attack (TIA) may have taken place. Four out of five sufferers of Thrombotic Stroke have histories of TIA's (National Stroke Association, 1988).

PROGNOSIS

Prognosis following the stroke can include death or some level of complete or partial functional recovery. Mortality rates, within the first week following a major stroke, can range from 25-50% (Ford & Katz, 1965). During the first month of recovery, a sizable group of survivors recover to the point of independent walking and self-care, while a large middle group still require minimal to moderate assistance, and a small group continue to require complete nursing assistance. Mortality for those who survive the initial stroke is 7-35% in the first year, 17-42% by the second year and 38-66% at the end of year five (Ford & Katz, 1965). The leading cause of death among stroke survivors is the recurrence of stroke.

There are a number of conditions associated with the stroke that point toward a higher probability for mortality. Ford and Katz (1965) observed that patients who enter the hospital in a coma have a mortality rate between 72-81%. Bilateral paralysis or a mid-brain lesion plus blood present in the spinal fluid are conditions associated with an over 80% mortality. Continued or progressive edema or hemorrhage may lead to herniation of the brain. This situation shows signs of deterioration of the patient's condition during the first few days following the stroke, which also is more likely to indicate future mortality. Some survivors have an "active" condition with multiple episodes, while others experience only a single (mild or severe) stroke. Prognosis did not seem to vary between singular or multiple strokes, but it was influenced by the type of stroke and its residual conditions.

POST STROKE PHYSICAL CONDITIONS

Physical damage from the stroke and related disabilities are directly associated with the location of the Cerebrovascular Accident in the brain. It usually occurs in one or the other (right or left) hemisphere of the brain. Degree and severity of damage depends upon the scope of the brain cell injury and the portions of body functioning controlled by the affected brain cells. Persons suffering a stroke on the right side of the brain may experience the following conditions:

> "- Paralysis on the left side of the body (left hemiplegia)
> - Excessive talking (verbalization)
> - Short attention span (high distractibility)
> - Memory problems
> - Poor judgment, especially related to safety awareness (typically an overestimation of physical abilities)
> - Time disorientation
> - Loss of left visual field (left hemianopsia)
> - Unconscious neglect of left limbs and environment
> - Impaired abstract thinking (concrete thinking predominates)
> - Brief and spontaneous emotional highs and lows (lability)
> - Lack of interest and motivation (lethargy)
> - Acting without thinking (impulsiveness)"
>
> (National Stroke Association, 1988:2-3)

When the stroke takes place on the left side of the brain, the following damage may occur:

> "- Paralysis on the right side of the body (right hemiplegia/hemiparesis)
> - Partial or complete loss of language (dysphasia or aphasia)
> - Impaired thought processes (information-processing delays)
> - Impaired voluntary motion (apraxia)
> - Confusion between left and right
> - Loss of right visual field (right hemianopsia)
> - Easy frustration
> - Compulsiveness or slowness"
>
> (National Stroke Association, 1988:3)

Damage to the brainstem where human survival functions are controlled may cause: coma, unstable vital signs, nausea and vomiting, impaired swallowing and paralysis on both sides of the body. Damage to the cerebellum which controls coordination and balance, may cause abnormal reflexes, balance problems, dizziness, nausea and vomiting (National Stroke Association, 1988).

Wade, Skilbeck, Wood and Hewer (1984) explored predictive variables for long term survival after stroke. Three factors gave the most predictive value for determining patient survival for 107 stroke patients two years after the stroke. These factors were severity of the stroke as identified by the individual's ability to walk soon after the stroke; the presence of pre-existing cardiovascular disease, and the patient's age. If walking recovery did not occur during the first 18 months after stroke, the probability of later recovery was less than one in 20 (Ford & Katz, 1965).

Considering the relationship of walking and long term survival and the environmental changes required to support this disability, person-environment fit for this study will focus on ambulation.

ACTIVITIES OF DAILY LIVING

Since the early 1960's, Katz and colleagues (1961, 1963, 1969, 1970), developed and refined a measure of biological and psycho- social functioning for older persons. They categorized normal every day tasks of life into an index known as the Index of Independence of Activities of Daily Living.

After evaluating thousands of activities for the elderly and chronically ill patients, two classifications, Physical and Instrumental, were created for the activities. Physical Activities of Daily Living focused on six basic functions:

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bathing, dressing, going to the toilet, transferring in and out of bed, continence and feeding. The older person's ability to function independently or dependently became a summative evaluation based upon seven degrees of independence. The summative rating was used for a variety of purposes. Similar to assessing a child's level of development for physical and learned or cultural behaviors, an older person's assessment could determine level of functioning and hence level of need for assistance (Katz, Ford, Moskowitz, Jackson, Jaffe & Cleveland, 1963). An individual's rating immediately following an injury could be compared with one taken after a period of recuperation, thus noting progress or decline in functioning.

The Instrumental Activities of Daily Living assessed a different level of culturally defined behaviors beyond basic functioning. The seven items identified as Instrumental Activities of Daily Living include the following: using a telephone, driving, using public transportation, shopping for groceries or clothes, preparing meals, doing light housework (dusting, washing dishes) or heavy housework (vacuuming, scrubbing floors). Assessment of functioning could determine need for assistive services for an older and/or disabled individual.

The Activities of Daily Living Index was used as a predictive factor for level of functioning that was corroborated two years later (Katz, Downs, Cash & Grotz, 1970). Using this instrument to measure the level of functioning can be accomplished in an objective fashion with this scale. Remeasurement over time can chart changes due to illness or aging. The OARS Instrument (Multidimensional Functional Assessments: The OARS Methodology, 1978) has used

the Activities of Daily Living as one component level of functioning for comparison with other physical and psychosocial characteristics for older persons.

USE OF AIDS OR DEVICES FOR AMBULATION

Equipment or aids are commonly used to assist with ambulation following a stroke. Most often these aids include canes, walkers, quadropods or tripods, crutches, or wheelchairs. Aids are either rented or purchased. Expenses incurred when obtaining the equipment may be reimbursable by insurance companies and Medicare if it fits the following requirements: "(1) the equipment must meet the definition of durable medical equipment (durable to withstand repeated medical related use); (2) the equipment is necessary and reasonable for the treatment of the patient's illness or injury for improving the functioning of a malformed body member (with physician's diagnosis, prognosis, and prescription for the aid); and (3) equipment is used in the patient's home" (American Occupational Therapy Medical Handbook, 1984).

Examples of reimbursable durable equipment, other than the mentioned aids used for ambulation, include: hospital beds, bedpans, bedside railings, commodes, lifts or trapeze bars. Items not reimbursable by insurance or Medicare, would be grab bars, raised toilet seats, bedside tables or trays that reach over hospital beds. These devices are considered convenience or self-help items that are not medically necessary or primarily medical in nature, and therefore not reimbursable according to Medicare.

The government publication, Technology and Aging America (Office of Technology Assessment, 1985), addressed the issues of inadequate marketing ar

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and knowledge of available aids and devices used to ease daily activities. Hiatt (1982) agreed that technology was an underdeveloped component of the physical environment for older people. The lack of financial resources from all public and private sources to fund technology (aids, devices) has been a major problem for years, and does not look promising for the future unless private donations increase. Donations would fund service organizations, like the United Way, who rent or purchase equipment for needy families.

Technologies for caregivers also had received little publicity (Office of Technology Assessment, 1985). Long term care has long been labor intensive with limited emphasis on technology. Persons typically performing caregiving roles (other than family members) have been classed with limited education, limited train- ing, limited professional identity or prestige with low income. When caregiving techniques are mastered, they are usually unrewarded, offering little encouragement to share these techniques with others. Technologies that would physically assist the caregiver are critical for the self preservation of their own physical being. Devices to allow the patient to independently ambulate would prevent the caregiver from excessive pushing or pulling. Devices for lifting and transferring the patient from chair to bed or chair to tub would save the caregiver's back and related muscle strain.

Finding the correct aid can be a challenging endeavor. ABLEDATA is a computerized listing by the National Rehabilitation Information Center of more than 12,000 commercially available products (Jensen, 1987). An 800 phone number can connect professionals and family members with an information specialist who would send a printout of potential aids or devices, the product de

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description, price and source for purchase or rental. The service is free to the public and subsidized by private donations.

A more critical issue than knowledge, access, availability or financing of aids or devices, is the psychological refusal to use aids (Demarest, 1984). For some individuals, using an aid is a sign of giving in and not being able to handle the environment independently. These individuals expend more time and energy in the struggle to get to the activity than in the enjoyment of the activity. Promoting the use of devices can be especially challenging for a caregiver when the stroke survivor may have cognitive and emotional impairments in addition to physical limitations (National Stroke Association, 1988).

Numerous aids and devices have been created for use by stroke survivors. The issues impacting upon usage include: awareness, availability, accessibility, expense, qualification for a medical tax deduction, patient and caregiver's psychological readiness to use the aid or device.

PHYSICAL CHARACTERISTICS OF THE HOUSING ENVIRONMENT

The physical environment is only one of many environments impacting upon the stroke survivor. It, however, plays a critical role as a support for independent functioning or dependence upon others providing services. Hiatt (1982) argued that the physical environment has long been an untapped resource in dealing with the basic needs of older persons. In health care settings, many staff members and administrators considered good staff capable of overcoming deficiencies in the environment. The staff served as a bridge between the patient's disability and functioning within the environment. This certainly has been the pattern in health care settings as well as in-home settings. Newman (1985) sited research that observed the relationship between features of the physical dwelling impacting on service delivery to elderly relatives. Environmental barriers were stimulating feelings of stress among family caregivers. Unfortunately this among other issues, has lead to rapid staff turnover and caregiver burnout.

The physical environment can be a part of a team approach to health care systems (Hiatt, 1982; Lavin, 1985). The physical environment's impact on the health of older persons includes the following: enhancing mobility and access to activities (Hiatt, 1982; Lifchez, 1979); acceleration of impairments such as sensory deprivation (Hiatt, 1982; Lawton, 1983; Wohlwill, 1974) or increased probability for falls (Carp, 1977; Raschko, 1982); plus serving as a tool for cognitive capabilities (Hiatt, 1982).

Cognitive development comes from learning lessons through the manipulation of the environment. These lessons can be negative, causing frustrations and depression, when the environment does not enable one to accomplish the intended task, whether it be hanging up a coat or washing dishes. Carp (1977) observed that the environment enhanced physical health in older persons when viewed as a coping mechanism. Coping was facilitated by an appropriate environment; one that provided ease in functioning with minimal use of energy. Stress was created by an inappropriate environment or one with barriers to functioning, which made the individual expend an excessive amount of physical energy.

There has long been a debate over the need for specialized housing as an appropriate environment versus continued in-home residence for older persons. Moos (1980) developed a conceptual framework for the evaluation and creation of specialized housing for older persons. These specialized settings included: skilled nursing facilities, board and care homes, congregate housing, foster care settings and single room occupancy housing (Heumann & Lareau, 1979-80; Lawton, 1981; Lawton, Greenbaum, Leibowitz, 1980; Moos, 1980; Newcomer, Lawton, Byerts, 1988). The elderly population could certainly benefit from many custom design features, particularly when the older person has a cognitive impairment or is incontinent. Incontinence frequently plays a pivotal role in the decision for placement of a family member in a nursing facility (Office of Technology Assessment, 1985). It is estimated that $8 billion is spent on incontinence in the United States annually. In nursing homes alone, costs associated with incontinence consume 8% of the annual budget (Office of Technology Assessment, 1985). Smallegan's (1983) study of families' decisions for nursing home placement, identified the following causes precipitating admission: frequent falls, general debility, confusion, fractures, strokes, incontinence and difficult behaviors.

Due to the rapid growth of the elderly and disabled populations, the demand for specialized housing greatly exceeds the supply. Thus housing options need to balance between existing single family housing stock and specialized settings (Altman, Lawton, Wohlwill, 1984; Heumann & Lareau, 1979-80; Newcomer, Lawton, Byerts, 1988). The existing housing situation, among other factors, determines the motivation for remaining in that setting, seeking alternatives, or making changes.

Newman (1976) reported findings from a national study of older persons indicating housing changes to be linked to the onset of disability. With severe disability came a move to a nursing facility or to the home of a relative for over 70% of the sample of 555 disabled elderly. A less likely move, but one that occurred none the less, was one in which another family member moved into the home of the disabled person. A move was additionally dependent upon whether there was a living spouse and upon the sex of the disabled person. If the male was disabled and married, more than likely the wife continued to care for the spouse in the home. If the wife was disabled, the male was less likely to care for the spouse, and a consequent housing change was more likely to be considered. Fillenbaum and Wallman (1984) supported these residential considerations with their study of household composition and the elderly population. Residential rearrangements were dependent upon marital status, health of spouse, and extent of help available from family and friends. Housing satisfaction with the existing setting also played a role in residential considerations.

Housing satisfaction for the elderly and disabled populations has been addressed in the literature (Perch, 1983,; Golant, 1982; Weaver & Ford, 1988). Housing satisfaction is a multifaceted concept that includes such components as: housing quality, ownership factors, income, neighborhood characteristics life satisfaction, leisure activities, health and other socio-demographic characteristics (Perch, 1983; Golant, 1982). Golant (1982) reported that older persons were more satisfied with their housing if they were less interested in novel environments, were happier with their lives overall; traveled less frequently away from their homes; and had lived in their dwelling for a long period of time (psychological attachment). Housing satisfaction also was associated with home ownership and having few financial difficulties. Life for a less mobile individual frequently revolves around his/her home environment and the treasures therein. Many older individuals spend as much as 80-90 percent of their time in their homes (Montgomery, 1972). Long term memories and attachment to this prized possession make environmental changes a painful decision-making process.

Perch (1983) provided research of housing satisfaction for households with and without disabled family members. Households with disabled members were as satisfied with their housing as their counterparts, even though these households had less desirable housing conditions. He speculated that funds should be provided for repairing and improving the disabled person's existing housing, rather than building specialized units, since housing satisfaction was high.

PHYSICAL CHANGES TO THE HOME TO FACILITATE AMBULATION

General construction codes for private housing deal with safety issues for materials and their installation. Codes do not address standards for handicapper accessibility of private dwellings. Barrier-free guidelines for handicapper accessibility have been defined in the construction codes for commercial buildings and 3-4% of apartment units within a new apartment complex (in Michigan based upon the Michigan Barrier Free Construction Codes, 1987; or 1% of apartments built elsewhere in the country to the American National

Standard Codes, 1980).

Numerous authors have applied these guidelines to private housing (Colvin & Korn, 1984; Costa & Sweet, 1976; Demarest, 1984; Hyman, 1982; Jones, 1980; Penton, 1979; Raschko, 1982; Steinfeld, 1980; Troop, 1981; Wittmeyer & Stolov, 1978). The Architecture and Transportation Barriers Compliance Board of the United States Congress (1977) developed an extensive literature review of resources concerning barrier-free environments. The National Stroke Association (1988) also has published environmental changes to assist stroke survivors. These guidelines, however, are not as generous as the Michigan codes, and should be used with caution.

General housing design that encourages ambulation includes: ease of entrance from the exterior without stairs; rooms on one floor; space to turn around when using a walker, crutches or a wheelchair; and door openings wide enough to accommodate a wheelchair. Other housing considerations incorporate kitchen and bathroom redesign for wheelchair usage; strategic placement of grab bars; lifts or elevating devices between floors of the home or for exterior steps. Removal of excessive furnishings to allow maneuvering through the rooms, and the use of low pile carpeting or hard surface flooring to ease ambulation are additional design concerns.

The Michigan Barrier-Free Construction Codes (1987) specify, among other requirements, standards for ramp construction; spacing for wheelchair turning radius; minimum door opening; placement of switches and outlets; placement of grab bars and plumbing fixtures, plus kitchen and bathroom cabinets. Recommendations for ramp construction should provide a minimum 1:12 ratio;

meaning, for every one inch of rise there should be 12 inches of run. A ratio of 1:20 would provide a very subtle rise on which an elderly person could easily self manipulate a wheelchair. The National Stroke Association recommended a 1:8 ratio, which is steeper than the 1:12 ratio for code.

The space required to make a 360 degree circle with a wheelchair is five feet by five feet. This spacing should be provided in a foyer, living room, kitchen, bathroom, and bedroom. Guidelines for door openings should have a minimum of 32 inches of clear passageway (the National Stroke Association, 1988, recommended 29 inches). Thirty-six inches provides ease of passage through a door opening without bruised elbows (Raschko, 1982). Placement of the swing of the door is a critical design decision in order to save wasted time and energy maneuvering around doors with a wheelchair. Barrier-free bathroom doors should swing out and not into the bathroom, again for ease of maneuverability.

Electrical requirements for outlets and switches should meet the needs of the older person. Recommendations for the height of electrical outlets range from 18 inches (Michigan Barrier-Free Construction Code, 1987) to 27 inches from the floor (Raschko, 1982) and are spaced every eight feet. Light switches should be mounted 36 inches on center, and preferably be of the toggle variety. Motion, auditory or thermal sensing devices can be obtained for controlling light fixtures.

OTHER ENVIRONMENTAL CONSIDERATIONS

Other environmental considerations deal with concerns for safety plus particularistic needs of the given disability (Carroll & Gray, 1986; Kenny & Spicer, 1984; Liang, Gall, Partridge & Eaton, 1983; National Stroke Association,

1988; Ramsey, 1985; Raschko, 1982). Safety considerations apply to all individuals, not only the elderly or handicapper populations.

One of the easiest safety measures is the removal of throw rugs or plastic runners to prevent falls. The National Stroke Association (1988) recommends the use of plastic runners, but frequently the sides of the runners curl up and create a hazard as one transfers from carpeting to runner. Providing a smooth transition between flooring types (eg. tiled flooring to carpeting or resilient flooring) also can prevent falls. Electrical and telephone cords should be secured to avoid tripping over them.

Other safety measures include the replacement of frayed cords on older appliances that many elderly individuals continue to use. Stairways should be in good repair with reinforced railings. Color contrast should be introduced on steps, between walls and flooring, counters and flooring, or between furniture and flooring to assist with loss of depth perception that is common among older persons.

Overall improvement of lighting with reduction of glare is a must for older eyes. Persons in their late 70's require three times as much light to perform the same task as teenage eyes (Hiatt, 1982). Glare is exaggerated for older eyes; so merely increasing light levels without controlling for glare can cause more harm than good. Improved lighting is the single most important intervention for reducing falls and home accidents (Laing, Gall, Partidge & Eaton, 1983).

One may want to avoid glass items in interior furnishings. Glass doors by the shower or bathtub may be broken if one is unsteady. Glass top tables should be removed from seating areas to prevent severe injuries should the stroke survivor fall onto them.

Furniture for sitting should to be strong, have arms, and be of substantial weight to support the weight of the stroke survivor in getting up or down. Seat heights may need to be elevated to 20 inches by providing additional firm padding or by securing blocks under the feet of the chair. This will prevent the problem of not being able to get up and out of low seating. Similarly, toilet seats can be elevated to 19 inches with extenders.

Bathroom accommodations can be extensive for a wheelchair user. A lower sink is required for ease of reaching the faucets and into the bowl. Plumbing pipes should be insulated under the sink to prevent scalding of legs. Lever faucets facilitate control for persons with dexterity problems. A mirror that is full length or tilted downward, if over a sink, provides visual accessibility. Roll-in shower stalls make bathing easier for the wheelchair user and the caregiver. Tubs sometimes cause problems with transfers, requiring physical strain for the caregiver or the use of a hoyer lift. Grab bars are a must in the tub and shower area, as well as by the toilet and sink. The Michigan Barrier-Free Construction Code (1987) specifies mounting height and positioning requirements for grab bars. Grab bars need to be installed on reinforced walls or they may not withstand the dead weight of someone whose limbs are impaired. Towel bars and toilet paper holders frequently are used as grab bars. Since they are not installed on a reinforced wall, they often pull out of the wall, leaving holes in the drywall or plaster that are difficult to repair.

Bedrooms need to be on the first floor for ease of accessibility. This sometimes means the conversion of a living room, dining room, or family room to a bedroom environment. A bathroom should be readily available from the sleeping area. Most bathrooms in private homes are not accessible for a wheelchair user, and they barely provide enough room for an older person to have assistance from a caregiver. The lack of space for maneuvering in a bathroom frequently encourages the use of bedside commodes and sponge bathing in the sleeping area. If this sleeping area is in a living room, dining room or family room, this could lead to concerns about privacy.

Bedroom areas should have telephone access and an emergency buzzer or intercom system to enhance communication. Bed height may be a problem for wheelchair transfers or getting up and down for someone who is more mobile. The National Stroke Association (1988) points out that if the bed is high, it is easier to sit down and stand up from the edge without assistance. If too high, feet dangling to the floor may not provide a steady start when standing up. Beds that are too low, however, are harder on weak legs for raising and lowering oneself. Twenty-two to 24" is a good height for the bed. It is important to stabilize the bed close to a wall or lock the wheels of a hospital bed, so it will not move while one gets in and out of it.

Kitchens can be modified to accommodate a wheelchair or to accommodate someone who wants to sit to rest while preparing a meal. Base and wall cabinets can be lowered to meet reaching requirements from a sitting position (Michigan Barrier-Free Construction Code, 1987). Space underneath a cook top and sink area should be provided for wheeling up to and under these areas. Plumbing pipes should be insulated to prevent scalding of the legs. The following appliance specifications ease problems with reaching: side by side refrigerator and freezer, side opening oven and microwave, and range controls on the side or front with overhead mirror to enable seeing into pots. The work triangle between appliances should range from 9-15 feet. This would reduce fatigue from transferring items from refrigerator to sink to range to the table.

As circulation problems arise for the older individual, controlling interior room temperature is important (Hiatt, 1982). Increased sensitivity to both hot and cold temperatures is not uncommon for stroke survivors. Raising the thermostat or utilizing air conditioning are the most common solutions to temperature changes. With this usually follows increased utility bills, which can be problematic for fixed incomes. Numerous energy conserving measures could be applied to the home.

Additional housing characteristics that may trigger an older person to live with adult children were observed by Newman (1976). The number of rooms in the house overall, plus the number of bedrooms were important predictors of changing living arrangements. An older person was more likely to live with an adult child if the adult child's house had six or more rooms and three or more bedrooms. Additional predictors of this intergenerational setting were the low ratios of persons to rooms plus the spaciousness of the home to accommodate another person. Most of these parents enjoyed the privacy of a separate bedroom. Only 10% of the over 500 elderly persons surveyed shared a bedroom with someone other than a spouse when living with an adult child.

In summary, housing changes require research, planning and financial commitment. Many elderly individuals and their caregivers are not able to take on this commitment, which results in their living with the existing situation. In Simos' (1973) study of adult children and aging parents, housing was identified as a problem area in all but five out of 50 case studies. Trieschmann (1987) stressed that the environment has always impacted on the quality and quantity of life for a disabled individual. As one ages and becomes weaker with declining energy levels, one becomes more vulnerable to the impact of the environment. Environmental changes are imperative to enhancing life satisfaction.

CAREGIVER CHARACTERISTICS

From the onset of the industrial revolution, there have been concerns that families, spread throughout the country in search of employment, would lose emotional attachment and abandon their filial responsibilities to the elderly (Brody, 1985). Springer & Brubaker (1984) cited literature that dispelled this myth of family abandonment. Eighty to ninety percent of medically related care, personal care, household maintenance, transportation, shopping assistance and emotional support come from family members (Brody, 1986). Not only are family members providing care, but those in their charge prefer family versus nonfamily sources of caregiving (Sander & Seelbach, 1981). Desire for families to serve as a primary source of care was found to be independent of age, gender, education and marital status.

Streib and Beck (1980) reviewed a decade of family literature including family networking and care providing. The family unit has long been the source of nurturing, both within the generation and intergenerationally. The kin family network has successfully prevailed into contemporary industrialized

societies. Strong relational bonds have transcended the physical distances that may separate family members. In a study of caregivers (Shanas, 1980), social and psychological support were found to be more important to closeness of relationships than geographic distance.

Overall, the family's involvement with caregiving has been extensive, both intergenerationally and within marital diads. Families continue to provide physical and emotional support as family members age.

CAREGIVER DEMOGRAPHICS

RELATIONSHIP TO PATIENT

Spouses provide tremendous support for each other as they age. Springer & Brubaker (1984) noted that if the disabled person's spouse was living, he or she would usually serve as the primary caregiver. Seventy percent of older men and 36% of older women are married and living with their spouses in an independent setting (Atchley, 1988). This is more than half of the older population. More younger persons in the over 65 age group are married than their older counterparts. Remarriage, particularly for older males, is not an uncommon phenomenon considering the larger population of available spouses (Atchley, 1988; Vinick, 1978).

Since the caregiving role was a strong part of the socialization of females for this generation, elderly wives tend to continue providing care for their husbands, as long as their health remains good (Newman, 1976). Females are usually younger than their husbands and live longer and therefore, generally are able to provide these services (Springer & Brubaker, 1984). Elderly spouses may be readily available to provide care, but this role can be very difficult for the caregiver. Horowitz and Shindelman (1983) reported that spouses who provided care experienced more stress than other family member caregivers. Male spouses did not provide as much reciprocal care for their disabled wives and turned to adult children or community sources of service including nursing home facilities for support (Newman, 1976).

If older persons are living alone, which includes approximately 40% of the older females and 15% of the older males (Silverman, 1987), or if both parents are ill, then caregiving responsibilities are frequently carried out by adult children (Springer & Brubaker, 1984). Typically the daughter or daughter-in-law takes on more responsibilities for providing or coordinating care than the son or son-in-law (Silverman, 1987). Additionally, Stoller (1983) found that daughters provided more actual hours of assistance to parents than did sons. Wake and Sporakowski (1972) observed that youngest daughters were most likely to support parental needs. Silverman (1987) indicated that daughters were caring for more mothers than fathers, and the gender difference may be attributed to a stronger mother-daughter bond than mother-son bond.

Johnson (1983) researched family support patterns among 167 posthospitalized elderly individuals. The goal of the study was to determine if care was provided by the family as a unit or by one individual, whether it be the spouse or adult child. Findings indicated that the caregiver was one person rather a team approach of many part-time caregivers. His study reported differences between the care provided by a spouse and that provided by an adult child. Attitudinal differences were observed, with adult children being more likely to report conflict and ambivalence in assuming caregiving duties. The conflicts could arise from the multiple roles the adult child must juggle, or from emotional conflicts carried from childhood into adulthood.

Horowitz and Shindelman (1983) reported on the influence of affection and reciprocity on caregiving behavior. Caregivers provided care with or without affection for those in their charge. However, prior affection without past interpersonal conflict strengthened the bonds during this time of caregiving. If caregivers felt that the relative had greatly contributed to their life in the past, then reciprocation made the caregiving less stressful. Jarrett (1985) observed kinship obligation, as a part of reciprocity, to be a stronger motivation for caregiving than filial affection. Affection did not always enable caregivers to cope with the ensuing stress. Cicirelli's (1983) research results indicated adult children's helping behaviors, attachment behaviors, and feelings of attachment would strongly influence future helping behaviors with aging parents. The influence of filial obligation provided only an indirect influence on attachment behaviors.

As an older person loses spouse and friends to old age, desires to strengthen intergenerational family ties frequently are pursued (Seelbach, 1978). The desire to strengthen these ties does not negate the potential for problems in family dynamics, as conflicts between age groups or as role reversals are experienced. Some aging parents feel it is the duty of the adult child to care for them in their old age when physical difficulties inhibit independence (Shanas, 1980). Brody, Johnsen and Fulcomer (1984) reported that older women preferred adult children to provide emotional support and financial management but not support for income. Expectations for carereceiving and the adult child's capabilities to provide these services may be in conflict. Other conflicts arise among adult children who wish to give care when the parent does not want to receive care.

GENDER OF CAREGIVER

The literature clearly identifies women as the primary caregivers of the elderly (Atchley, 1988; Brody, 1981, 1984, 1985; Collins, 1986; Horejsi, 1982; National Center for Health Statistics, 1984; Shanas, 1980; Silverman, 1987; Strieb & Beck, 1980; Stoller, 1983; Wood, 1987). Springer and Brubaker (1984) reported on research findings that found 94% in one study and 70% in another study where family caregivers were female. Similarly Wood (1987) found seven out of every 10 caregivers to be female.

The nurturing and caregiving roles have continued to be passed down from generation to generation through the females. Men have in the past been socialized differently than women. When young, men were discouraged from participating in household activities. More recently the males of the baby boom generation are being socialized to participate in household activities, particularly child care, but as yet this role has not transferred to caring for aging parents (Wood, 1987). Bathing a parent is far different than bathing a child, and males do not feel as competent in this area (Wood, 1987). Older parents may prefer the female touch. Brody, Johnsen and Fulcomer (1984) found more older women expected their working daughters to adjust their schedules to care for them than expected working sons to do so. As the children of the baby boom generation grow up and more males provide nurturing, then they and their future children may take a more equal role in providing care for the growing elderly population.

EMPLOYMENT

Brody (1981) discussed the increases in numbers of working women, including aging spouses (employed up to and in some cases beyond 70 years of age), middle-aged daughters, daughter-in-laws, and grand-daughters. Atchley (1988) indicated that at ages 65-69, 28% of the men and 15% of the women were employed, and at age 70 and over, 13% of men and 5% of women were still employed. Overall in 1986, 2.6% of the elderly population were in the U.S. labor force, and 3% were classified as unemployed (AARP, 1987).

As employed caregivers, these individuals juggle the heavy load of working and family responsibilities including younger families and older parents. Wood (1987) and Collins (1986) summarized the findings from the 1985 Travelers Corporation study of caregivers in the workplace. They noted that employed women spent an average of 16 hours a week providing care to older family members, as compared with the five hours spent by males. On the average employees spent 10.2 hours caring for an elderly relative. Stoller (1983) concurred with these findings, and additionally observed that employment significantly decreased the hours of assistance provided by sons but not by daughters.

MARITAL STATUS

As long as physical health remained good, spouses (particularly females) typically continued to provide care. When health declined, adult children were turned to for care. The marital status of adult child caregivers did seem to impact on the amount of care provided to the older individual (Collins, 1986;

Wood, 1987). Cicirelli (1983) found caregivers with disrupted marriages (divorced, widowed or remarried) gave significantly less total help, felt less filial obligation, and felt job obligations limited their ability to help. There was little difference in the amount of caregiving when comparing the subgroups of divorced, widowed or remarried adult children caregivers.

Stoller (1983) contradicted Cirirelli's findings. He indicated that married daughters contributed an average of 20.1 fewer hours per month than did unmarried daughters. These findings were reinforced by the intergenerational exchange model explored by Mutran and Reitzes (1984). Unmarried adult children had renewed and strengthened relationships and exchanges with aging parents. For sons, being married reduced the average level of assistance by 23.3 hours per week. This indicated that daughters-in-law carry more caregiving responsibilities than their spouses.

AGE OF CAREGIVER

Age of caregivers varies tremendously from elderly spouses to grandchildren and great-grandchildren. Caregivers over age 60 comprised 10.8% of the caregiving force according to the National Center for Health Statistics (1984). The majority of the remaining caregivers were middle aged adult children, however adult children continue to age along with their parents. Persons in their 70's and 80's could continue providing care for parents in their 90's and 100's. The more pressing issue of physical health seems more relevant than age. Individuals disabled in their 40's or 50's may be cared for by parents in their 60's or 70's. The health concern also applies to caregiving spouses. An 80 year old caregiver may not remember to give medications at appropriate times or may not be able to assist with transfers and the necessary lifting (Springer & Brubaker, 1984).

RACE OF CAREGIVER

Woehrer (1982) studied the family support and interactions of a variety of ethnic and racial groups. In terms of familial help and caring for the elderly, she found Black families exhibited strong kinship ties. Frequently intergenerational households were established for the sharing of emotional support and resources. Hays and Mindel (1973) observed similar findings for Black families. Rural Caucasian families were more likely to share extended kinship relationships than were urban Caucasian families. Mitchell and Register (1984) observed that Caucasian elderly persons saw children and grandchildren more often than Blacks, but Black elderly persons were more likely to receive help from children and grandchildren. Sander and Seelbach (1981) researched care preferences among Caucasians and non-Caucasians, and found more Caucasians than non-Caucasians preferred family to provide long term care. Blacks expressed the highest preference for nonfamily care alternatives. This contradicts the reported pattern of extended family caregiving.

RELIGIOUS AFFILIATION

The connection between religious affiliation and caring for aging family members has received limited coverage in the literature. Wake and Sporakowski (1972) indicated that filial responsibility for adult children tended to be stronger for Jewish families than Catholics or Protestants. Protestants reportedly had the least filial responsibility of the three groups. Legare (1980) concurred with the findings for Protestants and Catholics and linked the results to not only the adult children but also to their parents. He additionally noted that prior to the age of 65, adult children who had strong religious beliefs, regardless of the religious denomination, were more likely to provide caregiving tasks than persons without religious ties.

EDUCATION

Educational background of the caregiver did not seem to be a salient issue in the literature. None the less, since many caregivers are older in age, it is worth noting the trend in educational attainment for this group. The educational level of the older population has been increasing since the 1970's. In 1970 the median level of education was 8.7 years, and by 1986 the median level of education was 11.8 years. The percentage of persons completing high school between 1970 and 1986, rose from 28% to 46%. Approximately 10% had four or more years of college (AARP, 1987). With regard to receiving care, Sander & Seelbach (1981) reported education of the older person was independent of their preference for having family members provide care.

INCOME AND ECONOMICS OF CAREGIVING

According to the American Association of Retired Persons (1987) the median income of older persons in 1986 was $11,544 for males and $6,425 for females. The median income for families headed by persons over age 65 was $19,932. For Caucasian families it was $20,716, and for Black families the median income was $12,477. One in every seven families had incomes less than $10,000. Elderly persons living alone had much lower incomes of less than $7,000. The median net worth of older households was $60,300, which was above the $32,700 average net worth for the U.S. Net worth was below

$5,000 for 16% of older households, but was above $250,000 for 7% of the elderly population. Twelve percent of the elderly population were below the poverty level and received Medicaid. One in every nine Caucasian elderly individuals were poor as compared with one in three for Blacks (AARP, 1987).

Sources of income include Social Security benefits, private and public pensions, income from savings, investments and real estate, plus any continued employment. Michigan's elderly in 1984 reported income from the following sources: 55.6% Social Security; 15.6% jobs; 15.6% pensions, and 8.3% savings and investments (Kong, 1988). Inflation and changing return on investments continue to eat away at revenues (Schultz, 1985). As resources become limited for the older individual, families deal with issues of sharing resources among the generations. Strieb and Beck (1980) point out the linkage between economics and family interaction. To the extent that generations must choose between dispersing resources between the young and the old, frictions may be evident and increase over time. If incomes remain separate, then psychological independence for both groups remain in tact.

Arling and McAuley (1983) reported on financial and nonfinancial factors in providing care for the elderly. They observed physical conditions more so than financial factors to be the driving force behind institutionalizations. Since more families care for the elderly in the community versus institutions, concepts were explored for providing economic incentives for family caregiving. Payments made by insurance companies or the government to support older persons in their homes were suggested. Payments might serve to reduce family stress as expenses threaten the ability to provide care. Montgomery

(1982) agreed that financial concerns are a problem for families providing care. He supported the provision of public assistance to reinforce the unrecognized services that families provide.

The National Association of State Units on Aging (Michigan Office of Services to the Aging, 1988) presented a proposal for a major reform of the federal long term care policy for the elderly. Part of the proposal calls for a package of new benefits for community based long-term care within a new Medicare Part C plan. Eligibility would be based upon individual assessment of functioning for the Activities of Daily Living, and would provide a broad range of medical and nonmedical services to prevent impaired individuals from premature nursing home placement.

The Michigan proposed package would fill some of the voids created by the 1988 Medicare Bill (effective, January 1, 1989). The bill dealt with catastrophic illness, but created high deductibles that will prevent most elderly individuals from benefiting by the plan. It is estimated that only 9,000 of Michigan's one million elderly will benefit from the new bill (Kong, 1988).

One positive feature of the federal bill calls for income protection for spouses when financial resources diminish to the point of Medicaid application. Spouses would be able to have an income of up to $950 per month and assets of $12,000 exclusive of a private residence and one vehicle. Assets in the spouse's name at the time of application would be protected. Person's over age 70 could keep whatever life insurance they have. There was no asset protection under the prior legislation which left many spouses impoverished (The Senior Alliance, 1988).

SUMMARY OF DEMOGRAPHIC CHARACTERISTICS

According to the literature, caregivers are predominately spouses or adult children and are female. While some volunteer for the caregiving role, many are expected by their spouse or aging parents to take on the role. They generally provide care in an individual rather than family mode.

Age, employment, marital status, and education as factors in caregiving were reviewed in the literature. Caregivers represent all age groups, but elderly caregivers may be the most at risk physically and psychologically. Caregivers under age 65 were usually employed, and juggled many roles and conflicting schedules. Married family members provided more caregiving services than those who were not married regardless of employment status. Educational background of caregiver was not linked to caregiving activities.

Race and religious affiliation of the caregiver did not have a consistent impact on caregiving behavior, and there was conflicting information concerning caregiving patterns based on race. Familial bonds, previous patterns of family caregiving and geographic distance seemed to have a more significant influence on caregiving behavior than race. General religious beliefs more than affiliation with one particular denomination seemed to influence caregiving behavior.

According to the literature, financial strain was not as pervasive a problem among caregivers as emotional strain. Certainly individual family situations would demonstrate more financial hardships than others.

PHYSICAL HEALTH OF CAREGIVER:

Physical health of the caregivers can vary widely given the potential age range for this group. For the older caregivers, medical technology has shown that the majority of elderly individuals in their mid 80's are still able-bodied (Atchley, 1988). In 1986, 30% of the population over age 65 reported their health condition to be fair or poor (AARP, 1987). This can be compared to only 7% of the persons under age 65 reporting fair or poor health. There was little difference based on gender, but race has an impact on health status. Among Blacks, 45% reported fair or poor health as compared to 29% for Caucasians (AARP, 1987). The number of days during the year that activities are restricted because of health increases with age, and most older persons have at least one chronic condition. According to AARP (1987), the most frequently occurring physical conditions are as follows: "arthritis (48%), hypertension (39%), hearing impairments (29%), heart disease (30%), orthopedic impairments and sinusitis (17% each), cataracts (14%), diabetes and visual impairments (10% each), and tinnitus (9%)"

In 1984, 23% of the community based older population (6.0 million) had difficulties with one or more personal care activities and one or more home maintenance activities (AARP, 1987). Most of those requiring help with home maintenance were receiving assistance. Needs for assistance increased with age.

With regard to physical health and caregiving, George and Gwyther (1986), did not find evidence suggesting decreases in physical health among caregivers as an aggregate group. This is not to say that individual situations may not vary, with health problems exacerbated by the physical strain of providing care (Brody, 1985).

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In summary, physical health of the caregiver is an individual concern. Psychological strain from the caregiving role, can cause physical reactions such as headaches, stomach problems, high blood pressure and lack of sleep. Changes in eating patterns also would impact on the physical stamina of the caregiver. The literature points out that providing care may do more harm to the caregiver's health than good for the patient.

PSYCHOLOGICAL CHARACTERISTICS OF THE CAREGIVER

MENTAL HEALTH AND CAREGIVER STRAIN

Providing care to someone in need can be a stressful experience for some individuals. Individuals are more or less affected by strain depending upon the particular situation. Brody (1985) identified emotional strains that could result from caregiving. These included: depression, anxiety, frustration, helplessness, sleeplessness, lowered morale and emotional exhaustion. The symptoms were related to restrictions on time and freedom; isolation; conflict from competing family or work demands; difficulties in setting priorities; and interference with life-style and social or recreational activities. The literature acknowledges that the concept of caregiver strain or burden is a perception of the caregiver compounded by a multitude of situational factors (Canter, 1983; George & Gwyther, 1986; Hooyman, 1986; Poulshock & Deimling, 1984; Robinson, 1983; Strong, 1984).

Canter (1983) explored the relationship of 14 variables to caregiver strain. These included demographic variables, situational variables and attitudinal variables. The demographic variables were age, sex, race, socioeconomic

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status, marital status and relationship to caregiver. The situational variables were health status of carereceiver, work status of caregiver, caregiver's ability to manage financially and the amount of assistance provided by the caregiver. Attitudinal variables were the degree of worry; compatibility of relationship between caregiver and receiver; and attitude of caregiver towards the importance and value of family.

Canter's (1983) findings noted the following five variables that impacted the most on caregiver strain: a close relationship to the caregiver (the closer the bond the greater with strain); degree to which caregiver worries; attitudes about the role of the family; the sex of the caregiver; and the quality of the relationship between the caregiver and carereceiver. Strain was more associated with women who worry and have close bonds with the care-receiver,.while feeling strong family values for responsibility to providing care. Continual day to day caregiving involvement, particularly for spouses, put them at greatest risk. Deprivation of personal needs and socialization, without respite, would lead to burnout.

George and Gwyther (1986) concurred with Cantor's (1983) findings associating mental health with caregiver burden. Spouses were considered at greater risk, followed by adult children. Extended family or friend caregivers were at the lowest level of risk for caregiver burden.

Poulshock and Deimling (1984) observed a link between caregiver burden and the elder's impairment with the Activities of Daily Living as well as cognitive impairments. These impairments were difficult to deal with, and impacted on the family in varying ways, but both were connected with caregiver depression and thus caregiver burden.

Robinson (1983) developed and validated a 13 item Caregiver Strain Index. Three major areas were explored: carereceiver characteristics; caregiver's subjective perceptions of the caretaking relationship; and the physical and emotional health of the caregiver. King, Given and Given (1985) similarly associated caregiver burden with these three areas. Appendix A has a listing of the specific questions developed for the three categories of the Caregiver Strain Index (CSI). Robinson's research findings noted no significant differences between CSI scores for men and women. The relationship of the caregiver to carereceiver was not significantly related to CSI scores. Caregivers in poor health were expected to have more strain, but this was found not to be the case. Additionally, caregivers who lived with the carereceiver, versus those who lived elsewhere, had no significant difference in CSI scores. Both younger and employed care- givers experienced higher CSI scores. This implies that compounding of roles and less experience with caregiving may generate strain.

PREPAREDNESS AND HEALTHY CAREGIVER BEHAVIOR

Two additional psychological factors attended to by this author were preparedness for providing care and healthy caregiving behaviors. The literature did not address these variables. This highlights the need for additional research to observe the impact of preparedness and healthy caregiving behaviors on caregiving roles, caregiver strain and coping mechanisms.

HELP-SEEKING BEHAVIOR

Seeking assistance comes easily for some individuals and is difficult for others. Assessing when help is needed is a complicated task not effectively handled by all individuals (Nadler, 1983). Many may choose to endure hardships rather than utilize available sources of help.

Nadler (1983) points out that a help-seeking situation is viewed as a conflict between the need to alleviate current difficulties by seeking assistance and the need to protect one's self image as a competent and self-reliant individual. Sex differences, socioeconomic differences and self esteem issues are factors impacting on help-seeking. More women then men seek assistance. More lower income than higher income seek assistance, but pride and self esteem mediate this factor. Reciprocity also determines help-seeking if services have been previously shared (Gross & McMullen, 1983).

Burger and Cooper (1979) linked desirability for control and help-seeking behavior. Individuals feeling a sense of control over their lives would seek opportunities and resources to deal with problems that arise. This would include the assessment of a problem situation on the home front; realization that one's efforts alone would not correct the situation; and seeking help to address deficiencies.

Hooyman (1986) observed that caregivers who are stressed need to negotiate shared caregiving responsibilities and ways to build a helping network with friends, neighbors and acquaintances. If family caregiving is to thrive, the helping network needs to reinforce it, build upon it and link professionals and programs to strengthen it (Horejsi, 1982). Gray (1984) and Neubacher (1987) promote the care and support of the caregivers to prevent family breakdown. Neubacher feels this has to come not only from the extended social environment but also from the carereceiver, through conversation, thanks, and respect for assistance given.

SUMMARY OF PSYCHOLOGICAL CHARACTERISTICS

The literature points out that caregivers experience varying levels of psychological and emotional strain. Particularistic family factors determine the amount and type of strain. In general, spouses and adult children seemed to experience more strain than other family members or friend caregivers. Women tend to experience less caregiver strain than the caregiver husbands or adult children. The males may not be prepared to take on caregiving, and the adult children are juggling work and their own home life while providing care for their parents.

With regard to help-seeking, it is a function of conflict resolution. Factors influencing help-seeking behavior include gender, income and a sense of self control. Overall, females, those with lower income, and those with a strong sense of self esteem tend to seek out assistance from others.

SOCIAL AND COMMUNITY RESOURCES FOR CAREGIVERS

The role of caregiver can be enhanced by keeping in contact with supporting social and community resources. Selecting these resources carefully is important. Associating with positive individuals, who refuel the cognitive and physical energies, can bring renewed motivation for providing care. Negative associations can deepen depression and aggravated feelings.

Social network tends to diminish with age (Morgan, 1988). The networks seem to decrease as a function of declining resources. The implication is that older caregivers with declining resources may withdraw from social networks during a time when network linkages are needed the most.

Zarit, Reever and Bach-Peterson (1980) found caregiver burden to be less when more social contacts were paid to the caregiver and the disabled individual by friends and family. The number of visits to the household was more of an indicator of burden than were other characteristics about the patient's physical and mental condition. The authors encouraged increased social support to caregivers as a reduction of stress.

Beyond social support, community resources provide a transfer of caregiving roles from the family to the community in the hope of complementing the family's informal caregiving functions (Hooymen, Gonyea & Montgomery, 1985). Krout (1983) reviewed the literature concerning knowledge and use of services by the elderly. The degree of knowledge varied widely from study to study. Many older individuals had heard of programs, but were unable to explain the details of the service or how one might obtain the service. Better educated, female, and married older persons were more aware of programs than their counterparts.

Household caregiving functions for impaired elderly individuals take on different configurations based upon the sex of the caregiver, marital status and presence of children (Noelker and Wallace, 1985). Use of formal services by these households averaged less than one half day per week.

Utilization of services among the elderly population is far less than the degree of knowledge of these services or access to programs. Krout (1983) found Blacks, women, and persons with less income and education used more services. Users were a small fraction of the overall elderly population. Stoller and Earl (1983) found services to be primarily provided by informal family linkages rather than community sources. Krout (1984) concurred, noting the frequency of contact with adult children to be negatively related to dependence on formal services. O'Brien and Wagner (1980) suggested that the informal family ties block proper access to useful services rather than leading to more humane and cheaper alternatives to caregiving.

Hooyman, Gonyea and Montgomery (1985) studied the impact of termination of home services on caregivers. They found the presence or absence of chore services was not associated with caregiver burden or stress.

In summary, the literature supports the positive influence of social and community resources in reducing caregiver strain. Unfortunately, as one ages the network of resources tends to decrease at a time when needs increase. Awareness of programs and seeking the services of programs did not match with the need for services. In other words, persons in need did not always seek programs even if they were vaguely aware that a program existed. Females, well educated persons and married individuals more often sought programs. Type of service was associated with the reduction of caregiver strain. The literature suggested the need for more community based personal care services versus household chore services since personal care tasks generated more psychological strain.

HOUSING RESOURCES FOR CAREGIVERS

The literature with regard to caregiving and housing is limited to the physical design issues previously discussed in this chapter. Issues related to caring for one's home plus caring for a disabled individual are addressed in the literature under physical or psychological health of the caregiver. Increases in expenses, including housing expenses, are a part of the overall financial picture for the caregiver.

With regard to interacting with the physical environment, it is important to repeat the team role the housing environment can play in the caregiving arena (Hiatt, 1982). Supportive environments reinforce competencies while building coping strategies, and frustrating environments breed stress, depression and anger (Carp, 1977). This applies to the stroke survivor as well as the caregiver.

In summary, the literature suggests the need for the physical environment to work as a part of a team approach to health care. Examining the stroke survivor's ability to ambulate is an effective measure of person-environment fit. The ability to walk has been used to predict long term survival from a stroke, and ambulation using aids and devices (wheelchair) presents the most difficult design issue for barrier-free accessibility. The environment can work to enhance the stroke survivor's and the caregiver's level of functioning. Stress can be a product of poor person-environment fit. Encouraging older individuals to modify the home environment or move to a more supportive environment in search of person-environment fit, is a difficult task when the resident feels strong attachment and thus housing satisfaction.

Caregivers can play a key role in facilitating person-environment fit. Yet these typically older female spouses are less likely to make environmental changes or a housing move. They become the bridge between the stroke survivor's needs and the environment, which means that they lift, push and pull, bearing the physical burden themselves.

CHAPTER THREE

METHODOLOGY

The methodology chapter describes the research questions; research variables; research design; selection and description of the major project sample and sub-sample for this project; procedures used; instrumentation and data analysis. An exploratory, qualitative, case study approach is utilized to conduct the research. The purpose is to assess indicative characteristics of caregivers that facilitate or detract from person-environment fit for disabled stroke survivors. The findings have implications for future large scale, quantitative research for caregivers in general.

RESEARCH QUESTIONS

Person-environment fit focuses the relationship between a human being and the physical, psychological and social environment. Obtaining a good physical fit for someone who is disabled becomes a critical component for independence versus dependence in accomplishing routine or higher level activities of daily living. Good fit is contingent upon many variables, but a critical variable is the caregiver.

Three broad research questions are addressed in this study:

(1) What is the relationship between person-environment fit and

selected physical and demographic characteristics of the stroke survivor?

(2) What is the relationship between person-environment fit and selected caregiver characteristics?

(3) What is the relationship between the person-environment fit score and caregiver strain index?

RESEARCH VARIABLES

Many variables are explored in this multi-case study, qualitative methodology. The dependent variable is person-environment fit, as comprised by the relationship between the stroke survivor's pre and post-stroke health; his/her ability to perform the Activities of Daily Living; use of aids; the condition of the physical housing environment; and the caregiver's physical support. Figure 2 illustrates the relationship of case factors that lead to a summative person-environment fit score (the dependent variable).

The independent variables are characteristics of the caregiver. These characteristics include demographic, physical, psychological, social, and housing characteristics. Caregiver variables were analyzed for cases that exhibited problems with person-environment fit and in which the stroke survivor had problems performing the Activities of Daily Living. Figure 3 shows the relationship between the independent and dependent variables.

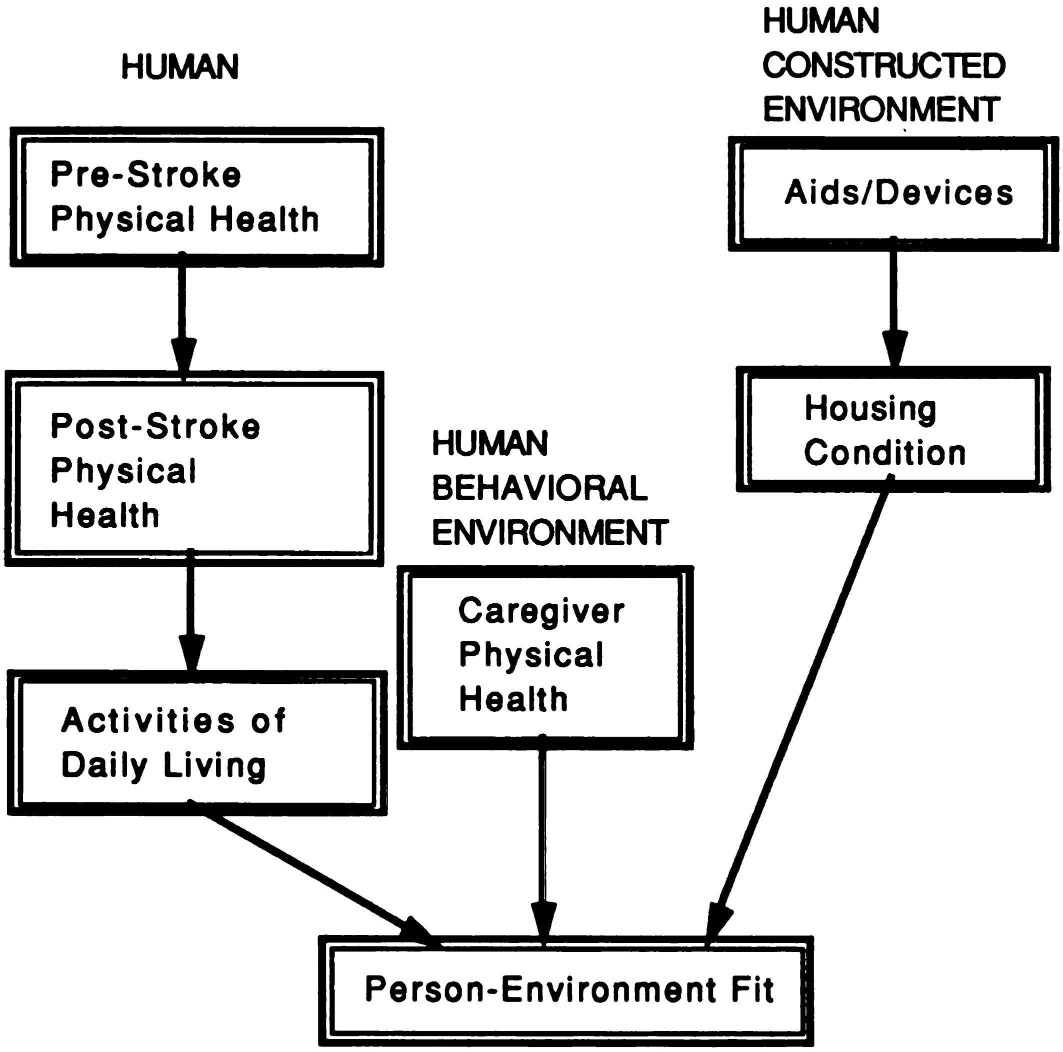

Figure 2: Factors Comprising Person-Environment Fit

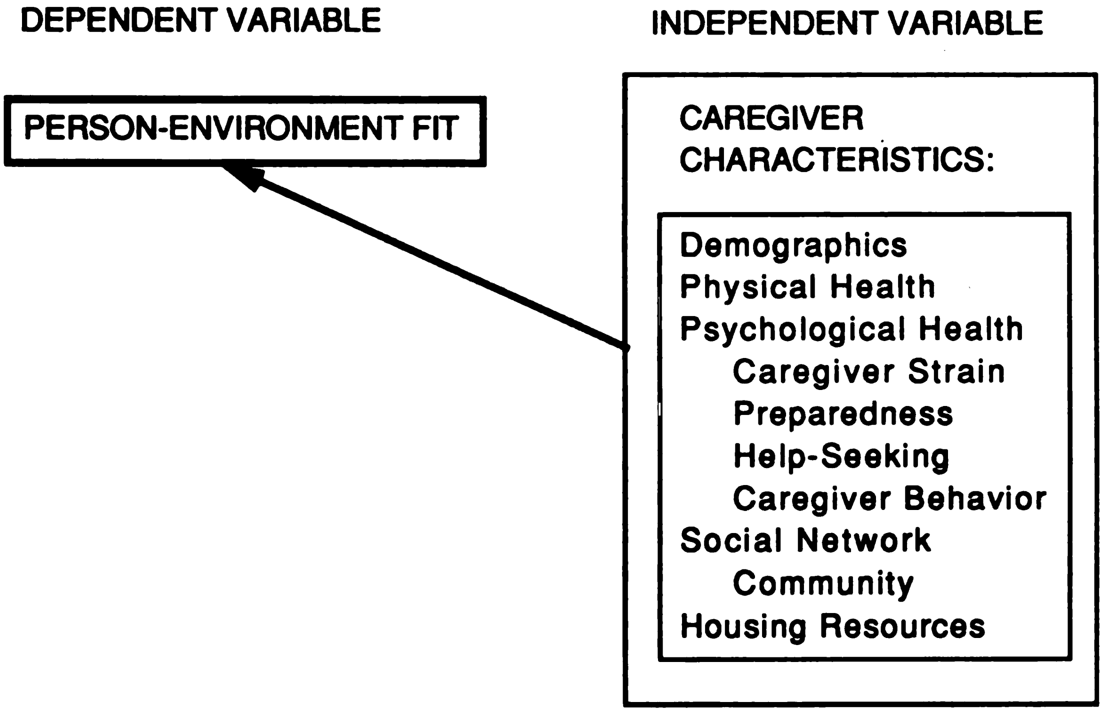

FIGURE 3.: Caregiver Impact on Person-Environment Fit

DEPENDENT VARIABLE

PERSON-ENVIRONMENT FIT

Conceptual Definition: This is the congruence between human physical needs and the physical environment serving as a support system enabling optimum functioning of Activities of Daily Living. For this study, person-environment fit concentrates on the fit provided for the stroke survivor's ambulation and maneuverability into and throughout the home environment.

Operational Definition: Person-environment fit is a summative measure of six categories that rate the fit between the person's physical ability to ambulate, and the supportiveness of the environment. The factors in the summative measure include:

1) Stroke survivor's pre-stroke ability to ambulate.
2) Stroke survivor's post-stroke physical characteristics that may inhibit ambulation.
3) Stroke survivor's ability to perform the Activities of Daily Living that deal with ambulation (walking and climbing stairs).
4) Stroke survivor's need for and use of aids and devices that enhance ambulation.
5) Physical conditions of the housing environment at the time of the interview and its supportiveness for ambulation.
6) Physical characteristics of the caregiver that enable him/her to assist the stroke survivor with ambulation.

Each factor is scored using a three point scale with numerical values of 1, 0, or -1. Scores from each of the six factors are totaled for an overall person-environment fit score. Interpretation of total scores are defined as follows:

Score	Definition
+6	Excellent person-environment fit: stroke survivor characteristics as compared with the use of aids and housing characteristics allow for ease of self ambulation; caregiver is in excellent health and can provide assistance if necessary.
+3	Good person-environment fit: stroke survivor may have minor problems with ambulation; aids and housing environment are generally supportive but may need minor changes; caregiver's health generally allows for assistance if necessary.
0	Person is coping with the environment: stroke survivor and caregiver are holding their own at this break even point. Stroke survivor has some problems with ambulation and the housing environment may not meet his/her needs, but it can be changed with minor effort; the caregiver can provide some assistance with ambulation if necessary.
-3	Poor person-environment fit: stroke survivor has difficulty with ambulation with or without an aid; the housing environment may require minor or some major changes to enhance ambulation; caregiver may provide a little assistance, but may have a few physical limitations of his/her own to deal with.
-6	Severe problem person-environment fit: stroke survivor has a severe disability and the environment has structural problems that do not allow for self or assisted ambulation; the caregiver is not able to provide the needed physical help with ambulation.

Pre-stroke Ambulation of the Stroke Survivor

Conceptual Definition: The physiological ability of the stroke survivor to walk or climb stairs prior to the stroke.

Operational Definition: Assessment of pre-stroke ambulation was made from questions IH9, IH7 and IH8 (question number refers to the informant's interview; see Appendix D for interview instruments). Question IH9 is a list of pre-stroke physical conditions. IH7 assesses the stroke survivor's overall pre-stroke health (ranked as either poor, fair, good or excellent). The level of interference of the physical condition on routine activities (ranked from no interference, to a great deal of interference) is explored in IH8. For the person-environment fit score, pre-stroke ambulation is rated as follows:

+1 Prior to the stroke, the stroke survivor could walk and climb stairs by him/her self with ease and may have used aids.

0 Prior to the stroke, the stroke survivor could walk and climb stairs but not with ease, and he/she easily became fatigued

-1 Prior to the stroke, the stroke survivor could not walk or climb stairs (with or without aids) without human assistance.

Post-Stroke Physical Characteristics of the Stroke Survivor

Conceptual Definition: The physiological changes occurring with stroke that potentially inhibit ambulation and may require environmental changes.

Operational Definition: Assessment of post-stroke ability for ambulation is achieved through question IH9, which provides a summary checklist of current physical ailments. Additionally, the following physical conditions impacting ambulation were reported in items IH27 A,B,C,E & N: weakness or paralysis of arms and or legs; loss or change in ability to feel sensations in arms or legs; loss of coordination of voluntary movements; jerkiness of movement; and problems in judging distances. For the person-environment fit score, post-stroke physical characteristics inhibiting ambulation are rated as follows:

+1 The stroke survivor has no residual paralysis of limbs and can easily ambulate.

0 The stroke survivor has minor paralysis of limbs, but demonstrates self ambulation, with aids if necessary.

-1 The stroke survivor has paralysis of limbs and self ambulation is difficult, requiring assistance.

Activities of Daily Living

Conceptual Definition: Activities of Daily Living are the overall performance of routine functions namely: bathing, dressing, going to the toilet, transferring, continence and feeding (Katz, Ford, Moskowitz, Jackson, Jaffe, Cleveland, 1963).

Operational Definition: Section IH28 - IH44 in the informant instrument uses an ordinal scale (needed help before stroke; can not do at this time; can do with aids and devices; can do with help from others; can do without help) to assess the stroke survivor's ability to perform Physical Activities of Daily Living (eating, dressing, grooming, walking on level surface; walking up and down stairs; getting in and out of bed; taking bath/shower, controlling bladder and bowel functions; transferring on and off toilet) and Instrumental Activities of Daily Living (using telephone, driving, using public transportation, shopping, meal preparation, doing light and heavy housework).

For the person-environment fit scale, only the Activities of Daily Living for walking and climbing stairs are used to determine ambulation capabilities. The following scores and definitions are used in the person-environment fit calculation.

+1 The stroke survivor has an average ADL rating of five (can do without help) for both items (walking and climbing stairs).

0 The stroke survivor has an average ADL rating of four or three (can do with help from others or with aids) for both items.

-1 The stroke survivor has an average ADL rating of two (can not do at this time) for both items.

Aids for Ambulation

Conceptual Definition: The device or apparatus in use to assist with walking, climbing stairs or general ambulation. Devices usually include canes, walkers or wheelchairs.

Operational Definition: For calculating person-environment fit, aids are assessed in terms of their need by the stroke survivor, availability to the stroke survivor, and the need for human assistance in using the aid. Question IH20 indicates the aids used by the stroke survivor; IH21 questions the need for human assistance with the aids, and IH23 notes the need for aids not currently available to the stroke survivor.

The following scores and definitions are used to calculate the need for and use of aids for ambulation for person-environment fit:

+1 The stroke survivor either does not need an aid for ambulation, or an aid is used easily without human assistance.

0 The stroke survivor needs an aid and uses one with difficulty by him/herself.

-1 The stroke survivor needs and uses an aid, but it is not self controlled thus requiring human assistance. OR an aid is needed and not provided.

Physical Characteristics of the Housing Environment

Conceptual Definition: The physical environment encompasses the housing structure, with its design; layout; presence of stairs; structural and non-structural changes, including special furnishings and surface treatments. The housing environment can enhance or inhibit the stroke survivor's level of functioning and the caregiver's ability to provide services.

Operational Definition: Only physical housing characteristics that enhance or inhibit ambulation are addressed here for person-environment fit. These characteristics include: stairs at the main entrance (IB27), number of stairs at the main entrance (IB28), stairs at secondary entrance (IB29), number of stairs at secondary entrance (IB30), stairs within the home (IB31), and number of interior stairs (IB32). In addition, it is important to note any bedroom adjustments (IB20); structural changes made to the inside or outside of the home (IB19); location of the stroke survivor's bedroom to the bathroom (IB17 & 18); and observational notes recorded by interviewers, when considering person-environment fit.

For calculating person-environment fit, the following scores and definitions are used for assessing the supportiveness of the physical environment for ambulation at the time of the interview.

+1	The house supports ambulation (clutter free for easy passage, no stairs or a ramp is provided).
0	The house has non-structural housing barriers (clutter, clogged passageways, excessive amount of furnishings) that could be corrected inexpensively.
-1	The house has structural housing barriers inhibiting ambulation (exterior and interior stairs, narrow door openings for wheelchair passage, reinforcing walls for the addition of grab bars or railings, etc.).

Physical Characteristics of Caregiver for Providing Assistance with Ambulation and Person-Environment Fit

Conceptual Definition: Caregiver's physical health since the stroke survivor's stroke, that enables or inhibits physical assistance with ambulation and person-environment fit.

Operational Definition: In the Caregiver interview, the caregiver was asked to rate his/her health prior to the stroke as being excellent, good, fair or poor (CH1). Current health problems and their impact on providing care and assistance to the stroke survivor were reported in questions CH5,7,9 and 11. For calculating person-environment fit, the following scores and definitions are used for assessing the caregiver's physical ability to provide assistance with ambulation.

+1 The caregiver is in excellent health and physically is able to provide support for ambulation.

0 The caregiver is in good health, but some physical problems may be aggravated by providing support to the stroke survivor for ambulation.

-1 The caregiver is in fair to poor health. Providing a lot of physical support for ambulation may do more harm to the caregiver than good for the stroke survivor. Caregiver is UNABLE to lift stroke survivor or wheelchair. Caregiver can NOT assist with transfers or provide physical support for ambulation.

INDEPENDENT VARIABLES

CHARACTERISTICS OF THE CAREGIVER

Conceptual Definition: Caregivers provide social, psychological and physical support to those in their charge. As a support system, a caregiver may serve as a linkage in providing person-environment fit for the patient. Sociodemographic characteristics, such as: relationship of the caregiver to the patient, the caregiver's gender, race, age, educational background, marital status, religious preference, employment status, and income (income adequacy since the stroke), may be factors in whether or not person-environment fit has been achieved. Additionally, the caregiver's physical health, psychological characteristics (caregiving behaviors, caregiver strain, help-seeking behavior), social and community resources, and housing resources may play fundamental roles in person-environment fit. Each characteristic is explored in the case studies.

Operational Definition: The following information is obtained from the Caregiver Survey Instrument (See Appendix D). Sociodemographic characteristics concerning the caregiver include the noted items and corresponding questions below:

Relationship to Stroke Survivor C10
  (spouse, daughter, daughter-in-law, son, son-in-law, brother, sister, mother, father, mother-in-law, father-in-law, grandmother/father, grandson/daughter, other relative, friend, neighbor, other.)
Gender of Caregiver CA1
  (male, female)
Race CA2
  (White, Black, Oriental, Spanish American, American Indian, other)
Age CA3
  (date of birth)
Education CA4
  (0-4 years; 5-8 years; high school incomplete; high school completed;, post high school, business or trade school; 1-3 years college; college completed; post graduate college.)
Marital Status CA5
  (single, married, widowed, divorced, separated, remarried.)

Religious Preference CA6
(open ended question requesting preference.)
Employment CD1
(full time, part-time, unemployed, homemaker, retired, in school part-time, in school full time, disabled, other)
Income CD9
($4,999 or less, $5,000-$9,999, $10,000-$19,999, $20,000-$29,999, $30,000-$39,000, $40,000-$49,999, $50,000-$59,999, $60,000-$69,000, $70,000-$79,999, $80,000-$89,999, $90,000 and up)
Number of persons living on that income CD10
Changes in financial situation CD11 (yes/no)
Income adequacy CD15 (not enough, just enough,some extras)

Physical Characteristics of Caregiver

Conceptual Definition: Physical health of the caregiver encompasses the pre and post stroke health and the impact of the caregiver's health on his/her ability to provide care for the stroke survivor.

Operational Definition: Physical health conditions before the stroke and increased health problems during the time of caregiving may have an impact on caregiver strain. The questions noted below were used to assess physical health as well as changes in eating habits since the stroke and their potential impact on physical health.

Physical Health (yes/no responses for 2,3,5,7,9,11)
CH1 Rating of health prior to (SS) stroke (excellent, good, fair, poor)
CH2 Prior to stroke, did health stand in way of doing what you wanted to do?
CH3 Did stroke affect pattern of physical activity?
CH5 Do you have any health problems or illnesses?
CH7 Do any of your health problems make it more difficult to care for (SS)?
CH9 Have any of your health problems increased because of caring for (SS)?
CH11 Are any of these health problems new since (SS) stroke?

Changes in eating habits since (SS) stroke. CI4, CI5
(yes/no responses)
- CI4A1 Change in amount of food eaten.
- CI4B1 Change in how often eat with friends.
- CI4C1 Change in how often eat out.
- CI4D1 Change in how well balanced the meals are.
- CI4E1 Change in time spent shopping and cooking.
- CI5 Weight or appetite change.

Psychological Characteristics of Caregiver

Conceptual Definition: The caregiver's psychological pre and post stroke health includes tendencies for worrying, satisfaction with life, caregiver strain, preparedness for caregiving, help seeking behavior, and healthy caregiving behaviors.

Operational Definition: The caregiver interview explores mental health of the caregiver from both the pre and post stroke emotional status. Questions assess the degree of worrying, satisfaction with life, and changes in emotional health with the onset of providing care. The following questions address the caregiver's emotional health.

Mental Health: (CF1-5)
- CF1 Frequency of worrying. (very often, fairly often hardly ever)
- CF2 Consider life dull, routine, or exciting.
- CF3 Satisfaction with life. (good, fair, poor)
- CF4 Present emotional health. (excellent, good, fair, poor)
- CF5 Comparison of emotional health now to before stroke. (better, about the same, worse)

Psychological characteristics also include the Caregiver Strain Index Scale developed by Robinson (1983) (CL1A 1-14). Factors used to assess the existence of caregiver strain included such factors as: sleep disturbance, financial burden, physical strain, family adjustments, and patient's behaviors as

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disturbing (See Appendix A for complete scale). The 13 item index used "yes/no" responses with the "yes" responses summed to create the caregiver strain score. A low score (1-3) indicated low caregiver strain and a high score (10-13) represented high caregiver strain.

Preparedness for caregiving lent insight into the caregiver's level of preparation for contacting health professionals, researching aids and devices plus changes to be made to the home. Additionally, this section of the survey instrument addresses the amount of time caregiving would involve. It also assessed whether the caregiver knew enough about strokes to understand the changes that took place with the stroke survivor. The questions below were used to note preparedness for caregiving:

Preparedness for Caregiving:
Ordinal scale for CG2A, 3A, 4A, 18A 19A, 20A: not at all prepared, a little prepared, somewhat prepared, very prepared, completely prepared.
CG2A Knowing who to contact when you had questions about (SS) care or health.
CG3A Knowing what equipment or devices were needed and where to get them.
CG4A Preparedness for dealing with the amount of time caregiving would take.
CG18A Having enough information on strokes.
CG19A Knowing what changes to make to the inside or outside of the house.
CG20A Finding someone to make these changes to the house.

Along with being prepared for caregiving, one must also seek help from time to time. Help seeking behavior was defined as the caregiver's willingness and frequency for obtaining assistance from family, friends, neighbors, and community services (resources beyond him/herself). For this study, 16 questions (CL4 a-q, see Appendix A) addressed sources for caregiver help-seeking, using an ordinal scale to indicate the frequency of help-seeking contacts (never, once or twice a year, monthly, weekly, more than once a week). The scores for the 16 items were averaged, with a score of five indicating active help-seeking from a variety of sources.

Beyond seeking help, other caregiving behaviors have been reviewed to note the caregiver's psychological adjustment to the situation. A measure for Caregiving Behavior was created with the items from CG30-48 (see Appendix A). Nineteen items were assessed with an ordinal scale (almost never, seldom, sometimes, often, almost always) for caregiver behavior. The scale included such caregiver characteristics as allowing others to stay with the stroke survivor; calling the doctor when needed; putting off taking care of oneself; and neglecting the stroke survivor. The wording of the questions in this scale made some ratings with a response of "almost never" to mean healthy caregiving behavior. Other questions with a response of "almost always" indicated healthy behavior. The scores from ten of the items were averaged, with a composite score of "five" indicating healthy caregiving behavior. The remaining nine items also were averaged, with a score of "one" denoting healthy caregiving behavior.

Social and Community Resources for the Caregiver

Conceptual Definition: The importance and frequency of visits from family and friends impacts upon the caregiver's social network for having someone to talk with and provide help. Use of community services also is an important caregiving network for promoting person-environment fit.

Operational Definition: Social resources were addressed in questions

CE1-8. These items noted the importance of visits from family and friends plus the frequency of visits since the stroke. This section also looked at the caregiver's network for having someone to talk with and having someone to assist with the caregiver's personal needs, as listed below.

Social Resources:
- CE1 Importance of regular visits from friends/family. (very important, important, somewhat important, unimportant, very unimportant)
- CE2 Had visits since (SS) stroke. (yes/no)
- CE3 Frequency of visits. (rarely, couple of times, weekly, 3-4 times a week, daily)
- CE4 See friends/family as much as would like. (yes/no)
- CE6 Have friends/relatives to talk with. (yes/no)
- CE8 Have others to help with personal needs. (yes/no)

For community services, question CJ1 was an open-ended question used to discern the community services currently in use by the caregiver.

Housing Resources for the Caregiver

Conceptual Definition: Housing resources are the caregiver perceptions to physical environmental issues: such as older family members living with younger family members; problems in caring for the home; satisfaction with the living arrangement; and future/ideal housing settings. In addition an increase in housing expenses since the stroke could be a cause for strain and infringe upon housing resources.

Operational Definition: Housing resources for the caregiver were identified by the following questions and cover a variety of housing topics:

Housing Resources: (yes/no CB 25,26,28,30,32)
- CB1 Tenure (own, rent, live with someone else)
- CB25 History of older family members living together.
- CB26 Problems in caring for home since stroke.
- CB28 Housing expenses increased since stroke.

CB30 Living arrangement working out well.
CB32 Future housing plans.
CB33 open-ended description of future housing plans.
CB36 open-ended description of ideal housing situation.

RESEARCH DESIGN OF MAJOR PROJECT

A qualitative study format was used to obtain 20 family case studies. Reinharz and Rowles (1988) affirmed the need for qualitative study in gerontology and provided a literature review for the philosophical rationale for qualitative research. The goal of qualitative research is to truly understand human behavior from the individual's own frame of reference (Cook & Reichardt, 1979). The rich, subjective, in-depth knowledge gained from face to face interaction puts responses into the familial culture and jargon. This gives meaning to quantitative information that may be collected. Additionally, observations assess environmental context, providing perspective for interview responses.

Personal in-home structured interviews, with both fixed responses and open-ended questions, were conducted with each of 20 families. During the six to eight hours the interviewers spent in the home, three interviews and general observations took place. The stroke survivor, an informant and a primary caregiver were interviewed. Given their limitations, the stroke survivors were predominantly asked questions that would generate yes/no responses. Open-ended responses were pursued when the stroke survivor was able to answer. The questions asked of the stroke survivor were personal perceptions that could not be answered reliably or validly by the informant. The informant interview explored the past and present condition of the stroke survivor; whereas the caregiver interview addressed the stroke's impact on the caregiver, as an individual, as well as the stroke's impact on the family.

A team of two interviewers made the initial visit, collecting the stroke survivor and caregiver data. Stroke survivors and caregivers were interviewed in separate rooms. Since the initial visit frequently consumed two to three hours, a second session was scheduled, within a week of the first session, for collecting the informant's information. In most cases the informant and the caregiver were the same person. Overall the study format offered an opportunity for in-depth familiarization with the family unit, its network, culture, interaction style and general surroundings.

SELECTION OF MAJOR PROJECT SAMPLE

Names of stroke survivors, over age 55, were obtained from hospitals and home health agencies in and surrounding three major cities (Lansing, Grand Rapids and Flint, Michigan).

Clients were initially screened by referring medical personnel as being recent stroke patients physically and mentally capable of responding to a structured interview. Stroke survivors were additionally screened by the researchers through a telephone interview obtaining the following information: age; date of stroke; incidence of multiple strokes; date of discharge from hospital or institution; type of stroke and general residual disabilities; plus residential situation, and name of informant and/or caregiver.(see Appendix B)

Due to the small number of referrals and small number of qualified and willing participants, a random sample was not possible. However, since stroke occurs randomly within the population at large, and the referred families represented varying socioeconomic levels residing in rural, suburban and urban locations, the researchers felt the sample was somewhat representative of those who experience stroke.

DESCRIPTION OF MAJOR PROJECT SAMPLE

Stroke Survivors

Of the 20 stroke survivors serving as the sample, 13 were male and seven female. Marital status indicated 13 married and seven widowed stroke survivors. The mean age was 73.2 years, with a range of 57 to 89 years. Mean age for the male stroke survivors was 69.3 years and 80.4 years for the females.

Since data are not available for the incidence or age of onset for stroke, the sample can be compared to the age at death from stroke. In 1985 the median age at death from stroke in Michigan was 79 years; 76 years for males and 82 years for females. Death rates were higher for women (70.2%) than men (50.9%) for all age groups; but the death rates for men, age 55-84, rose above women by 21.3% (Michigan Health Statistics, July 1987).

The racial breakdown of the major project sample was 80% Caucasian and 20% Black. Overall in Michigan 90.9% of the population is Caucasian and 8.8% is Black. In 1980 the proportion of Caucasian and Black population over age 65 was 10.4% Caucasian and 6.9% Black (AARP, Minority Elderly in Michigan, 1980 census). The 1985 stroke death rates for persons under age 75 were higher for non-Caucasians than Caucasians. In fact the incidence was 45.8% higher for non-Caucasian males and 64.0% higher for non-Caucasian females under 75. The trend reverses for persons over age 84 with more Caucasians dying from stroke than non-Caucasians (Michigan Health Statistics, July 1987).

The educational background for the sample showed that fourteen stroke survivors (70%) had not completed high school, three (15%) completed high school and three (15%) had at least a partial college education. For persons aged 25 and up, 67.7% in the U.S. and 67.9% in Michigan had completed high school. For the same age group, 10.9% in the U.S. and 14.2% in Michigan had completed a four year degree (Michigan Statistical Abstract, 1987).

Two stroke survivors were employed outside the home at the time of the stroke. Others were either homemakers or retirees. Income ranged from $4,999 to $69,000, with 68% reporting (N=16) income of less than $20,000. For all ages, the median family income in Michigan was $22,108 in 1985. The average per capita income was $13,867 (Michigan Statistical Abstracts, 1987). According to the U.S. 1984 census, 34% of the persons over age 65 had income under $10,000 (U.S. Census, February 1987).

Caregivers

The caregiver sample was comprised of 18 females and two males. Their relationships to the stroke survivors included: 13 spouses, three daughters, one son, one sister, one daughter-in-law, and one other relative. The mean caregiver age was 66.5 years with a range of 45 to 83 years. Marital status showed sixteen married, one single, one widowed, and two divorced. According to the National Center for Health Statistics, National Health Interview Survey on Personal Care (1984) women provided 80% of the caregiving, including wives, daughters and other females. Caregivers over age 60 comprised 10.8% of the caregiving force.

Education level for caregivers showed eight (40%) had completed less than a high school diploma, seven (35%) completed a high school diploma, the

remaining 25% completed post high school training or college. Ten caregivers were full time homemakers, six were retired and four were employed full time outside the home. Caregiver income paralleled and did not significantly vary from that of the stroke survivors. Again the range was $4,999 to $69,999 with the majority less than $20,000.

INTERVIEWING PROCEDURES FOR MAJOR PROJECT

Training of interviewers included a session with procedural discussions and observation of a trial interview. Interview instruments were pretested with stroke patients and their caregivers. Instruments were refined after this procedure (See Appendix D for the parts of the caregiver and informant instruments used for this study).

If the stroke survivor fit the study criteria, interview appointments were scheduled. Appointments were slated during hours when the stroke survivor would be well rested and fed. Researchers went to every effort to avoid disruption of family routines and schedules. Clients were called the night before or the day of the interview to be sure all was well.

As explained previously, interviewing was two tiered. During the first session, stroke survivors and caregivers were interviewed at the same time but in separate rooms. At that time consent forms (See Appendix C) were signed by both parties. The informant was interviewed at a second appointment that typically took place within the following week. Again a phone call preceded the second arrival.

Interviews were tape recorded. Although families did not seem to mind the presence of a recorder, they had the right to refuse taping.

Each interview was approximately two to three hours in length. Interviewees (especially the stroke survivors) were offered the opportunity for breaks. Following the completion of all family interviews, a thank you letter was sent.

CONFIDENTIALITY

During the initial prescreening telephone contact and the beginning of each formal interview, the respondents were informed of family confidentiality and data reporting procedures that would summarize general findings. The goals of the study were clearly explained. Each family knew that their input would not generate any personal benefits but would assist future families confronting similar issues. Families were assigned a case number as the interviews were completed to assure anonymity. Project procedures were approved by the University Committee for Research Involving Human Subjects (UCRIHS) (See Appendix E).

INSTRUMENTATION

Three parallel instruments were designed to cover similar topics for the stroke survivor, informant and caregiver interview. The following general topics were addressed in each of the three survey instruments: sociodemographics, housing, clothing, financial resources, social resources, mental health, physical health, nutrition, and community services.

The OARS Multidimensional Battery, prepared at the Duke University Center for the Study of Aging and Human Development (1978), served as the primary instrument to be adapted and modified to meet the major project's needs. It had originally been developed for clinical assessment of the elderly in five arenas. These topics included: social resources, economic resources, mental and physical health, and self care capabilities. Both reliability and validity have been substantiated in clinical settings. The format for surveying the Activities of Daily Living (Katz, Ford, Moskowitz, Jackson, Jaffe, Cleveland, 1963) also was taken from the OARS instrument.

Where standardized instruments were not available, sections for the three instruments were specifically developed for topics such as: nutrition, housing, caregiving and help-seeking behaviors.

The Caregiver Strain Index (Robinson, 1983) was incorporated into the Caregiver instrument. It was a validated survey instrument used to note perceived strain with the caregiver role. It was intended to serve as a predictive device for identifying caregiver populations at risk. For this study, Caregiver Strain Scores are compared with the stroke survivor's Person-Environment Fit Score.

SAMPLE SELECTION FOR CASE STUDIES

The initial goal was to select 10 cases for examination. The Activities of Daily Living and Person-Environment Fit score served as screening devices used to determine which cases would be reviewed for case study analysis. For the 20 families, the first level of screening involved the review of the stroke survivor's ability to perform Activities of Daily Living (ADL) . Eight stroke survivors could perform all ADLs. Families in which the stroke survivor could perform all the Instrumental and Physical Activities of Daily Living, meaning less physically demanding caregiving roles, were eliminated from the study. This reduced the sample from 20 to 12. For the remaining 12 cases, Person-Environment Fit Scores were tabulated with the following results:

Person-Environment Fit Score	Family Case Number
1	8
1	12
0	3
0	5
0	10
0	13
-2	7
-2	11
-2	17
-2	19
-3	18
-4	16

The two cases with a positive Person-Environment Fit Score indicated that the family had been able to create a good fit. These families were not analyzed so attention could focus on the 10 cases where person-environment fit was more problematic. Interview instruments for the cases with a 0 or less person-environment fit scores were pulled for case study analysis.

DATA ANALYSIS

A code book was prepared for the variables identified at the beginning of this chapter. Ten copies were made for recording case by case information transferred from informant and caregiver interview booklets. A narrative was developed for each case as a summary of the variables. The format for the case studies was as follows:

General family description of stroke survivor and caregiver relationship
Stroke Survivor:
- Pre-stroke physical health
- Post-stroke physical health
- Capabilities for Activities of Daily Living
- Psychological and social adjustment to the stroke
- Demographics.

Caregiver:
- Demographics
- Physical health
- Psychological health (caregiver strain, caregiver preparedness, help-seeking behavior, caregiver behavior)
- Social and community network

Housing Environment: analysis of person-environment fit
- Suggestions for an improved person-environment fit

A blank code book provided the framework for tabulating data for all cases on all variables. The information was categorized by Person-Environment Fit Score. Summary tables were prepared for item frequencies and open ended responses. A narrative of observations described the findings.

With a small sample size and qualitative case study format for this study, neither parametric nor non-parametric statistical analysis would be appropriate forms of data analysis. Parametric statistics apply to larger samples than the 10 cases examined here. Non-parametric statistics can be used when the sample size is small, but requires randomized treatment be applied to more than one group (Lehmann, 1975). Descriptive statistics of frequencies and average scores are more appropriate for this study; as is analysis of case study responses to open-ended questions.

CHAPTER FOUR

CASE STUDY SUMMARIES

Families were selected for case study analysis based upon the Person-Environment Fit Score as defined in Chapter Three, Methodology. Summaries were prepared for families with either a score of zero or a negative score. This included ten families overall. The format for the case studies was as follows: general case background, stroke survivor pre and post stroke physical and psychological health with post stroke behavior, caregiver physical and psychological health including, caregiver strain, caregiving behaviors, and social network with help-seeking behaviors. Housing environments were described and person-environment fit assessed with possible changes suggested.

Cases With a Zero Person-Environment Fit Score (Four Families)

Case 3 (Person-Environment Fit Score = 0)

The black couple in this case had been married for 36 years. The husband (age 57) was the stroke survivor. His wife (age 75), had a previous marriage with children, and was his primary caregiver. She was not very knowledgeable about her husband's physical pre or post stroke condition or his past employment, which was surprising considering the duration of their relationship. See Figure 4 for an illustration of this case.

Stroke Survivor: age 57, male, married
Caregiver: age 75, female spouse

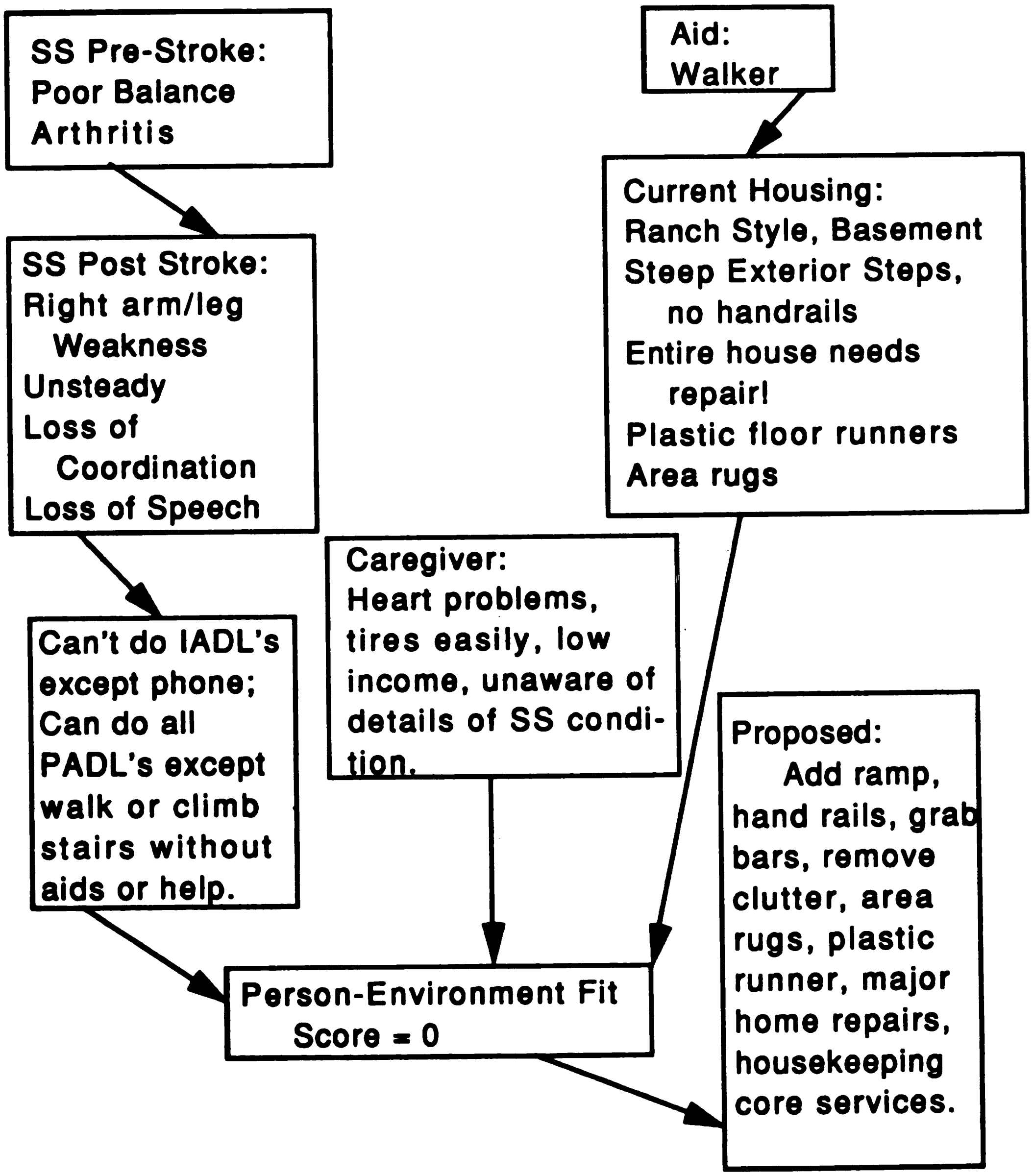

FIGURE 4: CASE 3 - Person-Environment Fit = 0

The stroke survivor was on disability leave from the Buick plant in Flint at the time of the stroke. Overall his physical health had been rated as fair before the stroke, but it did not impact on his ability to do the activities he wanted to do. The caregiver described his condition as "off balanced" and provided no additional details. Arthritis was the only identified ailment.

Since the stroke, the stroke survivor had weakness in his right arm and leg. An exercise bike was purchased to strengthen his limbs. Loss of coordination rendered him unable to write and unsteady or wobbly when using a walker. He had a heightened hot/cold sensitivity, with circulation problems in his limbs, describing his skin as "crawly", causing a reaction when touched. He also complained of stomach problems. A speech impairment made communication difficult.

In terms of the Activities of Daily Living, he could use the telephone but either never did or could not do at this time all the other Instrumental ADL's. . He commented that light or heavy housework was women's work. For the Physical ADL's, he could do all of them (bathing, eating, dressing, grooming, etc.) except for walking with an aid (walker) or climbing stairs with the help from others.

The stroke survivor's mental health was rated as poor since the stroke. His outlook on life had turned negative and sometimes violent. He was able to problem-solve, but the caregiver felt he never had much common sense before or after the stroke. Refusing to accept the stroke occurred frequently with resentment for having to use the walker. Appearing sad, tearful and describing himself as useless were also quite common behaviors. He showed a loss of appetite and seldom worked to improve his condition.

His social network included his mother, daughter and grand-daughter. Visits from friends were desired but had rarely taken place reportedly due to his speech impairment. Church (Baptist) affiliations were not strong and other community network or services had not been tapped.

Education attainment for both stroke survivor and caregiver was 5-8 years of schooling. The household income fell below $4,999. Basic needs were reportedly barely met. Medicaid was paying medical expenses. They were homeowners, but the home was in a poor state of repair (unevenly settled floors, cracks in walls, holes in bathroom wall with falling tub tiling and faucets barely functioning, etc.). Their financial situation had not changed since the stroke. The caregiver felt their income was just enough, which sounded as though she had adjusted to living on less. Produce from her daughter's garden was canned and provided a lot of their food needs.

The caregiver had been in fair health prior to her husband's stroke. High blood pressure, heart trouble and bad knees were her primary ailments. The knee problem was new since her husband's stroke. She fatigued rather easily, but when tired, she would rest and not worry about what was not getting done. "There's always tomorrow" seemed to be a common phrase for her. Since her husband's stroke, weight had been gained, and the caregiver's doctor was encouraging weight loss. Other changes in eating patterns had not affected her at this time.

There were three areas of strain noted on the Caregiver Strain Index (see Appendix A). Sleep disturbance was a problem that prompted a bedroom change. The caregiver moved to the guest bedroom, but could still hear stroke survivor getting up during the night for bathroom visits. Watching such a proud man have problems with walking and talking also had been upsetting and a strain to her. Her low Caregiver Strain Score was a 3 out of 13.

Psychologically the caregiver worried about things very often even though she gave herself a good rating for emotional health. She found life pretty routine but satisfying overall. Expressing concern about the future, she did not think her husband was progressing as much as he could. She felt completely prepared for her caregiving role and for obtaining devices. However, she was not at all prepared to cope with a stroke, nor determining physical changes for her home. Overall her Caregiving Behavior Score (see Appendix A for explanation of the scale) averaged 3.55 on the questions where a 5.0 score indicated healthy behavior, and a 2.0 average score on the items where a score of 1.0 designated appropriate behavior.

The caregiver's social network included friends who had visited a few times a month. Her family (daughter and grand-daughter) provided assistance with bill paying, filling prescriptions, shopping and serving as confidant. The contacts for help-seeking were few and limited. Neither neighbors nor friends were contacted on a regular basis. Her Help-Seeking Score (see Appendix A for a description of the scale) was 1.75, with a score of 5.0 as active help-seeking behavior. Community services were not used.

Their housing environment was a small two bedroom, one bath ranch style home with basement. As mentioned earlier, it was in disrepair and dirty. The caregiver expressed a problem with keeping the house up, but she was just going to do the best she could. The home was quite warm in temperature, but was reportedly kept warm because of their age more so than the stroke survivor's temperature sensitivity that had developed since the stroke. Walking was hampered by uneven floors and plastic runners used to keep carpeting clean. Stairs within the house led to the basement. Steep exterior steps met them at both front and rear entrances. Absence of hand rails made passage dangerous for all. Future housing plans did include installation of handrails, but time and money would delay construction. Overall they felt their home met their needs, and were satisfied with it since the caregiver indicated this would be their ideal home setting for the future. Providing independence and self sufficiency seemed to be its best virtue.

Given the stroke survivor's physical condition, person-environment fit could be enhanced by cleaning and removal of plastic runners and area rugs. A ramp at one of the entrances would prevent the reported problem with falling on steep stairs. They definitely needed to tap into a home repair project for low income elderly households. Repairs would bring the home up to safety codes. Bathroom grab bars added to toilet and tub area would be helpful since the stroke survivor had a problem with balance. Housekeeping services would benefit the caregiver because of her own ailing health.

Case 5 (Person-Environment Fit Score: 0)

Case 5 (See Figure 5) involved a (caucasian) couple who had been married for 56 years. The wife (age 83) and husband (age 87) and had owned the same house North of Flint for 30+ years. The husband suffered a stroke that affected his left side, leaving weakness in both the arm and leg. Initially his speech had been impaired but had improved with therapy. He had been hospitalized three times for pneumonia since the stroke. Due to a lack of mobility, skin sores were becoming a problem.

Prior to the stroke, he had reportedly been weak with poor health, exhibiting shortness of breath (emphysema) and dizziness (high blood pressure and circulatory problems) that interfered a great deal with his activities. A pacemaker had been implanted a few years back. Diabetes had been with him for 30 years and his loss of appetite since the stroke had complicated this on going problem. Cataract surgery a year ago had left his vision in fair condition before the stroke but vision was blurred since the stroke. Colon cancer, operated on two years ago, was another physical concern for the stroke survivor. Arthritis made life painful.

The stroke left the stroke survivor mentally alert and able to communicate feelings and decisions. He was able to problem- solve and show common sense. He seemed to accept the stroke by not showing concern or sadness about his dependencies, but tried to assist when he could with Activities of Daily Living.

Of the Instrumental and Physical Activities of Daily Living, he could not do any ADL's without assistance except he did have bladder and bowel control. He required help with eating, dressing, grooming, walking, bed and toilet transfer, bathing and all Instrumental ADL's. A home care agency provided some assistance with nursing care, bathing, dressing and exercising his left arm and leg. Help was also required with use of his wheelchair.

Stroke Survivor: age 87, male, married
Caregiver: age 83, female spouse

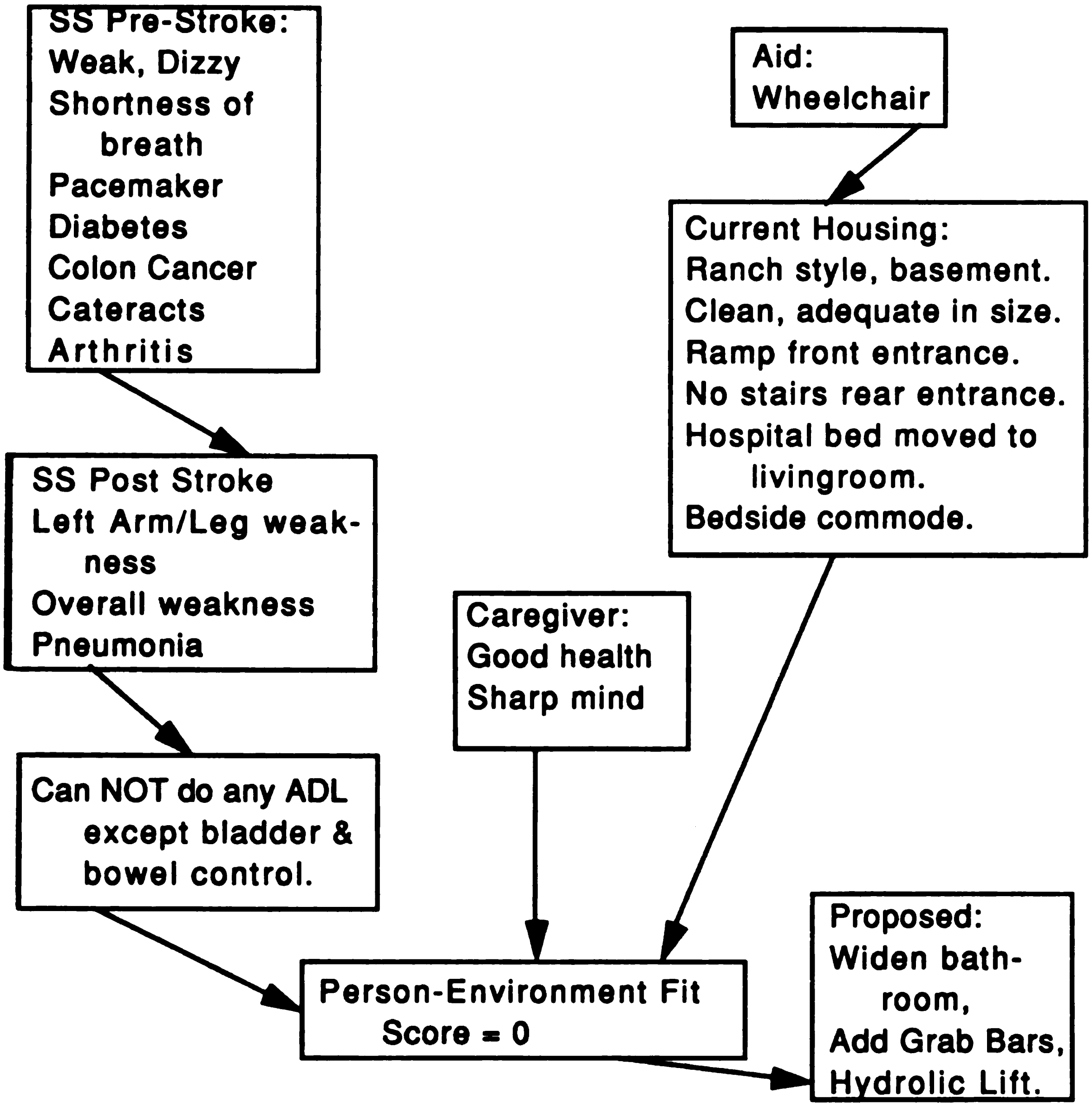

FIGURE 5: CASE 5: Person-Environment Fit Score = 0

The stroke survivor was retired with a combined income of $15,000-$19,000 that supported the couple. Their financial situation had not changed since the stroke and all basic needs were reportedly well met. Financial concerns were not an issue. His wife, the caregiver, was a spry 83 year old. A retired 4th and 5th grade teacher with a college degree, she had cared for both of her parents, who had suffered strokes, and they lived with her until their death. Recently a widowed niece (in her 60's) had moved in with them for a few weeks to assist with lifting her uncle from bed to wheelchair.

The caregiver's good physical health aided her energy level for providing care. Her only health problem was arthritis in hands and hips, but it did not seem to make her caregiving role difficult. Physical problems had not increased since the stroke and no new conditions had emerged.

Reportedly the caregiver rarely worried about problems and indicated good emotional health that had not changed since the stroke. She accepted what was happening and progressed through life with prayer for strength along the way (she had a strong Methodist background). Feeling very prepared for her caregiving role certainly contributed to her calm demeanor and effective behavior in caring for herself as well as the stroke survivor (score on Caregiver Behavior Scale averaged 4.9 on items where 5 showed effective behavior and a 1.6 score on behaviors where 1 was effective behavior).

Help-seeking came primarily from family, friends and neighbors plus the church. Visits from friends and family occurred as often as desired. Two daughters, one son, a daughter-in-law and grandson were identified as confidants and persons who could assist with personal care needs or stay with the stroke survivor. All lived in the community, with the grandson living next door. The caregiver had a low to moderate help-seeking score (averaging 2.5 out of 5) which implied that she sought help on a monthly or once or twice a year basis, but not from a wide variety of sources.

Concerns, as noted on the Caregiver Strain Index (low score of 2 out of 13), were few considering the severity of the stroke survivor's condition. Sleep was not a reported problem for the stroke survivor, but sleep disturbance was a strain for the caregiver. The other strain for the caregiver was a change in personal plans including not eating out as often as before the stroke, attendance at fewer church functions and not traveling to their summer cottage up north.

Their modest four bedroom, one bath home was a ranch style unit with basement. A ramp had been built at the front door by the grandson upon the recommendation of the occupational therapist from the rehabilitation unit of the hospital. Also upon therapist recommendation, a hospital bed was obtained. The size of the hospital bed forced them to move the stroke survivor into the living room. In spite of this bedroom shift, there were not any noted problems with privacy. The caregiver did indicate a problem in keeping up the home due to the extra cooking and cleaning involved with their niece living with them. Overall the caregiver felt their housing adequately met their needs in spite of a narrow bathroom, requiring the use of a bedside commode for the stroke survivor. No future housing plans were mentioned but the caregiver suggested an ideal housing set-up might include an apartment with some assistance and family living close by.

In summary it appeared that the caregiver was coping with her continued caregiving role in spite of the stroke survivor's intense ADL needs. An effective person-environment fit was achieved as much as possible given the short length of time (four months) since the stroke survivor left the hospital. If they were to stay in the home, the bathroom should be widened with grab bars or hydraulic lift added, but this is an expensive endeavor.

Case 10 (Person-Environment Fit Score = 0)

Case 10 involved a (caucasian) couple in which the husband at age 64 was the stroke survivor and his wife, age 70 was his primary caregiver (See Figure 6). Prior to the stroke, the stroke survivor had been in fair health, and this interfered a great deal with his activities. He was afflicted by an intestinal bypass (stapled stomach), urinary tract infections, arthritis, high blood pressure and bad knees.

The stroke caused weakness in the left arm and leg ("droopy foot"), reducing his ability to help out around the house. A walker provided mobility support since loss of coordination and jerkiness of movement also made it hard for him to steady himself. Loss of coordination also impacted his ability to write. Although his vision had been good before the stroke, blurred vision now caused dizziness. He suffered memory loss as a result of the stroke. There was an occasional loss of bladder control, but keeping a portable urinal handy had helped. This problem did prevent him from wanting to go out for such things as church attendance (Protestant).

Stroke Survivor: age 64, male, married
Caregiver: age 70, female spouse

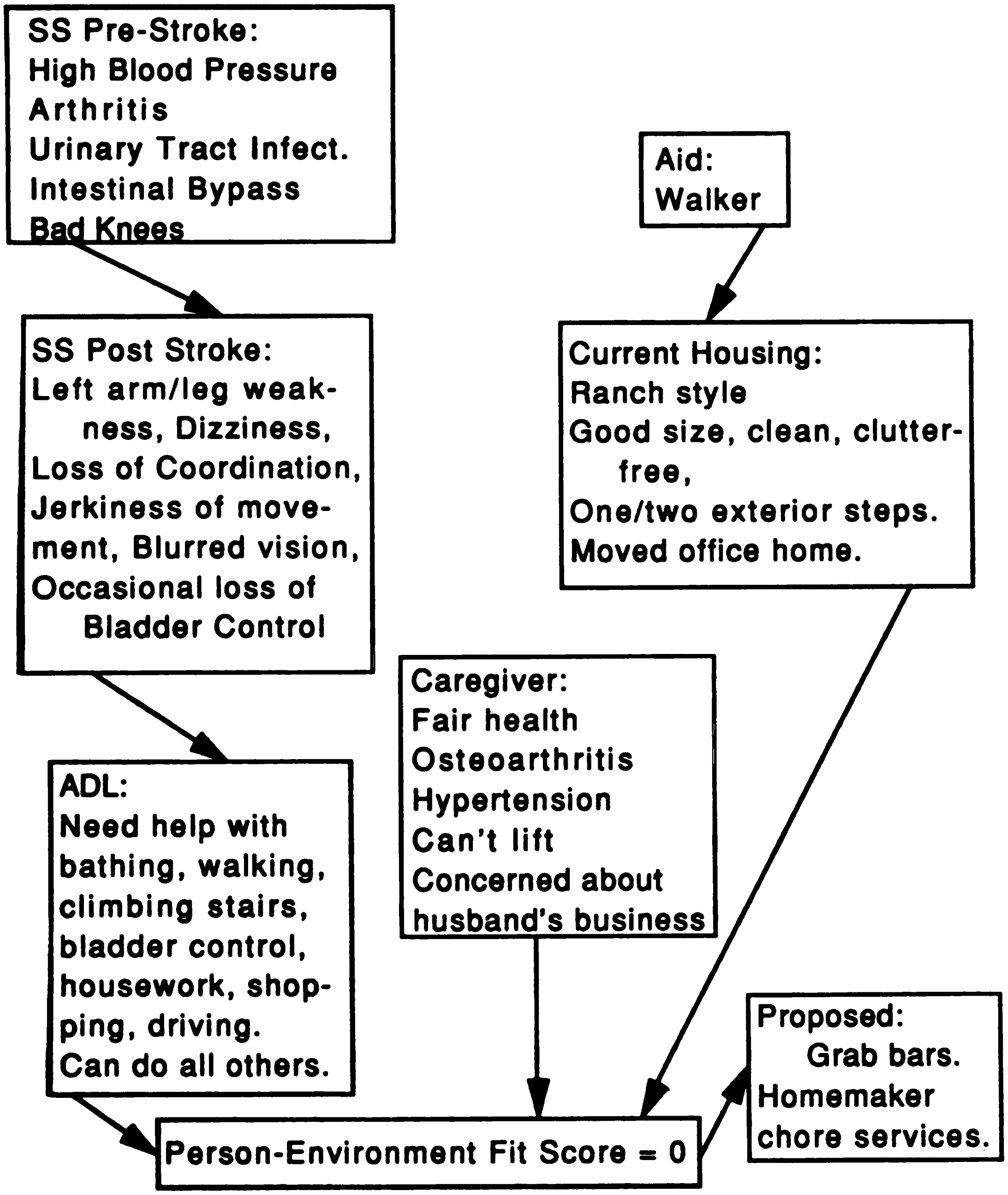

FIGURE 6: CASE 10: Low Caregiver Strain

The stroke survivor's ability to perform Activities of Daily Living (Instrumental) included use of the telephone and some meal preparation. He could shop and drive with the help of others, but he did not do housework or use public transportation even prior to the stroke. For the Physical ADL's, the stroke survivor needed help with bathing, bladder control, walking and climbing stairs. All other ADL's were handled by himself.

In general his mental health was fair after the stroke. Little things upset him. He was more impatient and easily excitable over minor issues. Irritability and frustrations with progress were reported, but he did work to improve his condition.

Socially, friends visited the stroke survivor three or four times a week. Two daughters were cited as alternative caregivers in addition to a sister-in-law. One of the daughters mowed the lawn and shoveled sidewalks for them. No other outside services were utilized.

The stroke survivor had a four year college degree. He had been a self employed full time insurance salesman and investment broker before the stroke. The family income (for 2) ranged from $10,000-$14,000. All financial needs were reportedly well met. However, the stroke had made a financial impact since his business was not as active as it had been. He moved his office to their home to cut back on personnel and reduce expenses overall. This also provided an opportunity to work part time and rest as needed.

His wife completed high school and was a homemaker, but she had an inactive real estate license. Her hypertension and osteoarthritis left her in fair health before her husband's stroke. These afflictions caused problems with lifting, so she could not lift her husband following the stroke. Performing housework was painful, and she had counted on her husband's support for completing these tasks. Caregiving took on the role of additional work that the stroke survivor had once completed. She reported a problem with keeping up her home. A positive outcome was an improvement in her hypertension because she was preparing better balanced meals.

Her present emotional health was rated as good, which was about the same as pre-stroke. Overall the caregiver was satisfied with life but did worry about things fairly often. She was fearful of the future should her husband regress and require nursing home placement. Preparedness for providing care was quite high on all accounts except when feeling fully informed about stroke. Her caregiving behavior was not always healthy as noted by her average score on the Caregiver Behavior Instrument of 3.0 when a 5.0 was healthy behavior, and 2.17 when a 1.0 was healthy behavior. She seemed to put the stroke survivor's needs above hers and did more for him than necessary at her own expense.

The three items noted to cause the caregiver strain on the Caregiver Strain Index were sleep disturbance, making emotional adjustments and feeling overwhelmed. Her Caregiver Strain Index Score was low (3 out of 13). The interviewer noted difficulties with the interview including long pauses, lack of emotion, and cold responses. She seemed to seek isolation.

Visits from friends were somewhat important, but she was very busy and did not want more visitors. The caregiver did not talk with anyone about her situation. She felt her two sisters and two daughters had enough of their own concerns that she would internally handle her own problems. This was consistent with her average low score of 1.25 (with five as active) for help seeking behavior. She rarely visited with friends, family or neighbors. Weekly church attendance was high on her help-seeking list.

They owned a three bedroom, two bath ranch style home. Location in a beautiful Grand Rapids neighborhood provided a view of an elementary school. The home was clean, neat and clutter free. The family room, which had an adjoining bath, became her husband's office. No interior stairs impeded the stroke survivor's mobility. One or two steps were present at both exterior entrances. They were satisfied with their home and had not made any environmental changes nor planned any for the future. Preferences were leaning toward staying in this home for as long as possible with additional outside help. A retirement home might be considered should their health warrant the move.

Overall they seemed to be coping with their environment. Suggested housing changes might include bathroom grab bars to assist the stroke survivor with his loss of coordination since he handled his own grooming. Obtaining homemaker chore services would certainly assist the caregiver with routine needs given her physical concerns.

Case 13 (Person-Environment Fit Score = 0)

This case included a (caucasian) couple in which the stroke survivor was the 70 year old husband, and his 66 year old wife served as the primary caregiver (See Figure 7).

Stroke Survivor: age 70, male
Caregiver: age 66, female, spouse

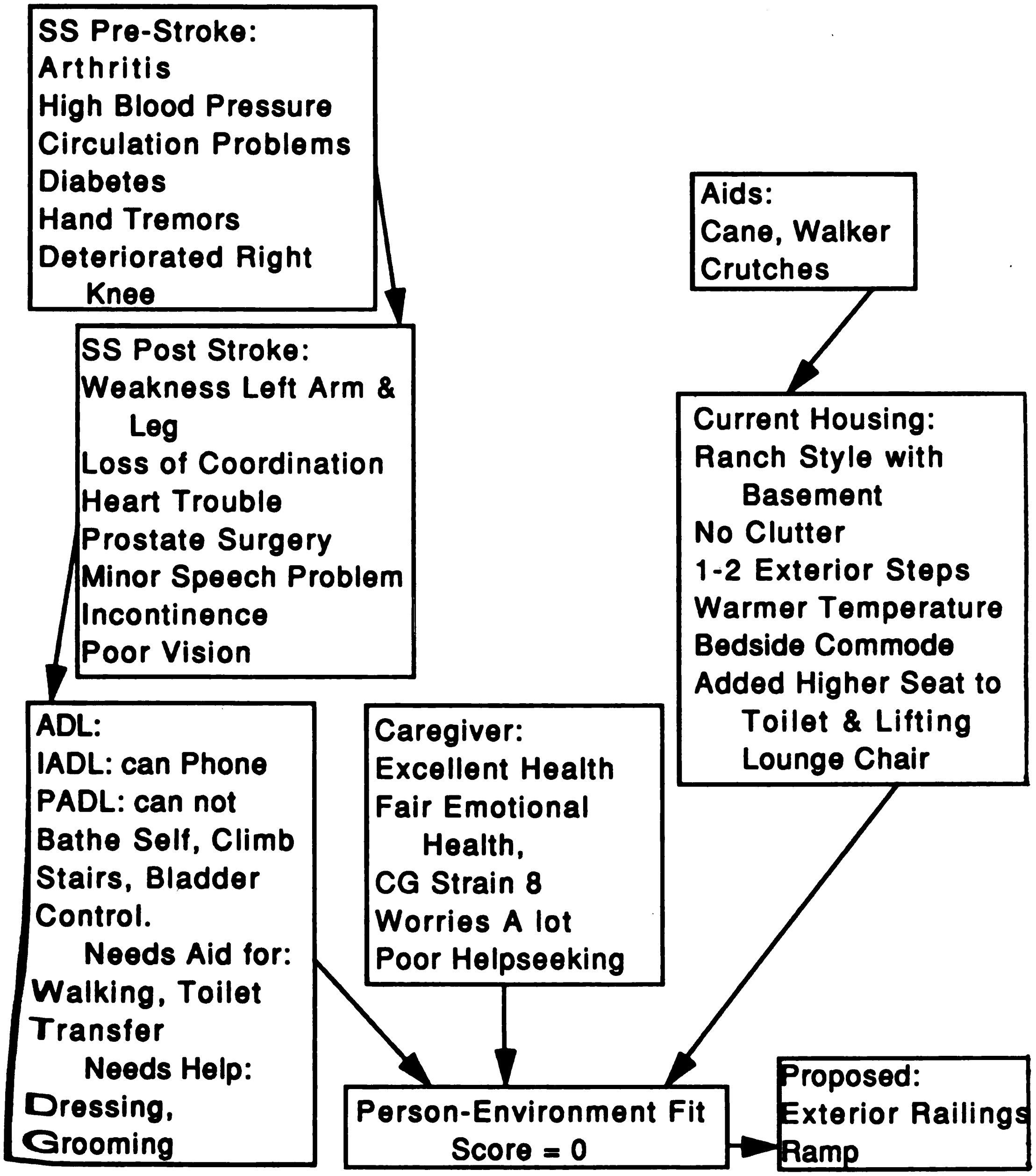

FIGURE 7: CASE 13: Person-Environment Fit Score = 0

The husband had been on retirement disability since 1976 for a deteriorated right knee. He had suffered a minor stroke a number of years back, with no residual physical limitations. Other health conditions that existed prior to this stroke were arthritis, high blood pressure, circulation problems, diabetes, hand tremors, and fair vision. Overall his health had been rated as fair, but it reportedly did not interfere with everyday activities. Since the stroke, he experienced weakness in the left arm and leg with loss of coordination. A cane, walker and crutches were used as mobility aids. Prostate surgery had occurred since the stroke and a heart condition had developed. His circulation was poor.and thus he was more sensitive to the cold, in spite of increased room temperature and wearing warmer clothing. A minor speech impediment and general hoarseness bothered the stroke survivor. His fair vision had turned to blurred vision, and he could not read for very long. He resented the caregiver reading to him. A memory change with loss of short term memory also was experienced.

The stroke survivor reportedly suffered the humiliation of daily loss of bladder control but not bowel control. This condition left him homebound for fear of an accident. Multiple bathroom trips during the day and night were exhausting for both the stroke survivor and caregiver. Increased laundry was another problem.

With regard to the Activities of Daily Living, the only Instrumental ADL that the stroke survivor could handle was telephoning. For the Physical ADL's, he could not go up and down stairs, bathe himself or maintain bladder control. With the use of an aid, he could walk and make toilet transfers. He required help with grooming and dressing, but could eat, get in and out of bed by himself, and maintain bowel control.

The stroke survivor's mental health was rated as excellent by the caregiver, yet his outlook on life had changed. His ability to cope had changed. He was showing signs of depression: sleeping difficulties, loss of appetite, negative attitude, low motivation, irritability, crying spells, sad affect and suicidal tendencies. The stroke survivor was upset by the unfairness of stroke and his dependencies; sometimes resenting the good health of others. He occasionally worked to improve his condition, but resented using aids and devices.

Socially, the stroke survivor had weekly visits from friends and family. A daughter, son and daughter-in-law were available to provide care. No outside community services were utilized.

The stroke survivor had not completed high school. Income ranged between $15,000 and $19,999. Reportedly there were no financial worries, yet medical care was marked as "not met" when all other financial needs including small luxuries were marked as "well met".

His spouse, the caregiver, was a 66 year old full time homemaker. She had 5-8 years of schooling. Her health was rated as excellent with no current problems. The caregiving role had impinged on her ability to exercise, but eating patterns had not changed. She was eating out less, and grocery shopping was rushed since she did not want to leave the stroke survivor home alone for long.

The caregiver's mental health was rated as good but had worsened since her husband's stroke. Finding life rather routine with a fair rating for life

satisfaction, the caregiver tended to worry a lot. Since it was her husband's second stroke, she reported feeling prepared for contacting professionals, obtaining aids and the amount of time caregiving would take. However, she desired more information about what to expect with stroke recovery.

According to the Caregiver Strain Index, this caregiver rated an 8 out of 13. She was stressed by the lack of sleep, the physical strain, caregiving being confining, changes in personal plans and emotional adjustments. Additionally, the caregiver was upset by the changes that had occurred with her husband since the stroke and his upsetting behaviors. She felt overwhelmed.

Her Caregiving Behavior Score would support these feelings. She rated a 2.4 when 5.0 was healthy caregiving behavior and a 2.1 when 1.0 was healthy behavior. The stroke survivor's doctor told her that she was loving him to death. She would do too much for him to the detriment of her own needs. The caregiver would not let others provide any care for her husband, and she avoided contacting the doctor. The Help Seeking Behavior Score of 1.8 (with 5.0 indicating one who would seek help often and from a variety of sources) showed her limited help seeking network. Talking to friends weekly seemed to be her only outlet. Family, doctors or agencies were not contacted. Church was never attended. No community services were used.

Their home was a ranch style unit with basement, that sat up on a hill next door to the farm they used to own and work. The house had three bedrooms and two bathrooms. It was clean and clutter free. One to two exterior steps could be found at both exterior entrances. Since the stroke, the house temperature had been kept warmer, a bedside commode was used, a higher seat was

added to the toilet, and a lifting lounge chair was purchased. In general they were satisfied with the house and did not foresee any future housing changes. As long as she could continue to care for him, she would not place him in a nursing home.

Overall, this caregiver was working herself rather hard. Planning for respite care would be in order, whether from family or the community. Suggested changes to the home might include exterior ramp construction and stair lift to aid the stroke survivor with stair climbing.

Cases with a Negative Person-Environment Fit Score (Six Families)

Case 7 (Person-Environment Fit Score = -2)

Case 7 involved a (black) couple in their 70's. The stroke survivor (age 73) was the wife with her husband (age 75) providing primary care (see Figure 8).

Her stroke affected the left side of her body. This weakened both the arm and leg and caused a loss of coordination. Shoulder stiffness rendered great pain and limited use. Depth perception became a problem even though other vision concerns were not identified. Loss of bladder control (three or more times per week) had increased cleaning and laundry responsibilities for this husband.

Overall her health had been rated as excellent pre-stroke, not affecting activities at all. However, arthritis, high blood pressure, diabetes and circulatory problems were the reported pre-stroke ailments. Her vision had been fair and not affected by the stroke.

Stroke Survivor: age 73, female, married
Caregiver: age 75, male spouse

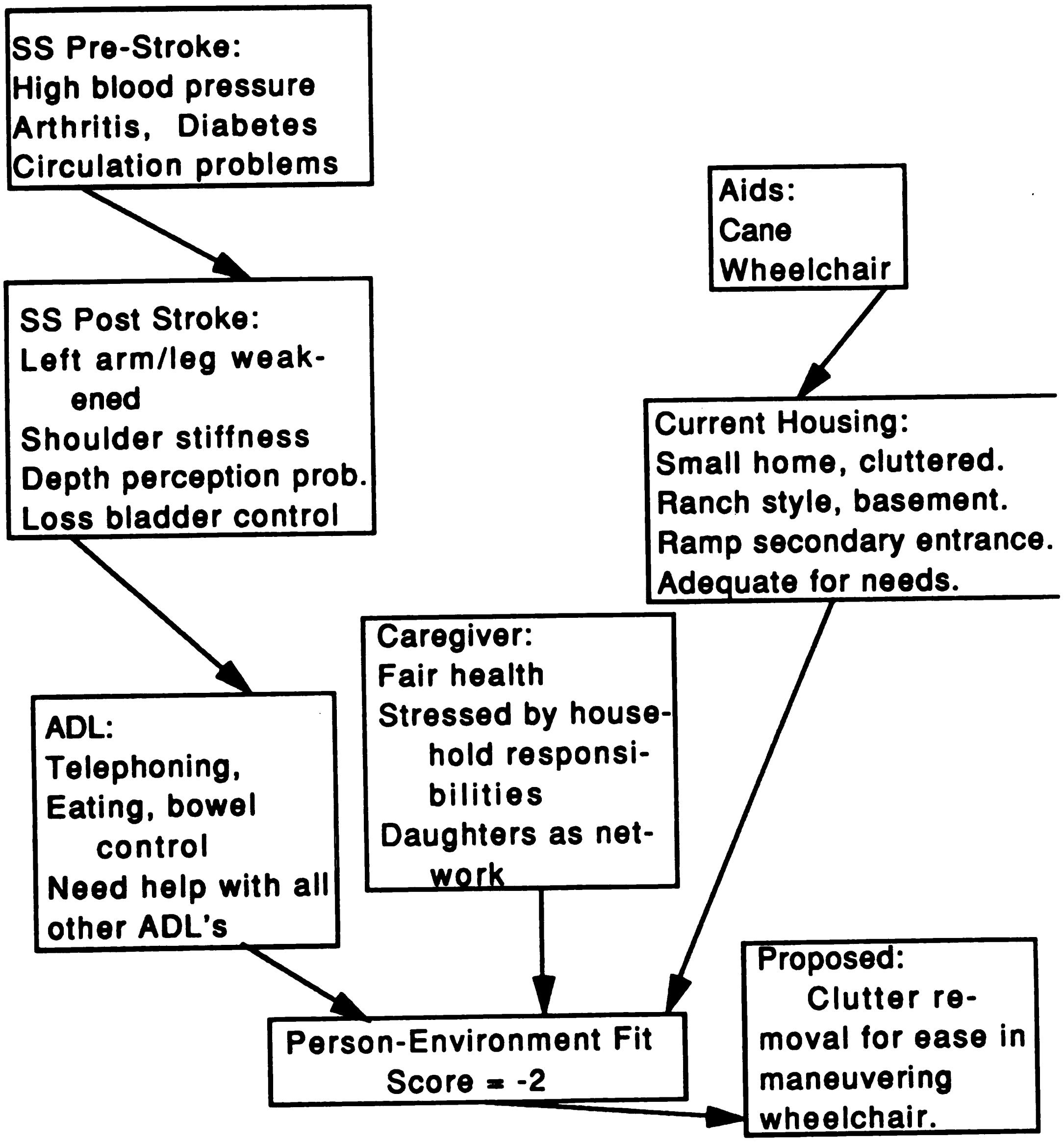

FIGURE 8: CASE 7: Person-Environment Fit Score = -2

The stroke survivor's ability to perform Activities of Daily Living changed dramatically after the stroke. The only Instrumental ADL that she could do was telephoning. For the Physical ADL's, she could not handle personal grooming or bladder control. Walking and climbing stairs required assistance from aids (cane and wheelchair) and others helping her use the aids. Dressing, bed and toilet transfer necessitated help from others, but she could eat by herself and had bowel control. Mental health for the stroke survivor was rated as good since the stroke, with her ability to make decisions and problem-solving capabilities in tact. Fortunately her memory also had not been affected. However, her outlook on life had reportedly been changed which impacted on coping mechanisms. She sometimes was sad and upset about the unfairness of stroke and her dependencies. Additionally she had a problem sleeping, being irritable and having a negative attitude. She seldom expressed acceptance of the stroke, and she reportedly did not always work to improve her condition.

From a social resource perspective, the stroke survivor did not want visits from friends or family, but was visited weekly none the less. Two daughters provided assistance with nurturing, meal preparation and interior and exterior housework. No other community services were utilized.

Five to eight years of school had been completed by the stroke survivor. She had always been a homemaker and her husband was now retired. Their income ranged between $15,000-$19,999 to support the two of them and had not changed since the stroke. A grandson was living with them in their small home in the Flint area, and he had his own income from social services.

Reportedly their financial resources did not meet or barely met their needs. They owned their own home and did not receive any assistance in paying housing expenses.

The husband caregiver was 75 years of age and completed 0-4 years of schooling. His health before his wife's stroke was rated as fair, but did not keep him from doing the things he wanted to do. No specific health problems were identified, nor a change in health status or pattern of exercise since the caregiving role began. No changes in eating habits, diet/appetite or time involved in meal preparation or shopping were reported.

Regular visits from family and friends were important to the caregiver, but he had not had visits from friends since his wife's stroke. Family made weekly visits and this attention was very important to him. A brother, sisters-in-law, daughters and a neighbor were identified as persons who provided a network of support. Help-seeking Behavior for the caregiver was an average of 2.88 out of five, seeking assistance from relatives, neighbors and the church (Baptist). He reported worrying very little about things and indicated good overall emotional health which had not changed since the stroke. His satisfaction with life was rated as fair, finding his days pretty routine. Getting out more often was an unfulfilled desire.

Factors that contributed to caregiver strain for the husband included lack of sleep and finding it upsetting to watch changes in his wife since the stroke Caregiver Strain Score was a 2 out of 13 indicating low strain. His caregiving behaviors wavered between healthy and unhealthy behavior (average score of 3.2 with five as healthy behavior, and 3.0 average score on items where a rating of one was healthy). However, this husband was not accustomed to providing care and indicated that he was not at all prepared for the amount of time caregiving would involve. He did not have enough information on stroke, but felt completely prepared with regard to seeking health professionals, aids/devices and making structural changes to the home.

He was having problems caring for their home. His wife always did the housework, and this task was now overwhelming to him. Their home was small in scale (2 bedroom, 1 bath) and cluttered. There was little room to walk between furniture which would make navigating a wheelchair difficult. The bathroom was on the same floor as the bedrooms. No bedroom adjustments were made nor privacy problems reported. The only interior stairs in the home led to the basement. Exterior stairs were at both entrances, but a ramp had been built at the secondary entrance. The therapist had suggested the ramp, and the caregiver and grandson paid for and completed the construction. Overall they were satisfied with the home and felt it adequately met their needs. No future housing changes were being planned. The caregiver felt this home was their ideal housing setting.

In summary, this family seemed to be coping with the changes that came with stroke. The network and support from family and neighbors seemed to be working effectively, but the concern is how the network will hold up long term. Their housing environment generally was conducive to their person environment fit, but clutter removal would enhance mobility.

Case 11: (Person-Environment Fit Score = -2)

This case included an elderly couple (caucasian) in their 80's with a protective daughter who came to the house to provide additional caregiving. The stroke survivor was the husband/father (age 85). His wife, the caregiver, was 82 (See Figure 9).

Prior to the stroke, the husband had been in poor health which affected his activities somewhat. He was weak and easily fatigued by heart problems, high blood pressure, circulatory problems, asthma, prostate surgery and arthritis.

The stroke caused weakness to his right arm and leg, but both legs were ineffective. These days he was primarily using a wheelchair versus his cane or walker. He needed help transferring to the wheelchair, and his daughter felt he could not be left alone. Loss of coordination prevented him from writing. The sense of touch had deteriorated, leaving limited feeling in his fingers. Poor circulation made him more sensitive to cold temperatures (legs cold and feet blue). His shoulder was painful but this was attributed to arthritis more so than the stroke. Loss of bladder control was a problem once or twice a week. Diapers or pads provided protection when he could not reach the bathroom in time. Approximately once a month the stroke survivor would have trouble with bowel control. This contributed to embarrassment for all and added laundry. Memory loss and a mild speech impediment also were ramifications of the stroke.

In terms of Activities of Daily Living, the stroke survivor could use the phone with assistance, but could not perform any other Instrumental ADL's.

Stroke Survivor: age 85, male, married
Caregiver: age 82, female spouse
Daughter came in to provide some care, in addition to outside agencies.

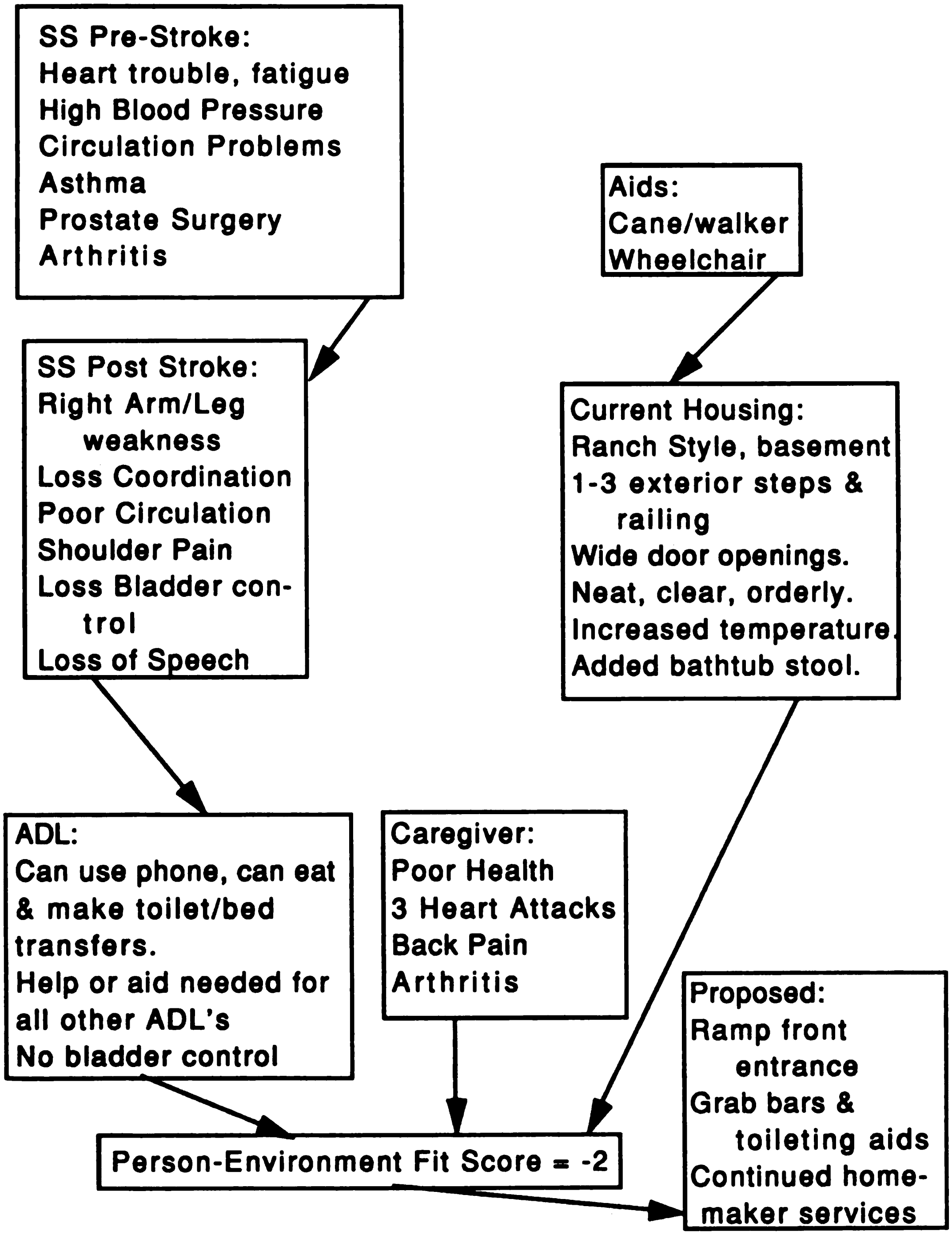

FIGURE 9: CASE 11: Person-Environment Fit Score = -2

For Physical ADL's he could eat and make toilet and bed transfers by himself. Dressing, grooming, bathing, bowel control and climbing stairs required help from others. He used an aid to ambulate on flat surfaces. Bladder control was the only Physical ADL cited that he could not do at this time.

Since the stroke his mental health was rated as fair. He showed signs of depression but was a good, cooperative (sometimes placid) patient overall. Loss of appetite and feeling that his difficulties were short term were two areas of concern even though he had reportedly accepted the stroke and did recognize progress in his condition.

Social resources for the stroke survivor included weekly visits from family and friends, especially his daughter. The community provided the following resources: personal care for bathing, dressing and physical therapy.

He had completed 0-4 years of education and his wife had 5-8 years of schooling. Both were retired production line workers for General Motors in Flint. The household income ranged from $5,000-$9,999. They felt their financial needs were well met in spite of increased medical related expenses.

The caregiver had been in poor health before her husband's stroke. She had suffered three heart attacks. Providing care required increased rest between spurts of activity, or chest and back pain would bother her. Arthritis also made caregiving difficult. She had lost weight since her husband's stroke. By the time she prepared a meal, she was too tired to eat. Her daughter did the grocery shopping and occasionally completed the cooking. Since the stroke they had not eaten out or with friends, which previously had been a weekly activity.

Emotionally she felt strain in all items on the Caregiver Strain Index except two (financial strain and other demands on her time). This meant that she was overwhelmed, made emotional, personal and family adjustments, had physical strain and sleep disturbance. She also found the stroke survivor's condition upsetting (Caregiver Strain Index Score was a high strain score of 11 out of 13). With all of this on her mind she would often worry about their future. It was interesting to note, however, that she rated her emotional health as excellent and a good satisfaction with life in general, which had not changed since her husband's stroke.

She was not at all prepared for the amount of time caregiving would require. Additionally, she was not prepared to make housing changes, nor did she have enough information on the ramifications of stroke. The caregiver did feel somewhat prepared with seeking help and obtaining devices. Her caregiving behavior wavered between healthy and unhealthy actions. Her average score was 3.9 for the items where a five denoted healthy behavior and 3.33 where a one denoted healthy behavior.

Her help-seeking behavior averaged 3.63, with five as active help-seeking behavior. She regularly sought out relatives and neighbors, spoke to doctors weekly, and attended church (Baptist) monthly. Visits from family and friends were reportedly very important to her. Since her husband's stroke, she had only received visits a couple of times a month but this was as much as she wanted to see them. Socially, the caregiver was able to confide in her.sister and two neighbors. Her daughter and the cleaning lady provided additional personal care. The caregiver was stressed by how her daughter gave orders and took over when she was around. The caregiver commented that she had been caring for her husband for a long time and felt she could handle things without her daughter's assistance.

The home they owned was a ranch style, 3 bedroom, one bath unit. Two short flights of stairs led to a basement. One to three steps could be found at the front and rear exterior entrances. A railing had been added to the rear steps. Addition of a ramp was being considered for the front entrance. Doorways appeared wide enough for wheelchair accessibility. Two minor changes to the home included a stool added to the bathroom tub and increased home temperature to accommodate the stroke survivor's increased sensitivity to the cold. Thanks to a housekeeper, the environment was neat, clean and orderly. In general they were satisfied with how the home met their current needs. No future housing plans were being made, but long term nursing home care might be considered for the stroke survivor.

Housing suggestions for this couple might include the addition of grab bars and supportive toileting aids used to ease bathroom functioning. Addition of an exterior ramp would greatly improve wheelchair accessibility, if they are to remain in this home. Continued support services, private and public pay, would enhance this couple's independent living. Caregiver strain seemed to come partly from the caregiver's own physical complications and conflict with her daughter over a caregiving power struggle.

Case 17 (Person-Environment Fit Score = -2)

The (caucasian) couple, who were identified as case 17, had the husband (age 70) as the stroke survivor (SS) and his wife (age 67) as his caregiver (see Figure 10). The husband's pre-stroke health was rated as good by his wife in spite of hypertension, arteriosclerosis, circulation problems with the arms and legs, kidney trouble and a compressed vertebra.

Following the stroke he had uremia, kidney failure that was aggressively treated for two weeks. He lost a great deal of weight during this time. Complications from the stroke included weakness in the left leg and arm, loss of coordination, jerkiness of movement, stiff left shoulder and loss of circulation in the left hand (some fingers turned black). The above limitations caused difficulty in using a walker so a wheelchair was provided. His vision had changed but to what extent had not been diagnosed. In general he could not read or write since the stroke. There also was a loss of bladder and bowel control, creating embarrassment with the changing of diapers. Urinary tract infections were becoming common place. A portable commode and urinal were used. He would not go out to visit friends or family for fear of an accident. He also experienced a sensitivity to hot and cold and a memory loss.

With regard to the Activities of Daily Living, the stroke survivor's abilities were quite limited. For the Instrumental ADL's he could only use the phone with help from others. The Physical ADL that he could perform by himself was eating. All other ADL's (bathing, transferring, grooming, etc.) required assistance, with bladder control, bowel control and climbing stairs as ADL's he could not do at all. Help was requiredwith the wheelchair and walker.

Stroke Survivor: age 70, male, married
Caregiver: age 67, female spouse
Paid care-providers provide daily assistance (13 hours).

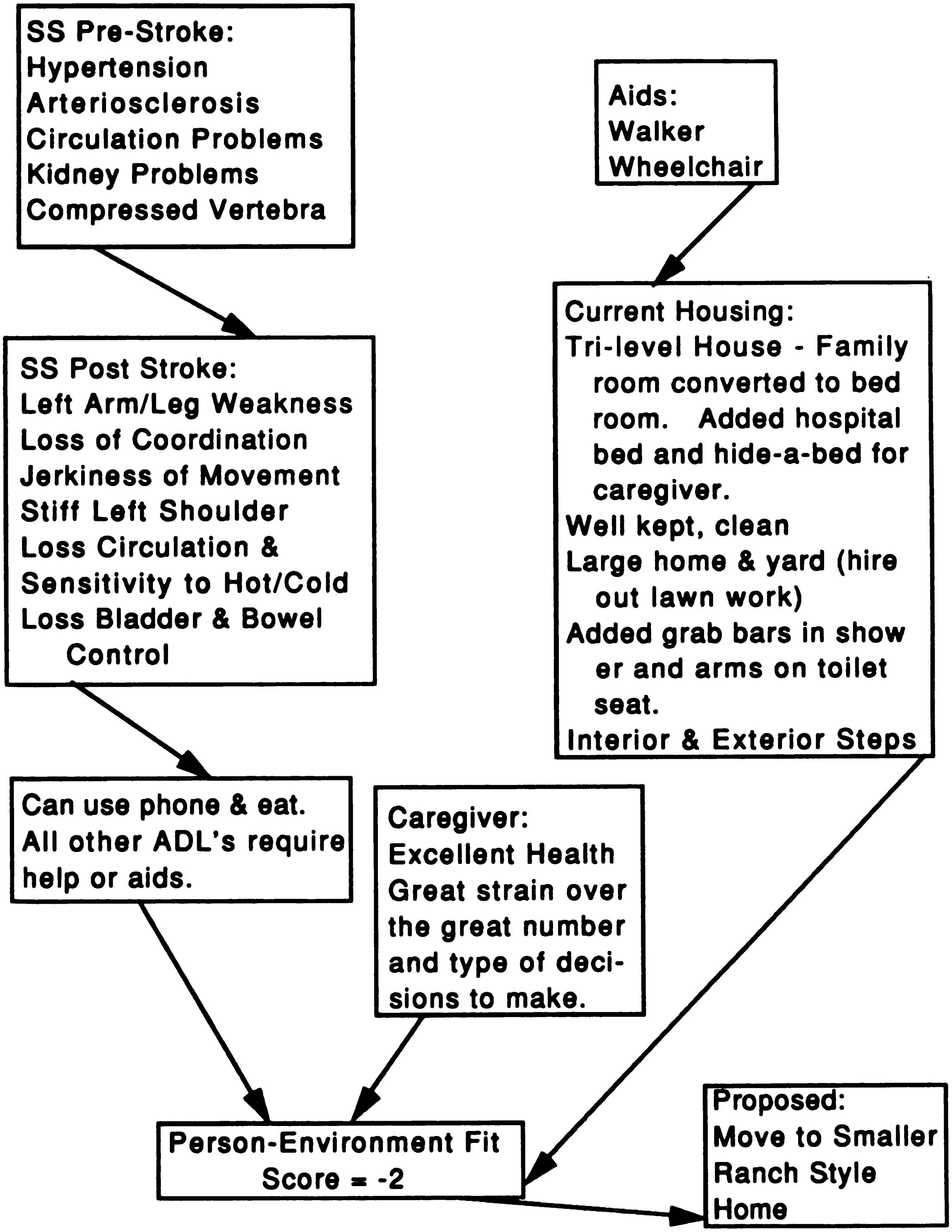

FIGURE 10: CASE 17: Person-Environment Fit Score = -2

His current mental health was rated as good, but his wife expressed concern that he was not really communicating his feelings. Abilities to problem-solve, use common sense and cope had changed for the worse since the stroke. He frequently appeared sad, had low motivation with high frustration about his lack of progress. Loss of appetite was another sign of slow recovery. The stroke survivor reportedly had accepted the stroke and would work hard to improve his condition.

From a social perspective the stroke survivor wanted friends and family to visit, which they did weekly. His daughter and sister-in-law were identified as additional confidants and care providers. Case management, nursing care, physical therapy and personal care needs were being met by outside agencies.

The stroke survivor had completed a four year college degree. At the time of the stroke he was a retired staff engineer from General Motors. His wife, who had a high school diploma, always had been a homemaker. Income for the couple ranged from $60,000-$69,000 and reportedly all financial needs were well met. Investment income was being used to pay for some of the health care, and this worried the caregiver.

The caregiver was younger than her husband and was in excellent physical health before and after her husband's stroke. Her major physical complaint was the lack of time for exercise (playing golf) since caregiving began. Her appetite had not changed, but all other food related issues had changed including improved diet, more cooking, more grocery shopping,and eating out less often.

Psychologically, she was under a great deal of caregiver strain as noted by a high score of 11 out of 13 on the Caregiver Strain Index. All but two stressors on the Caregiver Strain Index affected her. She found that sleep was disturbed and helping was inconvenient and a physical strain. It was confining, requiring family adjustments and changes in personal plans. Emotional adjustments had to be made and she felt overwhelmed. Adjusting to the changes in the stroke survivor were upsetting. In spite of their relatively high income, a financial strain was reported. Time demands and work adjustment were the two items that were not a problem.

In spite of all the strain, her emotional health was reportedly good and had not changed since her husband's stroke. She found life exciting but worried fairly often about the future. There were too many physical "wait and sees" with the stroke survivor, leaving her on a decision "roller coaster". The caregiver tried to keep a positive outlook, none the less. She was not at all prepared for: contacting health professionals, selecting devices or making changes to their home, understanding about stroke or the time involved with caregiving. Because of the extent of her husband's needs she wavered between healthy and unhealthy caregiving behavior (average score of 3.4 with a 5.0 as healthy behavior and 2.33 when 1.0 indicated healthy behavior.

The caregiver's social network included relatives, friends, neighbors, church (Protestant) affiliates and the medical profession (average score of 3.5 with five indicating active help-seeking behavior). Visits from friends were very important to her. They occurred 3-4 times a week, which was not often enough for the caregiver. She had six people (sister, two daughters and their spouses plus a neighbor) on whom she could depend for assisting with personal needs or serving as confidants. Two nurse aids provided 13 hours of care for the stroke survivor during the day and early evening.

They owned a well kept, tri-level home in a suburb of Flint. It had three bedrooms and two baths with stairs connecting all levels and exterior front steps. Their family room had been converted into a bedroom with hospital bed for the stroke survivor, and the caregiver slept on a hide-a-bed. This caused some removal and shifting of furniture. There was a bathroom close to the family room that had a few physical changes completed since the stroke. Grab bars had been added to the shower and "arms" were placed around the toilet for ease of use. These changes were recommended by the therapist and a handout from the hospital. A handyman was hired to do the work.

The caregiver complained of problems caring for the home, especially the outside maintenance. The large yard was too much for her. She had started to hire someone to complete these tasks which was an added expense since the stroke. Her future housing plans included a move to a smaller ranch style home or a condominium in the sunbelt. They had discussed this type of a move prior to his stroke, but discussions had not continued, and he was currently not able to make housing decisions.

Given this couple's economic resources, a move would certainly improve the person-environment fit. A tri-level home for a wheelchair user made him a prisoner in the family room. Ramps would not be feasible within this structure. Within the constraints of their given setting, it appeared that they were working hard to create an effective person-environment fit. The caregiver's strain seemed to stem from so many decisions in a limited amount of time.

Case 19 (Person-Environment Fit Score = -2)

This case was an interesting interaction between a black female stroke survivor and her caregiver son (see Figure 11). She was 73 and he was 45. They were living in a well kept home in a low income neighborhood of Flint. The stroke survivor was the homeowner and her son and nephew were staying with her. A lot of immediate and extended family either lived in homes within close proximity or walking distance.

The mother had been in good health in spite of her pacemaker, high blood pressure, and arthritis before her stroke. The stroke weakened her left arm and leg (circulation problems) creating a loss of balance, lack of depth perception, neglect of the left side of her body and jerkiness of movement. A wheelchair was in use when she was not in bed. A painful left shoulder created a difficult problem with bathing and dressing. The loss of bladder and bowel control necessitated the use of a catheter and pads. The catheter provoked chronic bladder infections. The bowel problem required constant cleaning and increased laundry. Bed sores and her speech impediment also complicated her life. The stroke survivor required full care. She could not perform any of either the Instrumental or Physical Activities of Daily Living. She was receiving nursing care, physical therapy and personal care.

Stroke Survivor: age 73, female, widow.
Caregiver: age 45, son
Outside agency provides daily care in addition to other local family.

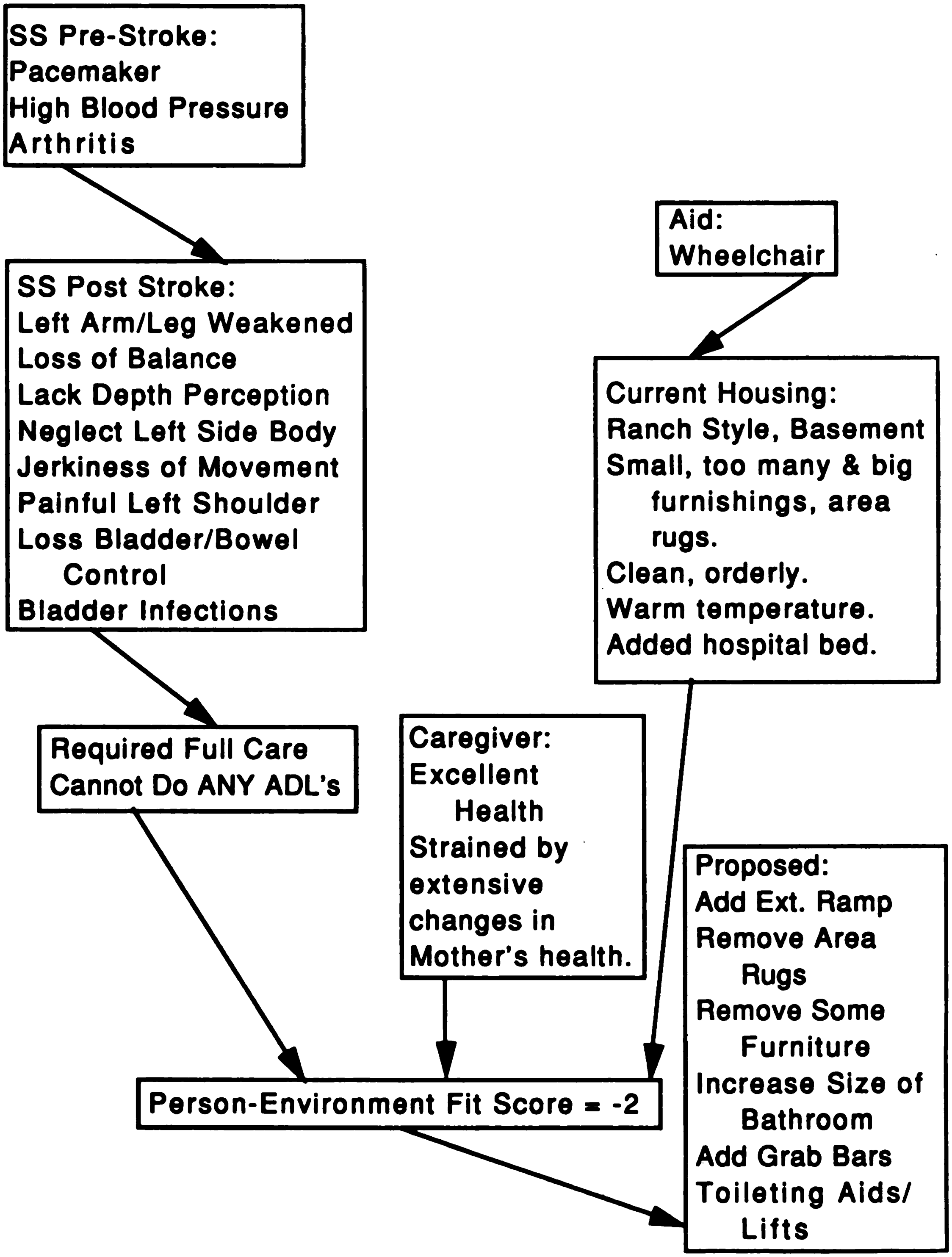

FIGURE 11: CASE 19: Person-Environment Fit Score = -2

On occasion she had memory loss, but in general her mental health was rated as good. She could make some decisions and problem-solve. Reportedly her outlook on life had turned negative since the stroke. She sometimes expressed sadness, exhibited low motivation, and was upset about her dependencies. The stroke survivor had problems accepting the stroke and reportedly did not work to improve her condition. Socially the stroke survivor had daily visits from friends and family which did cheer her up. Her family was lovingly giving back to her "all the care she had so generously given to them through the years".

The stroke survivor had completed high school and had been a homemaker most of her life. She was a widow with an annual income of $10,000-$14,999, but her financial needs were reportedly well met.

Her caregiver son lived with her. He was divorced with one child who resided with the mother. Having completed high school, he was employed full time in the evening shift for General Motors production. His income ranged between $40,000 and $49,999.

In general his health was good with no specific reported problems. He missed exercising with friends. His eating habits had not changed since his mother's stroke. Family members would care for the stroke survivor while he occasionally went out to eat. His sister did the grocery shopping and the majority of the cooking.

The caregiver's mental health also was rated as good, but this had become worse since taking on the caregiving role. His Caregiver Strain Index was 10 out of 13; therefore, strain was felt on all items except three (financial strain, physical strain and increased demand on time). He found life pretty routine, and expressed a fair rating for satisfaction with life. Great frustrations existed with his mother's limited progress, and he worried about her future and his own future physical health. The caregiver was not at all prepared for the amount of time caregiving would involve nor about the implications of stroke. Likewise, selecting devices and considering housing changes provided a great deal of concern.

His social network was very strong. The extensive family, friends and neighborhood comradeship provided daily companionship and respite care during this time of need. He said his family members had grown closer together since the stroke and were jointly working for his mother's benefit. Help-seeking behavior for the caregiver averaged a 3.94 with five as active help-seeking. He did not utilize his church (Baptist) or professional counseling in his help-seeking network.

Their home was small and crowded with too many furnishings, yet quite clean relative to the other low income housing in the neighborhood. Siblings all assisted with housekeeping duties. Excessive furnishings made wheelchair maneuverability difficult. Area rugs were on top of the carpeting in both the kitchen and living room. The house was a two bedroom, one bath ranch style unit with stairs to a basement. One to three steps could be found at both the front and rear exterior entrances.

Two minor changes had been made to the living environment. A hospital bed was moved into the stroke survivor's bedroom, requiring furniture removal. Secondly, the house temperature was raised since the stroke survivor was more sensitive to the cold. This caused aggravation for the younger residents. In general the caregiver felt the house adequately met his mother's needs, and he would not consider any other future housing arrangement.

If the stroke survivor remained primarily bedridden, the current environment would continue to meet her needs since nursing home placement was not a consideration for the family. If the stroke survivor gained strength and was using her wheelchair more often, then area rugs and some furniture should be removed for increased mobility. Bathroom changes would be in order including increasing its size (an expensive change) and the addition of grab bars, hydraulic lift and other toileting aids. A ramp would need to be added to one of the entrances, probably the front. The environment would need to be adjusted with time to fit her changing needs.

Case 18: (Person-Environment Fit Score =-3)

This case involved a 90 year old widow (caucasian), who was the stroke survivor, and her 57 year old daughter (See Figure 12). They had lived together for many years. The daughter was employed full time as a nurse and handled her mother's primary care.

Prior to the stroke, the mother's overall health was rated as fair and it interfered greatly with everyday activities. She had suffered from rheumatoid arthritis, emphysema, heart trouble, circulatory problems, allergies, thyroid problems, had hand tremors and poor vision.

Stroke Survivor: age 90, female, widow
Caregiver: age 57, daughter, single

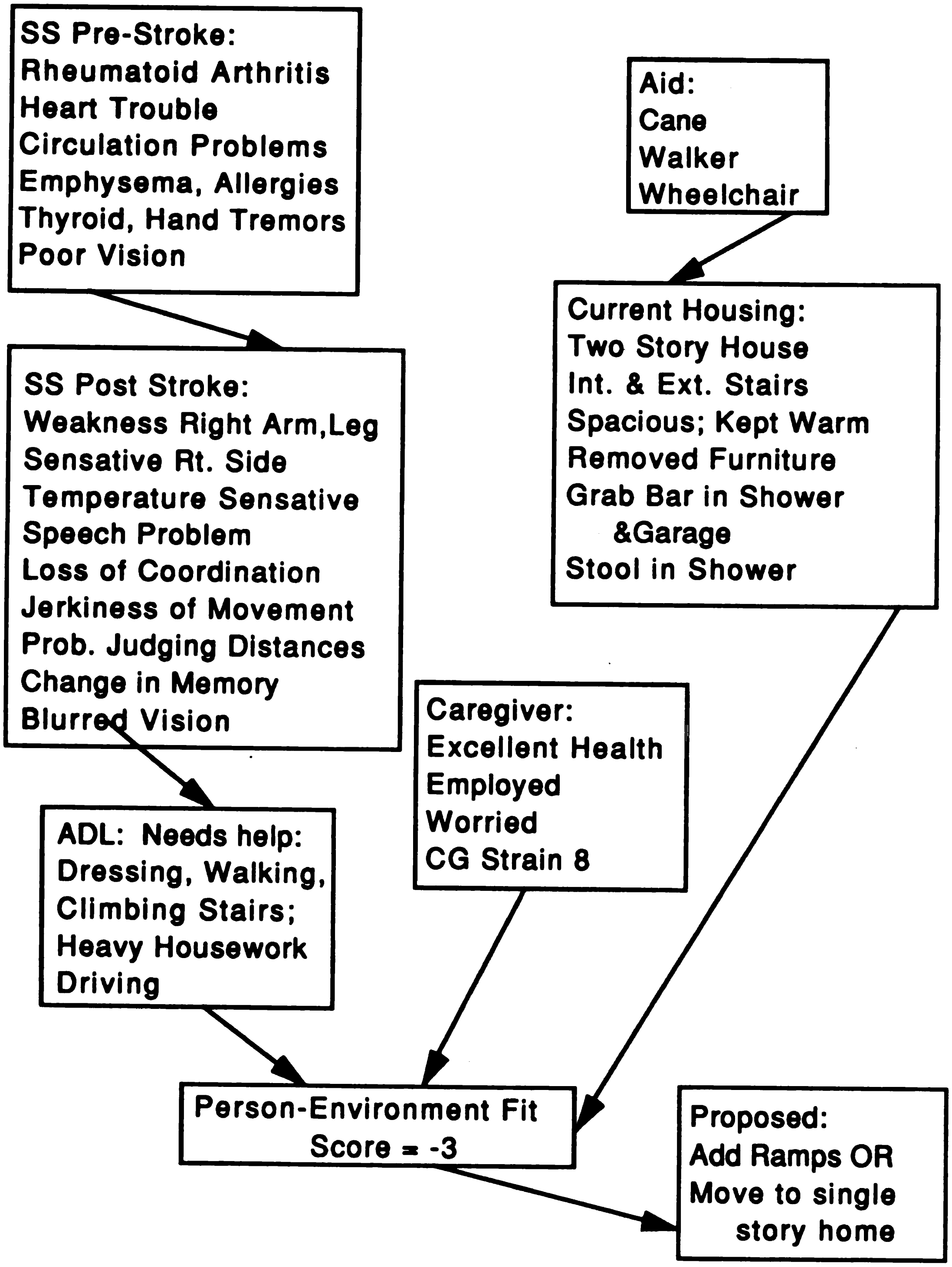

Figure 12: Case 18 Person-Environment Fit Score = -3

The stroke had affected her right side, causing weakness in both the arm and leg. The right side was generally very sensitive she avoided being touched. Temperature sensitivity overall also was a problem. The stroke survivor exhibited loss of coordination, balance and jerkiness of movement. Judging distances was difficult. A cane, walker and a wheelchair were used for mobility. Her poor vision was now blurred, making reading impossible. Short term memory had diminished, which was frustrating for both the stroke survivor and the caregiver.

With regard to the Activities of Daily Living, she could do most of both the Instrumental and Physical ADL's. The stroke survivor required assistance with driving, heavy housework and shopping; plus dressing and walking. She could not climb stairs at all, which was a concern in their multi-story home.

The stroke survivor's mental health was rated as excellent since she had somewhat adjusted to the effects of the stroke. She sometimes became frustrated when she could not do something, but generally she was good natured with a positive attitude, no loss of appetite or loss of sleep. She worked to improve her condition. Showing common sense prior to the stroke, the stroke survivor was now having problems making decisions. Her memory loss made her impatient at times.

Socially, the stroke survivor wanted and received weekly visits. Visits came from friends as well as her two daughters. No community services were utilized for support or caregiving.

In terms of education, the stroke survivor had 5-8 years of schooling. She had been the primary breadwinner of the family since her husband had been ill most of his life. She inspected industrial parts and received a retirement income ranging from $30,000-$39,999. All financial needs were well met.

The caregiver, her daughter, was a single 57 year old. As mentioned previously she worked full time as a nurse at a nearby hospital. A two year degree had been completed in her youth. Her income ranged from $20,000-$29,999.

Physically the caregiver was reportedly in excellent condition with no health problems. Her biggest complaint was lack of sleep, followed closely by feelings of confinement. After working all day she would work most of the night at home getting about three hours of sleep. She listed her emotional health as poor with fair life satisfaction. She worried a lot about anything and everything. In terms of being prepared for her caregiving role, she reported overall preparedness on all items except for making changes to the home.

For the Caregiver Strain Index, she scored an 8 out of 13. She was strained by sleep disturbance, caregiving being confining, changes in personal plans, emotional adjustments, feeling overwhelmed, having other demands on her time, finding her mother's behavior upsetting and being upset about watching the changes take place in the stroke survivor's condition. On the Caregiving Behavior Scale, she scored a 2.9 when 5.0 indicated healthy caregiving behavior and a 3.4 when 1.0 indicated healthy behavior. The caregiver felt guilty when others wanted to care for her mother. She put off her own needs, and did more for the stroke survivor since it took her mother so long to do things for herself.

Help-seeking behavior fit the pattern of caregiver doing it all. Her score was a 2.4 with 5.0 being active help seeking from a variety of sources. She had given up TV, friends and going out. Visits from friends took place a couple times a month and she indicated that she wanted visits to occur less often. Church did, however, continue to play a weekly role in her community outreach. The caregiver was Catholic. Prayer was her primary coping mechanism.

The housing environment was a two story, three bedroom, two bath home. It reportedly was spacious and well kept, although the caregiver reported a concern about keeping things going. Interior and exterior stairs connected many floor levels. The interior temperature was kept warm which had increased utility expenses since the stroke. Recent changes made to the home included a grab bar added to the shower and a stool placed in the shower. Grab bars were added to the garage wall to aid in getting into the home. A brother-in-law installed the grab bars. Furniture was removed from some rooms to enhance wheelchair movement. Overall they indicated satisfaction with this housing situation and did not foresee a future move. Future changes to the home environment as specified by the caregiver, might involve building ramps at both entrances and obtaining a cleaning service.

This family seemed to be functioning on borrowed time. It was not clear how long the caregiver could continue her schedule and lack of sleep. Reaching into extended community services might provide respite care, since it seemed evident that either the family had not provided caregiving assistance or the caregiver was not allowing them to do so. A move to a single story home would aid in the problem with stairs and wheelchair mobility.

Case 16 (Person-Environment Score = -4)

Case 16 involved an 89 year old (caucasian) mother residing with her retired son and daughter-in-law who were both in their mid-60's (See Figure 13). The stroke survivor was the mother and the caregiver was the daughter-in-law, even though her husband played a key role in assisting with heavy lifting tasks. Before the stroke, the mother had been living in her own home a few blocks away. A friend/neighbor had been serving as a full-time paid caregiver. After the stroke, the stroke survivor moved in with her son and the paid caregiver continued to provide 40 hours a week of 9-5 weekday assistance.

The stroke survivor's pre-stroke health was rated as fair, affecting her activities a great deal. Heart trouble, high blood pressure, circulatory troubles, asthma, arthritis, diabetes and skin sores were combined to cause great fatigue. The stroke rendered weakness in her left leg and arm, and that coupled with loss of coordination, loss of depth perception and jerkiness of movement. A wheelchair was used for mobility and she needed assistance transferring to and from the chair. The limited use of her left hand made her spill things, and she could not pursue her lifelong pleasure of crocheting. To replace that task she was reading large print books since her vision had not been affected by the stroke. The stroke survivor had experienced an increase in sensitivity to hot and cold temperature. Occasional low blood pressure and a thyroid problem were new medical concerns since the stroke. There was no loss of bladder or bowel control. She could not perform any of the Instrumental Activities of Daily Living, but could do all PADL's with helpfrom aids or caregivers.

Stroke Survivor: age 89, female, widowed
Caregiver: age 65, Daughter-in-law, married
Husband provides some care and
a paid care-provider gives 40 hours of service.

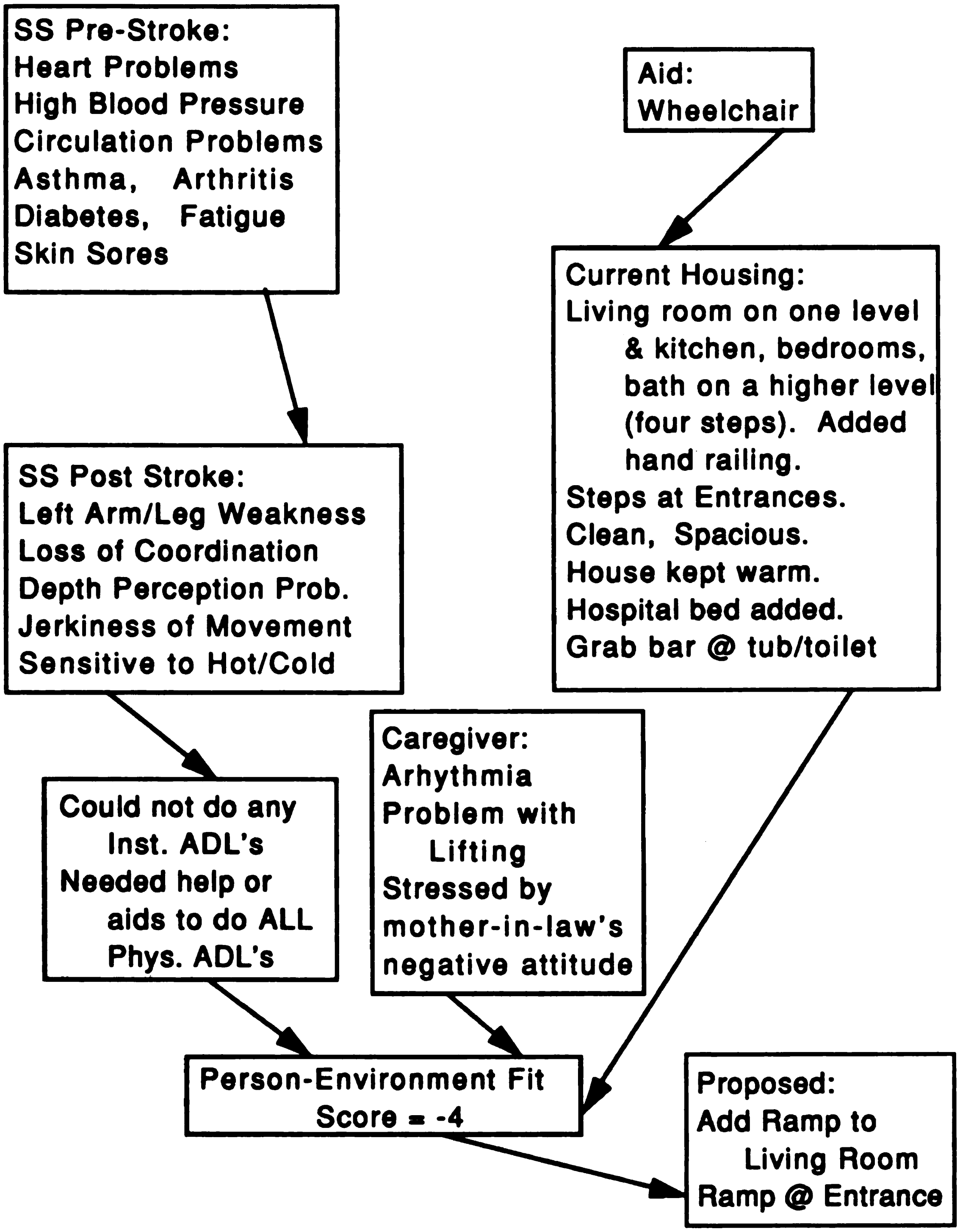

Figure 13: Case 16 Person-Environment Fit Score = -4

Her mental health was rated as fair. She had become rather argumentative and negative since the stroke. The unfairness of stroke and her dependencies were upsetting. The stroke survivor frequently appeared sad, sometimes making suicidal statements. Considering herself useless, she sometimes had a loss of appetite and difficulty sleeping. She seldom accepted the stroke and did not always work to improve her condition.

Social resources primarily included family members. She rarely had visits from friends. The stroke survivor's daughter or grand-daughter were identified as additional caregivers. No other community resources were tapped, but their private pay caregiver provided extensive help.

The stroke survivor had completed 5-8 years of education. She was a widow with an income of less than $4,999. Her needs were well met because of her children's support. Her son was retired with an income of $20,000-29,999. There was no change in finances reported since his mother's stroke. His wife, the caregiver, who had a high school diploma, had always been a homemaker.

The caregiver was age 65 and had been in good health before her mother-in-law's stroke. She suffered from arrhythmia that was aggravated by the stress of caregiving. Lifting bothered her, but her husband was around to aid with groceries and the lifting involved with caring for his mother. The caregiver complained about not having the freedom to exercise. They used to go walking together in the evening. Her diet had improved since she was preparing healthier meals for her mother-in-law. Eating out less often was frustrating for her since she was having to cook more often. She also was grocery shopping alone these days, and she missed her husband's companionship and assistance with this task.

In spite of all the assistance the caregiver was receiving, she was experiencing Caregiver Strain in all categories except financial strain (Caregiver Strain Index of 12 out of 13). She was feeling overwhelmed making emotional, physical and family adjustments, and changes in plans and time demands. Her sleep was disturbed and caregiving was inconvenient. She worried about things fairly often and noted that her mental health had worsened (reportedly a fair mental health rating) since her mother-in-law had arrived in their home. She reported that life was pretty routine, but overall she was satisfied with it. She felt that it was hard to be a mother to a mother, and her mother-in-law's negative attitude was fatiguing.

She did not feel she would be able to cope without her husband or the paid caregiver. Her coping strategies were using free time to its utmost by getting out of the house. She attended church social functions, and the couple worked together at a low income soup kitchen once a week. Craft projects and prayer were also coping mechanisms.

Because of the stroke survivor's past health problems, the caregiver felt prepared for all aspects of the caregiving role. She was well informed about stroke. Her caregiving behavior averaged 4.3 with five as healthy behavior and a 2.67 when one indicated healthy behavior.

Her help-seeking behavior averaged 2.94 with five as active help-seeking. She sought out family, neighbors, friends, church (Protestant) affiliates and the medical profession. Visits from others were very important to her. Even though they occurred three to four times a week, she preferred them to be more often. A daughter and sister-in-law were available to provide respite care.

They owned a clean spacious three bedroom house in the suburbs of Flint. The living room was four steps down from the rest of the home. Kitchen, bedrooms and the one bath were all on the same level. A hand rail had been added to the living room stairs. One to three steps were found at the primary and secondary exterior entrances.

Physical environmental changes that had been made by the son included hand rails in the bathtub and grab bars by the toilet. A hospital bed had replaced the guest bed for the stroke survivor. The home was kept warmer than usual because of her increased sensitivity to cold temperatures. They did not foresee any future changes being made to the house. In general the housing arrangement was working out, but the stroke survivor was so negative that it was hard to tell how satisfied she really was with the set-up. The family had considered possible nursing home placement should her condition worsen.

Potential physical changes to be made to the housing environment could include the addition of a ramp to part of the living room stairway. A ramp also would be of assistance at one of the entrances since the stroke survivor spent most of her time in the wheelchair, and she was the only case where a stroke survivor had used a wheelchair before the stroke. Caregiver strain seemed to stem more from the stroke survivor's negative and argumentative nature versus physical caregiver strain.

CHAPTER FIVE

SUMMARY OF FINDINGS AND DISCUSSION

Data from the ten case studies was compared according to person-environment fit scores. Four families had zero person- environment fit scores and six cases had negative person- environment fit scores (p-e fit). This chapter summarizes the findings for the three research questions and the related variables as defined in the Methodology Chapter.

RESEARCH QUESTION (1): What is the relationship between person-environment fit and selected demographic and physical characteristics of the stroke survivor?

DEMOGRAPHIC CHARACTERISTICS OF THE STROKE SURVIVOR

The review of demographics for the two groups included the variables of gender, race, age, marital status, education, employment, and spouse employment. Table 1 summarizes these frequencies by p-e fit score. Only two variables show a tendency toward more effective p-e fit. These were gender and marital status. For all cases where the p-e fit score was zero, the stroke survivors were male and married. Spouse employment showed the wives of these stroke survivors to be either full time homemakers or retired from past employment. The finding of marital status to be related to p-e fit was consistent with the findings of DeJong and Branch's (1982) study of stroke patient's ability to live independently.

TABLE 1

Frequencies of Select Demographics For the Stroke Survivor by Person-Environment Fit Score

DEMOGRAPHICS	PERSON ENVIRONMENT FIT SCORE	
	Negative Score(n=6)	Zero Score(n=4)
Gender		
Female	4	0
Male	2	4
Race		
Caucasian	4	3
Black	2	1
Exact Age	70	57
	73	64
	73	70
	85	87
	89	
	90	
Marital Status		
Married	3	4
Widowed	3	0
Education		
0-4 years	1	0
5-8 years	3	1
high school incomp.	1	2
4 yr. college	1	1
Employment		
Employed Full Time	0	1
Homemaker	2	0
Retired	4	2
Disabled	0	1
Spouse Employment		
Full-time Homemaker	1	2
Retired	2	2

In terms of age, the negative p-e fit group was in the 70 and 80 age range with one 90 year old; whereas the other group showed a broader range of ages, from 57-87 years. More older individuals were in the negative p-e fit group (average age of 80 years versus 69.5 years).

Education and employment variables did not show any trends for p-e fit. Both groups showed a wide range of education as noted in Table 1. For employment, only one stroke survivor had been employed. He was in the zero p-e fit group. All other stroke survivors were full time homemakers, retired or on disability leave from employment at the time of the stroke.

With regard to financial resources, Table 2 shows income and numbers of persons supported by that income by p-e fit score.

TABLE 2

Stroke Survivor Income and
Number of Persons Supported on the Income
by Person-Environment Fit Score

	PERSON-ENVIRONMENT FIT SCORE	
	Negative Score (n=6)	Zero Score (n=4)
INCOME		
$4,999 or less	1	1
$5,000-$9,999	1	0
$10,000-$14,999	1	1
$15,000-$19,999	1	1
$30,000-$39,999	1	
$60,000-$69,999	1	
NA		1
Number of Persons Supported on the Income		
One	3	1
Two	3	2
NA		1

A wide range of income was reported by both groups. The negative p-e fit group had income ranging from less than $5,000 to $70,000, and the zero p-e fit group had income ranging from $5,000 to $20,000. All cases but one in the negative p-e fit group indicated that their food, housing, clothing, medical and small luxury needs were well met by their financial resources. Two-thirds of the zero p-e fit group also reported these needs were well met. Financial ability to make housing changes seemed more evident for the negative p-e fit group than their counterparts.

PHYSICAL CHARACTERISTICS OF STROKE SURVIVOR

When reviewing the physical characteristics of the stroke survivor three broad areas were addressed. These areas involved pre-stroke health, post stroke physical limitations and the stroke survivor's ability to perform the Activities of Daily Living.

Pre-Stroke Health

For pre-stroke health, seven conditions reoccurred among the cases in question. In order from highest to lowest frequency of occurrence the conditions included arthritis, high blood pressure, circulation problems with limbs, heart trouble, diabetes, urinary tract disorders and emphysema or asthma. These findings are consistent with those of the American Heart Association (1987), excluding arthritis which has more association with aging than stroke. Table 3 summarizes the frequency of conditions by p-e fit score.

TABLE 3

Pre-Stroke Physical Conditions for the Stroke Survivor by Person-Environment Fit Score

PRE-STROKE CONDITION SCORE	PERSON-ENVIRONMENT FIT		
	Negative	Zero	Total n=10
Arthritis	5	4	9
High Blood Pressure	5	3	8
Circulation Problems	5	2	7
Heart Trouble	4	1	5
Emphysema or Asthma	3	1	4
Diabetes	2	1	3
Urinary Tract Disorders	1	1	2

Stroke Survivors from the negative p-e fit group averaged 4.17 pre-stroke ailments in contrast to 3.25 ailments for their zero p-e fit counterparts. This may imply that some families were experiencing problems with person-environment fit prior to the stroke, and the stroke may have compounded the problem fit. Overall as shown in Table 4, pre-stroke health of the stroke survivor was ranked by the informant from poor to excellent with health interfering from not at all to a great deal. No clear cut conclusions could be made between the two groups. Health interfered a great deal with activities before the stroke for half the sample in both groups.

TABLE 4

Pre-Stroke Overall Health Rating and
Health Interference with Activities
by Person-Environment Fit

	PERSON-ENVIRONMENT FIT	
Overall health of SS before stroke:	Negative Score (n=6)	Zero Score (n=4)
Poor	1	1
Fair	2	3
Good	2	0
Excellent	1	0
Health interfered with activities before stroke:		
Not at all	1	2
A little	2	0
A great deal	3	2

Post Stroke Health

Emerging patterns among frequencies of post stroke health conditions for the stroke survivors showed the negative p-e fit group to have more limitations than their counterparts. However, very debilitated patients existed in both p-e fit groups. Table 5 tabulates frequencies of specified post stroke conditions. Disabling conditions were consistent with expected post stroke conditions, as listed by the National Stroke Association (1987).

All stroke survivors had some reported weakness in either the right or left limbs. The majority in both groups were impaired on the left side or right brain hemisphere. The negative p-e fit group showed more physical limitations than their counterparts for the following characteristics: loss of coordination, jerkiness of movement, problems judging distances, memory loss, and loss of bladder and/or bowel control. The zero score p-e fit group reportedly had more vision problems than the other group.

TABLE 5

Frequencies of Post Stroke Physical Conditions by Person-Environment Fit Score

POST STROKE CONDITIONS	PERSON-ENVIRONMENT FIT SCORE Negative Score (n=6)	Zero Score (n=4)
Weakness in arms or legs	6	4
Left leg only	1	0
Left arm and leg	3	3
Right leg only	0	0
Right arm and leg	2	1
Change in feeling sensations:	2	2
Loss of coordination:	6	3
Jerkiness of movement:	5	1
Shoulder problems:	4	1
Problems in judging distances:	4	0
Change in vision:	1	3
Change in memory	5	2
Loss of speech	2	2
Loss of bladder control:	4	2
Loss of bowel control:	3	0

The degree to which physical problems impacted upon the stroke survivor's ability to function independently has been explored in their ability to perform the Activities of Daily Living.

Activities of Daily Living

The Activities of Daily Living (ADL) (Katz, Ford, Moskowitz, Jackson, Jaffe, Cleveland, 1963) is a format for ranking an individual's Instrumental and Physical capabilities for everyday functions. The stroke survivor's competencies for each of the activities were ranked by the ordinal scale: needed help before, cannot do now, can do with aids, can do with help or can do without help.

In general for the Instrumental ADL's, persons with a negative p-e fit could not drive, use public transportation, shop, prepare meals or do any housework. One stroke survivor in this group was able to do light housework and prepare meals if assisted. One third of the group could not use a telephone at all, one third needed help and the remaining individuals did not require assistance with the phone. Their counterparts with zero p-e fit scores had the same general limitations. However, one person was able to prepare some meals and shop with assistance. Only one person was unable to use the phone.

For the Physical ADL's, the categories of eating, dressing, grooming, bed and toilet transfer plus bladder and bowel control were addressed. Only one person in the study could not handle any of the ADL's, and this person was in the negative p-e fit group. With regard to eating for the rest of the sample in both groups, the majority of the stroke survivors could eat without assistance. One person in each group required some help with eating. For dressing and grooming, all persons in the negative p-e fit group required some assistance, whereas half of the zero p-e fit group needed help. For bed and toilet transfers, half of both groups reportedly needed help. As mentioned earlier, more persons in the negative p-e fit group had difficulties with bladder and/or bowel control. Overall, the Physical ADL's were accomplished by more of the zero p-e fit group. However, persons requiring a great deal of care existed in both groups.

The ability of the stroke survivor to ambulate was the key element tabulating the person-environment fit score. Table 6 summarizes the sample's capabilities for walking and climbing stairs.

TABLE 6

Performance of Activities of Daily Living for Ambulation by Person-Environment Fit Score

AMBULATION ADLs	PERSON-ENVIRONMENT FIT SCORE Negative Score (n=6)	Zero Score (n=4)
Walk on level surface		
Needed help before	0	0
Cannot do now	1	0
Can do w/ aids	2	2
Can do w/ help	3	2
Can do w/o help	0	0
Go up and down stairs		
Needed help before	0	0
Cannot do now	3	2
Can do w/ aids	2	0
Can do w/ help	1	2
Can do w/o help	0	0

As noted in the table, all person in both groups either could not walk or climb stairs at all, or they required aids or human assistance to get around.

<u>Use of Aids for Ambulation</u>

All stroke survivors used one or more aids for ambulation. Table 7 summarizes the type of aids used by each of the p-e fit groups.

Table 7

Types of Ambulation Aids by Person-Environment Fit Score

TYPE OF AID	PERSON-ENVIRONMENT SCORE Negative Score (n=6)	Zero Score (n=4)
Cane	3	1
Walker	3	3
Crutches	0	1
Wheelchair	6	1

All of the stroke survivors in the negative p-e fit group used a wheelchair for ambulation as compared to only one person in the other group. Canes and walkers were heavily depended upon by persons in both groups.

One person in the zero p-e fit group reported the need for assistive aids not currently owned. Four of the six persons in the negative p-e fit group required help when using ambulatory aids. This compared to one of four stroke survivors in the zero p-e fit group.

Physical Characteristics of the Housing Environment

Descriptions of the current physical environments included specific housing characteristics such as tenure and residence issues, design, layout, number of rooms and presence of stairs within and on the exterior of the home. For housing tenure, either the stroke survivor or the caregiver was the home-owner. None of the families were renting their dwelling. All caregivers lived with the stroke survivor, and only one stroke survivor had made a move to this home since the stroke (negative p-e fit group). Two caregivers in the negative p-e fit group and one caregiver in the zero p-e fit group reported family members living with other older family members as a family tradition.

Housing Characteristics for Ambulation

All zero p-e fit families resided in single story, ranch style homes, with basements. For the negative p-e fit group, three families were in ranch style homes and the other three had more interior stairs including two, two-story homes and one tri-level unit.

All of the homes had one or more steps at the main entrance and one zero p-e fit family had built a ramp over the stairs. Two families in the negative p-e fit group did not have stairs at the secondary entrance, but all others in both groups had stairs. One negative p-e fit family constructed a ramp at the secondary entrance.

Five families in the negative p-e fit group and two families in the zero p-e fit group had made changes to the inside or outside of the home. Changes for the negative p-e fit group included: ramp added to back entrance, railings on stairs, stool in bath tub, grab bar by toilet or in the shower, and the shifting or removal of furniture. All of these changes were self financed. One handyman was used to make the changes; other households relied on family members. A therapist provided input into these changes.

For the zero p-e fit families, a ramp was added to the front of one home, and was self financed and constructed by family members based upon consultation with a therapist. Other housing changes made by this group included: the raising of a toilet seat, and the purchase of a reclining, lift chair. Changes made to all homes were consistent with construction code (Michigan Barrier-Free Construction Code, 1987) and general design guidelines for disabilities (National Stroke Association, 1988; Raschko, 1982).

Other Housing Characteristics

Most homes had two or three bedrooms, with one zero p-e fit family living in a four bedroom home. For the intergenerational households, the number of bedrooms was consistent with Newman's (1976) findings that these families usually had three or more bedrooms. Two-thirds of the homes had one bathroom, with one third of both groups having two bathrooms. In all cases bathrooms were located on the same floor as the sleeping quarters of the stroke survivor. In cases where bedrooms were shared, they were shared with spouses. No privacy problems were reported.

Bedroom adjustments were made in most of the cases. Adjustments made in the negative p-e fit households included: a hospital bed moved to the family room and the caregiver slept on a hide-a-bed; a hospital bed replaced a regular bed; and bedside commodes were used. Zero p-e fit homes experienced the following bedroom adjustments: a hospital bed moved to the living room; spouse moved from shared bedroom to guest room; and bedside commodes in use.

Housing Satisfaction and Future Housing Plans

Future housing plans were proposed by three families in the negative p-e fit group and only one family in the other group. The negative p-e fit group reported the desire for the addition of exterior ramps and a move to a ranch style home as their future plans. The zero p-e fit family only requested the addition of handrails.

All cases indicated their housing environment adequately met the stroke survivor's needs. A high level of housing satisfaction is consistent with the findings for housing satisfaction and the elderly population (Golant, 1982; Weaver & Ford, 1988) and for disabled family members (Perch, 1983). All zero p-e fit families felt the stroke survivors were satisfied with the housing situation. Four of the six negative p-e fit families felt the stroke survivor was satisfied with the living situation. For this group, half of the stroke survivors were not able to make housing decisions, and all were capable of doing so before the stroke.

RESEARCH QUESTION (2): What is the relationship between person-environment fit and selected caregiver characteristics for these families?

DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS

Demographic characteristics of caregivers included: gender, relationship to the stroke survivor, race, age, marital status, religious affiliation, education, employment and financial resources. All variables excluding financial resources have been summarized in Table 8 ,and are categorized by person - environment fit score.

As anticipated most of the caregivers were female, with two males serving as caregivers in the negative p-e fit group. With regard to the caregiver's relationship to the stroke survivor, all caregivers in the zero p-e fit group were spouses, similar to the findings by Springer and Brubaker (1984). Half of the negative p-e fit group were spouses, and the other half were adult children. More caucasian families than blacks were a part of the case analysis.

Age of the caregivers ranged from the mid 40's to early 80's . The average age of all spouse caregivers was 73 years, and the average age of adult children caregivers was 55.6 years. The average age of the negative p-e fit group was 63.5 years in comparison to the zero p-e fit group whose average age was 73.5 years.

All caregivers in the zero p-e fit group were married to the stroke survivor. Most caregivers were married in the other group, excluding the one adult child who was single and the adult child divorcee.

Table 8

Frequencies of Select Demographics for Caregivers by Person-Environment Fit Score

DEMOGRAPHICS	PERSON-ENVIRONMENT FIT SCORE	
	Negative Score (n=6)	Zero Score (n=4)
Gender		
Female	4	4
Male	2	0
Relationship to SS		
Spouse	3	4
Daughter	1	0
Daughter-in-law	1	0
Son	1	0
Race		
White	4	3
Black	2	1
Exact Age	45	66
	57	70
	65	75
	67	83
	75	
	82	
Marital Status		
Single	1	0
Married	4	4
Divorced	1	0
Religious Affiliation		
Protestant	5	3
Catholic	1	0
Education		
0-4 years	1	0
5-8 years	1	2
high school completed	3	1
1-3 years college	1	0
4 years college	0	1
Employment		
Homemaker Full-time	2	3
Retired	2	1
Employed Full-time	2	0

Religious affiliation indicated the majority for both groups to be Protestant, with one Catholic in the negative p-e fit group. All caregivers except one from the zero p-e fit group indicated a religious affiliation. Overall this finding is consistent with those of Legare (1980), who linked providing care with any religious affiliation regardless of denomination.

Educational backgrounds of the caregivers were varied and for both groups education ranged from 5-8 years to completion of a college degree. One of the negative p-e fit caregivers had 0-4 years of education. Regarding employment, all but two caregivers were either retired or full time homemakers. Two of the adult children in the negative p-e fit group were employed full time. These two also indicated problems with caregiver strain, which fits Robinson's (1983) prediction of more strain for younger and employed caregivers.

Table 9 reports caregiver income, the number of persons supported on the income, changes in financial situation since the stroke and income adequacy, sorted by the person-environment fit score. Generally speaking, financial situations had not changed since the stroke, except for two families in the negative p-e fit group.

In open-ended responses, negative p-e fit caregivers reported financial concerns in spite of their higher incomes and financial resources. One negative p-e fit caregiver noted a drop in income since the stroke survivor had been self employed prior to the stroke and was now only working part-time. Another negative p-e fit caregiver expressed concern over the use of investment income to pay for private attendant care and home care. Higher income families could deplete their resources more rapidly than other families since they do not qualify for many state supported services (Schultz, 1985). Lower income families are used to living on less and doing without, and may not feel the financial changes that a higher income family might experience.

The caregivers in the zero p-e fit group generally had lower incomes than their counterparts. Half of the zero p-e fit families reported financial resources to be just enough to meet basic needs. All other families either reported no financial worries or reported they had income for extra amenities.

TABLE 9

Income and Number of Persons Supported,
Changes in Financial Situation and Income Adequacy
by Person-Environment Fit Score.

	PERSON-ENVIRONMENT FIT SCORE	
	Negative Score (n=6)	Zero Score (n=4)
Income		
$4,999 or less	0	1
$5,000-$9,999	1	0
$10,000-$14,999	0	2
$15,000-$19,999	1	1
$20,000-$29,999	2	0
$40,000-$49,999	1	0
$60,000-$69,999	1	0
Number of Persons Supported on Income		
One	2	0
Two	2	4
Financial situation changed since stroke:		
Yes	2	0
No	4	4
Income is:		
Not enough	0	0
Just enough	0	2
Some Extras	4	0
No Financial Worries	2	2

PHYSICAL CHARACTERISTICS OF CAREGIVERS

Physical characteristics for the caregivers included a rating of pre-stroke health, health standing in the way of activities, current health problems, any increases in physical problems or new ones since the stroke. Caregiver's pre-stroke health reportedly ranged from fair to excellent for both p-e fit groups. One negative p-e fit caregivers reported poor pre-stroke health. Table 10 summarizes this variable.

Table 10

Caregiver Health Before Stroke
by Person-Environment Fit Score

	PERSON-ENVIRONMENT FIT SCORE	
	Negative Score (n=6)	Zero Score (n=4)
Health Before Stroke		
Poor	1	0
Fair	1	2
Good	2	1
Excellent	2	1

Overall, caregiver pre-stroke health ratings were similar to national figures for reported fair and poor health (AARP, 1987). Generally speaking, the younger caregivers were in better health than their older counterparts. For those who were ailing, however, the variety of ailments varied, as noted in the case studies. Overall, health did not reportedly interfere with activities. Two of the six caregivers in the negative p-e fit group had health problems that made caregiving difficult. These health problems had been exacerbated since taking on the caregiving role. No new ailments had developed. Four of the six caregivers noted a problem with caregiving affecting their ability to get out and exercise.

For the zero p-e fit group, one caregiver reported that her physical problems had interfered with routine activities before the spouses's stroke. Since the stroke, three of the four caregivers noted physical problems, but conditions had not increased in severity. Only one caregiver felt the physical problems interfered with aiding the stroke survivor. One caregiver reported experiencing new physical problems since the caregiving role began. Inability to exercise was a concern for another caregiver.

In summary, half of the caregivers from both groups had health related problems impacting on the care providing role. This is similar to Springer and Brubaker's (1984) research findings.

Changes in eating or meal preparation habits for the caregivers did not show any specific trends between the two p-e fit groups. Table 11 shows the frequencies for changes in the following items since the stroke: amount of food eaten, how well balanced the meals were, weight or appetite change, time spent shopping or preparing meals, eating out or eating with friends.

Table 11

Changes in Eating or Meal Preparation
Patterns for Caregivers Since the Stroke
by Person-Environment Fit Score

	PERSON-ENVIRONMENT FIT SCORE			
	Negative Score (n=6)		Zero Score (n=4)	
	Yes	No	Yes	No
Change in amount of food eaten:	2	4	0	4
Weight or appetite change:	1	5	1	3
Change in how well balanced the meals are:	2	4	1	3
Change in time spent grocery shopping and preparing meals:	4	2	1	3
Change in how often eat with friends:	2	4	2	2
Change in how often eating out:	4	2	2	2

For the negative p-e fit group, four of the six caregivers reported changes in the amount of time spent shopping and preparing meals plus a change in how often they ate out. For the zero p-e fit group, half of the sample noted changes in how often they ate with friends and how often they ate out.

PSYCHOLOGICAL CHARACTERISTICS OF CAREGIVERS

Psychological characteristics encompassed pre and post stroke mental health, plus the degree of worrying and satisfaction with life. Preparedness for caregiving, caregiving behavior and help-seeking behavior also were explored for the two groups.

All of the zero p-e fit caregivers and half of the negative p-e fit group reported good emotional health. The other three negative p-e fit caregivers each reported present emotional health as excellent, fair and poor. In all zero p-e fit cases emotional health had not changed since the stroke. The majority of the negative p-e fit counterparts reported that emotional health also had not changed since the stroke, but two caregivers indicated their emotional health had worsened.

All but one of the caregivers felt life was pretty routine. One negative p-e fit caregiver rated life as exciting. Half of the caregivers in both groups rated satisfaction with life as good and the other half rated it as fair.

The amount of worrying the caregivers experienced varied widely for both groups. One caregiver in both groups hardly ever worried, but the rest of the individuals were split between worrying fairly often or very often.

On the issue of preparedness, caregivers rated themselves on the following items: seeking help from health professionals; finding information about aids/devices and physical changes for the home; finding someone to make the changes; the time involved with providing care; and knowing about stroke. An ordinal scale was used to measure preparedness, which was collapsed into three categories: not prepared, somewhat prepared and very prepared. Table 12 summarizes the frequencies for caregiver preparedness for the six items categorized by person-environment fit score.

TABLE 12

Caregiver Preparedness for Six Items
by Person-Environment Fit Score

	PERSON-ENVIRONMENT FIT SCORE					
	Negative Score (n=6)			Zero Score (n=4)		
PREPAREDNESS	NP	SP	VP	NP	SP	VP
Knowing whom to contact:	2	1	3	1	0	3
Knowing what aids or devices were needed:	2	1	3	0	0	4
Knowing what changes to make to inside or outside of house:	3	1	2	2	2	0
Finding someone to make changes:	4	0	2	1	0	1
Amount of time caregiving would take:	4	1	1	0	0	3
Having information about stroke:	4	0	2	2	1	1
TOTAL SCORE:	19	4	13	5	3	12

NP: not at all prepared or a little prepared
SP: somewhat prepared
VP: very prepared or completely prepared

Preparedness varied for both groups depending upon the item in question. The negative p-e fit group seemed less prepared on most of the issues than their counterparts, but no clear cut patterns emerged as did in the other group. Half of the group were very prepared to contact professionals and obtain aids or devices. Half of the caregivers in the negative p-e fit group were not prepared to make housing changes, with the majority not prepared to contact someone to make the housing changes. The majority of this group also were not prepared for the amount of time caregiving would require; nor did they have enough information about stroke. The divided reactions could be explained by the mixture of caregiver characteristics that make up the group. Males and females were represented with varying education, employment backgrounds, and they were spouses or adult children.

The zero p-e fit group seemed more prepared for most issues. The majority were very prepared for the amount of time caregiving would require; for knowing who to contact for assistance; and for obtaining aids or devices. They were less prepared for making housing changes. Half of the group were not prepared with enough information about stroke or knowing who to contact to make housing changes. All of these findings are in line with the literature. These caregivers were female spouses, who had been full time homemakers or were retired, and had been involved for a long time in providing care to their spouse (Brody, Johnsen & Fulcomer, 1984). They would be more likely to know who to contact for help (Gross & McMullen); yet less likely to be prepared to make housing changes (Newman, 1976).

The Caregiving Behavior Scale noted healthy behaviors that benefited not only the caregiver's mental health but also that of the stroke survivor. For items where an average score of 1.0 designated healthy behavior, the negative p-e fit group averaged 2.85 and the zero p-e fit group averaged 1.75. For the items where an average score of 5.0 indicated healthy behavior, the negative p-e fit group averaged a 3.48 and the zero p-e fit group averaged 3.43. Generally speaking the zero p-e fit group was exhibiting slightly more healthy caregiving behavior than the negative p-e fit group.

For the Help-Seeking Behavior Scale, the variety and frequency of help-seeking was identified. An average score of 5.0 indicated high help-seeking from a variety of sources. The negative p-e fit caregivers had an average score of 3.12 versus an average score of 2.0 for the zero p-e fit group. This could be interpreted that the negative p-e fit group explored more assistance from a variety of sources then their counterparts. The negative p-e fit group also had higher caregiver strain, which would fit Hooyman's (1986) findings that caregivers experiencing high strain built a broader help-seeking network.

SOCIAL CHARACTERISTICS OF CAREGIVERS

Social characteristics of the caregivers included social visits from family or friends, and the frequency and desire for visits. Half of the zero p-e fit caregivers considered visits to be "somewhat important" with the other half classifying them as "important" or "very important". The negative p-e fit group showed four of the six caregivers regarded visits as "important", with the remaining two caregivers considering them "very important". Reportedly, four of the six negative p-e fit caregivers had not received visits since the stroke; versus one of the four zero p-e fit caregivers. The zero p-e fit group had visits since the stroke and less caregiver strain which is consistent with Zarit, Reever and Bach-Peterson's (1980) findings of more visits, reducing caregiver strain.

Table 13 shows the frequency of visits from friends, and whether the caregiver sees the friends as much as desired, as compared by person-environment fit score.

TABLE 13

Desire to See Friends by Person-Environment Fit Score

	PERSON-ENVIRONMENT FIT SCORE	
	Negative Score (n=6)	Zero Score (n=4)
How often friends stop by		
Rarely	0	0
Couple times month	2	3
Weekly	1	1
3-4 times week	3	0
See friends as much as want to:		
No- want to see friends less often	1	0
Yes	2	2
No- want to see friends more often	3	2

The frequency of friends stopping by seemed inconsistent with the reported visits following the stroke. The negative p-e fit group indicated they had not been visited since the stroke, yet their friends stopped by more often than the zero p-e fit group. Likewise this group had mixed reactions as to whether they wanted to see friends more or less often. The majority of the zero p-e fit group seemed to see friends less often then their counterparts. In this group, half of the caregivers saw friends as much as they wanted to, with the other half desiring more visits.

Social characteristics also included having someone to talk with or to provide personal care needs, and the use of community services. All caregivers from both groups had someone to talk with and identified friends or family members to assist with personal needs. Two caregivers from the negative p-e fit group and one from the zero p-e fit group used community services for additional caregiving for the stroke survivor. The limited use of community services among caregivers is consistent with the literature (Krout, 1983). The strong informal network for these families may discourage seeking services that could provide respite for family members (O'Brien & Wagner, 1980).

Housing Resources for the Caregiver

As previously mentioned, all caregivers lived with the stroke survivors. All but one of the caregivers were homeowners. The one son lived in his mother's home to provide care (negative p-e fit group).

Caregivers were asked about problems with caring for the home, and whether there were any increases in housing expenses since the stroke. Although two caregivers in the negative p-e fit group and one in the zero p-e fit group were having problems caring for their homes, the majority were not. Specific examples have been cited in the case studies. Similarly these families reported increases in housing expenses since the stroke.

All caregivers felt the current living arrangement was working out well. In spite of these feelings, future housing adaptation plans were being made by three caregivers (two from the negative p-e fit group and one from the zero p-e fit group). Housing plans mainly centered around a move to a single story home or moving the stroke survivor to a nursing facility. The interviews clearly linked bladder and bowel incontinence to plans for a move.

When asked to describe an ideal housing arrangement for the stroke survivor and caregiver, six of the ten caregivers considered their current setting to be ideal. Other descriptions of ideal housing arrangements included seeking a nursing facility for the stroke survivor, making a move to a single story home or condominium; adding a ramp; remaining in close proximity to family; and obtaining more assistance with housekeeping.

RESEARCH QUESTION (3): What is the relationship between the person-environment fit score and the Caregiver Strain Index?

Table 14 compares the Caregiver Strain Index Scores (Robinson, 1983) with the person-environment fit score by family case numbers. Except for the two cases that are marked (*), the general pattern seems to be that households with zero p-e fit scores have caregivers exhibiting lower caregiver strain, and households with negative p-e fit scores have caregivers who report higher caregiver strain. No clear explanation can be found for the two cases that do not fit this pattern.

Table 14

Comparison of Caregiver Strain Score and
Person-Environment Fit Score by Case Numbers

Family Case Number	Caregiver Strain	P-E Fit Score
5	2	0
7	2	-2*
3	3	0
10	3	0
13	8	0*
18	8	-3
19	10	-2
11	11	-2
17	11	-2
16	12	-4

Table 15 summarizes the data for the specific caregiver strain items by person-environment fit score. In general, all caregivers from both groups were strained by sleep disturbance. For the negative p-e fit group, factors that seemed to contribute to high caregiver strain were as follows: changes in the stroke survivor were upsetting; feeling overwhelmed; making emotional adjustments; some of the stroke survivor's behaviors were upsetting; making changes in personal plans; and feeling confined due to restricted free time. Other stressors for some caregivers included family adjustments, the inconvenience of helping, physical strain and work adjustments.

Table 15

Caregiver Strain Index
by Person-Environment Fit Score

	PERSON-ENVIRONMENT FIT SCORE			
	Negative Score (n=6)		Zero Score (n=4)	
STRAIN	Yes	No	Yes	No
Sleep Disturbance	6	0	4	0
Inconvenient to Help	4	2	0	4
Physical Strain	3	3	1	3
Free Time Restricted	5	1	1	3
Family Adjustments	4	2	0	4
Change in Personal Plans	5	1	1	3
Other Demands on Time	2	4	0	4
Emotional Adjustments	5	1	2	2
Stroke Survivor's Behaviors are Upsetting	5	1	2	2
Upsetting to Find Changes in the Stroke Survivor	6	0	2	2
Work Adjustments Made	3	3	0	4
Financial Strain	1	5	0	4
Feeling Overwhelmed	5	1	2	2

The zero p-e fit group reported four stressors that affected half of the group. These included emotional adjustments, feeling overwhelmed, and finding the stroke survivor's behaviors and physical changes upsetting. Separate individuals noted problems with the physical strain of caregiving, restricted free time and changes in personal plans.

Experiencing caregiver strain fits with Carp (1977), Hiatt (1982) and Lawton's (1983) concern that the physical environment can negatively impact on those who function therein. Frustrations with the environment can lead to frustrations with other facets of one's life. The specific nature of the relationship between caregiver strain and the physical environment needs to be more fully explored with additional probing questions for this sample.

In summary, the individual characteristics of the stroke survivors, their environments and caregivers did not deviate from trends predicted in the literature. The following chapter compiles an overall description of the negative p-e fit group as compared with the zero p-e fit group for all variables, noting patterns for the composite group. Implications of the findings and the need for future research directives are explored.

CHAPTER SIX

CONCLUSIONS AND RESEARCH IMPLICATIONS

Chapter Six provides an analysis of the models used in this study. It also summarizes the stroke survivor and caregiver characteristics for the negative p-e fit group and the zero p-e fit group. Trends and conclusions are highlighted, and implications from the findings of this study are explored. Suggestions have been provided for changes in public policy and future research endeavors.

ANALYSIS OF MODELS

This study reviewed qualitative data for ten families who were dealing with the day to day struggle of recovery from a stroke. Each family was assessed from an ecological perspective. The relationships between the stroke survivor (his/her physical limitations and abilities to perform Activities of Daily Living), the physical environment (aids and devices plus the housing characteristics), and the human behavioral environment (caregiver characteristics) were observed. Interactions with the community resources and the natural environment were noted (See Figure 1).

The ecological model was used for analysis of the relationship of variables for this study. It was developed from the writings by Bubolz, Eicher and

Sontag (1979) and Morrison (1974), plus Bubolz and Whiren's (1984) study of families of the handicapped. The interdependency of the stroke survivor and the caregiver were linked to the physical environment. The linkage can result in an appropriate person-environment fit or an inappropriate fit. Poor fit in turn impacts on the caregiver, the stroke survivor, and the physical environment (eg. scarred walls as a wheelchair maneuvers corners). The community serves as a surrounding environment and a potential resource to support the family ecosystem. Professionals can provide environmental consultation to improve person-environment fit and assist with facilitation of the changes.

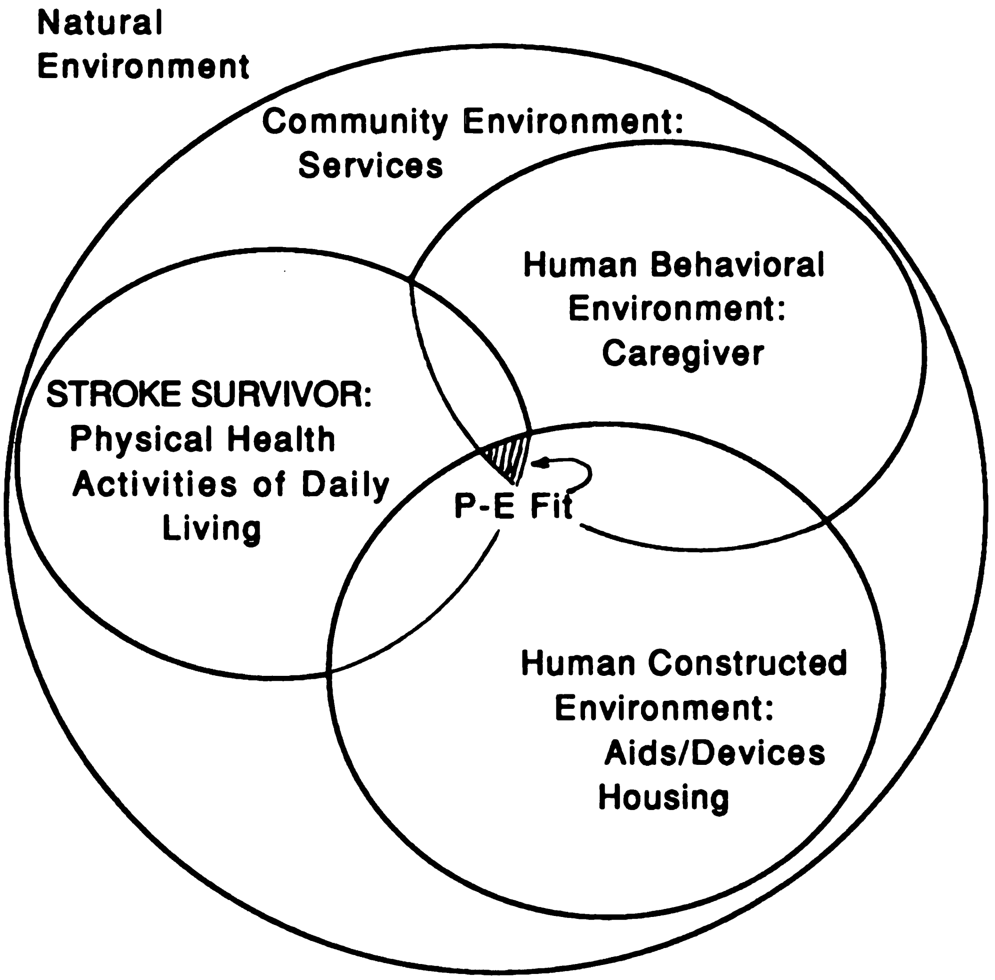

Figure 1: Stroke Survivor's Ecological Model

The dynamics of the interconnected ecosystem and person-environment fit continue to evolve. They shift in and out of fit over time. The shifting occurs as a result of changes to any component of the system. For example, a stroke survivor, who predominantly had been confined to a bed, improves to the point of using a wheelchair. The wheelchair cannot easily pass through the house, and must be lifted when entering or exiting the house. An environment that worked well for an immobile individual may present a problem fit as mobility increases.

Figure 2 illustrates the component factors that specifically comprised person-environment fit for case study analysis.

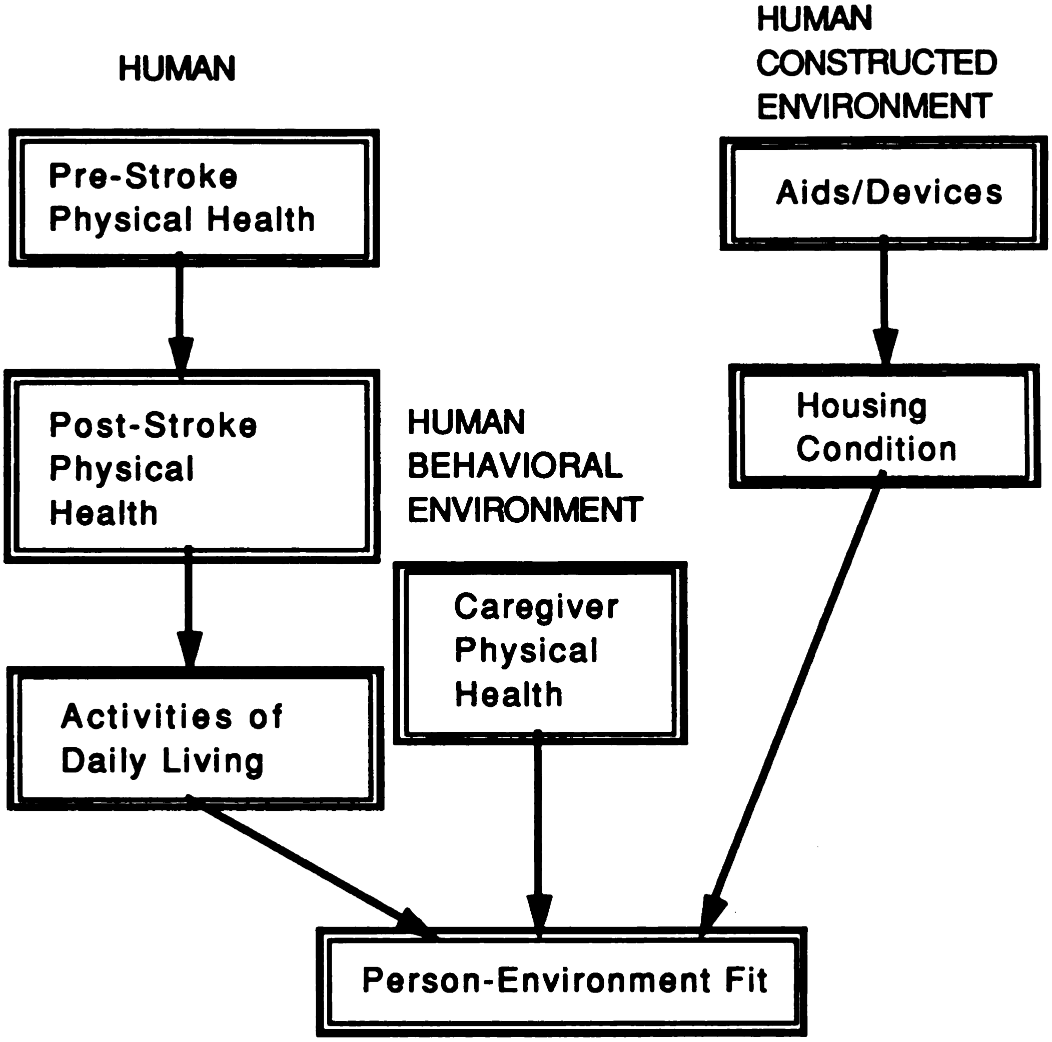

Figure 2: Factors Comprising Person-Environment Fit

The format of the person-environment fit relationship was derived from DeJong and Branch (1982). It pulled together key elements for p-e fit, while tying in the additional component of caregiver characteristics. This relationship was not addressed in the literature.

For this study, the format of person-environment fit worked effectively with case study analysis. The secondary data, however, did not always fit the format. It is recommended that future projects prepare tailored questions to directly assess all factors in the format. For this study, additional questions needed to be asked concerning pre-stroke ambulation and characteristics of the physical environment. Assessment of these two factors had to be derived from a variety of open-ended questions or interviewer notes, more so than direct questioning.

CONCLUSIONS FROM THE COMPARISON OF THE TWO P-E FIT GROUPS

The previous chapter summarized specific data for each of the variables, noting relationships to literature findings. For each variable, the findings from this study were consistent with the literature. This section compares overall characteristics of the person-environment fit groups for each of the research questions. Some interesting trends emerged from the data collected.

RESEARCH QUESTION (1): What is the relationship between person-environment fit and selected demographic and physical characteristics of the stroke survivor?

Of the many variables explored for this research question, a few characteristics about the stroke survivor provided some distinctions between person-environment fit groups. Table 16 highlights stroke survivor characteristics by person-environment fit.

Table 16

Stroke Survivor Characteristics
by Person-Environment Fit Score

NEGATIVE P-E FIT SCORE (n=6)	ZERO P-E FIT SCORE (n=4)
Older	Younger
Males and Females	All males
Half were married	All married
More pre-stroke ailments	Fewer pre-stroke ailments
More post stroke ailments	Fewer post stroke ailments
More bladder and bowel problems	Half with bladder problems
More problems with ADLs	Fewer problems with ADLs
All used wheelchairs	One wheelchair user
More needed help with aids	One needed help with aids
Broad range of income	Less income
Multi-story homes	All single story homes
More exterior stairs	Some exterior steps
Made more housing changes	Fewer housing changes
Had more future housing adaptation plans	No future housing adaptation plans
Most satisfied with housing	All satisfied with housing

The negative p-e fit group was older than the zero p-e fit group and had more disabilities pre and post stroke. Increased disability and the use of an ambulatory aid (wheelchair) that could not move into or throughout the home created a problem p-e fit. This group did however make more housing changes than their counterparts. The changes did not greatly affect ambulatory p-e fit.

There were problems with incontinence for most of the stroke survivors in the negative p-e fit group. This problem did not directly affect the p-e fit scale for this study, but poor ambulation certainly compounds an incontinence problem. Having trouble reaching the bathroom can add to an increase in household cleaning. As was discussed by the caregiver, the problem may have raised the concern for moving the stroke survivor to a nursing home. The literature confirms that incontinence is a contributing factor in institutionalization (Office of Technology Assessment, 1985).

The negative p-e fit stroke survivors had a broad range of income. Those with higher income had more resources with which to plan future housing changes or moves. Families with higher incomes indicated the following future housing changes: adding a ramp; moving to a ranch style home; or placement of the stroke survivor in a nursing facility. In spite of the potential changes, most of the group indicated satisfaction with the housing situation.

The relationship between housing satisfaction and person-environment fit of older individuals living in their own homes has not been explored extensively in the literature. Housing satisfaction deals with a broader psychological involvement and long term attachment to the home (Golant, 1982; Weaver & Ford, 1988). Perch (1983) observed that disabled individuals also were satisfied with their homes, even if these environments were not in good shape. This seems to be the situation for the negative p-e fit group. As Newman (1976) noted, considering any change is a painful process for older individuals strongly attached to their homes. If physically compensating for a poor p-e fit is less painful than the thought of making an environmental change, then compensation will continue until this pain outweighs that of a move (Nadler, 1983). Denial and continual decline can last a long time before forced change can no longer be ignored.

The zero p-e fit group had younger stroke survivors with fewer pre and post stroke disabilities (except one stroke survivor), but all had problems with ambulation. Their homes were more conducive to ambulation with the use of aids, since the only interior stairs led to basements. Exterior stairs were a problem, but they were traversed with assistance from the caregiver. The one stroke survivor who used a wheelchair had an exterior ramp to aid access in and out of the home. Once out of the home, however, the caregiver in that family had problems transferring the stroke survivor into the car by herself. The caregiver was not strong enough to lift the wheelchair into the trunk of the car. This prevented the caregiver and stroke survivor from going out on their own without assistance from other family members. As the environment supports the functions, so too can independence be supported with less demand on those individuals providing care.

RESEARCH QUESTION (2): What is the relationship between person-environment fit and selected caregiver characteristics for these families?

Table 17 compiles the general trends that emerged among the many caregiver variables when sorted by p-e fit scores. The findings imply that persons in the zero p-e fit group may have been more prepared to take on the after stroke caregiving role than their counterparts. All were older, female spouses serving as full time homemakers who already were providing care to their husbands. Physical health for some may have been a strain, but emotional health for the zero p-e fit group was better than the other group. Emotional health had not changed since the stroke. They saw friends less often and exhibited less Help-Seeking Behavior, potentially because they perceived less help was needed. Their Caregiving Behavior was healthier, which meant that they would let others help if needed, and they took care of themselves as well as the stroke survivor.

Table 17

Caregiver Characteristics
by Person-Environment Fit Score

NEGATIVE P-E FIT SCORE (n=6)	ZERO P-E FIT SCORE (n=4)
Mostly female; 2 males	All females
Spouses & adult children	All spouses
Younger average age	Older average age
Higher income	Lower income
Some had health problems affecting caregiving.	Some had health problems affecting caregiving.
Most couldn't get out to exercise.	One was concerned about exercise.
Most had changes in eating out and time with meal preparation.	Half ate out less often & less with friends.
Half had good emotional health.	All had good emotional health.
Two felt emotional health had worsened.	Emotional health had not changed since the stroke
Most worried often.	Most worried often.
Less prepared overall for caregiving.	More prepared for caregiving.
Not as healthy Caregiving Behavior.	Slightly healthier Caregiving Behavior.
Most hadn't received visits from friends since stroke.	Had visits since stroke.
Saw friends more often.	Saw friends less often.
More Help-Seeking Behavior.	Less Help-Seeking Behavior.
All felt housing met needs.	All felt housing met needs.
Not prepared to make housing changes and did not know whom to contact for changes.	Not or somewhat prepared to make housing changes; half did not know whom to contact to make changes.
Two had problems caring for home.	One had problems caring for home.

The negative p-e fit caregivers were younger then their counterparts, half being adult children. This group seemed less prepared for their caregiving role. The adult children may have been experiencing some of the pressure of the sandwich generation. They were caring for themselves while being employed full time, plus caring for their parents and the younger generation (Brody, 1981). Since the stroke survivors of this group had more ailments than their counterparts, the caregivers may have had more potential for caregiving demands.

In both groups the caregivers felt that the housing needs of the stroke survivor were being met. Those in the negative p-e fit group were reportedly not as prepared to make housing changes nor did they know whom to contact for housing changes, as compared to some of the zero p-e fit caregivers. They, however, had made more environmental changes and had more income to do so, yet all the person-environment fit needs were not being met. It must be remembered that these families were interviewed only 30 days to six months post hospitalization. This was an unsettled period of adjustment to the disability and a time of hope for the stroke survivor's recovery from initial physical limitations. Creating person-environment fit may not have been a key concern for these families, considering the other demands in their lives. Additionally, lack of recognition that a poor person-environment fit existed may have been part of the problem. Psychologically the negative p-e fit group may not have been ready to recognize or explore person-environment fit issues or solutions. Follow- up interviews with these caregivers might lend insight into long term responses to environmental needs.

RESEARCH QUESTION (3): What is the relationship between the person-environment fit score and the Caregiver Strain Index?

As noted in the previous chapter, the general relationship between these two variables showed higher caregiver strain associated with negative p-e fit, and lower caregiver strain associated with zero p-e fit caregivers. If the stroke survivor was frustrated with accomplishing daily tasks in an uncooperative environment, this could generate frustrations for the caregiver both physically and psychologically (Carp, 1977).

Caregivers frequently initiate and implement environmental changes. If these individuals are under a great deal of strain, then researching solutions for changes would be an additional burden. For some it would be easier to continue to aid the stroke survivor with such tasks as walking, climbing stairs, and making transfers than to find alternative solutions. The duration of providing continual assistance in light of personal physical limitations would certainly compound the caregiver strain. Springer and Brubaker (1984) addressed this concern particularly for older caregivers. However, younger caregivers also could injure themselves from lifting or become physically drained as they care for two households.

The delegation of caregiving roles, including physical care, emotional support, coordinating in-home services, and researching environmental changes, is a must for the preservation of the caregiver's health (Horejsi, 1982). Keeping the caregiver healthy prevents family breakdown (Gray, 1984), and truly assists the patient or stroke survivor overall (Neubacher,1987).

STUDY IMPLICATIONS

Since the findings for each of the individual variables were consistent with those found in the literature, this small sample could be considered representative of the stroke survivor population at large. However, generalizations about study implications need to be made with caution when the sample size is ten families.

From this study one could infer that there is a cyclical relationship between person-environment fit and caregiver strain. A poor fit leads to more work on the part of both the caregiver and stroke survivor. This leads to psychological strain as a result of both caregiver and stroke survivor frustration. Psychological strain also could lead to physical strain for both parties. Caregiver strain could worsen the already poor fit, and the cycle repeats itself.

Consider the example of the female stroke survivor, who suffered from incontinence but refused to use sanitary pads or a portable commode. She continually became upset with herself since she could not quickly reach the bathroom using her walker through a cluttered home environment. This daily, if not hourly, problem led to refusal to consume liquids and subsequent dehydration. It also discouraged any outings away from home. The caregiver was frustrated by her mother's refusal to use the aids provided; by the continual laundry problem posed by the incontinence; and by the household cleaning of flooring, carpeting and furniture. Increases in household work load led to physical strain for the caregiver. Psychological strain for the caregiver was a result of internalizing her mother's humiliation, her own frustration, and worrying about the physical harm dehydration could cause.

Frustrations led to a lack of household maintenance and a resultant increase in clutter. Frustration also generated caregiver anger toward the stroke survivor.

Appropriate interventions could break the cycle. Service providers might have discussed the incontinence problem with the stroke survivor. Helping the stroke survivor see the entire picture might have encouraged her to use the sanitary pads. The caregiver might have had the environmental issues highlighted by a service provider. These issues might have included clutter removal for ease of maneuvering a walker through the home; providing privacy for the stroke survivor to use the portable commode; and changing surface materials to those that are very easy to clean and do not support bacterial growth.

An improvement in the environment may reduce caregiver strain. A good person-environment fit, in the first place, could support and encourage both the caregiver and stroke survivor, thus reducing caregiver strain from this part of their lives. It is important to realize that fit changes over time. This includes over the course of the day, as both the stroke survivor and caregiver become fatigued. A good fit in the morning may not be a good fit in the evening.

It is amazing how readily our society provides environmental support for children (eg. smaller chairs, coat hooks lower on the wall, or stools to increase height when using a sink)., yet does not readily recognize the need for that support at the other end of the life cycle. As one ages, it is sometimes personally and societally perceived that humans are capable of accommodating themselves to any environment without assistance; similar to a test of adulthood and independence. Providing a good p-e fit for the child encourages independence, self assurance and self esteem. The same is true for persons with physical limitations, and at the same time the independence and self assurance of the caregiver is enhanced.

The use of devices frequently is rejected by many, who fear dependence on the device. Persons wearing eye glasses are dependent on this device and would certainly be handicapped without it. Assistive aids need to be considered in the same light. Cultural attitudes tend to reject the use of aids or devices, and discourage barrier-free residential design. If a shift in attitudes can be encouraged, all would benefit.

Study findings highlighted caregiver characteristics that could enhance person-environment fit. Common characteristics include the following: good physical health, good emotional health, feeling prepared for the caregiving role, and exhibiting healthy caregiving behaviors that promote attention to one's own health as well as that of the stroke survivor. Marital status and no employment outside the home also related to a better person-environment fit. Educational background was not a factor.

Implications can be found for disseminating person-environment fit information based on other caregiver characteristics. Female caregivers tend not to pursue environmental changes as much as their male counterparts (Newman, 1976); yet they seek other kinds of help more so than males (Nadler, 1983). Since the literature confirms that there are more female caregivers than males, strategies for developing readable and easily understood materials that explain environmental changes may encourage action on their part. Bringing the information to the caregiver through existing helping channels (eg. professionals already coming into the home to provide other medical related services) may alleviate the frustration of not knowing what changes to make or whom to contact for making the changes. Intervention can occur at the onset of stroke or three months after the stroke when initial recovery from disabilities has occurred. Environmental intervention would function like other medical interventions.

IMPLICATIONS FOR SERVICE PROVIDERS

Initially following a stroke, the family has many issues with which to cope. Many of these issues are addressed by helping professionals (eg. visiting nurses, occupational therapists, speech therapists, social workers, family therapists). One area that is not addressed by the helping professionals is the physical environment. On occasion, advice is given by persons not trained to make environmental recommendations. A recommendation from this study would be to train the community professionals who provide in-home services, so accurate advice can be given. Caregivers may not perceive the existence of a problem person-environment fit unless it is brought to their attention. Once a problem is recognized, alternatives for action can be explored.

Service providers need to recognize the assistance design professionals can make as a team member in patient rehabilitation. They can serve as a resource for providing suggestions to improve person-environment fit. Design professionals may not be readily consulted since the avenue of design for disability is a relatively recent trend in design education. Lower income families would find design consultation cost prohibitive. Most consumers and service providers are either not aware of these competencies in design professionals or find the services too expensive; so they handle environmental issues themselves. Again, training service providers to prepare environmental assessments can benefit low income families as well as networking housing information to female caregivers who seem less comfortable with seeking this information.

IMPLICATIONS FOR PUBLIC POLICY

The aging population will continue to grow, and the disabled population will do likewise. The public policy implications from this study revolve around policies for universal design for private housing and funding environmental assessment and changes. Current public and private funding policies for the acquisition of "not medically necessary" devices that support independence also have important implications.

Medical insurance does not cover the expenses associated with environmental assessments. Because of this, professionals providing in-home services could not bill insurance companies for the time it might take to provide clients with environmental guidance. These services need to become recognized as a part of a viable team approach to rehabilitation treatment. If occupational therapists can bill their services to insurance companies, so should the design professional.

Funding policies for insurance coverage for supportive aids and devices should be reconsidered. Coverage should include those devices that encourage self assistance as well as those that are medically necessary (American Occupational Therapy Medical Handbook, 1984). Encouraging stroke survivor independence is medically necessary in the long run for support and medical wellbeing of the caregiver.

More public and private funding sources need to be accessible to varying income groups for supporting the acquisition of aids and devices and making environmental changes. Lower income families have a greater range of options than do middle income households. Many families are unaware of devices that can be obtained from organizations like the United Way. Additionally, many families are unaware of the tax laws that allow the deduction from personal income taxes of environmental changes or expenses for aids as medical expenses. The environmental changes or items need to be recommended by a physician (eg. a doctor can write a prescription for a ramp) before they can be considered tax deductible. Unfortunately, environmental changes are not a part of the training curriculum for doctors, and unless the patient or caregiver asks for such a prescription, the doctor may not think to write one. Initial outlay of capital is required for writing off the expense, and this may be cost prohibitive if other medical related needs have to be paid out of pocket. The middle income households with limited insurance could be hardest hit.

Public policy also needs to address the concern for older and disabled individuals remaining in housing that is dilapidated or provides a poor person-environment fit. Individuals tend to adapt to the conditions of their environment instead of changing the environment to meet the human needs. The federal government needs to control federal spending on all programs through reallocation of funds versus new funding, during this time of high federal deficit. However, between 1980 and 1988 the budget for the Department of Housing and Urban Development has been reduced from $33 billion to $7 billion. During this time, construction for low-income housing and housing for the elderly has dropped dramatically; federal rent subsidies have been reduced; and the number of homeless has increased tremendously. Until the deficit is reduced, it is unlikely that tailored housing for elderly individuals and handicapper needs will be constructed with federal dollars. One housing option that would not require additional federal dollars would be to change the construction code to require all new housing to be spatially barrier-free (universal design). This would allowing everyone to grow old or become disabled in their existing home while expanding the housing stock for these populations.

Funding, however, is needed to enhance community support for services that enable persons to remain in their homes as long as possible. Persons are emotionally seeking the security of their home setting as a stable component to their lives. Many do not want others to know that they can no longer handle the home by themselves, and fear other future housing options. Whether to remain or leave becomes a stressful decision. Additional federal funds for home repair and chore services would reduce much of the physical stress for the older person caring for the home, as well as the psychological stress from worrying about a move. Providing financial incentives to family caregivers may support their involvement, therefore deterring the premature placement of older individuals into nursing homes. The need for these incentives will grow as the baby boom generation ages and as the demand for services drastically increases.

IMPLICATIONS FOR ECOLOGICAL FAMILY RESEARCH

An ecological approach to family research addresses the dynamics and the complexity of the family system. It is a system that evolves and changes over time and modifies itself to cope with varying events or crises that may occur. The synergy of the system denotes the relationship of the variables or factors comprising the system, and observes that one factor impacts on all other factors to varying degrees. The person- environment fit relationship is as dynamic as the ecological system. Fit is fragile and changes over time. Person- environment fit, for example, may work in the morning when the stroke survivor has more energy; yet may not function effectively as fatigue increases.

Many family studies address individual issues rather than family issues. For example, studies focus on the older individual or on the caregiver, but do not readily look at the relationship between the two or the impact on the overall family system. It is critical to study this relationship from the dynamics of the entire system. Doing so requires collaborative efforts from many disciplines. It can be a lengthy and costly process because ecological inquiry requires a qualitative approach.

In spite of the difficulties involved with conducting ecological studies, the breadth of data concerning the entire family system collected through this approach is well worth the time, energy and expense. A holistic perspective can more effectively be obtained from this methodology versus survey research.

FUTURE RESEARCH

Further research with the sample of ten stroke survivors and their families could shed light on longitudinal implications for person-environment fit. Exploring life a year or two after the stroke would identify permanent disabilities and housing adaptations families have or have not created to deal with the disabilities. Additional questioning could clarify some of the inconsistencies found in the data between closed and open-ended responses. An ethnographic approach could pursue some of the inconsistencies. Assessing the impact of long term caregiver strain in relation to both person-environment fit and caregiver coping strategies could enrich the literature in the study of- both caregiving and housing.

Studies should pursue the relationship between housing satisfaction in private homes of the elderly or handicappers and person-environment fit. Many older homeowners have strong emotional and financial attachment to a home environment that no longer fits their physical needs and causes frustration at every turn. The emotional commitment and satisfaction can not be denied. If homes were universally designed to accommodate growing old or becoming disabled, then making changes or moving would not be an issue. Data need to be collected concerning attitudes about universal design among younger homeowners. This hopefully would document favoritism for this housing option, providing the statistical push to encourage builders to supply this product. With time, younger cohorts could grow old or become disabled in their universally designed homes. The home, with its time, money and emotional attachment, would not have to be modified or abandoned when disability affected a family member. Universal design would not diminish the need for specialized housing options (eg. nursing facilities or age congregate housing), but with the rapidly increasing elderly population, demands for all types of housing will be critical.

Research to validate the person-environment fit scale should be explored with a quantitative methodology using a larger sample of elderly stroke survivors. Focus on fewer variables with a larger sample would refine the scale and more readily lend generalizability of findings to the population of older stroke patients. Testing the person-environment fit scale with a different population (eg. Alzheimer patients) would lend credence to the transferability of the research tool.

Further research should explore the extent to which medical personnel suggest physical environmental changes and related information to patients and their families. The present study only scratches the surface for this issue. The need for medical personnel to have additional training in housing and design issues should be explored, given the consultative role many of them play for stroke survivors and caregivers. In-service seminars or the inclusion of design content as a part of the core curriculum for visiting nurses, occupational, physical and speech therapists, social workers, and family professionals would enrich their practical knowledge for holistic family solutions.

In summary, there are many research endeavors awaiting attention. Person-environment fit has been discussed within the design community and for large scale housing complexes for the elderly population. Research on single family dwellings needs to continue because the majority of the current and future older cohorts will reside in their own homes. Stroke is one of many disabling conditions of aging. Those coping with other disabilities can benefit from person-environment fit research. Considering the physical environment as a tool for physical and psychological wellbeing will benefit those experiencing disabilities, their caregivers and service providers.

APPENDICES

APPENDIX A

APPENDIX A

ESTABLISHMENT OF SCALES FROM SURVEY INSTRUMENT

CAREGIVER INSTRUMENT:

Caregiver Strain Index (Robinson, 1983) CL1A 1-14 (yes/no)

1. Sleep disturbed.
2. Inconvenient to help.
3. Physical strain.
4. Confining - free time restricted.
5. Family adjustments were made.
6. Changes in personal plans.
7. Other demands on time.
8. Emotional adjustments.
9. Some of (SS) behavior is upsetting.
10. Upsetting to see the changes in (SS).
11. Work adjustments were made.
12. Financial strain.
13. Feel overwhelmed.
14. Total score of yes responses.

Scores (14) of one, two or three denoted low caregiver strain.
Scores (14) of ten, eleven, twelve, or thirteen denoted high caregiver strain.

Caregiving Behaviors:

Ordinal scale for CG30-48: almost never, seldom, sometimes, often, almost always.

CG30 Let others provide care when they offer.
CG31 Put off things because caring for (SS).
CG32 Let others stay with (SS) when go out for enjoyment.
CG33 Do things for (SS) as soon as he/she wants.
CG34 Let others care for (SS) when running errands.
CG35 Ask others for help when needed.
CG36 Call doctor/nurse when needed.
CG37 Do for (SS) since it takes him/her so long.
CG38 Put off taking care of own needs.
CG39 Reluctant to let strangers care for (SS).
CG40 Neglecting (SS) when doing own work.
CG41 Let (SS) do everything possible for self.
CG42 Hard to not do for family when caring for (SS).
CG43 Let others know what (SS) is trying to say.
CG44 Let others know how I feel.
CG45 Having to do new things scares me.
CG46 Try to do everything for (SS).
CG47 Patient with others.
CG48 Getting upset is not acceptable.

Scores from items 30, 33, 34, 35, 36, 41, 44, 46, 47, and 48 were averaged to create a composite score. A score of five was considered healthy caregiving behavior. Scores from items 31, 32, 37, 38, 39, 40, 42, 43, and 45 were averaged to create a composite score. A score of one was considered to be healthy caregiving behavior.

Help Seeking Behavior:

CL4 a-q (This section deals with the frequency of caregiver and family obtaining information and interacting with a variety of sources). Ordinal scale: never, once or twice a year, monthly, weekly, more than once a week.

a. Sharing our difficulties with relatives.
b. Seeking information and advice from persons in other families who have faced the same or similar problems
c. Seeking advice from relatives.
d. Asking neighbors for assistance and favors.
e. Accepting gifts and favors from neighbors.
f. Seeking information and advice from the family doctor
h. Facing problems head-on and trying to get solutions right away.
i. Watching television.
j. Attending church services.
k. Sharing concern with close friends.
l. Doing things with relatives.
m. Seeking professional counseling and help for family difficulties
n. Participating in church activities.
o. Asking relatives how they feel about problems we face
p. Seeking advice from a minister.
q. Sharing problems with neighbors.

Scores from all the above items were averaged to create a composite help-seeking score. A score of five denoted active help-seeking from a variety of sources.

APPENDIX B

MICHIGAN STATE UNIVERSITY
COLLEGE OF HUMAN ECOLOGY

THE EXPERIENCE OF STROKE AS A CRITICAL LIFE EVENT: SUPPORTIVE ECOSYSTEMS FOR OLDER PERSONS AND THEIR FAMILIES

SUBJECT SCREENING

My name is ____________________. I am calling from Michigan State University. We are working in conjunction with Bay Valley Home Health Service and are talking with patients and families who have experienced a stroke in the past six months. I understand ____________________________ may be one of those persons. (SS or "you")

Yes
No -- IF NO, CLARIFY, THANK AND TACTFULLY TERMINATE CALL.

Do you have a few minutes now that I could explain our study and see if ________________________ (SS or "you") is/are someone we would want to talk with?

Yes
No -- IF NO, when might be a better time for me to call back? (arrange time and then terminate call).

A group of concerned persons who teach at Michigan State University have received monies from the American Association of Retired Persons in order to talk with people who've had a stroke and their families. Our purpose is to understand more about the needs of people with strokes and their families. When we have talked with many people, we will put all the information together and be able to tell those persons who help stroke patients - doctors, nurses, social workers - more about how they could help people after they have had a stroke. While this won't directly benefit you right now, it will benefit other people in your situation in the future.

In order to determine if _____________(name or "you") are someone we might want to talk with I'd like to ask you a couple of questions.

1. Is this (SS) first stroke?
   1. yes
   0. no

2. (IF NO) How many previous strokes has (SS) had? _____________

IF TWO OR MORE, THANK PERSON AND TERMINATE.

GO TO PAGE 3, QUESTION 11.

3. (IF ONE PREVIOUS STROKE) How many years has it been since (SS) first stroke? ______________
(If less than 3 years, thank and terminate).

4. In what ways was (SS) affected by the first stroke? (prompt with physically, emotionally)?
____
____
____

5. Do you feel (SS) fully recovered from the first stroke?

1. yes
0. no

6. (IF NO) In what ways was (SS) still affected by that first stroke? ______________________
____

7. How did (SS) adjust to those changes? _________
____

____

8. What changes did you and your family have to make to adjust to those changes? _________________
____
____

9. (IF YES) So (SS) returned to his/her previous activities with no remaining difficulties?

1. yes
0. no (IF NO) CLARIFY - MAY NEED TO ASK "IF NO" QUESTIONS).

10. In what way(s) did the previous stroke affect how you and your family have handled this stroke? ___________
____
____

IF (SS) MEETS THE CRITERIA THUS FAR - CONTINUE ON WITH PAGE 3, QUESTION 11.

IF NOT, THANK PERSON FOR THEIR TIME, AND TERMINATE .

11. How old is (SS)? (IF SS DOES NOT MEET THE AGE CRITERIA FOR THE STUDY) -- thank person and terminate.

12. When did (SS) have the/this stroke? (IF LENGTH OF TIME DOES NOT MEET CRITERIA FOR THE STUDY) -- thank person and terminate.

13. Approximately how long did (SS) stay in the hospital?

14. Did (SS) come home directly from the hospital or did (SS) go to a rehabilitation center? (IF A REHAB CENTER) how long did (SS) remain at the rehabilitation center?

15. So (SS) has been home since approximately ____________?

16. Was (SS) affected in any way by the stroke? In what ways? (Physically, emotionally, cognitively, ability to communicate).

17. So (SS) would be able/unable to answer our questions ?

1. yes, able to answer
0. no, unable to answer

18. (IF UNABLE: would (SS) understand our questions and be able to signal yes or no, since the questions we will ask can all be answered that way.)

1. yes -able to signal answer
0. no- unable to signal answer

19. (IF NOT ABLE) Then we would not disturb (SS), but we would still like to talk with the person who provides care or is responsible for (SS) care.
Would that be you?

1.yes
0.no-(IF NO) DETERMINE WHO THAT PERSON IS AND MAKE ARRANGEMENTS TO CONTACT THAT PERSON. THANK PERSON AND TERMINATE CALL.

20. We would very much like to talk with (SS) and the person that provides care for (SS) or is responsible for (SS) care. Would that be you?

1. yes
0. no

21. (IF YES) We would very much like to talk with you if you would be willing to do that. While it will not benefit

you, it would be a benefit to other persons and their families who go through a stroke at some time in the future. Would you be willing to do talk with us?

1. yes
0. no (IF NO) Thank and terminate.

22. (IF YES) - Let me tell you how we will go about it.

Two of us will come to your home (IF SS IS NOT INTERVIEWED ONLY ONE WILL VISIT) at a time that is convenient. It should be a time when no other visitors (nurses, therapists or others) are there. (IF SS IS PARTICIPATING) One of us will talk with (SS) and the other will talk with you.(IF SS IS NOT PARTICIPATING-CONTINUE) It takes about 1 and 1/2 to 2 hours. If you (or SS) get tired at any time, we will stop, take a break or plan to continue at another time. All your answers are confidential -they are put together with the answers from all the other persons we talk to - so you remain anonymous. If you decide, at any time, you want to stop you are free to do so.

(IF SS IS TO BE INTERVIEWED)-- We need to plan a time that (SS) is rested. What time of day would be best for that?

One of the interviewers will come back the following week and talk with you only.

ARRANGE CONVENIENT TIME; GET TRAVEL DIRECTIONS; GIVE PERSON YOUR NAME AGAIN AND TELL HIM/HER YOU WILL CALL THEM THE DAY BEFORE IN ORDER TO CONFIRM THE APPOINTMENT AGAIN. THANK AND TERMINATE.

APPENDIX C

MICHIGAN STATE UNIVERSITY

COLLEGE OF HUMAN ECOLOGY
INSTITUTE FOR FAMILY AND CHILD STUDY

CONSENT FORM

I, ____________________, agree to participate in the study, "The Experience of Stroke as a Critical Life Event: Supportive Ecosystems for Older Persons and Their Families," which is being conducted by the Committee on Aging of the College of Human Ecology. The purpose of the study has been explained to me and I have been given the opportunity to ask questions. I understand that I will be asked to identify other persons (family members, friends, neighbors) who are important in providing me support. Unless one of these persons also agrees to participate, I will not be eligible for further participation in the study.

If I am selected to participate in the study, I understand that I will be interviewed and asked questions related to the needs and problems I have experienced since having a stroke. I also will be asked questions concerning my physical and mental health, my economic resources, and the services available to me. I will be asked similar questions in a follow-up interview in approximately six months.

The interviews will be taped. Tapes will be destroyed after they have been transcribed. I understand that one of the persons identified by me will be asked similar questions about me as well as their role in providing me support.

I understand that my participation in the study does not guarantee any beneficial results to me. I am free to discontinue my participation in the study at any time, and such action will have no influence on the care or services I receive. I also may decline to answer any questions I find unacceptable. I understand that my responses and all information about me will be treated in strict confidence and that I will remain anonymous. General results of the study will be made available to me at my request.

Signed ____________________________________ Date __________

Witness (if available)______________________

CONSENT FORM

I, ____________________________, agree to participate in the study "The Experience of Stroke as a Critical Life Event: Supportive Ecosystems for Older Persons and Their Families," which is being conducted by the Committee on Aging of the College of Human Ecology. The purpose of the study has been explained to me and I have been given the opportunity to ask questions. I understand that I will be asked questions related to the needs and problems which ____________________________ has experienced following a stroke. These questions cover areas such as physical and mental health, economic resources, and services utilized. I also will be asked questions related to the type and amount of support which I provide as well as questions that relate to the effect which provision of this support has had on me or my family.

I understand that I will be asked similar questions in a follow-up interview in approximately six months. These interviews will be taped, but the tapes will be destroyed after they have been transcribed.

I understand that my participation in the study does not guarantee any beneficial results to me. I am free to discontinue my participation in the study at any time and such action will have no influence on the care or services I receive. I also may decline to answer any questions I find unacceptable. I understand that my responses and all information about me will be treated in strict confidence and that I will remain anonymous. General results of the study will be made available to me at my request.

Signed: ____

Dated: ______________________________

APPENDIX D

STROKE SURVIVOR: INFORMANT

I1. Card/line # ______________________ 0 9

I2. Family ID# ______________________ __ __

I3. Respondent's ID ______________________ 2
(1) Stroke Survivor:Self
(2) Informant about stroke survivor
(3) Caregiver 1
(4) Caregiver 2

I4. Respondent's Address ______________________ __
Street & Number

____
City State Zip

CODE
1 Grand Rapids
2 Lansing
3 Flint

Respondent's Telephone # ( ) - ______________________

I5- Date of Interview ______________________ __ __
I7. (Month) (Day) Year
__ __
__ __

I8. Time Interview Began & Ended ______________________ __ __ __
(Compute length in minutes for coding)

I9. Interviewer's Name ______________________ __ __

I10. Relationship of Respondent to Stroke Survivor

______________________ __ __

01 Spouse
02 Daughter
03 Daughter-in-Law
04 Son
05 Son-in-law
06 Brother
07 Sister
08 Mother
09 Father
10 Mother-in-law
11 Father-in-law
12 Grandmother/father
13 Grandson/daughter
14 Other relative
15 Friend
16 Neighbor
17 Self: Stroke Survivor
18 Other (specify)
99 MD

Blank
(09/20)

IB14. How many full bathrooms are there in the home (includes sink, tub/shower, toilet)? ______

IB15. Are there any half bathrooms (sink and toilet only)?
1 Yes
0 No
9 Not answered

IB16. If YES: How many half baths are there? ______

IB17. Is the bathroom primarily used by (SS) on the same floor on which (SS) spends most of his/her time?
1 Yes
0 No
9 Not answered

IB18. Is there a bathroom next to the place where (SS) sleeps?
1 Yes
0 No
9 Not answered

IB19. How many bedrooms are there?
1 One
2 Two
3 Three
4 Four or more
9 Not answered

IB20. Were any bedroom adjustments made to accommodate (SS') needs following the stroke?
1 Yes
0 No
9 Not answered

IB21. If Yes: What adjustments were made?

A1 ______

A2 ______

A3 ______

(09/80)

Card # 1 0
FAM ID ___ ___
R ID ___

IB22. If a bedroom adjustment was made: How do the other people living in the home feel about the change?

A1 ______

A2 ______

(10/9)

IB23 Does (SS) share a bedroom with anyone?
1 Yes
0 No
9 Not answered

IB24. If YES: With whom does he/she share a bedroom?

(Relationship to (SS). Use codes for I10)

IB25. Are there problems with privacy among persons in the household?
1 Yes
0 No
9 Not answered

IB26. If YES, explain the problems with privacy.

IB27. Are there stairs at the main entrance on the outside of this home?
1 Yes
0 No
9 Not answered

IB28. If YES: Are there:
1 One or two steps
2 Three or more steps
3 A ramp is provided
4 Other (please specify) ____________________

IB29. Are there stairs at another outside entrance to this home?
1 Yes
0 No (mark no if there is no other entrance)
9 Not answered

IB30. If YES: Are there:
1 One or two steps
2 Three or more steps
3 A ramp is provided
4 Other (please specify) ____________________
9 Not answered

IB31. Are there stairs within the home?
1 Yes
0 No
9 Not answered

IB32. If YES: Are there:
1 One or two steps
2 One long flight of stairs
3 Two short flights of stairs with a landing
4 More than two flights within the home
5 A ramp or ramps are provided
6 Chair lift or elevator provided
7 Other (please specify) ____________________
8 Inappropriate
9 Not answered

(10/21)

IH6. Before the stroke how well could (SS) see--excellent, good, fair, poor, or is (SS) totally unable to see? ___

1 Totally unable to see
2 Poor
3 Fair
4 Good
5 Excellent
9 Not answered

IH7. How would you rate (SS') overall health before the stroke--excellent, good, fair, or poor? ___

1 Poor
2 Fair
3 Good
4 Excellent
9 Not answered

IH8. How much did (SS) health stand in the way of his/her doing the things he/she wanted to do before the stroke--not at all, a little (some), or a great deal? (14/36)

1 Not at all
2 A little (some)
3 A great deal
9 Not answered

In order to get a better picture of (SS) health condition before the stroke and now, I'd like to read you a list of health conditions that older people often experience.

Hand Informant pink card.

Interviewer: Coding will be done directly from the table.

1H9. Does (SS) have any of the following health conditions at the present time?
(If "YES") How much does it interfere with (SS) activities?
Did (SS) have the illness during the six months before the stroke?
(If "YES") How much did it interfere with (SS) activities?

	1	2	3	4
			(If SS has condition now)	
Illness	Present 1 Yes 0 No 8 DK 9 NA	How much it interferes 1 Not at all 2 A little 3 Moderately 4 A great deal 9 Not answered	6 months before stroke 1 Yes 0 No 8 DK 9 NA	How much it interfered 1 Not at all 2 A little 3 Moderately 4 A great deal 9 Not answered
a Arthritis or rheumatism	___	___	___	___
b Glaucoma	___	___	___	___
c Asthma	___	___	___	___
d Emphysema or chronic bronchitis	___	___	___	(14-52)
e Tuberculosis	___	___	___	___
f High blood pressure	___	___	___	___
g Low blood pressure	___	___	___	___
h Heart trouble	___	___	___	___
i Circulation trouble in arms or legs	___	___	___	___
j Diabetes	___	___	___	___
k Ulcers (of the digestive system	___	___	___	(14-80)
l Other stomach or intestinal disorders or gall bladder problems	___	___	___	(15-09)
m Liver disease	___	___	___	___
n Kidney disease	___	___	___	___
o Other urinary tract disorders (including prostate trouble)	___	___	___	___
p Cancer or Leukemia	___	___	___	___
q Anemia	___	___	___	___
r Parkinson's Disease	___	___	___	___
s Epilepsy	___	___	___	___
t Cerebral Palsy	___	___	___	___
u Multiple Sclerosis	___	___	___	___
v Muscular Dystrophy	___	___	___	(15-49)
w Effects of Polio	___	___	___	___
x Thyroid or other glandular disorders	___	___	___	___
y Skin disorders such as pressure sores, leg ulcers or severe burns	___	___	___	___
z Speech impediment or impairment	___	___	___	___
aa Allergies	___	___	___	(15-69)

Card # 1 5
Fam ID ___ ___
R ID ___

Interviewer: Coding will be done directly from table.

IH20. Does (SS) use any of the following aids all or most of the time <u>now</u>?

(IF YES) Did (SS) use them during the six months <u>before the stroke</u>?

1	2	
Now	Before the Stroke	
1 Yes 0 No 8 DK 9 NA	1 Yes 0 No 8 DK 9 NA	
___	___	a Cane (including tripod-tip cane)
___	___	b Walker
___	___	c Crutches
___	___	d Wheelchair
___	___	e Leg brace
___	___	f Back brace
___	___	g Artificial arm or leg
___	___	h Hearing aid
___	___	i Glasses, contacts or magnefying glass
___	___	j Dentures or partial plate
___	___	k Colostomy equipment
___	___	l Urinary catheter
___	___	m Breathing equipment
___	___	n Pacemaker
___	___	o Other 1. ________________ (specify)
___	___	p Other 2. ________________
___	(17/80)	q Other 3. ________________

Card # 1 8
FAM ID ___ ___
R ID ___

IH21. Of the devices (SS) has, does she/he need help using them (e.g. putting on glasses, leg brace, hearing aid)? ___
1 Yes
0 No
8 Inappropriate
9 Not answered

IH22. If YES: What help does (SS) need?

A1 ______________________ __ __

A2 ______________________ __ __

A3 ______________________ __ __

IH23. Does (SS) need any aids (supportive or prosthetic devices) that he/she currently does not have? ___
1 Yes
0 No
9 Not answered

IH24. If YES: What aids does (SS) need?

A1 ______________________ __ __

A2 ______________________ __ __

A3 ______________________ __ __

A4 ______________________ __ __

A5 ______________________ __ __

IH25. If an agency or insurance fund would pay for an aid or device, would this influence the decision to obtain it? (18/24)
1 Yes
0 No
8 Inappropriate
9 Not answered

IH27. We would like to know something about (SS's) physical health as a result of the stroke. I will mention some common physical problems and ask you if you, (SS), or family and friends have been affected and how you have coped.

A1. Does (SS) have weakness or paralysis of the arms or legs?

1 Yes

0 No — (Go to B1) →

If YES:

A2. Which arm or leg was affected?

1 Left arm only

2 Left leg only

3 Left arm and leg

4 Right arm only

5 Right leg only

6 Right arm and leg

A3. Is the arm and/or leg affected weakened or completely paralyzed?

1 Weakened

2 Completely paralyzed

What difficulties in daily living has this problem caused

A4. For (SS)?

A5. For the family and friends? (Probe for relationship to (SS)

What has been done to cope with this problem

A6. By (SS)?

A7. By family and friends? (Probe for relationship to (SS)

A8. Would aids, devices or changes to the home be helpful, if available? (Specify)

Blank

IH27.

__ B1. Does he/she have <u>loss or change in ability to feel sensations</u> in the arms and/or legs?

1 Yes
2 No — (Go to C1) →

If YES:

__ __
__ __
(18/80)

B2. Can you describe the changes that have occurred in how (SS) feels sensations?

Card # 1 9
FAM ID __ __
R ID __

(For Coding above answer)
01. Needles and pins sensations (paresthesias)
02. Sensations changed
03. Total loss of sensory feeling in affected arm and leg.

What difficulties have these sensory changes caused in everyday activities

__ __
__ __
B3. For (SS)?

__ __
__ __
B4. For family and friends? (Probe for relationship to SS)

What has been done to cope with these changes

__ __
__ __
B5. By (SS)?

__ __
__ __
B6. By family and friends? (Probe for relationship to SS)

Blank
(19/22)

IH27.

C1. Has there been any loss of coordination of voluntary movements such as walking, writing (ataxia)?

1 Yes

0 No ——(Go to D1)——→

If YES:

C2. Can you describe this loss of coordination of voluntary movement?

In what way does this loss of coordination of voluntary movements cause problems

C3. For (SS)?

C4. For family and friends? (Probe for relationship to SS)

What has been done to cope with the problems caused by this loss of voluntary movements

C5. By (SS)?

C6. For family and friends? (Probe for relationship to SS)

C7. Would aids, devices or structural changes be helpful if available?

Blank

(19/48)

IH27.

E1. Does (SS) experience any <u>jerkiness of movement</u> or does he/she hold any part of his/her body in a particular position? ___

1 Yes

0 No——(Go to F1)

IF YES:

E2. What parts of the body are affected and in what way are they affected? ___ ___

___ ___

___ (19/20)

Card # 2 0

FAM ID ___ ___

R ID ___

What problems does this movement cause

E3. For (SS)? ___ ___

___ ___

E4. For the family and friends? (Probe for relationship to SS) ___ ___

___ ___

What has been done to cope with these problems

E5. By (SS)? ___ ___

___ ___

E6. By family and friends? (Probe for relationship to SS) ___ ___

___ ___

Blank (20/22)

IH27.

___ N1. Does SS have problems judging distances, recognizing common objects or doing activities he/she did prior to stroke?

1 Yes
0 No——(Go to O1)

If YES:

___ ___ N2. What kinds of changes has (SS) experienced?

(22/80)

Card # 2 3
FAM ID ___ ___
R ID ___

(For Coding of above answer)
01 Impaired judgment of depth, height, or width
02 Difficulty recognizing how to use common objects
03 Unable to get started with or do an activity (SS) knows how to do

What kinds of difficulties have these changes problems caused

___ ___
___ ___ N3. For (SS)?

___ ___
___ ___ N4. For family and friends? (Probe for relationship to SS)

What has been done to adjust to these changes

___ ___
___ ___ N5. By (SS)?

___ ___
___ ___ N6. By family and friends? (Probe for relationship to SS)

___ ___ N7. Would aids, devices or changes to the home would be helpful, if available? (e.g., marking stairs, outlining counters, or sinks to provide visual clues for depth perception, etc.)

Blank
(23/24)

Card # 2 5
FAM ID ___ ___
R ID ___

Interviewer: Code directly from table.

I will now read a list of frequent daily activities. Some of these I may have asked you about before, however we would like a complete picture of (SS) daily routine. Please tell me if (SS) (Hand informant black card)

1 Needed help before the stroke.
2 Cannot do at this time.
3 Can do with aids or devices
4 Can do with help from others.
5 Can do without help.
9 No answer

Instrumental ADL

IH28. Using Telephone ____

IH29. Driving ____

IH30. Using public transportation ____

IH31. Shopping for groceries or clothes ____

IH32. Preparing own meal ____

IH33. Do light housework (e.g. dust, do dishes) ____

IH34. Do heavy housework (vacuum, scrub floors, take out garbarge/trash) ____

Physical ADL

IH35. Can eat ____

IH36. Can dress and undress ____

IH37. Can do personal grooming (e.g. combing hair, shaving) ____

IH38. Can walk on a level surface ____

IH39. Can go up and down stairs ____

IH40. Can get in and out of bed ____

IH41. Can take a bath or shower ____

IH42. Has bladder control ____

IH43. Has bowel control ____

IH44. Can get on and off of toilet

Blank
(25/23)

CAREGIVER: SELF

C1. Card/line # ______________________ 3 3

C2. Family ID# ______________________ __ __

C3. Respondent's ID 3
(1) Stroke Survivor:Self
(2) Informant about stroke survivor
(3) Caregiver 1
(4) Caregiver 2

C4. Respondent's Address ______________________ __
Street & Number

____
City State Zip

CODE
1 Grand Rapids
2 Lansing
3 Flint

Respondent's Telephone # ( ) -

C5- Date of Interview ______________________ __ __
C7. (Month) (Day) Year
__ __
__ __

C8. Time Interview Began & Ended ______________________ __ __ __
(Compute length in minutes for coding)

C9. Interviewer's Name ______________________ __ __

C10. Relationship of Respondent to Stroke Survivor

______________________ __ __

01 Spouse
02 Daughter
03 Daughter-in-Law
04 Son
05 Son-in-law
06 Brother
07 Sister
08 Mother
09 Father
10 Mother-in-law
11 Father-in-law
12 Grandmother/father
13 Grandson/daughter
14 Other relative
15 Friend
16 Neighbor
17 Self: Stroke Survivor
18 Other (specify)
99 MD

Blank
(33/20)

A. SOCIODEMOGRAPHIC INFORMATION

Interviewer: Please indicate the following about the subject.

CA1. Sex of Subject
1 Male
2 Female

CA2. Race of Subject
1 White (Caucasian)
2 Black (Negro)
3 Oriental
4 Spanish American (Spanish surname)
5 American Indian
6 Other
9 Not answered

We'd like to begin by asking you a few general informational questions.

CA3. When were you born? ____________________
(Month) (Day) (Year)

CA4. How many years of school have you completed?
1 0-4 years
2 5-8 years
3 High school incomplete
4 High school completed
5 Post high school, business or trade school
6 1-3 years college
7 4 years college completed, BS Degree
8 Post graduate college, MA, Ph.D., Ed.d
9 Not answered

CA5. Are you single, married, widowed, divorced, separated, or remarried?
1 Single
2 Married
3 Widowed
4 Divorced
5 Separated
6 Remarried
9 Not answered

CA6. What is your religious preference? ____________

3 Blanks
(33/35)

B. HOUSING

I'd like to ask you some questions about your housing or living arrangements.

CB1. Do you own or rent your home? ___

1 Own
2 Rent
3 Does not own or rent but lives with someone else.
9 Not answered

CB2. Do you receive any help in paying for your home? ___

1 Yes
0 No
9 Not answered

CB3. If YES: From what sources is help received?

A1 ______________________ ___ ___
A2 ______________________ ___ ___

CB4. Interviewer: Does (SS) live with caregiver? ___

1 Yes ________ Go to CB25., Page 9
0 No ________

CB5. What type of home do you live in? ___

1 Single family home
2 Apartment
3 Trailer/mobile home
4 Condominium/cooperative
5 Complex for the elderly
6 Other ______________________
9 Not answered

CB6. Who lives with you? (Code relationship to Caregiver as in C10)

A1 ______________________ ___ ___
A2 ______________________ ___ ___
A3 ______________________ ___ ___
A4 ______________________ ___ ___
A5 ______________________ ___ ___

CB7. How many miles is your home from (SS) home? ________ ___ ___ ___

7 Blanks
(33/63)

If Caregiver and (SS) live in the same home, ask questions CB25 - CB36.

CB25. Has it been a common practice in your family or your spouse's family for the older family members to live with other family members? __
1 Yes
0 No
9 Not answered

CB26. Since (SS) stroke, have you noticed any problems in caring for your home (eg. keeping up with cleaning, repairs, etc.)? __
1 Yes
0 No
9 Not answered

CB27. If YES: explain

A1 ______________________________ __ __

A2 ______________________________ __ __

CB28. Have you noticed an increase in your housing expenses since (SS) stroke (eg. higher utility bills, hiring housekeeping or lawn care)? __
1 Yes
0 No
9 Not answered

CB29. If YES: What expenses have increased?

A1 ______________________________ __ __

A2 ______________________________ __ __

CB30. In general, would you say this living arrangement has worked out well for those involved? __
1 Yes
0 No
9 Not answered

CB31. If NO: Please explain

A1 ______________________________ __ __

A2 ______________________________

4 Blanks
(34/64)

__ CB32. Have you considered alternative housing arrangements for (SS) future (eg. moving family to different home, moving (SS) to another relative's home, moving (SS) to nursing home, etc.)?

1 Yes →
0 No
9 Not answered

CB33. If YES: What housing arrangements have *you considered*?

__ __ A1 ________________________

__ __ A2 ________________________

CB34. Why have you considered these housing arrangements?

__ __ A1 ________________________

__ __ A2 ________________________

CB35. How do you or family members feel about these arrangements?

__ __ A1 ________________________

__ __ A2 ________________________

__ __ CB36. If you could choose any type of living arrangement for yourself and (SS), what would that be like?

____

____

____

____

Blank
(34/80)

Card # 3 5
Fam ID __ __
R I D __ 3

D. FINANCIAL RESOURCES

To get an accurate financial picture of the families in our study, we need to know something about your work and income.

CD1. Are you working for pay; either full or part-time? (Please circle as many as apply) __ __

01 Yes, employed full-time (35+ hours/week) or with a job but not at work at present because of temporary illness, vacation, or strike.
02 Yes, employed part-time (less than 35 hours/week)
03 Unemployed, laid off, looking for work.
04 Full-time homemaker.
05 Retired.
06 In school part-time
07 In school full time
08 Disabled
09 Other (Please specify ______________________)
99 NA

(If not working, skip to CD5, page 14

CD2. (If working) Please give us some information about the type of work you do now. __ __ __

A1 What is your main occupation or job title?

____

A2 What kind of work do you do; that is, what are your main duties on the job?

____

A3 In what type of business or industry is this; that is, what product is made or what service is given? ______________

9 Not answered

CD3. Do you have any other job in addition to your main job? __

1 Yes
0 No
9 Not answered

CD4. A1 (IF YES) What is your job title? __ (35/71)

____

A2 What kind of work do you do; that is, what are your main duties on this second job?

____

A3 In what type of business or industry was that?

____

999 Not Answered
997 Inappropriate: C not working

CD9. Next, think about the total income for 1986 received by you and your family C. This is the total income before taxes from all sources including social security, pensions, investments or interest. (Circle the letter of the category that is closest to your total family income.) (Hand C blue card)

01 $4,999 or less
02 $5,000-$9,999
03 $10,000-$14,999
04 $15,000-$19,999
05 $20,000-$29,999
06 $30,000-39,999
07 $40,000-49,999
08 $50,000-$59,999
09 $60,000 -$69,999
10 $70,000-$79,999
11 $80,000-$89,999
12 $90,000 and up
99 Not answered

CD10. How many people live on this income---that is, it provides at least half of their support? ____________

CD11. Think about your financial resources before (SS) stroke occurred and now. Has your financial situation changed from what it was before the stroke?

1 Yes
0 No
9 Not answered

CD12. If YES: In what ways has it changed?

A1 ________________________________

A2 ________________________________

A3 ________________________________

CD13. What have you had to do to adjust to these changes in your financial situation?

A1 ________________________________

A2 ________________________________

A3 ________________________________

CD14. Have money issues related to (SS) stroke and care affected you and your family? For example, disagreement among family members (spouses, brothers, sisters, etc.); changes in physical health, social and recreational activities, emotional changes or spending behavior: (If family member is affected, then probe for relationship to Caregiver).

A1 ________________________________

A2 ________________________________

A3 ________________________________

8 Blanks
(36/36)

___ CD15. Do you feel your income

1 is not enough to meet all bills and expenses.
2 is just enough to meet necessities but nothing extra.
3 is enough to meet necessities and <u>some</u> extras or small luxuries.
4 is enough to not cause financial worries.
9 Not answered

If C's perception of income sufficiency is #1 or #2 above, ask the following questions. If response is #3 or #4, skip to Social Resources, Section E, page 18)

___ CD16. Is your financial situation such that you feel you need financial assistance or help beyond what you are already getting?

1 Yes →
0 No
9 Not answered

CD17. If YES: What would you need financial assistance to cover?

___ ___ A1 ____________________

___ ___ A2 ____________________

___ ___ A3 ____________________

CD18. From where have you tried to get financial assistance?

___ ___ A1 ____________________

___ ___ A2 ____________________

___ ___ A3 ____________________

CD19. **(If Caregiver tried but didn't get financial assistance)** What stopped you from receiving financial assistance?

___ ___ A1 ____________________

___ ___ A2 ____________________

___ ___ A3 ____________________

8 Blanks
(36/64)

E. SOCIAL RESOURCES

I'd like to turn our attention now to the people you might spend time with.

___ CE1. How important is it for you to have regular visits from your friends or relatives?

1 Very unimportant
2 Unimportant
3 Somewhat important
4 Important
5 Very important
9 Not answered

___ CE2. Since you have been caring for (SS) have you been able to visit with friends or relatives besides those persons who live with you?

1 Yes
0 No
9 Not answered

___ CE3. How often have friends stopped by or called to visit?

1 Rarely
2 Couple times a month
3 Weekly (about once a week)
4 Three or four times a week
5 Daily
9 Not answered

___ CE4. In general, do you see your friends or relatives as much as you want to?

36/68)

1 No - I want to see them less often than I do now.
2 Yes
3 No - I want to see them more often than I do now.
8 Inappropriate
9 Not answered

CE5. How important is it to you to receive attention or recognition from those around you? ___
1 Very unimportant
2 Unimportant
3 Somewhat important
4 Important
5 Very important
9 Not answered

CE6. Do you have relatives or friends that you could talk with about almost anything you wanted to? ___
1 Yes
0 No
9 Not answered

CE7. If YES: Who would those relatives and friends be?

	Name	Relationship (to caregiver)		
A1	______________________		___	___
A2	______________________		___	___
A3	______________________		___	___
A4	______________________		___	___
A5	______________________		___	(36/80

(If only spouse named above) Would there be anyone other than your husband/wife?

Card # 3 7
FAM ID ___ ___
R ID ___ 3

___ CE8. Are there any people who would help you with your own personal needs or responsibilities if you asked them?

1 Yes
0 No
9 Not answered

CE9. If YES: Who are these people?

A1A ___ ___
A1B ___ ___
A2A ___ ___
A2B ___ ___
A3A ___ ___
A3B ___ ___
A4A ___ ___
A4B ___ ___
A5A ___ ___
A5B ___ ___

	Name	A Relationship (to caregiver) (code as C10)	B Type of help
A1	________	________	________
A2	________	________	________
A3	________	________	________
A4	________	________	________
A5	________	________	________

(If only spouse named above) Is there someone else, besides your husband/wife?

___ ___ CE10. Of all the persons you know, including family, friends and neighbors, who do you feel provides the most support or help to you?

____
(Name and relationship to caregiver (use codes C10)

___ CE11. Do you feel you have as much say in (SS) care as you would like?

1 Yes
0 No
9 Not answered

CE12. If NO: what makes it difficult for you to have as much say in (SS) care as you would like?

___ ___ A1 ____
___ ___ A2 ____
A3 ____

(37/35)

F. MENTAL HEALTH

Next, I'd like to ask you some questions about how you feel about life in general.

____ CF1. How often would you say you worry about things -- very often, fairly often, or hardly ever?
3 Very often
2 Fairly often
1 Hardly ever
9 Not answered

____ CF2. In general, do you find life exciting, pretty routine, or dull?
1 Dull
2 Pretty routine
3 Exciting
9 Not anwered

____ CF3. Taking everything into consideration how would you describe your satisfaction with life in general at the present time -- good, fair, or poor?
3 Good
2 Fair
1 Poor
9 Not answered

____ CF4. How would you rate your mental or emotional health at the present time -- excellent, good, fair, or poor?
1 Poor
2 Fair
3 Good
4 Excellent
9 Not answered

(38/41) CF5. Is your mental or emotional health now better, about the same, or worse than it was prior to (SS) stroke?
3 Better
2 About the same
1 Worse
9 Not answered

G. CAREGIVING /RECEIVING

CG1. Now please tell me how you think (SS) is doing compared to when he/she left the hospital. Is s/he doing:

5 Much better
4 Somewhat better
3 About the same
2 Somewhat worse
1 Much worse
9 Not answered

COMPETENCY/CONCERN

When a person gets out of the hospital, those who care for him/her are faced with a new situation. Looking over the time since (SS) was released from the hospital, first tell me how prepared you felt for the following situations and second, how much worry or concern they are for you <u>now</u>? **(Interviewer: Code directly into the table. Hand caregiver light blue card.)**

A1	<u>Competency Scale</u>	A2	<u>Concern Scale</u>
1	Not at all prepared	1	No concern at all
2	A little prepared	2	Very little concern
3	Somewhat prepared	3	Some concern
4	Very prepared	4	Quite a bit of concern
5	Completely prepared	5	A great deal of concern
8	Not appropriate	8	Not appropriate
9	Not answered	9	Not answered

A1 Competency	A2 Concern	
____	____	CG2. Knowing who to contact when you had questions about (SS) care or health.
____	____	CG3. Knowing what equipment or devices were needed and where to get them.
____	____	CG4. Dealing with the amount of time care-giving would take.
____	____	CG5. Deciding when to call the doctor or nurse about (SS).
____	____	CG6. Dealing with your own emotional feelings about caring for (SS).
____	____	CG7. Knowing where to call for helping services you or (SS) needed.
____	____	CG8. Knowing where to seek emergency assistance.
____	____	CG9. Having persons you don't know well coming in to help.
____	(39/80)	CG10. Dealing with the (SS) limitations.

Card # 3 9
Fam I D __ __
R ID __ 3

CG11. Knowing how to give the physical care (SS) needed, such as bathing, getting in and out of bed, walking, exercises. ____ ____

CG12. Giving (SS) the right medicine on time. ____ ____

CG13. Dealing with the things you needed to do besides caring for (SS). ____ ____

CG14. Knowing what services were covered by insurances. ____ ____

CG15. Dealing with (SS) emotional upsets. ____ ____

CG16. Adjusting to the changes in your life. ____ ____

CG17. Knowing what progress to expect (SS) to make. ____ ____

CG18. Having enough information on what strokes are all about. ____ ____

CG19. Knowing what changes to make to the inside or outside of the house. ____ ____

CG20. Finding someone to make these changes to the house. ____ ____

The following are possible areas of concern for people who care for a family member. Using column two on your card, can you tell me how much worry or concern the following are for you?

CG21. Leaving (SS) with others while you go out. ____

CG22. Not getting everything done each day. ____

CG23. Not understanding what (SS) is trying to say. ____

CG24. Not having some time to yourself. ____

CG25. Not knowing when to let (SS) do things for him/herself. ____

CG26. Wondering if anyone else feels the way you do. ____

CG27. Asking too much of other people. ____

CG28. Having <u>too</u> many different agency people coming in. ____

CG29. Needing <u>one</u> person to organize or coordinate the kind of help (SS) needs ____

(39/34)

Interviewer: Code directly from the table

BEHAVIORS

Now I will read some general statements about you and (SS), and about you and others. Please tell me how frequently these are true for you. (Hand C gray card)

1. Almost never
2. Seldom
3. Sometimes
4. Often
5. Almost always
9. Not answered

____ CG30. I let other family members or friends provide care for (SS) when they offer.

____ CG31. I put off other things I need to do because I am caring for (SS).

____ CG32. I let others stay with (SS) while I go out for a little enjoyment.

____ CG33. I try to do things for (SS) as soon as he/she wants me to.

____ CG34. I let others take care of (SS) while I go out on errands.

____ CG35. I ask others for help when I need it.

____ CG36. I call the doctor or nurse when I have any questions.

____ CG37. I do things for (SS) since it takes him/her so long to do them.

____ CG38. I put off taking care of my own needs.

____ CG39. I am reluctant to let people I don't know well, from agencies or the community, care for (SS).

____ CG40. I feel I am neglecting (SS) when I do my other work.

____ CG41. I let (SS) do everything possible for him/herself.

____ CG42. I find it hard when I can't do things for other family members because I am caring for (SS).

____ CG43. I let others know what (SS) is trying to say.

____ CG44. I let others know how I really feel.

____ CG45. Having to do new things scares me.

____ CG46. I try to do everything for (SS).

____ CG47. I am patient with others.

____ (39/53) CG48. Getting upset is not acceptable to me, no matter what the reason.

CG49. Non variable, no coding.

H. PHYSICAL HEALTH

We would like to ask you a few questions about your health.

____ CH1. How would you rate your overall health before (SS) stroke--excellent, good, fair, or poor?
1 Poor
2 Fair
3 Good
4 Excellent
9 Not answered

____ CH2. Before (SS) stroke did your health stand in the way of your doing the things you wanted to do?
1 Yes
0 No
9 Not answered

____ CH3. Has (SS) stroke affected your pattern of physical activity or exercise?
1 Yes
0 No
9 Not answered

CH4. If YES: In what ways has it been affected?

____ ____ A1 ____________________
____ ____ A2 ____________________
____ ____ A3 ____________________

____ CH5. Do you have any health problems or illnesses?
1 Yes
0 No (IF NO, Skip to page 42)
9 Not answered

CH6. If YES: What are these health problems?

____ ____ A1 ____________________
____ ____ A2 ____________________
____ ____ A3 ____________________
____ ____ A4 ____________________
____ (40/59) A5 ____________________

CH7. Do any of your health problems make it more difficult to care for (SS)? __

1 Yes
0 No
9 Not answered

CH8. If YES: In what ways

A1 ____________________ __ __

A2 ____________________ __ __

A3 ____________________ __ __

CH9. Have any of your health problems increased because of caring for (SS). __

1 Yes
0 No
9 Not answered

CH10. If YES: In what ways have these problems increased?

A1 ____________________ __ __

A2 ____________________ __ __

A3 ____________________ __ __

CH11. Are any of these health problems new since (SS) stroke? __

1 Yes
0 No
9 Not answered

CH12. If YES: Can you tell me what these health problems are?

A1 ____________________ __ __

A2 ____________________ __ __

A3 ____________________

__(40/80)

CI4. Has your involvement in caring for (SS) affected your own diet or nutrition in any of the following ways:

CI4A1. The amount of food you eat?
1 Yes
0 No
9 Not answered

CI4A2. If YES: In what way?

CI4B1. How often you eat with friends?
1 Yes
0 No
9 Not answered

CI4B2. If YES: In what way?

CI4C1. How often you eat out?
1 Yes
0 No
9 Now answered

CI4C2. If YES: In what way?

CI4D1. How well-balanced your meals are?
1 Yes
0 No
9 Not answered

CI4D2. If YES: In what way?

(41/58)

CI4E1. The amount of time you have for grocery shopping and meal preparation?
1 Yes
0 No
9 Not answered

CI4E2. If YES: In what way?

CI5. Has your involvement in caring for (SS) affected your own diet or nutrition in any other way? For example, has your weight changed, has your appetite changed?

1 Yes
0 No
9 Not answered

CI6. If YES: In what way?

A1

A2

A3

(41/68)

Interviewer: Code directly from table.

CL4. We are interested in you and your family's general reactions to stressful events. How frequently are the following statements characteristic of you and your family? (Hand C yellow card).

1 Never
2 Once or twice a year
3 Monthly
4 Weekly
5 More than once a week

___ a Sharing our difficulties with relatives

___ b Seeking information and advice from persons in other families who have faced the same or similar problems

___ c Seeking advice from relatives (grandparents, etc)

___ d Asking neighbors for assistance and favors

___ e Seeking assistance from community agencies and programs designed to help families in our situation

___ f Accepting gifts and favors from neighbors (food, taking in mail, etc.)

___ g Seeking information and advice from the family doctor

___ h Facing problems "head-on" and trying to get solutions right away

___ i Watching television

___ j Attending church services

___ k Sharing concern with close friends

___ l Doing things with relatives (get togethers, dinners, etc.)

___ m Seeking professional counseling and help for family difficulties

___ n Participating in church activities

___ o Asking relatives how they feel about problems we face

___ p Seeking advice from a minister

q Sharing problems with neighbors

(43/58)

22 Blanks
(43/80)

Card # 4 4
Fam Id ___
R ID ___ 3

Card # 5 3
Fam ID __ __
R ID __ 3

J. COMMUNITY SERVICES

~~In our next interview we will talk about the Community services that~~ (SS) receives. Today we would like to focus on the community services you or other family members use.

CJ1. Are there services which you are currently using which in some way assist you in adapting to your care-providing role? (e.g., transportation, handling legal matters, counseling, church assistance) __

1 Yes
0 No
9 Not answered

CJ2. If yes: What are these services?

A1 ______ __ __
A2 ______ __ __
A3 ______ __ __
A4 ______ __ __
A5 ______ __ __
A6 ______ __ __

CJ3. Are there community services which you or other family members would like to receive? __

1 Yes
0 No
9 Not answered

CJ4. If Yes: What are these services?

A1 ______ __ __
A2 ______ __ __
A3 ______ __ (53/25)

APPENDIX E

MICHIGAN STATE UNIVERSITY

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
206 BERKEY HALL
(517) 353-9738

EAST LANSING • MICHIGAN • 48824-1111

August 3, 1988

IRB# 88-282

Deborah L. deLaski-Smith
501 Victoria Sq.
Brighton, MI 48116

Dear Ms. deLaski-Smith:

Subject: "CAREGIVER CHARACTERISTICS THAT CONTRIBUTE TO PERSON-ENVIRONMENT FIT FOR OLDER STROKE SURVIVORS: A QUALITATIVE, EXPLORITORY STUDY IRB# 88-282"

The above project is exempt from full UCRIHS review. I have reviewed the proposed research protocol and find that the rights and welfare of human subjects appear to be protected. You have approval to conduct the research.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval one month prior to August 3, 1989.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

John K. Hudzik, Ph.D.
Chair, UCRIHS

JKH/sar

cc: B. Ames

LIST OF REFERENCES

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