Title

Families living with senile brain disease

Author

Hirschfeld, Miriam Judith

Publication Date

1978

FAMILIES LIVING WITH SENILE BRAIN DISEASE

by

Miriam Judith Hirschfeld
B.A., Tel-Aviv University 1973
M.S., University of California, San Francisco 1973

DISSERTATION

Submitted in partial satisfaction of the requirements for the degree of

DOCTOR OF NURSING SCIENCE

in the

GRADUATE DIVISION

(San Francisco)

of the

UNIVERSITY OF CALIFORNIA

[redacted]

Date Librarian

Degree Conferred: JUN 25 1978

ABSTRACT

Life with senile brain disease was studied by interviewing 30 impaired persons and their 30 caregivers living in one household. The impaired persons' and their caregiving family members' physical health, mental health, social resources, economic resources, and performance level for activities of daily living were assessed by the OARS Multidimensional Functional Assessment Questionnaire. Through focused interviews and participant observation, the investigator also assessed the problems these families were facing in the presence of senile brain disease.

A wide array of problems resulting from the disease itself, the caregiving situation, and the wider social context confront these families. While not one of the impairment measures from either the impaired person or the caregiver determined a family's ability to continue home care, the tension resulting from the disease and the caregiving situation did. The Lewinian term tension denotes the number and kind of highly valued unmet needs.

Two major typologies emerged from this exploratory study. The first describes a range of dyadic interaction leading to what the author has described as types of mutuality. These mutuality types (the quality of the dyadic relationship) seem to have a major influence upon these families' quality of life. The second typology combined mutuality, tension, and the families' management ability to describe different family situations. This typology is predictive of families' capacity to care for a person with senile brain disease at home. The following equation describes the interrelationships of these variables along with the role that can be played by nursing intervention in maximizing the family's capacity to care for a severely disabled old person:

$$\begin{array}{l}\text{Capacity to}\\ \text{care for a}\\ \text{senile brain}\\ \text{diseased}\\ \text{person in}\\ \text{the home}\end{array} = \left[\frac{\text{Management Ability} + \text{Mutuality}}{\text{Tension}}\right] \cdot \left[\begin{array}{l}\text{Nursing}\\ \text{Intervention}\end{array}\right]$$

The lower the perceived tension and the higher a family's mutuality and management ability, the less likely they were to consider institutionalization.

Several implications for health service were derived from the study: (1) the need to educate health care professionals to recognize the prime importance of cognitive decline in old age, assess its source, and distinguish between acute reversible and chronic irreversible brain syndromes; (2) the need to reorganize the health care system and its financing so that families coping with physical and mental decline could receive support before a breaking point is reached; and (3) the development of programs specifically designed to alleviate the family impact of caring for a severely impaired kin.

This study suggested the need for research in four major areas: (1) methological research to establish the armamentaria necessary to measure family impact; (2) added knowledge on the development of family coping over time in relation to the length of the caregiving situation, the kind of impairment, and the point on the individual and family life cycle; (3) evaluative program research in regard to services for families living with senile brain disease; and (4) cross cultural research on families in caregiving situations.

ACKNOWLEDGEMENTS

I appreciate the support of the many individuals who have helped in the process of completing this dissertation.

Foremost, I wish to thank the families who accepted me into their homes and so generously shared their valuable insights, feelings, and time with me. I am very grateful to the members of my committee who consistently provided guidance and support. Dr. Anne J. Davis, my major adviser, has been a source of intellectual stimulation and encouragement throughout my graduate education. Dr. Jeanne C. Hallburg gave generously of her time and knowledge; Dr. Majda T. Thurnher's guidance in the area of adult development and research was of major importance for this dissertation; Dr. M. Margaret Clark offered provocative criticisms and most valuable suggestions. I am appreciative for the individual contributions of each of the committee members, as well as for their collective facilitation of my work.

I especially want to thank Tamar Krulik for her unconditional friendship and intellectual clarity which were crucial to this effort.

The following sources of economic support are gratefully acknowledged: Tel-Aviv University, Keren Avi Fund; Kupat Holim; Graduate Division - UCSF, Earl C. Anthony Fund;

and the Association for the Planning and Development of Services for the Aged in Israel. Without the support of Tel-Aviv University, my graduate study would not have been possible.

I wish to thank the many health professionals and the institutions they were affiliated with for enabling me to contact the study population. In particular, I thank Mr. Sid Friedman and his staff at the Jewish Home for the Aged, San Francisco, for their important help.

I am thankful to my colleagues in Israel for their encouragement. In particular, I wish to thank Dr. Rebecca Bergman and Dr. Rifka Adams for their active interest and support throughout my professional career.

A special note of thanks is extended to my fellow doctoral students at UCSF for their warmth and spirit of cooperation.

Finally, I would like to thank Dr. Alan Bostrum for his major assistance with the statistical and computer analysis, Mary Ann Holstein for transcribing the interview tapes, Sayo Nakagawa for typing the dissertation, and Nellie Cady for facilitating financial support through the UCSF Graduate Division.

There are many individuals who have had an important impact upon my personal and professional life, thereby contributing to this dissertation. I wish to thank all of them.

San Francisco June 14, 1978

TABLE OF CONTENTS

LIST OF TABLES

LIST OF DIAGRAMS

CHAPTER I

INTRODUCTION

This study has as its purpose to examine the impact of living with senile brain disease upon the family. The importance of such a study can be demonstrated by first viewing it in the larger social context.

> What we are witnessing in the 'developed' societies of today is something that has never existed before on the present scale in human history: it is the Survival of the Unfittest. The advances made in this century by medicine and the social services have combined to reverse a biological law. No longer are the unfit eliminated; instead they are nurtured and protected. Man, alone among the animals, is now provided with the means of survival in a state of unfitness. It is now normal for life to close, as it began, with a period of prolonged dependency; but whereas we have for long organized our society to care for the helpless infant and the developing child, we are only beginning to seek means of dealing with the problems created by dependency in old age . . . (Old people are desperate for help), not because famil(ies) neglect (them), not because there (is) a shortage of beds or residential homes, but because the full implication of the biological change that has been taking place in these last two or three decades has yet to be grasped (Isaacs, Livingstone, and Neville, 1972, p. 3).

Worldwide the older population is increasing and predictions indicate the largest increase for the old old-age group of 75 and over (Brotman, 1977a). One consequence of the life span prolongation points to an increase in the number of elderly with senile brain disease. The statistics agree that these brain syndromes become more frequent with rising age, until in the over 80 age group, as many as 20 percent of the population may be affected (Kay, 1972).

Synonymous terms such as senile brain disease, chronic brain syndrome, organic brain syndrome, senile dementia, and cognitive impairment, describe the deterioration of mental processes. The individual can no longer store new facts and loses the ability to retrieve and synthesize past or present facts or experiences in order to plan for the future. One experiences confusion of time, of physical environment, and of his relation to the environment. If death does not intervene, the disease progresses so that the individual experiences complete helplessness, loss of ability to communicate verbally, loss of sphincter control, and total dependency (Berry, 1975; Pfeiffer, 1977). The most crucial fact remains that, at our present state of knowledge, this process is irreversible.

The size and impact of this problem in human and in economic terms is staggering. While large numbers of old people with senile brain disease at different stages live in the community, either alone or with their families (Isaacs *et al.*, 1972; Wang, 1977), at least half the population of the institutionalized aged (about 500,000 old people presently and a projected one million persons by the year 2000 in the United States alone) suffer from irreversible brain disease. The cost for the nursing care of those institutionalized aged 75 and over suffering from senile brain disease will amount to 80 percent of the total current USA medical care expenditure for all aged 65 plus. This conservative cost projection for the year 2000 (Wershow, 1974, 1977) does not include the amount of human suffering for the affected old person himself, for his family and friends, and even for the professional caregivers (it is not easy to face mental decline and disintegration eight hours a day, five days a week).

While the extent and impact of senile brain disease presents a social problem and a personal tragedy, one of the most profound aspects of this tragedy can be found in the misuse of this label. It is a common phenomenon that people dismiss an older person as "senile" with the often terrifying consequences of medical neglect and/or institutionalization when he exhibits reversible symptoms of apathy, confusion, or disorientation caused by a wide array of circumstances (Butler, 1975). The age related losses of health, income, social status, the impact of multiple deaths, acute and chronic physical illness, and sensory loss and deprivation can all be the cause of the cognitive impairment of an acute brain syndrome. A change in mental status remains the commonest presenting symptom of something going wrong with an aged person (Agate, 1971).

Limited answers to acute brain syndromes include our being aware of the immense danger inherent in false labeling, attempting to prevent, and when too late for prevention, treating the underlying causes of cognitive change. However, these answers do not address the problem of the "true" senile brain diseases. The "no answer" situation, despite the epidemic proportions of senile dementia and the problems it presents, stems from the fact that it remains a taboo topic (Wershow, 1977). The prerequisite for a search to answers is that ". . . one must acknowledge the importance of bringing the issue (of senile brain disease) out of the closet, into the classrooms, on to the planning tables, and ultimately up to the decision-makers" (Cohen, 1977, p. 295).

Vital Health Statistics (1973) estimate 260,000 elderly living in the community suffer from senile brain disease in the USA today. This would lead us to a conservative estimate of half a million directly affected family members. Considering the scope of the problem, only minimal amounts of research have been undertaken on the effect this disease has on the person himself and the family involved. While this author has not found any research specifically designed to study the impact of senile brain disease upon the family, several studies with different foci have gathered data relevant to the subject (Isaacs *et al.*, 1972; Sainsbury and Grad, 1970; Sanford, 1975; Sheldon, 1948). The two findings these studies agree upon are: (1) families do not discard their "senile" members, but care for them with dedication and responsibility (of course, there are exceptions), and (2) the burden of this care weighs heavily upon the caregivers.

PURPOSE OF STUDY

This study proposes to:

1. explore the factors influencing a family (the caregiver) to continue living with and caring for an old person with irreversible senile brain disease;
2. describe the problems in daily living an old person and his/her family must face in the presence of senile brain disease;
3. describe the strategies these families (impaired members and caregivers) have devised to handle these problems.

SIGNIFICANCE OF STUDY

The significance of this study lies in its implications for practice. Planning adequate services for individual families and for communities must be based on:

1. the identification of factors crucial to managing a person with senile brain disease in the home;
2. an understanding of the kind and the size of the

burden involved;

3. an assessment of the behaviors leading to successful management or overwhelming stress;
4. increased knowledge of strategies, which enable families to manage life with senile brain disease.

Data relevant to these four aspects important to practice were gathered in this study.

CONCEPTUAL FRAMEWORK

> One of the basic paradoxes of science is that, whereas observation provides the ultimate test of a scientific theory, the language of description employed by the scientist influences his observations. The very fact of having a descriptive concept available serves to sensitize the observer to certain phenomena; it helps him to see what is there . . .. Any description should be "two-faced", looking simultaneously to the world of data and to that of concepts. It is this double-directedness of description that allows concepts both to describe and to explain . . .. If . . . it can be shown that certain events "must" occur because the corresponding concepts are related in a particular way, then these events have been explained (Cartwright, 1959, p. 13).

The conceptual framework for this study derives from Kurt Lewin. The author will first describe the concepts used and will then discuss the advantages and limitations of Lewinian field theory for this research. The author's diagrams serve to illustrate the dynamic interrelationship of concepts and do not represent Lewin's topology or hodological space, which have been severely criticized (Madsen, 1968, p. 141) and do not seem helpful in explaining events.

The basic Lewinian concept, life space, refers to all the facts which determine behavior of an individual at a certain time. Lewin maintains that behavior and development depend upon the state of a person and his psychological environment, B = F(P,E). In this equation the person and his environment are mutually dependent. To understand, or to predict behavior, the person and his environment have to be considered as interdependent factors (Lewin, 1951).

Earlier, Lewin related life space to marriage (Lewin, 1948), but it was only in one of his last publications (Lewin, 1951) that he began to develop constructs such as "social field", "social space", and "group life space", when he attempted to conceptualize the interdependence and interaction of several individuals. Family members' life spaces overlap in many central areas (those vital to each individual) and a high degree of interdependence results.

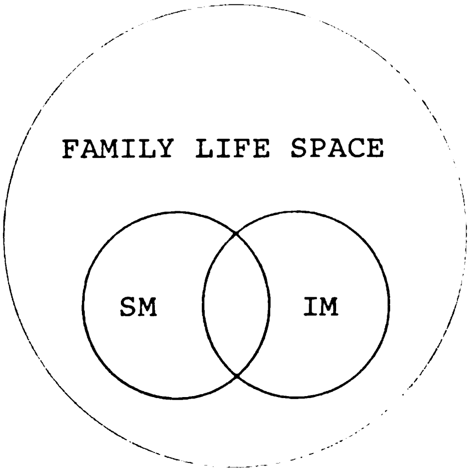

Diagram 1. Supportive member's (SM's) and impaired member's (IM's) life spaces overlapping within the family life space.

Although the investigator is aware that the family life space includes many more significant individuals, this study focuses only upon the family life space of the senile brain diseased person (IM) and his caregiver (SM). The properties of the supportive family member (SM), the cognitively impaired family member (IM), and of their environment conceptually exist in one interdependent field. SM and IM influence each other and their environment and vice versa. Lewin's concepts, need, tension, and valence, are considered crucial to this family life space interaction.

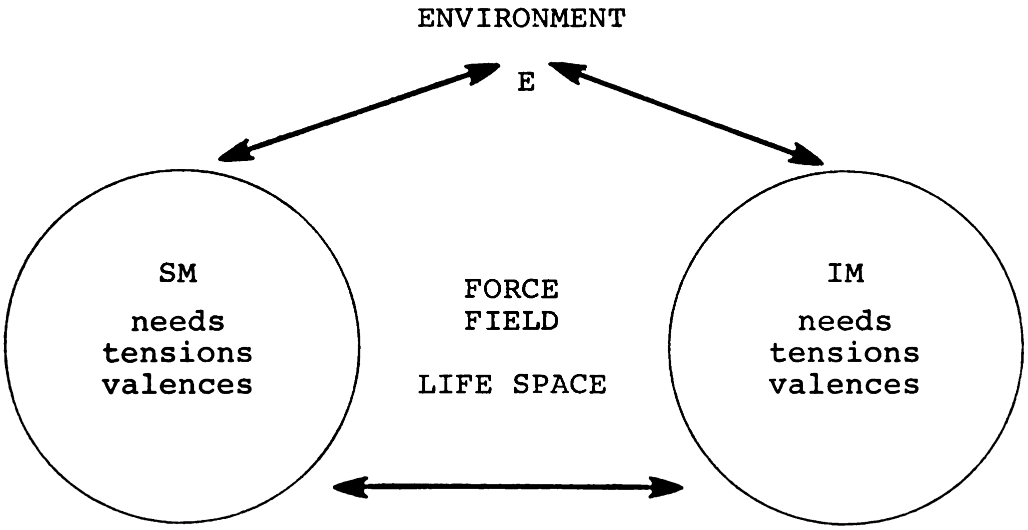

Diagram 2. SM and IM needs, tensions, valences, and their environment within the force field of family life space.

Needs. Needs have the character of "organizing behavior" (Lewin, 1951, p. 273) and the tendency to bring about action is basic to a need (Lewin, 1951). Lewin does not specifically define the content of "need" *per se*, but he does refer to hunger, physical closeness, sex, freedom of movement, socializing, etc., as needs in his research.

Tension.

> The concept of tension is coordinated to the existence of a need: if a need or "quasi need" (i.e., an intention) is activated, then the magnitude of tension of a corresponding inner-personal region is greater than zero. The stronger the need, the greater is the magnitude of tension and, according to the principle of the spread of tension, the larger is the number of regions under tension. Overconsumption (satiation) results in a state that may be thought of as "negative tension", which also may spread (Cartwright, 1959, p. 30).

Valence. Life space regions of need/tension have positive valence if they are attractive to the person and negative valence if they are repulsive (Cartwright, 1959).

Although Lewin did not develop the concepts as they relate to family study in any depth, his framework does enable us to view the family as a whole and is therefore useful to the study of families in general and to the study of families living with senile brain disease in particular.

This theoretical frame allows the research to direct questions toward how the SM and how the IM perceived:

1. their own needs versus the needs of the other (e.g., what is important to you? versus what is

important to your husband/wife, mother/father, daughter/son . . .?)

2. their own tension versus the tension of the other (e.g. What are the problems, frustrations you are experiencing? versus What are your father's/son's . . . problems, frustrations?).
3. their valence of own needs and tensions versus their valence of the other's needs and tensions (e.g., what are the good and bad aspects of this situation? What is the hardest part? If not for . . ., what would you do differently, what would your life be like? And how is this for . . .?)
4. fit or conflict of own needs and tensions and valences in regard to the other and the environment versus the perceived fit or conflict of the other's needs, tensions, and valences in regard to self and the environment (e.g., how would your life be different without him/her? How would his/her life be different without you? Some people consider institutionalization (moving to a home); what are your thoughts (his/her thoughts) in regard to this?)

In studying the family unit, the phenomenological reports of the different members became but one source of information. Lewin did not equate the psychological environment with the phenomenal world. His basic criterion was whether any given fact had an effect on behavior, not whether it appeared in conscious awareness. Observation of interaction, analyzing coping strategies, and the fit of verbal and non-verbal behavior served as additional sources of information consistent with field theory.

Both the phenomenal experience as well as the unconscious life space are not determined by the present situation alone. Lewin considered the psychological past of memory, sense of belonging, commitments, and feelings of guilt, as well as the psychological future with its expectations, fears, plans, and hopes, as simultaneous parts of the psychological field at a given time. So the time perspective changes continually (Lewin, 1951). Thus Lewinian theory directed the inquiry toward how a family (an individual) perceives its past and future at the present time.

Lastly, two additional Lewinian concepts salient for the conceptual framework of this study are values and boundary zone. The boundary zone is composed of the perceived impact of the physical and social world upon the individual or family life space. To assess this area, questions regarding services available, transportation, living arrangements, the perceived effects of inflation, and crime in the streets, etc. were asked. The interviews also included an inquiry into the values ("shoulds") of the individuals, as well as the values of the family unit.

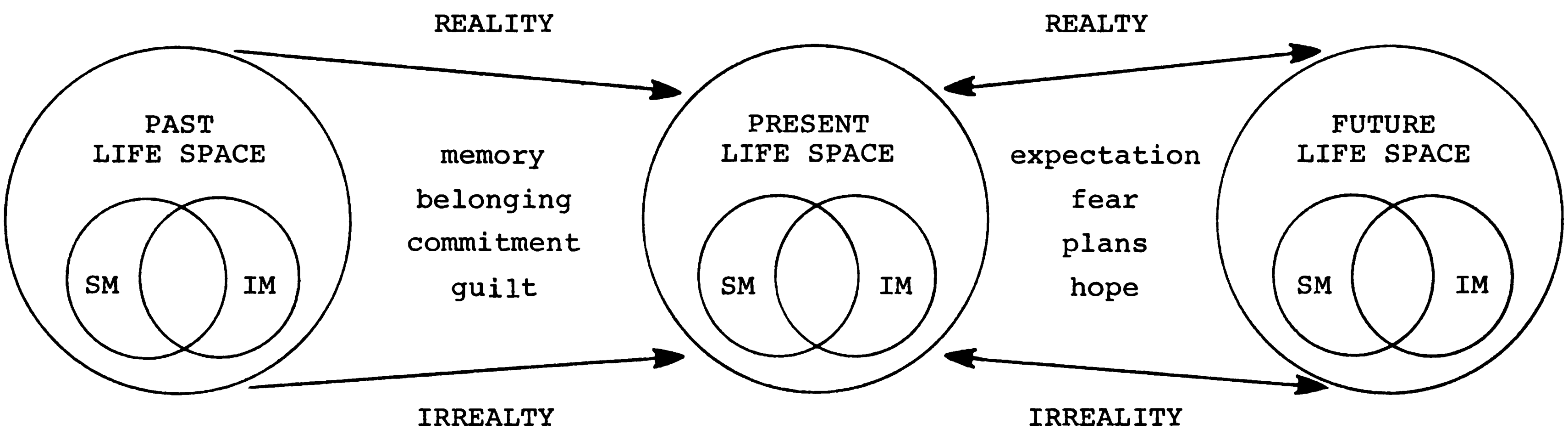

Diagram 3. SM and IM perception of their past and future family life space in the present.

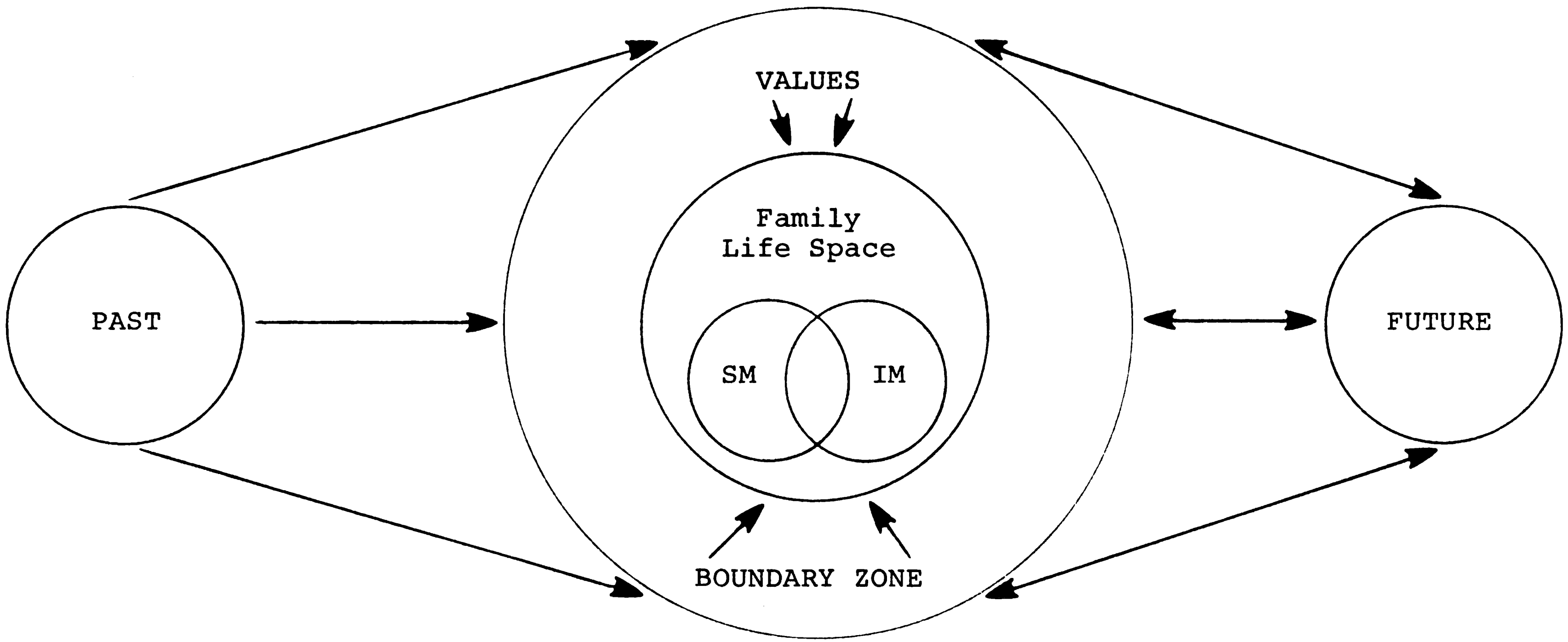

Diagram 4. Values, boundary zone, and time perspective influencing the family life space.

The main limitation in the application of field theory as the conceptual framework for this research lies in the nature of the problem involved: assessment of the cognitively impaired person's (IM's) needs, tensions, valences, forces, and his/her life space can be done to some degree, but to obtain a reflective "weighing of factors" from the person's own point of view is not possible. Field theory does not give the key to unlock the "black-box" of phenomenal experience for the person unable to verbalize it (or perhaps experience it in any conscious way). Although the IM has both an active and a passive impact upon the family unit life space, often one can only collect data from the supportive member's (SM's) point of view. One can only infer the IM's point of view from his/her behavior.

In one of his early articles Schaie (1962) proposed a view of cognitive behavior and aging by explaining developmental changes through field theory concepts. He never used the conceptual approach described in this article in his later research and does not consider it helpful to explain or facilitate research on cognitive change in aging (personal communication, San Francisco, November 19, 1978).

The main value of field theory for this research lies in the setting of focus:

1. "Field theory is . . . a method of analyzing causal relations and of building scientific constructs" (Lewin, 1951, p. 45). This research had

the purpose of attempting to understand the causal relations of these families' behaviors, as well as to "discover" interactional constructs determining the handling of the situation.

2. ". . . social observation should look toward units of sufficient size" (Lewin, 1951, p. 157). The immediate family unit (SM and IM living in one household) seemed a unit large enough to be meaningful, and small enough to be manageable.
3. ". . . the observer should perceive the units in their particular setting" (Lewin, 1951, p. 157). The researcher gathered data in the home setting.
4. ". . . scientific predictions or advice for methods of change should be based on an analysis of the "field as a whole", including both its psychological and nonpsychological aspects" (Lewin, 1951, p. 174). In addition to the phenomenal reports and behavior observations, the researcher assessed the SM's and the IM's social resources, their economic resources, the services available to them, their mental and physical health, and their physical environment.

Field theory as a conceptual frame, dictated the specific research questions, the choice of tools, and the method of data analysis.

RESEARCH QUESTIONS

This study was designed to ask the following questions:

1. What problems in daily living confront an old person and his/her family in the presence of senile brain disease?
2. What strategies have these families devised to handle these problems?
3. What factors influence the impaired member's and the supportive member's tension?
4. What factors influence the impaired member's and the supportive member's morale?
5. What factors influence the supportive member's management ability?
6. What factors influence a family (the supportive member) to continue living with and caring for an old person with irreversible senile brain disease or to consider his/her institutionalization?

DEFINITION OF TERMS

The (cognitively) impaired family member (IM). A person labeled in his/her medical or social service record as having either of the following two characteristics: (1) a diagnosis of one of the following: senile brain disease, organic brain disease, chronic brain disease, cerebral arteriosclerosis, senile dementia, mental impairment, cognitive impairment; or (2) a person showing the symptom of disturbance or impairment of memory together with one or more of the following symptoms: impairment of intellectual functioning or comprehension, impairment of judgment, impairment of orientation, affective changes, impairment of reality testing. The stated diagnosis or symptoms have been evident for a minimum of one year, but do not date further back than the subject's fiftieth birthday (in order to exclude people with life-long cognitive impairments).

The supportive family member or caregiver (SM). The relative living in the same household with the cognitively impaired family member who assumes the main caregiver role and principal responsibility and involvement in any decision in regard to the impaired person's care.

SM management ability. A caregiver's score* on the SM Management Scale.

IM morale. An impaired person's score* on the IM Morale Scale.

SM morale. A caregiver's score* on the SM Morale Scale.

IM tension. An impaired person's score* on the IM Tension Scale..

SM tension. A caregiver's score* on the SM Tension

---

*For detailed discussion of the items determining the scale scores, see pages 71-74.

Scale.

SM mutuality. A caregiver's score* on the SM Mutuality Scale.

Before describing this study's path (methodology) toward answering its research questions, it seems imperative to review the literature in regards to four aspects basic to the problem:

1. What do we know about the nature of senile brain disease?
2. What is the prevalence of senile brain disease (the size of the problem)?
3. What interventions are available?
4. What do we know about senile brain disease and the family?

---

*For detailed discussion of the items determining the scale scores, see pages 71-74.

CHAPTER II

REVIEW OF THE LITERATURE

> I fear I am not in my perfect mind.
> Methinks I should know you, and know this man;
> Yet I am doubtful; for I am mainly ignorant
> what place this is; and all the skill I have
> Remembers not these garments; nor I know not
> Where I did lodge last night.
> (King Lear, Act IV, Scene 7)

INTRODUCTION

The scientific literature addresses different aspects related to King Lear's condition; one such area addresses the nature of dementias. In Latin "demens" means "out of one's mind", however such terms as senile dementia, organic brain syndrome, chronic brain syndrome, senile psychosis, chronic brain failure, cognitive impairment, and intellectual decline are used inconsistently and alternately by different authors in labeling syndromes such as King Lear's dementia. Wang (1977) gives an overview of the historical development of the terms and documents that no universal consensus of terminology exists. In addition, the combining of symptomatic and etiological classifications adds to the confusion. Related epidemiological studies are another area of research vital to determining the size and extent of the problem, as well as the implications for services.

But one must consider the lack of consensus in terminology in evaluating these studies' validities and comparability. The range of possible interventions is a further important research area.

The drama that King Lear describes does not only reflect the deterioration of an old man, but also powerfully illustrates what scientific literature might categorize under the topic "the aged and their families". This review of the literature explores the research in this area under four major topic headings.

I. The nature of dementia
    (1) The "true" dementias versus the pseudo-dementias
    (2) Brain changes underlying dementia in old age
    (3) Presenile versus senile dementias
    (4) Dementia as an exacerbation of normal aging versus dementia as a pathological entity
II. Epidemiological studies on prevalence - the size of the problem
III. The range of interventions available
IV. Families and dementia.

I. THE NATURE OF DEMENTIA

Dementia, a clinical syndrome of varying underlying pathology, describes the deterioration of mental processes. Recent memory is affected, which leads to confusion of time and relation to the physical environment resulting in a wide range of behavioral changes. In advanced dementia a persons' intellectual functioning, his communication with the interpersonal and social environment deteriorates to the level of a "vegetative" existence (Berry, 1975; Pfeiffer, 1977).

The literature reflects lack of agreement in the use of different nosological concepts and the underlying disease nature and entities. Major discussion seems to focus around four areas: (1) how can the "true" dementias be distinguished from the "pseudo-dementias" or confusional states; (2) brain changes in old age; (3) the relationship of presenile dementias (Alzheimer's Disease in particular) and the senile dementias; and (4) the question of dementia as an exacerbation of normal aging changes in the brain versus dementia as a pathological entity.

(1) The "True" Dementias Versus the Pseudo-Dementias

Kiloh's (1961) and Post's (1975) term, pseudo-dementia, and Libow's (1973) term, pseudo-senility, refer to a wide array of physical, emotional, social, and environmental factors which produce symptoms such as confusion, disorientation, anxiety, memory deficit, and motor retardation simulating senile brain disease. In the elderly, impairment of physical, mental, or social health becomes inextricably entwined. A complex relationship develops between the physiological and cognitive functioning, which has been studied in the research on stress, disease, aging, and behavior. A discussion of this wide area of research remains beyond the scope of this literature review, since it does not relate directly to this study. Eisdorfer and Wilkie (1977) wrote a comprehensive review of the subject in the recent edition of the Handbook of the Psychology of Aging.

In the old person trauma, malnutrition, dehydration, incontinence, constipation, infections, reactions to bereavement, metabolic diseases, depression, neoplasms, cardiac failure, loneliness, and drug intoxication can lead to cognitive impairment. Especially with underlying senile brain disease, these insults can cause mental and behavioral decompensation (Foley, 1972), acting as the proverbial straw breaking the camel's back. Acute confusional states are always a medical emergency in the elderly (Anderson and Davidson, 1975; Kral, 1975).

Sensory perceptual decline may also cause or add to mental impairment. Fozard, Wolf, Bell, McFarland, and Podolsky (1977) discuss the research relating to age, visual perception, and communication; Corso (1977) discusses the research on changes in auditory perception with age; Engen (1977), the changes in taste and smell; and Kenshalo (1977) reviews the research regarding age changes in touch, vibration, temperature, kinesthesis, and pain sensitivity. The reception and processing of information from the environment through the senses is crucial to cognitive functioning.

The effects of brain disease *per se*, upon the behavior of an old person cannot be understood independently of the possible effects of sensory decline and the resulting communication difficulties, of fatigue, poor physical health, or poor motivation (Fozard and Thomas, 1975). Since many of the causes underlying the acute confusional states (acute brain syndromes, pseudo-dementias) can be treated or remedied successfully, a thorough assessment and differential diagnosis of elderly persons with cognitive impairment is emphasized by all authors.

(2) Brain Changes Underlying Dementia in Old Age

Neuropathologically two common types of brain deterioration can be identified. One is characterized by neuronal loss, senile plaques, neurofibrillary tangles, and granulovacuolar degeneration. The cause of this cellular degeneration is still unknown. The other type of change is considered a vascular disorder. In addition to neuronal loss, focal cerebral softening or multiple lacunar infarcts are found. These changes result most likely from cerebral arteriosclerosis or hypertension (Corsellis, 1977; Tomlison, 1977; Wang, 1977). In a large group of people, the "mixed cases", these two types of brain deterioration occur together

(Lauter and Meyer, 1968; Malamud, 1972; Simon and Malamud, 1965; Tomilson, Blessed, and Roth, 1970). Senile dementia from cellular deterioration forms the largest group and constitutes between 50 to 80 percent of intellectual function loss in the aged. Vascular changes only account for 12 percent of the cases studied. Senile dementia (cellular type) is more common among females, while arteriosclerotic dementia is more common in males (Tomlison, 1977).

(3) Presenile Versus Senile Dementias

Terry and Wisniewsky (1972) demonstrated with electron microscopy similar histological changes in presenile Alzheimer's Disease as well as in the senile dementias. These findings lead to a growing consensus in the literature on the existence of only one disease entity of presenile and senile dementias. Along with marked cortical atrophy and ventricular dilatation on the macroscopic level, diffuse lipofuscin pigment generation, neurofibrillary tangles, and senile plaques are the major manifestations of cell degeneration on the microscopic level. These changes occur as one disease process, distinguished only by different ages of onset (Berry, 1975; Sherwin and Seltzer, 1976; Tomlison, 1977).

(4) Dementia as an Exacerbation of Normal Aging Versus Dementia as a Pathological Entity

The accelerated aging hypothesis suggests that dementia results from accelerated and intensified aging of the nervous system. This hypothesis rests on two basic assumptions. The first states that neuropathological changes occurring in the brain of the demented person are essentially the same as those occurring with normal aging. The second assumption states that both normal aging and dementia involve failing memory, intellectual decline, increased rigidity in behavior, and a general deterioration in emotional and cognitive adaptability.

Miller (1974), Malamud (1972), and Lauter and Meyer (1968) review the research relating to the first assumption. They report conflicting research findings and conclude that insufficient evidence precludes an acceptance or rejection of the notion of one and the same neuropathological process in normal aging and dementia. Tomlison (1977) reports marked and statistically significant differences of senile brain changes (i.e., cellular degeneration) in groups of demented and normal old people. Nevertheless, some senile plaques and neurofibrillary degeneration was also found in the normal group. Seventy-one percent of the normal non-demented group showed some ischemic lesions, but regarding the quantity of softening found in individuals, the two groups differed significantly. These authors do seem to agree that quantitative and not qualitative morphological changes distinguish the demented from the normal aging population.

With the exception of Tomlison (1977), the above researchers seem to accept the results of the "intellectual decline studies", which support the second assumption of intellectual decline as an integral part of normal aging. These studies are cited as evidence supporting this assumption. However, recent awareness of the methodological deficiencies in these psychological studies casts severe doubt as to their validity. Schaie and Gribbin (1975) and the excellent review by Labouvie-Vief (1976) speak to an accumulation of cross-sectional studies which, due to inadequate samples and inappropriate comparison of young and old samples with chracteristic variance, report data on cognitive decline which at best, can only be considered evidence for generational differences. In reviewing the longitudinal studies, they point to apparent cognitive deficit related to different environmental effects upon age cohorts, rather than to aging *per se*. Selective subject dropout poses an additional methodological problem in the lognitudinal studies and in this case, obfuscate intellectual decline with age.

Using the Senility Index of the Chicago studies on "adjustment in old age", Carp (1969) demonstrated how "garden-variety maladjustment" (neuroticism, anxiety, etc.)

became identified with senility. In her study, a group of college students scored "more senile" than the group of old community residents. She thus demonstrated how methodological problems can create a questionable "scientific fact". While a vastly exaggerated picture of decline among the elderly had been drawn, authorities now generally accept that aging is associated with gradual decline in many psychological functions (Eisdorfer and Wilkie, 1977). Botwinick (1977) concludes that although some intellectual decline seems part of the aging picture, this decline starts later in life, is smaller in magnitude, and may include fewer functions than prior research had indicated.

No definite answers exist as to how normal aging and senile dementia relate on the neuropathological or the psychological-functional level. A danger arises in accepting an "all or nothing" answer. On the one hand, the self-fulfilling prophecy of intellectual decline and the threat of prejudice and labeling are very real phenomena. On the other hand, Kinsbourne's argument, warning of the danger inherent in denying age-related intellectual decline, is convincing.

> The danger is that if one does not believe in the existence of these declines, one can do nothing to help the victims of such decline. They will then have to trade personal effectiveness and even happiness for the satisfaction of a more optimistic label . . . the thing to do is not to deny that (these declines) exist, but to recognize that they do and do something about it (Kinsbourne, 1977, p. 230).

II. EPIDEMIOLOGICAL STUDIES ON PREVALENCE

> Pneumonia may well be called the friend of the aged. Taken off by it in an acute, short, not often painful illness, the old man escapes those "cold gradations of decay" so distressing to himself and to his friends (Osler, 1904).

But the old man's friend is dead, a victim of medical progress. Technical advances extending life have become methods of extending disease. The course of senile brain disease in old people has been extended from three years to over twelve years and the prevalence rate hence has risen three or four times (Gruenberg, Hagnell, Öjesjö, and Mittelman, 1976). These figures emerge from a convincing and frightening argument based upon the analysis of the Lundby data gathered in a study on incidence and disease expectancy of mental illness over a 10-year period of all (99 percent) of the inhabitants in a limited area in south Sweden (Essen-Möller, 1956; Hagnell, 1966, 1970).

Worldwide the older population is increasing. The projected growth rates suggest a 58 percent increase of the population, aged 65 and over in the developed countries, whereas the number of aged in the less developed countries will almost triple between 1970 and the year 2000 (Hauser, 1976). Additionally, the older population itself is aging, since the percentage of older old people is growing faster than the percentage of younger ones. In the United States between 1975 and 2000, a 16 percent increase is predicted for the 55-64 age group, a 23 percent increase for the 65-74 group, and a 60 percent increase for those 75 and over (Brotman, 1977).

Increased dementias have become one consequence of the life span prolongation and the significant increase in people 75 years old and over. The number of elderly people with senile dementias is expected to rise at a higher rate than the average growth rate of the elderly population (Wang, 1977). All statistics and studies agree that brain syndromes become more frequent beyond the age of 60 or 65. A sharp increase seems to occur with those in the over 80 group when as many as one-fifth of the population may be affected (Kay, 1972). Prevalence studies of chronic brain syndromes (dementias) in Japan (Kaneko, 1975), England (Kay, Beamish, and Roth, 1964a, b), Denmark (Nielsen, 1962), Switzerland (Ciompi, 1968), Sweden (Essen-Möller, 1956; Hagnell, 1966), and the United States (Pfeiffer, 1975) all testify to this phenomenon of rising prevalence rates with rising age.

Gunnar-Svensson and Jensen (1976) discuss the comparability of epidemiological investigations, especially as to their utility in planning for services. They compared nine studies in relation to factors such as the purpose of investigation, description of the population, selection of subjects, the statistical concepts used, the collection of data, and the main results. They conclude that comparison of the various results is difficult since most researchers did not intend their investigations for mutual comparison. The studies, an expression of local truth, present limited conclusions useful mainly for local planning. The authors suggest that future investigations should aim for standardized methods and better correlated descriptions.

The above remarks point to a crucial problem when one considers transferring practical implications for institutional planning or community services from one geographic area to another. Although to date, the epidemiological studies may be poor guidelines for the actual planning of services, they do provide data for grasping the size and scope of this health problem. Wang (1977) summerizes the results of 17 epidemiological studies on senile brain disease done worldwide. He computed a mean and a median from the statistics of these 17 studies and arrived at a mean rate for prevalence of severe dementia in the aged of 4.8 percent of the populations studied and a median of 5.3 percent. In addition, the mean rate for prevalence of mild dementia in the aged in these study populations was 10.14 percent and the median, 10.0 percent.

In light of these data, Wershow's (1977) controversial thoughts to rearrange our research and service priorities toward "maintenance" of the senile brain diseased cannot be ignored. Neither the reality of brain pathology nor the scope and size of the problem can be denied. One may disagree with Wershow's conclusions regarding the use of resources and the direction of planning in research and health service, but he begins with a sound premise. In face of impossible adversity, denial may be a functional defense mechanism for patients and their families. Denial is an indefensible position for a professional and scientific community.

III. THE RANGE OF INTERVENTIONS AVAILABLE

Many authors (Anderson and Davidson, 1975; Pfeiffer, 1977; Robinson, 1977; Verwoerdt, 1976; Wang, 1977) emphasize the need for thorough medical, psychological, social, functional, and environmental assessment and an accurate differential diagnosis, especially in differentiating the irreversible brain dementias from the reversible pseudodementias. The specific diagnostic techniques used to determine the neuropathological base of brain failure are regional measurements of brain flow, the electro-encephalogram, cerebral arteriography, pneumo-encephalography, and recently, computerized tomography (Emiscan) (Wang, 1973; Caird, 1977). These tests are used extensively in the large medical centers.

In the hope of attacking senile dementias on the neuro-chemical level, an intense search has begun for medications to reverse or slow cognitive impairment and the concomitant behavioral decline. A wide range of drugs has been investigated as to their effectiveness, but none of the cognitive acting drugs has demonstrated significant long-term reversal of intellectual impairment (Dawson-Butterworth, 1970; Eisdorfer and Stotsky, 1977; Jarvik, 1973).

Drug induced and drug aggravated brain failure are common problems in geriatric practice. Confusion and cognitive impairment accompanied by depression, agitation, agression, and abnormal thought patterns may indicate the need for drug prescription; but the notion that "every diagnosis deserves a drug" is a commonly accepted fallacy especially with the aged (Powell, 1977). The initial results on the administration of pure oxygen administered under high pressure (hyperbaric oxygenation) reported marked improvement in memory and orientation (Jacobs, Winter, Alvis, and Small, 1969), but these positive findings were not confirmed in replication studies (Goldfarb, Hochstadt, Jacobsen, and Weinstein, 1972; Thompson, 1975).

The Philadelphia Geriatric Center conducted the most extensive research project to date with regards to intervention. They studied 82 mentally impaired and institutionalized aged Jewish women intensely for three consecutive years. They devoted the first year to the evaluation of an individualized "excess disability" (i.e. the gap between actual and potential functioning as determined by a multidisciplinary team) treatment program. In the second and third year, the researchers undertook a longitudinal investigation in the changes of functioning. The experimental group received indivudalized treatment (not described in detail, but noted as extensive) aimed at reducing the excess diabilities, but not at reversing the effects of senile brain disease *per se*. In the experimental group, 15 women died during the first year of the study and 24 women during the following two years. Lower levels of baseline functioning tended to be associated with subsequent death. As a group, the subjects had considerable cognitive deterioration; 85 percent of the survivors demonstrated losses in Mental Status Questionnaire (MSQ) scores over time. With respect to directly observed behavior, only 37 percent declined and an equal number of old women maintained their plateau of functioning over two years while a small number showed behavioral improvements. Although the study showed a linear decline, the findings indicated a marked amount of behavioral variability. No two subjects seemed exactly the same, implying that behavioral functioning is influenced by many internal and external factors. After the withdrawal of experimental therapy, the gains made dissipated, although the Center, one of the best in the United States, continued regular treatment. Researchers conclude that only sustained treatment input can help maintain the gains in an older population with organic brain syndrome (Brody, Cole, and Moss, 1973; Brody, Kleban, Lawton, and Moss, 1974; Brody, Kleban, Lawton, and Silverman, 1971; Kleban, Lawton, Brody, and Moss, 1976).

Individual psychotherapy or counseling is a useful intervention mode also with the cognitively impaired elderly (Brody *et al.*, 1971; Goldfarb, 1972; Gottesman, Quarterman, and Cohn, 1973). The various professional groups in mental health settings seem to share a sense of futility and therapeutic nihilism about old age in general and the "senile" in particular. Although this sense is unwarranted by research findings (Butler, 1975). For the actual therapeutic process, Goldfarb (1972) advocates the importance of allowing and even encouraging emotional dependency. Feeling secure and protected,the impaired old person becomes more active and feels in better control of his/her scarce resources. Loss of confidence, a decreased ability to gain pleasure, and a decreased sense of self-esteem lead to feelings of helplessness that follow upon loss of resources. Even elderly individuals with brain failure can be helped to gain pleasure if they are encouraged to feel effective and successful in personal relationships with those who care for them.

Successful use of group psychotherapy has been documented with this population group. Silver (1950) and later Linden (1953, 1956) first described group therapy with the senile elderly. Goldfarb (1971), focusing on groups led by psychiatrists, and Burnside (1970a), on groupwork conducted by people of different disciplines, provide two useful literature reviews of this treatment modality with the aged. Burnside (1969, 1976) describes relevant basic information and guidelines for the actual work with the regressed elderly (the institutionalized in particular) in groups. She especially advocates the use of touch as a powerful therapeutic tool along with the essential qualities of the therapist as warmth, perseverance, and an active listening ability (Burnside, 1973, 1976).

Eisdorfer and Stotsky (1977) review the literature related to the term "milieu therapy", introduced to describe techniques for reorientation, remotivation, and resocialization involving the entire staff as well as the patients themselves in institutional settings. Reality orientation, a technique to reverse or halt confusion, disorientation, social withdrawal, and apathy, was designed to be used by everyone coming in contact with the "senile" person (Letcher, Peterson, and Scarbrough, 1974). Often the actual intervention is centered in a classroom setting using visual aids, e.g., blackboards, clocks, and calendars (Burnside, 1970b; Ireland, 1972; Taulbee and Folsom, 1966) and multiple repetition in teaching basic facts of daily living. Few controlled studies have been conducted so the findings remain tentative, but some consider reality orientation a promising therapeutic intervention form, at little cost, in an area where therapeutic nihilism is endemic (Barnes, 1974; Harris, 1976).

Remotivation groups focus upon reminding or reawakening the institutionalized elderly to sense the often small things in life which may give joy. Stimulation of sensory awareness through smell, texture, taste, and music are effective means by which this may be achieved (Bowers, 1967; Burnside, 1971; Henessey, 1976; Kastenbaum and Slater, 1964; Sturrock and Kastenbaum, 1967). Verwoerdt (1976) defines resocialization groups as a level just above the remotivation groups. With patients still interested in their environment, resocialization can assist them to maintain or relearn basic social skills as well as those skills necessary for functioning independently in daily life. Barns, Sack, and Shore (1973) and Ebersole (1976) provide thoughtful surveys of the literature in the area of group work.

Grosicki (1968) used operant conditioning, another intervention employed predominantly for excess disabilities, in an interesting nursing study for modification of incontinence in old patients with organic brain syndrome. Her findings did not confirm the effectiveness of behavior modification, but she considers this lack of confirmation due to extraneous variables such as institutional problems surrounding nursing research, and not due to the power of the independent variable.

Environmental intervention seems to be the most promising area of research not only for treatment of the institutionalized elderly, but also for those living in the community. Lawton and Nahemow's Ecological Theory of Adaptive Behavior and Aging is a provocative theoretical approach explaining the parameters of the area. Lawton and Nahemow (1973) developed a model that relates the aging individual to his physical and interpersonal environment. They consider the model especially appropriate for indivduals with low competence, e.g. brain damage. The components of the model are:

1. Degree of individual competence - a person's cognitive ability, psychological adjustment, physical health, and other qualities.
2. Environmental press - the forces and demands of the environment as they interact with the individual. The individual defines his positive or negative quality rather than the environment *per se*.
3. Adaptive behavior - the outer manifestation of individual competence as it results from the individual-environment transaction. Both social norms and values define what is adaptive.
4. Affective responses - the internal emotional states of the individual-environment transaction.
5. Adaptation level - the area where the individual's behavior is adaptive and he experiences external stimuli as neither too strong nor too weak. The

> intensity of the stimulus, the context in which it appears and previous experience of the individual determine the adaptation level.

An individual reacts with positive affect to an environment in which the stimuli correspond to the adaptation level. Wohlwill (1966) suggests that those stimuli in the environment, either weaker or stronger than a certain area around the adaptation level will elicit negative affect - a phenomenon he calls "optimization principle". Environmental demands which are both slightly lower (in direction of sensory deprivation situations) and slightly higher (toward stressful or overloading situations) than the adaptation level, permit a margin for intervention where a feeling of comfort within one's environment still exists.

Improved functioning through the "minimal goals" approach can thus be achieved by slightly increased environmental demands which elicit adaptive behavior (performance) just above the individual's usual performance. Decreasing competence on the other hand could be compensated by slightly reduced environmental demands. Thus this theory predicts the possibility of enabling an individual to retain adaptive behavior and positive affect, even on a lower competence level. Much of the environmental research points to the need to create a "prosthetic environment" (Lindsley, 1964). Several studies demonstrated the effect of physical environment changes on institutionalized senile patients. Furniture adapted for the aged and arranged to optimize the possibility for communication, mealtime routines appropriate for the patients, sufficient light, signs and colors, all simple devices, improved both functioning and quality of life (Gotestam and Melin, 1976; McClannahan and Risley, 1975; Sommer, 1969).

Day care centers and day hospitals have a great potential for operationalizing the Lawton and Nahemow theory and creating prosthetic environments. Historically, the concept of daytime care for adults developed in the psychiatric domain with programs in Moscow in 1932, and Montreal in 1946 (Farndale, 1961). Weissert (1976) undertook a comparative study of ten adult day care programs in the United States and found programs following two different models. Model I, the "day hospital" center, focuses mainly on rehabilitation, while Model II, multipurpose programs, tends to serve a less disabled and more heterogenous population. Weissert suggests the need for further research on the appropriateness, outcome, and cost effectiveness of both models. From the British perspective, Arie (1975) considers psychogeriatric day care an extension of long-term care, or an alternative to long-term hospitalization with supportive care and tolerance for confused behavior as its main function.

In an evaluation study of the day care program of the

San Francisco Jewish Home for the Aged, Lurie and Chiriboga (1975) found that for the cognitively impaired, day care brought about improvements in mood, in orientation to time, place, and person, in interaction with staff and other participants, and in overall participation in the program itself. Rathbone-McCuan (1976) studied a day care program's effect on families and concludes that day care services benefit families in three ways: they share significantly in the burden of daily care and supervision of the old person; they provide psychological support in the knowledge that the old person receives peer interaction; and they extend the possibility by which the family can keep the aged person at home.

Considering the complexity of the problem, the answer may not lie in any single one of the interventions described or even in their combination. The impact of senile deterioration on the individual, family, and society warrants a reevaluation of basic values, of views on health and disease, and a resulting restructuring of the health care system, if either neglect or "more intervention" are not to add to the disastrous impact of this disease (Brody, 1973; Isaacs, 1971; Wershow, 1977).

IV. FAMILIES AND SENILE BRAIN DISEASE

The viability of family ties has been widely documented. That families "dump" the aged has become a stereotypical myth although, of course, individual cases of neglect do exist. Traditional family tasks, as patterns of economic and psychological aid, exchange of services, and support in times of health crises continue to be performed today (Riley, 1968; Rosenmayr and Köckeis, 1965; Rosow, 1967; Shanas, 1968; Spark, 1970; Weihl, Nathan, Avner, Finkelstein, and Getter, 1970). Sussman (1976) sees families in modern society performing an additional task. Kin function as facilitators, protectors, and mediators for elderly family members in handling the demands of organizational and institutional bureaucracies. Despite extensive helping patterns, a demographic dilemma does confront kin networks. Increased life expectancy, especially for women, which is often accompanied by prolonged dependency; declining fertility rates (fewer younger family members are available to share the responsibility of support); increased mobility; and economic developments (a growing number of middle-aged women who must choose between nursing frail parents or working to support their own families) are factors severely straining kin resources for the day-to-day care of aging relatives (Treas, 1977).

In comparing long-term care patterns in six countries, Kane and Kane (1976) defined the demented elderly person as the single most insurmountable problem. In caring for him or her in the community, a heavy toll was exacted from the families. Despite the immense size and impact of this problem only a few studies directly address the question of mental impairment in the aged and its effect on the family. Two powerful descriptions of the impact of senility were written by family members themselves. In Death of a Mind, a daughter describes her father:

> . . . after a period of absence, . . . when we met I knew with immediate certainty that I had lost the companion of my earlier years. The change was yet mainly a loss of intellectual clarity and he remained himself, but a self that was subtly devitalized . . .. An illness of this kind affects others besides those who suffer from it, and the idea that a loved person - or oneself for that matter - might be transformed into something alien is disquieting. Pain and incapacity and disfigurement can be faced with fortitude,but the sight of a disease which seems to rot the self is hard to bear (Anonymous, 1950, pp. 1012, 1014).

And Gramp recorded on camera and tape-recorder by the two grandsons, who had rallied together with the entire family to the care of their senile grandfather, documents a three-year ordeal (Jury and Jury, 1976). Using grounded theory, Calkins (1972) studied lower income families caring for a dying relative. The supporting relatives did not question their sense of obligation and they perceived shouldering the burden as the only viable alternative. In caring for a chronically ill person, the family stressed the disease process until illness seemed to merge with the old person's identity. The illness became a focal point for family interaction and a basis of the family members' life style. Calkins does not report whether caregivers perceived physical and mental deterioration as similar strains.

As a part of a five-year longitudinal psycho-sociological study of normative transitions of the adult lifespan, Robinson and Thurner (1976) looked at parental caregiving. Their data speak to the larger stress inherent in caring for a mentally deteriorating relative, rather than for one with physical impairment. Berezin (1970, 1972) coined the term "partial grief" in discussing family members' reactions to a declining relative. In a case study, Cath (1972) draws a vivid picture of the pain and anguish experienced by a family in the process of institutionalizing a senile parent. Soyer (1972) and Savitsky and Sharkey (1972) use family case studies to demonstrate possible professional interventions in the realm of counseling.

The bestselling Japanese novel of 1972, <u>A Man in Ecstasy</u>, gives a different and fascinating view of senility and the family. Sawako Ariyoshi describes the senile decline of an old man through the eyes of his daughter-in-law caring for him. There is drudgery and the burden, but also some sad beauty in the Japanese emotional and spiritual grasp of "the age of ecstasy", which quickly became a fashionable euphemism for dotage (Plath, 1973).

While this author has not found any research designed specifically to study the problem of senile decline and the family, several descriptive studies have gathered data relevant to the subject. All of these studies were done in Great Britain. In the classic work of the gerontological literature carried out between 1945 and 1947, Sheldon (1948) assessed both medical and social aspects of 477 randomly selected older people living in their homes in Wolverhampton (population: 150,000). The survey collected as much information as possible relating to the medical and social problems associated with aging and old age. Four percent of the study population were considered "forgetful and childish" and "demented". Sheldon's major finding in relation to senile deterioration indicated that the immense strain shouldered by the relatives caring for these elderly was often severe and almost intolerable.

Sainbury and Grad (1970) compared the effect of a hospital-centered and community-centered psychiatric care service to old people and their families in two districts. They assessed the family burden in 119 households in which a person had been referred for psychiatric care. More than 75 percent of families in which the patient is over 65 years old faced severe problems. In 58 percent, the physical health of the closest relative is affected; in 36 percent, the home routine (housework, shopping, etc.) is upset; social and leisure activities are restricted in one-half of the families; and in 14 percent of the households, income is reduced by at least 10 percent. Still families preferred to care for their elderly sick by themselves and the extent to which families could do this before seeking help surprised the researchers. The demented and bedfast patient interfered most drastically with home life. The researchers emphasize the need to supplement the clinical care of the patient with regular social support for the family and the need for flexibility in finding an appropriate balance between hospital and community care for different families and at different times in the disease trajectory.

Which problems do families feel able to cope with and which do they regard as an absolute barrier to home care? To answer these questions Sanford (1975) interviewed the person principally involved with the home support of an old person, who had been admitted to a London hospital because the relative or friend could no longer cope. Problems encountered by the supporters fell into three groups: (1) dependents' behavior; (2) their own limitations related to the dependent; and (3) environmental and social conditions. Most supporters (92 percent) were able to identify the problems which needed alleviation to restore a tolerable situation for home care. Most problems (80 percent) the supporters felt unable to cope with fell into the group one of dependent's behavior. Sleep disturbance and fecal incontinence were common and very poorly tolerated problems (both associated with senile dementia), while urinary incontinence, also a common problem, was considered tolerable in 81 percent of the cases. Inability to get in and out of bed and on and off the commode were other frequent and poorly tolerated factors. Dangerous behavior (turning off the gas, locking doors) and falls were fairly well tolerated by the supporters. Group two, the supporter's limitations as related to the dependent, contained only 16 percent of all the problems identified, with the most common being anxiety and depression, usually attributed to the caregiving situation. Although more than half of the supporters were over 65 years old themselves, only few considered their own health problems a barrier to continuing care. In group three, the environmental and social conditions, restriction of social life was indicated in 42 percent of cases. Many supporters had not had a day off, or even an evening out in years. Most supporters in this study were old women clearly devoted to their dependents.

Isaacs (1971) studied a sample of 280 geriatric patients referred from their homes and accepted for admission to a geriatric unit in Glasgow. Many of his findings are similar to those of Sanford. While the "principal helper" dealt with the physical burden, even incontinence, without complaint, they viewed mental abnormality as an overwhelming strain. Both the patient dangerous to his surrounding or to himself (this finding does not concur with Sanford's), as well as the patient who never expressed appreciation or gratitude, were the most burdensome cases to their caregivers. Two-thirds of the old people admitted needed hospitalization either because they had no relatives, or because the family had become overburdened by the strain. Neglect by relatives played a negligible part in the need for geriatric admissions.

One of the most informative and humanely written research accounts in the gerontological literature, _Survival of the Unfittest_, (Isaacs _et al._, 1972), is mainly based on a survey of 612 people referred routinely to the Department of Geriatric Medicine of the Glasgow Royal Infirmary Group of hospitals from 1966 to 1968. The department conducted medical assessment of the patient, physical and social home environment assessment, and an interview of the family, or other caregivers (neighbors, friends). For each referred patient, a matched control from the patient load of the same general practitioner was assessed. In a small substudy of incontinence (N = 20), the researchers gathered detailed information about the measures used at home to manage the symptom of incontinence. They also analyzed the final illness of all Glasgow residents, aged 65 years or older, who died during the year 1968, and studied a subsample of 260 subjects retrospectively to determine medical and social disabilities in the period preceding the old person's death at home, or his last admission to the hospital. Under extremely difficult physical and social conditions, many of these old people lived with great resilience and dignity, as did the heavily burdened caregivers.

The studies focusing on the time before death revealed that a period of "pre-death" occurred in a high proportion of all deaths in old age. Loss of mobility, incontinence, or mental abnormality had rendered the person unable to care for himself. The average duration of the "pre-death" period and of the consequent need for hospitalization increased strikingly, the older a person was at the time of his/her death (Isaacs, Gunn, McKechan, McMillan, and Neville, 1971).

The scope, complexity, and importance of senile brain disease become evident in considering the literature addressing the nature of the disease, its prevalence, the possible (and as yet impossible) interventions, and its impact upon families. Dementia, a disease that conjures up images of dread, remains a reality that society and the health professions will have to deal with.

Seasons of blankness as of snow,
The silent bleed of a world decaying,
The moan of multitudes in woe,
These were the things we wished would go;
But they were staying.
(Thomas Hardy, 1917)

CHAPTER III

METHODOLOGY

STUDY INSTRUMENTS

The study instruments consisted of the OARS Multidimensional Functional Assessment Questionnaire (OMFAQ), in-depth focused interviews, and participant observation.

The OARS Multidimensional Functional Assessment Questionnaire (OMFAQ)

The questionnaire, developed at the Center for the Study of Aging and Human Development, Duke University, North Carolina (Pfeiffer, 1975a, 1975b; Laurie, 1977), assesses an adult's status in five areas of functioning: (1) social resources, (2) economic resources, (3) mental health, (4) physical health, and (5) activities of daily living. The format of questions in each area permit a convenient summary. A respondent's functional impairment in each of these five areas is summarized from the responses to the interview questions and the researcher (interviewer) assigns a rating on a scale from one to six; one is excellent functioning, two is good functioning, three rates mild impairment, four stands for a moderate impairment, five for severe impairment, and six is a rating for total impairment in the given functional area. The individual's overall functioning can then be further summarized by adding the functional ratings of each of the five areas to form a single number Cumulative Impairment Score, with a possible range from five to thirty. In general, low Cumulative Impairment Score ratings indicate good overall functioning, while high ratings indicate significant impairment in several areas of functioning.

With regard to (1) social resources, the OMFAQ assesses the extent, quality, and availability of social interactions. This includes marital status, living arrangements, the availability of a confidant whom the individual can trust and confide in, and the presence, availability, and willingness of someone in the environment to provide services and care in case of illness or disability. The scoring process allows for a weighing of subjective and objective data by the investigator.

The questionnaire assesses (2) economic resources as an important variable which affects social, mental, and physical functioning, as well as access to services. The employment status, current earnings, amount and sources of income, home ownership or rent, and the individual's subjective financial evaluations are all taken into consideration.

To consider (3) mental health, several factors are included in the OMFAQ. The first part of this section, the

Short Portable Mental Status Questionnaire (SPMSQ), assesses intellectual intactness or cognitive impairment. Although the researcher did not make the diagnosis of senile brain disease, a score for the degree of cognitive impairment was important for the comparison of different individuals in the sample in regard to this key variable. The SPMSQ provides this score and is, therefore, a crucial section of the OMFAQ for this research.

The SPMSQ (Pfeiffer, 1975b) is a ten-item test of orientation, recent memory, long term memory, and capacity for serial calculation. It indicates the present level of cognitive intactness or deterioration. Four distinct levels of intellectual functioning are distinguished: (1) intact intellectual functioning (0 - 2 errors)*: persons scoring in the intact range are entirely capable of self-care from a cognitive point of view; (2) mild intellectual impairment (3 - 4 errors): persons scoring in the mildly impaired range can handle routine self-care, but may require assistance in intellectually complex matters; (3) moderate intellectual impairment (5 - 7 errors): persons scoring in this range in general warrant a diagnosis of organic brain syndrome (senile brain disease, dementia) and usually need regular, though not continuous assistance with more complex tasks; (4) severe intellectual impairment (8 - 10 errors): persons scoring in this range in general warrant a diagnosis of organic brain

---

*All scores are adjusted for race and educational level.

syndrome and most likely require continuous care and supervision of their activities. For a discussion of the SPMSQ validity and reliability studies, see Appendix I.

A second area evaluated in the OMFAQ mental health section focuses upon the presence or absence of functional psychiatric symptoms. The Short Psychiatric Evaluation Schedule (Pfeiffer, 1975c) is a 15-item Monotonic Scale of "yes-no" questions measuring the presence of anxiety, depression, suspiciousness, hypochondriacal complaints, and other physical manifestations of emotional problems. Additional OMFAQ information regarding mental health comes from the individual's subjective view of his/her life satisfaction and interest and his/her own mental health. As with social and economic resources, the information regarding mental health is summarized into a single score on the mental health rating scale.

(4) This fourth major section of the OMFAQ is physical health; information is gathered on number of doctor's visits, number of disability days at home and length of stay in a hospital or nursing home, medications taken, significant illnesses and physical handicaps, and the extent to which the subject finds them serious or disabling. The schedule also obtains information of the subject's view of his/her own physical health and summarizes this information into a single functioning rating on the physical health rating scale.

(5) The fifth OMFAQ part considers Activities of Daily Living. Two areas of self-care capacity are assessed. Activities in the one area are necessary to maintain an independent household, e.g. use of the telephone, the capacity to use transportation, to go shopping, prepare meals, do routine housework, to take one's own medication, and to handle one's own money. Functioning in the other area assesses the individual's capacity to take care of his/her own bodily functions, e.g. to eat by him/herself, to dress/ undress, to take care of his/her own appearance, to walk, to get in and out of bed, to shower or bathe, as well as to maintain bladder and bowel continence. All this information is summarized into a single functional Activities of Daily Living rating scale. The questionnaire also seeks information regarding utilization of services. Reliability and validity of the OMFAQ have been established (see Appendix II).

Advantages and Disadvantages of the OMFAQ for this Study

Advantages:

1. The instrument serves to assess the needs and tensions in the individual's life space, and therefore it fits with the conceptual framework, i.e. Lewinian Field Theory.
2. The evaluation of needs and tensions (needs unmet) in five major areas of functioning is systematic and comprehensive.

3. The instrument is standardized.
4. Validity and reliability studies are satisfactory.
5. The scoring system is simple and allows for a high degree of objectivity.

Disadvantages:

1. The instrument,as a whole is too long and complicated for the comprehension, attention span, and tolerance level of cognitively impaired subjects.
2. The theoretical validity of the Cumulative Impairment Score - the adding of the five intactness/impairment scores in the major areas of functioning with equal weighing of each score may be problematic, although no research evidence exists to refute the assumption underlying this score.

The In-Depth Focused Interviews

Field theory guided the construction of the in-depth interviews for this research. They were designed to answer the research questions related to a family's ability to live with a senile brain diseased individual in the home. These interviews compliment the OMFAQ questionnaire in gathering data on the family life space, the impaired and supportive family members' needs, tensions and valences, their perceptions of the environment, their perceptions of the past, present, and future, and of the boundary zone and their values. The strategies of adaptation and management became a major focus of these interviews.

The Interview for the Supportive Family Member

The interview focused upon the impact of living with a person who has senile brain disease and upon the family members' own lives; the daily routine; strategies useful in managing the impaired person, as well as their own lives; the perceived rewards of the caregiving situation; the price in emotional, social, or physical well-being they considered themselves paying for assuming the caregiving responsibility; their attitude toward institutionalization and their imagined reaction to the imagined relief of the caregiving responsibility through the impaired person's death; their view of the past relationship with the impaired person and significant others, of the past and of the future; of support or lack of support they received; their ideas on health care services, including which factors they considered helpful, which detrimental, and which desirable.

The Interview for the Cognitively Impaired Person

The investigator modified the interview schedule according to the subject's capacity to comprehend and tolerate verbal interaction. Whenever subjects comprehended, the questions focused upon their view of their daily lives. They commented on the things they considered positive and those they saw as negative (e.g. socializing, feeling restricted, etc.); upon their own view of their cognitive functioning in the past and present; upon their attitude toward family and friends and toward their caregiver in particular; upon their general view of the past, the present, and the future, including their thoughts and feelings on life and death and an alternative living arrangement, such as moving to an institution.

Participant Observation

The investigator used participant observation as an additional research tool throughout the data-gathering process. She observed the verbal and non-verbal interactions between the impaired family member and the supportive family member. Observations of the physical home environment added additional information toward evaluating the family's life space.

TRAINING AND PRETESTING

The investigator attended a two-day workshop at the Duke University Center for the Study of Aging and Human Development in May 1976. Training included detailed instruction in the administration of the OMFAQ questionnaire and training in rating it. The investigator then pretested both the OMFAQ and the in-depth interviews with two families for (1) clarity, (2) length of time of administration, (3) acceptability to the family member, (4) comprehensibility as well as attention span and tolerance of the cognitively impaired person, and (5) acceptability to the cognitively impaired person.

Administration of the OMFAQ to the supportive family member took approximately 70 minutes and the focused interview to the family member about three hours. Both tools were clear and most supportive family members were eager to answer the questions and share their experiences, thoughts, and feelings. The investigator decided to leave the length and number of interview sessions flexible to accommodate the time restraints and levels of fatigue, need to talk, or tension of the subjects.

Although the two cognitively impaired subjects in the pretest were only moderately impaired intellectually, and in good physical condition, the OMFAQ interview seemed overwhelming. They had difficulty following the questions and became irritable, restless, and anxious after approximately 30 minutes. The investigator therefore decided to gather all of the objective information from an informant (the supportive family member, and when that information seemed lacking, from the health care provider). This left only the subjective questions of the OMFAQ questionnaire (those printed within the black frames) for the cognitively impaired subject. The researcher discussed this alteration with

Dr. Pfeiffer at Duke University, who considered it a feasible solution. Answering the subjective parts of the OMFAQ took approximately 20 minutes. The length of the investigator's focused interview varied greatly with the impaired person's cognitive and emotional state, and his/her attention span and willingness to talk. The investigator, well aware of the danger of catastrophic anxiety in brain-damaged individuals, did not persist in asking specific questions or continuing the interview when the subjects showed discomfort.

SAMPLE

The population for this study consists of a non-random Caucasian sample of 30 individuals with irreversible senile brain disease (impaired family members) and their 30 caregiving family members (supportive family members) in the San Francisco Bay area. The criteria for inclusion in the sample were:

1. The impaired and caregiving family members lived in one shared household for at least six months prior to the interviews.
2. The impaired family member was labeled in his/her medical or social service record as having a diagnosis of senile brain disease or its descriptive equivalent (see Definition of Terms, pp. 16-17).
3. The stated diagnosis or symptoms had been evident for a minimum of one year. This criterion excludes

acute confusional states or acute brain syndromes which are reversible. The irreversibility of senile brain disease was considered an important variable regarding the impact upon families.

4. The stated diagnosis or symptoms did not date further back than the subject's fiftieth birthday. Age 50 was chosen to include individuals with presenile dementias, but to exclude individuals who had suffered from life-long mental impairment. The investigator assumed that the caregiving relationship is very different when such impairment is life-long or when only developed in mid or late life after a different kind of relationship.
5. The supportive family member (caregiver) assumes the principal responsibility for the impaired member's care and is involved in any decision in regard to the impaired member's life.

Initially, the investigator planned a Jewish sample for several reasons: (1) being from Israel, she assumed that sample access would be easier. (2) She would be better able to grasp the cognitive map of Jewish subjects because of similar cultural background. Since communication with cognitively impaired subjects is difficult, this aspect is relevant. (3) She would be more likely to find a common language - Yiddish and German - if subjects do not speak English well, or have reverted to their first language.

(4) It would be easier to transfer the knowledge gained from this study to the Israeli scene for clinical and policy implications, as well as continuing research.

Only after exhausting the Jewish Service Agencies and other possible resources for Jewish subjects such as rabbis and physicians associated with Mt. Zion Hospital and having gained access to only 16 families, the investigator decided to change the ethnic criterion to gain access to an additional sample pool. To minimize the cultural and language differences, this "additional pool" was to include only Caucasian subjects.

DATA COLLECTION (OR THE INCONVENIENCE OF A CONVENIENT SAMPLE)

Sample Selection

After approval of the study protocol by the University of California Committee on Human Research, the investigator approached the Director of the San Francisco Jewish Home for the Aged. With his cooperation, she presented the research plan at a staff meeting, and asked for help in approaching subjects. The Jewish Home Day Care Center director and the investigator decided together that family members of patients in day care who were potential study subjects, should be approached by a letter. This letter from the day care program director asked the family member for permission to release his/her name and phone number to the investigator so that she could contact them, explain the study, and ask for their participation. Ten families were thus approached, all of which agreed to participate in the study. Several family members contacted the day care program director asking for information and reassurance regarding the nature of the research before they granted permission to be contacted. Two additional families were approached by an intake worker of the Jewish Home for the aged over the phone (the family members had contacted the institution as a possible resource, but the impaired members were not on the waiting list of the home), asking for permission to have the investigator contact them. Both family members assented.

The investigator then approached the Director of the San Francisco Jewish Community Center, who agreed to let the investigator write a letter similar to that sent by the Jewish Home Day Care Center. This letter, written in the Director's name to eight Center members whom she identified, resulted in two of these family members agreeing to be contacted by the investigator and ultimately, both agreed to participate in the study.

The investigator then cleared the research project in writing with the Director of the Mt. Zion Hospital Outpatient Clinics and the Mt. Zion Hospital Committee on Human Research through the nurse in charge of the Mt. Zion Home Care Project. The social worker of the Mt. Zion Medical Outpatient Clinic referred the investigator to eight physicians associated with this institution, and the investigator contacted them by phone. The constant refrain of all of these interested and cooperative professionals was "I could easily name several cognitively impaired (senile) people who somehow manage to live on their own; or names of several people who did live with families, but are now in an institution because once we see them, the situation is so bad they usually get institutionalized". Three physicians did approach one family each, who then agreed to participate in the study.

Next, the investigator approached four rabbis, three of congregations in the San Francisco Sunset area and one affiliated with Mt. Zion Hospital. All were interested in the problem, but only one rabbi was aware of families in his congregation who lived with a cognitively impaired member. One family in the sample was approached through him. The Jewish Family Service was not aware of families living with a member with senile brain disease. The investigator spent 12 months gaining access to 16 Jewish families (two families referred through the above sources were not Jewish), and decided at this point to change the criterion "Jewish" to "Caucasian".

Two families in the sample were first approached by a psychiatric nurse specialist, a mutual acquaintance of these families and the investigator. The social worker in charge at the San Francisco Home Health Agency suggested to the investigator that she present her research at the agency's staff meeting, asking the nurses and social workers for cooperation in finding subjects. She and the director of the agency had first interviewed the researcher as to the merit of the research project. Two families were thus added to the sample. Through the University of California Medicine and Neurology Outpatient Clinics another two families were added. All these professionals contacted their clients by phone and gained permission to release their names and phone numbers to the investigator.

Since April 1977, the investigator, has attended the monthly meetings of the Family Survival Task Force, a self-help group of families of brain-damaged adults. Three family members attending the meetings volunteered to participate in the study when they were approached by the investigator. The last three families in this sample were contacted through the San Francisco Geriatric Services, affiliated with San Francisco General Hospital. After gaining permission from the administrative level, the researcher presented the study at a staff meeting and gained the cooperation of the staff. In home visits, the families gave permission for the investigator to contact them.

Mistaken Labeling

Before asking the health professionals to contact a certain family, the investigator listened to the case description. In several instances it was decided not to contact a family since the investigator had considerable doubt in the validity of the assumed diagnosis. But there were eight additional referrals where heatlh professionals assumed that the impaired members did suffer from senile brain disease. The investigator contacted these families and found the supposedly "senile" individuals suffering garden-variety type maladjustment problems, but not irreversible brain disease; one woman was psychotic, another unhappy in her marriage and looking for a student boarder, a third woman suffered concentration-camp survivor symptoms. One old woman had grown tired of a life time of serving her husband and had now assumed a passive role in her household, still caring for herself, keeping up with daily political events and the lives of her children, but not cooking or cleaning, and had thus become labeled "senile". The frequent inaccurate labeling of old people with the diagnosis of "senility" by experienced and conscientious health professionals seems an important, if not new, serendipidous finding of this research.

Refusals

Five family members refused to participate in the study after discussing it on the phone. It is the investigator's impression that these were individuals under severe stress, who perceived the interviews as an additional unneeded stressor in their lives. One man shared over the phone, "I feel bad to say 'no'; I know such research is needed. I am a social worker myself. But I just don't feel up to it. I hold a regular job and at night I get up every two hours to turn my mother. She is incontinent and can't communicate at all; she is completely senile. I am really torn whether a home would be better for her. Perhaps she could get better care there - no, I don't think so . . ." A woman's response was, "I am sorry, but we can't take anything more. We have four children, my husband just lost his job; but anyway we couldn't talk with you openly; my mother-in-law wouldn't leave us alone for one minute. She is not only completely confused, she is also suspicious. My husband wouldn't send her out of the room; he would do anything not to upset her . . ." Another woman, "No, no - I don't want to talk. It is crazy to do this. My mother is 94 and she is driving me insane. But at least I will be able to look at myself in the mirror without turning green with shame that I put my mother away when she became senile. But if anyone asks you, tell them not to take it upon themselves. It drives you senile yourself . . ."

One family refused to continue participation in the research after the first interview. At the time of the interview, the husband was recently released after a four-week assessment period in a psychiatric hospital where he had been diagnosed as suffering from chronic brain syndrome. In the first interview he and his wife had spoken about their daily lives and his illness. It was a friendly, slow-paced interview over coffee and cake, with both of them tense but eager to share at the same time. The wife called the investigator a few days later and said that her husband had become very anxious anticipating questions in the next interview and that they both felt it would be better not to continue.

At the end of this process, the study sample consisted of 30 white families, half of them Jewish. Two-thirds were married couples and one-third were children caring for a parent. While 60 percent of the impaired persons were men, 73 percent of the caregivers were women. The mean age for the impaired person was 80, and for the caregiver, 69. While the study population fell into all SES categories, the modal family income was $500 per month. Details of sample characteristics can be found on pp. 89-113.

Interview Process

The investigator initially intended to ask written consent of both the supportive family member as well as of the impaired family member. She soon realized that most of the impaired members were unable to read and understand the consent form, so that their signature became meaningless and a farce to "informed consent" with the family member saying "sign here". After clearing with the University of California committee on Human Research, written consent was only asked from the family member, while oral consent was asked from the impaired member in the family member's presence. A copy of the consent form (Appendix III) with the investigator's home phone number was left with the family.

With several family members, the first interview was scheduled at a time the impaired member would not be present (e.g. attending day care). Whenever possible, the investigator tried to interview the supportive family member and the impaired family member in private. This was not always possible since in a few cases, the supportive family member hesitated to leave the room when the impaired member was interviewed. In a few cases the impaired member needed supervision and therefore had to remain in the room during the supportive member's interview. In a few other cases the physical set-up of the apartment did not permit privacy. Although the investigator considers it preferable to interview each family member without the other present, she does not think that the joint interviews impeded the validity of the information gathered. The advantage of the joint interviews was an opportunity for prolonged observation of interaction between the family members.

After gaining consent, data collection began with the focused interview of the supportive family member with several open-ended questions: "What is life like for you with your . . .? How did it start? What is difficult? What is positive?" Most of the supportive family members appreciated having an interested listener with whom to share their worries, frustrations, thoughts, beliefs, hopes, fears, anger, and satisfactions. They were encouraged to expand upon the topics which they considered especially relevant to them. Only after this first open-ended interview was the OMFAQ questionnaire administered to the supportive family member.

After gaining consent from the impaired family member, his/her interview began with the question, "Please tell me about yourself, your life." After this "warm-up" introduction, the investigator interwove the focused interview with the OMFAQ questionnaire. Since the thought processes in these cognitively impaired persons are concrete and either rambling or bland, frequent silences characterize verbal interaction. The interview was designed to elicit additional information to the different OMFAQ sections without changing the topic area focused upon. The length and depth of the interviews with the impaired members varied greatly according to the individuals' intellectual and emotional states. While some of the severely impaired subjects were unable or unwilling to answer even one single question, the interview with other impaired subjects ranged from one-half to three two-hour sessions.

After completing the focused interviews and the OMFAQ questionnaires with both the supportive and the impaired family members, the investigator scheduled a final session with the supportive family member. The objectives of this session were to (1) utilize the caregiver as the informant for answering the objective OMFAQ questions, (2) verify factual information gathered from the cognitively impaired member, and (3) fill gaps in the data sought.

All interviews were tape-recorded. After being assured of the confidentiality of the tapes and a few minutes of "getting used to", none of the subjects had any objections to the taping or seemed bothered by it. The investigator also asked to see the entire living space, in order to evaluate the physical home environment. All subjects answered this request without hesitation or misgiving.

DATA ANALYSIS

The investigator constructed separate coding documents* for the impaired person and the caregiver. Each coding document included three types of codes: (1) the OMFAQ questions were coded according to the OMFAQ coding procedure, (2) the open-ended questions of the investigator interviews were coded according to ratings determined by content analysis, and (3) observed behavior was also rated and coded according to content analysis.

"The reliability of behavioral observation measures . . . is usually defined as the agreement among observers

---

*See Appendices IV and V.

. . .. The reliability of observations can be estimated by correlating the observations of two or more observers." (Kerlinger, 1973, p. 540) Two experts in the field of adult development independently coded the transcribed interviews of five families. With setting up conventions, a high degree of inter-rater reliability was achieved.

While both the impaired members' and the caregivers' social and economic resources, their mental health, physical health, and ADL performance were measured on the OMFAQ scales, the investigator needed to construct scales for the other crucial study variables (i.e. IM and SM morale, IM and SM tension, SM management ability, SM mutuality, and IM senile brain disease functional impairment). None of these variables was covered by the OMFAQ ratings.

Morale and tension scales were constructed for both the impaired family member and the supportive family member, since morale and tension had relevance to each individual regardless of impairment or caregiving role. Management ability rated a caregiver function and therefore this scale was constructed for the supportive family member only. Since mutuality was defined as the perceived quality of the SM:IM relationship and only the caregiver was able to share this information, only an SM mutuality scale was built. A senile brain disease functional impairment scale (SBDFI) was only constructed for the impaired person, since this scale rated disease-related items.

The investigator constructed these seven scales (i.e. IM and SM morale, IM and SM tension, SM management ability, SM mutuality, and IM SBDFI) with the help of statistical computer analysis. She started with a pool of items selected for face validity. The items were then adjusted to be in the same direction. Using SPSS with varimax rotation factor analysis determined the item weights on each of the items chosen. For each individual and each scale the item scores were then converted into Z scores [item response minus mean for that item] divided by [standard deviation for that item]. The Z scores were multiplied by the factor score coefficients (weights) for the first factor and summed. The resulting sum was also a Z score and constituted the scale score. The range of the scales was then determined and the distribution of the study population on each of the seven scales.

There was some variation in the item pools of the IM and SM morale scales, since face-validity suggested some items as particularly relevant to IM morale and other items particularly relevant to SM morale.

IM Morale Scale. Item pool:

Attitude toward life and death
Feels lonely
Worries
Finds life exciting, routine, or dull
Present life satisfaction
Attachment to caregiver

IM Morale Scale. Item pool (continued):

Attachment to another significant other (if existent)

Perception of family life space

All these items are based on subjective evaluations of the impaired family member.

SM Morale Scale. Item pool:

Feels lonely

Finds life exciting, routine, or dull

Present life satisfaction

Takes psycho-pharmaca and/or sleeping pills

Feels helpless and/or hopeless and/or guilty and/or resentful

Perception of future

Perception of family life space

While valence of needs unmet was a crucial element in building the SM tension scale, valence could not be included in the construction of the IM tension scale. Most impaired persons were unable to share their valences of their met or unmet needs.

IM Tension Scale. Item pool:

All unmet needs were weighted '3'

All partially met needs were weighted '2'

SM Tension Scale. Item pool:

All unmet needs with high valence were weighted '3'

All unmet needs with medium valence were weighted '2'

All partially met needs with high valence were weighted '2'

SM Tension Scale. Item pool (continued):

All partially met needs with medium valence were weighted '1'

According to Lewinian field theory, tension is determined by needs unmet and influenced by the subjective value (the valence) the individual ascribes to a specific need.

SM Management Scale. Item pool:

Amount of instrumental help available

Amount of emotional help available

IM attends day care

Hours of hired nursing

Amount of time the caregiver can 'get out of the house'

Number of problems perceived as major stress

SM Mutuality Scale. Item pool:

Level of caregiver's perceived obligation to IM's care

Attachment of caregiver to IM in the present

Caregiver's perception of past relationship with IM

Quality of caregiver's obligation to IM's care in terms of perceived gain or loss for caregiver's own life

Senile Brain Disease Functional Impairment Scale. Item pool:

Number of errors (score) on the Short Portable Mental Status Questionnaire (SPMSQ)

Quality of self (intact, blurred, or eroded)

Continence of bladder and bowel

Amount of nursing care and/or supervision needed

Senile Brain Disease Functional Impairment Scale. Item pool (continued):

Wandering

Mobility

The scales used for the data analysis of this study are summarized in the following table.

TABLE 3.1. IMPAIRED FAMILY MEMBER AND SUPPORTIVE FAMILY MEMBER RATING SCALES

Impaired Family Member (IM)	Supportive Family Member (SM)
OMFAQ Social Resources	OMFAQ Social Resources
OMFAQ Economic Resources	OMFAQ Economic Resources
OMFAQ Mental Health	OMFAQ Mental Health
OMFAQ Physical Health	OMFAQ Physical Health
OMFAQ Activities of Daily Living	OMFAQ Activities of Daily Living
OMFAQ Cumulative Impairment	OMFAQ Cumulative Impairment
IM Morale	SM Morale
IM Tension	SM Tension
Senile Brain Disease Functional Impairment (SBDFI)	SM Management
	SM Mutuality

Correlations, one way analysis of variance, two independent sample t-tests, and cross-tabulations demonstrate similarities and differences within the sample population.

These tests were chosen for their statistical appropriateness in answering the working hypotheses. Since this study was largely explorative, much of the data are not quantifiable. The investigator uses descriptive reporting for these qualitative data.

CHAPTER IV

FINDINGS AND ANALYSIS

In this chapter the author will present four sets of data and their analysis. First is the presentation of a typology of mutuality in social relationships which has emerged from the qualitative data analysis. This typology will be illustrated by case material demonstrating that mutuality is a critical variable in the possibility of retaining home care for the severely impaired elderly person. Second, the author will present the demographic, social, and health characteristics of the thirty impaired persons and their principal caregivers. A series of working hypotheses dealing with the relationship of these characteristics to mutuality, management ability, morale, tension, and the caregiver's attitude toward institutionalizing the impaired person have been tested and will be reported. The third part of this chapter describes the problems that families living with senile brain disease face and the strategies they developed to manage their lives. This section will include a description of the activities the impaired person still enjoys. Finally,the author will present a series of working hypotheses dealing with the interrelationship of mutuality, the caregiver's management ability, the impaired person's and the caregiver's morales, their tension levels, and the family member's attitude toward institutionalization of the impaired person. These hypotheses were tested from the data collected.

I. DESCRIPTION OF THE SAMPLE ACCORDING TO MUTUALITY AS A CRUCIAL PARAMETER GOVERNING THE FAMILIES' MANAGEMENT-RELATIONSHIP PATTERNS

In qualitative data analysis, mutuality between the supportive and the impaired family members emerged as the major parameter for families managing life with senile brain disease.

In the face of immense problems posed by the impact of the decline itself, the implications of caring for a senile brain diseased person and the difficulties rooted in the social environment, mutuality became the important strategy. This strategy grew out of the caregiver's ability to find gratification in the relationship with the impaired person and meaning from the caregiving situation. Another important component to mutuality was the caregiver's (SM's) ability to perceive the impaired person (IM) as reciprocating by virtue of his/her existence. The study population fell into four distinct groups according to this parameter regardless of the actual severity of the disease or any of the socio-demographic variables:

Group 1 - high mutuality from within the SM:IM relationship ("internally reinforced mutuality")

Group 2 - high mutuality due to circumstances ("externally reinforced mutuality")

Group 3 - low mutuality

Group 4 - no mutuality "survived"

These groups constitute four major management-relationship patterns, as they emerged from the interview data, characterizing these families' lives.

Group 1 - High Mutuality "Internally Reinforced"

In this group (N = 7), all impaired members had moderate to severe cognitive impairment and three IMs had severe physical problems as well. Despite their severe impairment, these IMs had all retained an important function in the lives of their caregivers. All of these SMs considered the imagined loss of the IM as a major loss in their own lives. Although managing everyday life was fraught with severe problems due to the IM's impairment, these SMs considered themselves to be managing well under the circumstances.

Eighty-seven-year-old Mrs. Gold*, aphasic, incontinent, with severe cognitive impairment, was sitting in a wheelchair while her 57-year-old son was caressing her. He was a self-employed accountant, responsible for his mother's care for the last four years. He had hired nurses for the time he was at work. "Only the nurses' salaries are over $20,000 a

---

*All names are fictitious.

year and I take care of mother at night. For me this is the only thing to do and while I give a lot, she gives a lot in return. I really want to spend time with her, so I decided to give up some clients. It is a calculated gamble, because I am not sure I will earn enough to cover our expenses. On the other hand, I might wake up one day with the money and my mother will be gone. So what good will the money do me? Yes, I often think about losing her and this is why it is good now. I am lucky that I can take care of her. I take one day at a time. It is a good day if she moves her hand and feels well. Like today - she had a good bowel movement; it is a good day. If I would wait for the big things to happen, like her lifting her arm, or leading a real conversation, there would be no good days. It is down to the real basic things if you are happy or not."

Mrs. Bary is 56 years old and has Alzheimer's Disease. Her speech is garbled and she spends most of the days taking things in and out of drawers and hiding them. Her husband, retired from the U.S. Army, is 70. "Sure I want her around. She put up with me; why can't I put up with her? I gave her a harder time than she gives me. In the military our wives were secondary; we were always under orders. This has been coming on for the last four or five years. Somehow she can't put things together. It is just like that disease is eating her brain away. But as long as she recognizes me, I am going to keep her. Then I might put her in a home where

I can keep close touch on her. Sometimes I get tired, get burnt up - if I can't get my exercise or she is in such a terrible mood that she doesn't let me read. Once in a blue moon, we see some relatives, or friends, but she wouldn't enjoy meeting people, so I figure it is not fair to put her through it and I wouldn't leave her alone. She can't talk and can't enjoy company. And am I going to sit here and laugh and joke and her they can't talk to? Hell no. I don't even want them around. Because if you can't talk, right away you are ignored. Of course, I don't know whether it means anymore to her now. But it used to. If she can bear with me, I think I can bear with her."

Mr. Bosworth is severely physically and mentally impaired. His 68-year-old wife feeds him, bathes him, puts him to bed at night. "He's a wonderful man. But now he is so confused and just like a child, a child that I love very much. Once in a while he still talks, but does not like to see me cry. He knows there's something wrong. We used to sing together and now he doesn't sing anymore. Of course, I do everything for him, but I need him just as much as he needs me. He is someone to talk to, someone to touch, he is there and gives me a lot that way. I cannot be alone. As long as we are together I don't feel alone. It is dreadful sometimes. He's fighting everything, every minute - getting dressed, going up stairs. But most of the time he is satisfied and if I am happy, he is then happy too. We have lots of friends and they have been wonderful help."

Group 2 - High Mutuality "Externally Reinforced"

In this group (N = 6), the presence of the IM is essential to the SM's style of life. As a family unit they are able to do together what neither of them could do on his or her own. In these families there was little difference in the overall mental, physical, or socio-economic competence levels of the IM and the SM, which ranged from mild to severe impairment.

Mrs. Franklin was 66 years old and lived with her 87-year-old mother, who was at times confused and "crazy". Both women had handicapping physical problems and both lived on minimal income. While the daughter provided her mother practical help with shopping, getting dressed, etc., the mother provided the apartment, which the daughter would be unable to afford. Neither have close relatives or friends; they are each other's closest human support. "As long as my mother is not violent - and this is now taken care of by the medicine - we manage a good life together. I will take care of her as long as she lives."

Mrs. Silver's memory was failing. She let the pots burn on the stove and had grown very confused on a recent trip. Physically, she was in excellent shape, going swimming three times a week at age 86. Her husband had severe heart disease and while he would compensate for her memory loss by assuming household chores and smoothing social interaction, she gave him undivided attention, concern, and admiration. They decided to move to the Jewish Home for the Aged together to be able to continue their lives in a more protected environment, where medical help would be readily available.

Group 3 - Low Mutuality

In this group (N = 8), all caregivers considered the cognitive impairment, whatever its actual severity, an immense problem in their ability to relate emotionally to the IM. These families were so overwhelmed by the impact of the disease upon everyday life that the value they attached to the IM's continued presence was in jeopardy. Outside intervention seemed necessary to free some time and energy to these caregivers in order for them to perceive in the impaired person a valued individual, despite the disease. The quality and extent of services (e.g. respite care, day care, etc.) would seem to determine whether these families will move toward a pattern as in Group 1 (IMs retaining a positive role in their caregivers' lives) or to a pattern as in Group 4 (SMs overwhelmed with no positive function attached to the IM's presence).

Mrs. Rosch was a wiry old lady, her eyes darting; she sat at the edge of the chair, wringing her hands. She lived with her overweight son, who suffered from high blood pressure and ulcers, her daughter-in-law, and her 16-year-old granddaughter. The son and daughter-in-law spoke in an intertwining duo. "Right now we have no life; the whole atmosphere is so bad. Mother used to be a big help; we always lived together and it was perfect. She never had a mean streak in her, but now everything has become so difficult. She forgets, leaves the water running, insists on cooking and can't do it anymore, she constantly wants to feed us and is always accusing or blaming us for something. She doesn't realize that something is wrong with her. You can't talk to her anymore. Now, the biggest problem: when a little child doesn't act reasonably, you tell her, or you put her in a corner and that's it. You can't do that to an old person. What are you going to do? We would like her to go to the Jewish Home, but she resents it. It is hell if we do make her go and it is hell if we don't."

Mr. Green was 78, but looked at least ten years younger. He had a pleasant smile and a vacant expression and his answers were limited to: "I don't know", "I am an old man, I am nothing now, I don't know". Mrs. Green, wearing make-up and jewelry, held herself very erect in her living room filled with oriental vases, figures, and plastic dust covers over the furniture. "Three times he was missing; he just walked out of the house, once for 72 hours. His memory cells are absolutely smashed. He doesn't remember if he eats or where he lives. I cannot go away with him because every minute I have to watch him. Let's say if he has to go to the men's room. I have to stand at the door and wait; he might walk to the opposite direction and get lost. He can still play chess; he is an intelligent man and sometimes he plays bridge not badly. He had terrific knowledge, but he never shared it with anyone. He is very selfish. Nothing bothers him. This is not very commendable, but it is true. His daughter is like him, selfish - no matter how much I did for her. She knows no justice, decency, or appreciation. His daughter sued me now and this is my greatest pain, the ungratefulness. I got my husband, his sister, his daughter all affidavits (to come to the United States). Always I worked and I supported them. I am hurt that my husband's family treat me the way they do. We are married for 35 years and it is hard to imagine to live without someone that you shared life with for so long. But he is not quite a comfort to me. Gradually his sickness and the way his family treats me healed the shock or the unbelievable loss his death would have been, should it have happened earlier. I have so many problems and worries, so much unhappiness from this situation that I am not sure how I would feel now. There is only the fear of being all alone in the world; my parents died, my children didn't grow up (she had had three miscarriages) - it's to be alone. I am alone now, but somehow it is a habit to take care of someone, to share with someone. He can't answer me and I can't come to him with my problems, but somehow you are not alone. And, he is not a help, but he is there."

Group 4 - No Mutuality "Survived"

In this group (N = 9), the IMs range from mildly to totally impaired with the one common factor that none of these impaired family members seem to play any "positive" role in their caregivers' lives. All of these SMs would be relieved to know that their IM is well taken care of in an institution; some would be relieved by the IM's death.

Seventy-three-year-old Mrs. Moraga had been caring for her severely impaired 87-year-old husband for the last three and a half years. "You see, all the doors have three locks; he wants to go out and he wets the bed every night. I have to change the bed at least two to three times a night, but the worst is that he screams - he talks of other times, he pushes me away. When I give him supper he says 'I never get anything to eat' and he eats a tremendous amount of food. No, he definitely does not appreciate me; he doesn't even know. This is now nearly four years. He sits, stares, and then screams that he is scared. I tell him I protect him and then he asks if I am sure to protect him. He calms down for a minute and then he forgets again. No, medications don't help. The only thing that does help is to take him for a ride in the car, but at night it is too dangerous. Whenever our daughter comes - they always loved each other so much - he says 'I dont have a daughter; get out of my house!' It is not a life. Yes, it would be easier if he would die; I am honest about it. I am quite active and I cannot do anything I would like to do."

Mr. Irwing lives with his daughter. He is 92 and his memory is failing. "I forget much more than I used to, but I don't need to know these things anymore. I am too old; I realize I am in the way. This I don't do well and that I can't do. I am irritated with myself that I am still alive. I want to end my life in a way that everyone should be pleased with me." And his daughter. "I am working. I have a job that is very demanding and sometimes I just don't have the time to make all the arrangements. Talking to the doctor, calling here, coordinating the women who take care of him, going to pick up medicines for him. It takes time to work, to care for him, to cook, to keep house. I am completely tied down. He takes everything for granted. He thinks it's got to be that way. But not really. I think he doesn't like the thought that I have applied to the Old Age Home to have him admitted. But he will be better off there. He will get better care and be among people."

Mr. Madrid was 57 years old and looked 75. His wake-sleep pattern was four hours awake pacing and banging doors and four hours sleep. His wife, in a house-robe, seemed too weary to get dressed; the home conveyed a feeling of "falling apart". "He was a wonderful father and the greatest husband. Our house was never delapidated. He always wanted to work and then it started about five years ago when we noticed he would forget things . . . The oldest son hasn't finished his thesis; he works as a night watch guard. The second boy dropped out of college and Anne is not doing anything; she was such a good student; now she just sits at home." Oldest son expressed it thus: "I used to love my father; I used to love to see him come through the door. Now, when he comes, I hate it. It is like my emotions have changed. I hate to think that I hate my father now, but I just hate that disease he has. It's like I consider him dead three or four years ago. And the change in emotions from love to hate, or resentment - like seeing him come through the door. Oh no - I feel my energy sort of drain. It's very hard and I don't know how to deal with that. Some people say 'that's your father', but when you hear a door banging all night long, you can't sleep. It is every night, not just once in a while. All of our personalities have changed in a way to be able to live in the house with him now. We either tolerate or ignore him. My brother would be sitting here and talking and he is walking back and forth and we're oblivious to him. And then when I realize that we are, it is like the static in the background that you try to ignore. At other times he will block whatever we are doing and we will have to deal with him. You can be the dutiful son or daughter and take care of him, or you can try to get away for a while. I could come home happy about something and I want to tell my mother and my brother and say, 'look what's happened to me today', but pretty soon it winds down and I'm looking at Dad and I'm not happy anymore. He is like a symbol of how we live and waste away slowly. Sometimes I wish that he would die and I feel guilty for wishing that. Some things are worse than death. Like Ma said that we are talking about putting him in a home, but there is no place that will take him. And she told that nurse, 'Well, if you don't have a home, how about a zoo? There must be a cage somewhere.' When she said that it was so good, because it is true. He is in a cage. If you would put him in a cage, you'd do the same thing. He is living in a zoo and we are all living in a zoo with him, trying to lead normal lives."

For the purposes of comparison and the testing of working hypotheses, mutuality was operationalized according to four discrete variables on the family member coding document (items 0622 to 0625; see page

(1) the amount of emotional satisfaction the SM gained from the caregiving situation;

(2) the SM's attachment to the impaired person in the present;

(3) the SM's perception of their past relationship; and

(4) the quality of the family member's obligation to the IM's care in terms of gain versus loss.

II. DEMOGRAPHIC, SOCIAL, AND HEALTH CHARACTERISTICS OF THE STUDY POPULATION AND RELATED WORKING HYPOTHESES

The conceptual framework and the study questions determined the direction of data analysis. Answers were sought to which variables influence (1) the caregiver's ability to manage, (2) the caregiver's and the impaired person's morales, (3) the caregiver's and the impaired person's tension levels, and (4) the caregiver's attitude toward continued home care or institutionalization of the impaired person. In addition, data analysis tried to isolate the variables influencing mutuality which emerged as the critical parameter from qualitative analysis.

The age and sex distribution of this sample of families in caregiving relationships is similar to that reported in the literature (Isaacs _et al._, 1972; Robinson and Thurner, 1976; Treas, 1977). It is the middle-aged and old woman who carry the burden of care for her ailing spouse or parent. Nevertheless, it is noteworthy that in this sample 27 percent of the supportive family members (SMs) were men who assumed the full responsibility for the care of their often very impaired spouse or parent. In this study, 18 impaired persons (60 percent) were men and 12 (40 percent) were women. Their ages ranged from 56 to 92 years with the mean age of 80.13 and the mode 87 years of age. Eight caregivers (27 percent) were men and 22 (73 percent) were women. The ages of these supportive family members ranged between 45 and 88 years with the mean age 69 and the modal age 66.

The variables of the IMs' and SMs' sex and age made no statistically significant difference* in the caregiver's (SM's) management ability, their sense of mutuality (the perceived reciprocity of the relationship), their level of tension (number of highly valued unmet needs), and their attitude toward institutionalization of the impaired family member. While the impaired person's sex did make a statistically significant difference in relation to the caregiver's morale and the impaired person's tension level, SM sex and age of either family member were not related to these variables. SM morale was higher whenever the IM was female ($t = 4.22$; $p < .000$). A combination of two factors seems responsible for this finding. The first factor relates to the fact that in this society, men are not expected to be able to care for their impaired spouses, while women are. Four men derived considerable pride from their caregiving "achievement", which was a source of high morale not available to the female spouses. The other factor relates to family constellation. Five impaired mothers were cared for by SMs living with their own family, which provided emotional and instrumental support as one source of higher morale. These two factors apply to 75 percent of the caregiving situations where the IM was female. In two-thirds of the

---

*For this study, $p < 0.05$ was considered the lowest level of statistical significance acceptable.

families where the IM was male, the caregiver was a wife who faced a severe burden with little support. This fact also explains why IM tension was higher for male IMs ($t = 2.50$; $p < .018$). Many wives were the sole source of meeting their impaired husbands' needs and had difficulty doing this with own diminished resources.

The family constellations of impaired persons and caregivers were as follows. Thirteen IMs were married to their first spouse, seven to their second or third spouse, and ten IMs were widowed. Of the caregivers, 17 were married to their first spouse, seven to their second or third spouse, one was widowed, one separated, two were single, and two supportive family members lived in a gay relationship. Sixteen families were Jewish, nine Catholic, four Protestant, and one family was Greek Orthodox. Of the Jewish families, seven were Hitler refugees.

In 20 families a spouse, in one family a sibling, and in nine families a child was the main caregiver. This is not a surprising finding. According to Kaplan (1975), the majority of older people living with families consists of elderly married couples and Donahue's statistics indicate that three out of ten older people in the United States live in households with their children (Donahue, 1969). Family support for the aged has also been extensively documented (Shanas, 1973; Sussman, 1976; Treas, 1977). In 19 families the SM and IM lived in their common household, in two families the SM lived in the IM's household, in two families the IM had moved into the SM's household before evidence of senile brain disease, in five families the IM had moved into the SM's household after evidence of senile brain disease, and in two families the IM and main SM lived in their child's household.

The author assumed that religion and generational relationship may influence the caregivers' management ability, mutuality, and attitude toward institutionalization, as well as the IM's and SM's morales and their tension levels. Statistical analysis did not prove these working hypotheses. None of the above attitudinal and behavioral variables showed statistically significant differences when measured according to religion (Jewish versus non-Jewish), or according to whether the caregiving relationship was between spouses or child and parent.

The 30 families' SES is summarized in Tables 4.1, 4.2, and 4.3.

TABLE 4.1. YEARLY FAMILY INCOME (N = 30).

Income Range	N	%
$4,000 - $4,999	4	13
$5,000 - $6,999	7	23
$7,000 - $9,999	6	20
$10,000 - $14,999	3	10
$15,000 - $19,999	2	7
$20,000 - $29,999	5	17
$30,000 or more	3	10
TOTAL	30	100

TABLE 4.2. MAIN OCCUPATION OF IM AND SM.

Occupation	IM		SM	
	N	%	N	%
higher executive, major professional	1	3	1	3
business manager, medium sized business owner, lesser professional	0	0	4	13
administrative personnel, small business owner, semi-professional	7	23	4	13
clerical and sales workers, technicians	5	17	7	23
skilled manual employees	4	13	1	3
semi-skilled workers	5	17	5	17
unskilled workers	0	0	2	8
housewife	8	27	6	20
TOTAL	30	100	30	100

At the time of the interviews, six SMs worked full-time. two worked part-time, and one SM was a part-time student.

TABLE 4.3. DISTRIBUTION OF FAMILIES ON OMFAQ ECONOMIC RESOURCES SCALE.

Economic Resources	N	%
excellent economic resources	2	7
good economic resources	10	33
mildly impaired economic resources	9	30
moderately impaired economic resources	3	10
severely impaired economic resources	6	20
TOTAL	30	100

In 1975 half of all older couples in the United States lived on incomes of less than $8,000 (Brotman, 1977b). The median family income in this sample is comparable to the national average, but the distribution of the low income families differs. While over a quarter of the elderly fell below the near-poor level ($4,071) and seven percent under the poverty level (Brotman, 1977b), not one family in this sample fell into these categories. A certain minimal income seems necessary for families to even attempt to care for a severely impaired person in the home. The author assumed that economic resources would influence a caregiver's management ability, mutuality, and attitude toward institutionalization, as well as the caregiver's and the impaired person's morale and tension levels. None of these hypotheses proved statistically significant. Nevertheless, it would be a grave mistake to discount the importance of economic resources. Elderly people typically do not perceive that they have serious economic needs and ask for very little help (Barney, 1977). This trend also applied to low income families in this sample. Since the basic needs of food and housing were met for all of these families, the behavioral and attitudinal variables measured were not affected. Notwithstanding, there is no doubt in the researcher's mind that improved economic resources could have greatly reduced the burden of care for the lower income families by affording them hours of hired relief.

While the actual functional impairment of the senile brain diseased family members spanned a wide range, most of them were severely impaired. As measured by the Short Portable Mental Status Questionnaire (SPMSQ), seven IMs (23.3%) scored mild cognitive impairment, four (13.3%) moderate, and 19 (63.3%) scored severe cognitive impairment. The modal SPMSQ error score was ten (the score for highest impairment) and the mean was 7.6. The pattern of information retained by senile brain diseased people seems noteworthy. While approximately 40 percent of the impaired persons knew their address, birth date, age, and mother's maiden name, only 17 percent could subtract three from 20 (and continue subtracting until zero) or remember the day of the week, and only two IMs knew the date and the name of the former U.S. president.

Twelve (40 percent) impaired persons had trouble getting to the bathroom on time and one IM had an indwelling catheter. Twelve IMs needed 24-hour nursing care and supervision, 11 IMs could be left alone for several hours, three IMs needed a few hours of nursing care daily, three IMs needed nursing care occasionally, and only one impaired person did not need nursing care or immediate supervision. Eleven IMs (36.7 percent) tended to wander or had gotten lost. Five IMs (16.7 percent) had sensory aphasia and three (10 percent) were completely unable to communicate verbally.

Senile brain disease affects the differentiation of an individual's personality. The unique human ability of assigning meaning to thoughts and emotional reactions seems affected by the disease process and behavior results, which conveys degrees of blandness to the observer. The acuity of the self seems to fade and leave at first a "blurred" devitalized human being who, as the disease progresses, becomes even more undifferentiated or "eroded". The researcher rated this quality of the IM's "intactness of self". Nine impaired persons (30 percent were rated "intact", ten (33.3 percent) "blurred", and eleven (36.7 percent) "eroded".

The impairments related to senile brain disease and reported in the above three paragraphs were summarized by factor analysis to construct the senile brain disease functional impairment scale (SBDFI) (see pp. 73-74). The author assumed that the level of an individual's impairment as measured on this scale would influence the supportive family member's management ability, perception of mutuality, his/her attitude toward institutionalizing the IM, as well as the SM and IM morale and tension levels. None of these working hypotheses proved statistically significant differences in the above attitudinal and behavioral variables according to the IM's impairment level. This is a surprising finding considering the severity of impairments and the burden of care.

Several aspects of the caregivers' social support systems were assessed. The availability and quality of social relationships were rated on the OMFAQ Social Resources Scale (see Table 4.4). While 27 percent of the SM subjects had very good social relationships, 40 percent perceived their relationships as unsatisfactory or of poor quality with very little help available to them.

Two-thirds of the SMs had a confidant they could turn to and this role was filled by spouse, children, relatives, or friends in roughly equal proportion. In most incidences the confidant resided within the city and in only five of the 20 cases (ten SMs had no confidant) did she/he reside at

TABLE 4.4. DISTRIBUTION OF SUPPORTIVE FAMILY MEMBERS ON OMFAQ SOCIAL RESOURCES RATING SCALE.

Social Resource	N	%
excellent social resources	1	3.3
good social resources	7	23.3
mildly impaired social resources	10	33.3
moderately impaired social resources	7	23.3
severely impaired social resources	5	16.7
TOTAL	30	100.0

a distant location and was not readily available. Examining the availability of practical and emotional support to the SM in regard to caring for the IM, practical help appeared more accessible than emotional help (37 percent as compared to 17 percent). While not always readily available, most subjects could count on at least some practical and emotional support. Only for 13 percent no practical and for 20 percent no emotional help was available. About half of the SM subjects had hired help with household chores. Regarding kin, SM subjects differed widely in terms of the family roles they occupied and on the number and availability of children. Forty percent of the caregivers were childless, while about half had at least some contact with children. In order to facilitate comparisons of the subjective quality of kin support, ratings of positive/negative perceptions of family life space were used. Most SM subjects had positive perceptions of their familial relationships and only one-third conveyed indifferent or negative attitudes.

The investigator assumed that a caregiver's social resources would influence his/her management ability, perceived mutuality, attitude toward institutionalization of the IM, as well as the SM's and IM's morale and tension levels. None of these working hypotheses proved statistically significant differences.

The social support system of the impaired person was based mainly upon the caregiver. About one-third of the IMs frequently interacted with an additional significant person, while about half the IMs had no significant human being, other than the principal caregiver to interact with. One-half of the IMs had a confidant they could turn to. For eight IMs this role was filled by a spouse and for four IMs by a child. All of these resided in the same household as the IM. No IM had a confidant in a distant location. Half of the IM subjects had positive perceptions of their family life space, while only 20 percent conveyed indifferent or negative attitudes. For one-third of the IM subjects, the investigator was unable to rate their family life space perception, even by inference. For nine IMs, day care provided a highly valued social support (for more detail, see pp. 131-132).

In contrast to the caregiver's social resources, those of the impaired person show statistically significant differences according to the attitudinal and behavioral variables measured. These findings will be summarized in Table 4.5.

TABLE 4.5. CORRELATIONS OF IM SOCIAL RESOURCES WITH SM AND IM ATTITUDINAL AND BEHAVIORAL VARIABLES (N = 30).

IM Social Resources	Pearson R	Significance
SM management ability	0.55	0.002
SM mutuality	0.55	0.001
SM morale	0.40	0.032
IM morale	0.43	0.015
SM tension	0.61	0.000
IM tension	0.53	0.003
SM attitude toward institutionalization	n.s.	

These findings speak to the centrality and the overriding importance of the IM:SM relationship within the lives of these subjects. The amount and quality of IM social resources are mainly determined by the caregiver. While the SM's social resources are not a decisive variable in influencing his/her ability to manage, high IM social resources depend upon high SM management ability. High SM mutuality toward the IM is independent of the SM's social resources (which do not include the IM as an active resource), but IM social resources will be better whenever the SM's perception of their mutuality is higher. The crucial importance of the IM:SM dyad over any other relationship seems also to explain the differential impact of SM and IM social resources upon morale. While SM social resources do not correlate with morale, high IM social resources (the caregiver's continued availability) correlates with high SM and IM morale. Good IM social resources correlate with less IM tension (fewer IM needs are unmet) and less SM tension (fewer highly valued needs were unmet). When comparing this finding to the lack of correlation between the SM's social resources and IM or SM tension levels, the prime importance of the dyadic relationship in meeting each other's needs becomes again apparent.

Outlook on life is the essence of life satisfaction or morale. It is a major element in the subjective assessment of life's quality, of a person's well-being or mental health. While one-third of the impaired persons were very satisfied with life, 43 percent of the IMs reported low life satisfaction. For 20 percent of the IMs, life satisfaction could not be rated since the individuals were unable to share this information. The IMs' loneliness feelings closely resembled the distribution of life satisfaction. About one-third hardly ever felt lonely and 40 percent did experience loneliness at times or even frequently. Again, seven IMs were unable to share whether they felt lonely or not. Life satisfaction is a crucial variable of mental health. Behavioral characteristics descriptive of the impaired members' mental health are summarized in Table 4.6.

TABLE 4.6. FREQUENCIES OF IM BEHAVIORAL CHARACTERISTICS IN DESCENDING ORDER (N = 30).

Behavioral Characteristic	N	%
usually cooperative	23	76.7
anxious	18	60
"overall" satisfied	17	56.7
angry, aggressive	14	46.7
physically restless	13	43.3
feeling useless, dull, "nothing"	13	43.3
bland	12	40
sad, not depressed	8	26.7
depressed	7	23.3
euphoric, jovial	7	23.3
suspicious	6	20
paranoid	5	16.7

While many IMs were very troubled or "bland", most of them were cooperative with their caregivers. The exceptions were IMs exhibiting aggressive behavior and/or paranoid ideation. The distribution of IM's and SM's OMFAQ mental health ratings are summarized in Table 4.7.

TABLE 4.7. DISTRIBUTION OF SMs AND IMs ON OMFAQ MENTAL HEALTH RATING SCALE.

	Supportive Family Member (SM)		Impaired Family Member (IM)	
Rating	N	%	N	%
good mental health	15	50	0	0
mildly impaired mental health	13	43	4	13.3
moderately impaired mental health	2	6.7	5	16.7
severely impaired mental health	0	0	11	36.7
totally impaired mental health	0	0	10	33.3
TOTAL	30	100	30	100

Resorting to medications was one way of handling the difficulties in the area of mental health (see Table 4.8).

While these medications were usually given to the impaired persons to control anxious and restless behavior, the caregivers took them in an attempt to control "unhappiness".

Forty percent of the caregivers were very satisfied

TABLE 4.8. PSYCHO-PHARMACA AND SLEEPING PILL CONSUMPTION BY IM AND SM ACCORDING TO FREQUENCY (N = 60).

	Never		Now and Then		Regularly		Not Codable	
	N	%	N	%	N	%	N	%
IM	14	46.7	4	13.3	11	36.7	0	0
SM	12	40	6	20	11	36.7	1	3.3

with life, while 60 percent rated themselves fair to low on life satisfaction. Nearly one-third considered life exciting. These SMs were either spouses or children and no common denominator seemed evident. The nearly one-third who considered life as dull were all spouses. Half of the caregivers reported feeling lonely and those 11 (37 percent) who experienced loneliness frequently were all spouses. The main reason for these supportive family members' unhappiness was the loss of their partner to senile brain disease.

The investigator assumed that IM and SM mental health would influence the attitudinal and behavioral measures. IM mental health did not. SM management ability, SM mutuality, SM morale, SM attitude toward institutionalization and SM and IM tension levels showed no statistically significant differences according to the IM's mental health. Even the relationship to IM morale was not significant. This can be explained by the fact that the IM mental health rating (OMFAQ) was heavily weighted by the level of cognitive impairment, which seems to have no correlation with life satisfaction.

The SM mental health showed no statistically significant differences according to SM management ability, SM mutuality, SM attitude toward institutionalization, IM morale and IM tension. High SM mental health does correlate with high SM morale [$R = 0.46$; $p < 0.013$] as would be expected and impaired SM mental health correlates with high SM tension levels [$R = 0.39$; $p < 0.038$].

While for the IMs in the sample mental health and daily living activity impairments were even larger than the physical deficits, impairment of physical health was the most severe restriction for the SM group. Seventeen SMs suffered from at least one chronic disease and eight SMs had been hospitalized in the six months prior to the interviews. Although 22 SMs (73 percent) were above age 60, the frequency and severity of physical impairment for the SM subjects seems higher than expected for this age group. While only 25 percent of the elderly in the Durham County Community Survey ($N = 997$) (Pfeiffer, 1975a) were physically impaired (OMFAQ rating of moderate to complete impairment), the rate of physical impairment for the SM subjects was more than double (57 percent). The impact of the caregiving situation is a possible explanation of the low SM health. Although a cause effect relationship could not be established in this research, such a finding is consistent with the literature (Sainbury and Grad, 1970).

Twenty IMs suffered from at least one chronic disease aside from senile brain disease and ten had been hospitalized in the six months preceding the interviews. Ratings of IMs' and SMs' overall physical health, their vision, hearing and medication consumption are summarized in the following three tables (Tables 4.9, 4.10, and 4.11).

TABLE 4.9 DISTRIBUTION OF SMs AND IMs ON OMFAQ PHYSICAL HEALTH RATING SCALE.

	Supportive Family		Impaired Family	
Rating	N	%	N	%
good physical health	2	6.7	7	23.3
mildly impaired physical health	11	36.7	7	23.3
moderately impaired physical health	12	40	5	16.7
severely impaired physical health	5	16.7	10	33.3
completely impaired physical health	0	0	1	3.3
TOTAL	30	100	30	100

TABLE 4.10. IM AND SM VISION AND HEARING WITH GLASSES OR HEARING AIDES ACCORDING TO ACUITY IN ABSOLUTE FREQUENCIES (N = 60).

Vision and Hearing	Good		Fair		Poor		Total	
	N	%	N	%	N	%	N	%
IM vision	13	43.3	14	46.7	3	10	30	100
IM hearing	14	46.7	10	33.3	6	20	30	100
SM vision	23	76.7	6	20	1	3.3	30	100
SM hearing	25	83.3	3	10	2	6.7	30	100

TABLE 4.11. IM AND SM CONSUMPTION OF LIFE SUSTAINING MEDICATION (e.g. against heart disease, high blood pressure, diabetes) IN ABSOLUTE FREQUENCIES (N = 60).

	None		Now and Then		Regularly		Total	
	N	%	N	%	N	%	N	%
IM	16	53.3	0	0	14	46.7	30	100
SM	12	40	2	6.7	16	53.3	30	100

The author assumed that SM and IM physical health would influence the behavioral and attitudinal measures. But IM physical health showed no statistically significant difference according to SM management ability and mutuality to the SM's attitude toward institutionalization, to SM and IM morale, and to IM tension. The only statistically significant correlation was between IM physical health and the SM tension level. The more impaired the IM's health, the more highly valued SM needs remained unmet [$R = 0.37$; $p < 0.045$]. The SM's physical health was not significantly related to SM management and the caregiver's attitude toward institutionalization, as well as IM and SM morale. It is an astonishing finding that SM and IM health were unrelated to morale and the author is unsure of how to explain this fact. In previous research, poor health has been found to be strongly related to low morale (Chatfield, 1977; Palmore and Luikart, 1972; Spreitzer and Snyder, 1974). A possible explanation may come from distinguishing physical dependency from poor health. Physical dependency is a primary cause of low morale (Clark and Anderson, 1967), but while physical dependency is usually associated with poor health, this was not the case for this sample. The SM subjects tended to be independent and very resourceful in finding help when needed. They did not perceive themselves as physically dependent whatsoever. This perception might have been even reinforced by their role of principal caregiver.

Better SM physical health correlates with higher SM tension [R = 0.42; $p < 0.027$] and lower perception of SM:IM mutuality [R = 0.53; $p < 0.003$]. It seems likely that perceived deprivation in activity levels is higher for healthy SMs than for those with own serious health problems. This would explain the effect of SM health upon SM tension (unmet highly valued needs) and SM mutuality (the caregiving relationship is perceived as an overall loss). IM tension is also higher whenever SM health is better [R = 0.42; $p < 0.020$]. The intervening variable of SM mutuality seems to best explain this fact: lower SM mutuality impedes the caregiver's response to the impaired person's needs.

Of all functional impairments, the IMs' most severe deficits were in the performance of activities of daily living. This affected not only the impaired persons themselves, but also had an immediate impact upon the caregivers. In most cases the SM had to compensate for the IM's functional declines. The need for help with the activities of daily living is summarized in Tables 4.12 and 4.13.

The impaired person's ADL performance was statistically unrelated to any of the behavioral or attitudinal measures. While the caregiver's ADL performance was also unrelated to SM mutuality, SM attitude toward institutionalization, IM and SM morale, and IM and SM tension, SM ADL performance showed a statistically significant correlation with SM management. At first glance, the direction of this correla-

TABLE 4.12. LEVEL OF IM PERFORMANCE OF ACTIVITIES OF DAILY LIVING ACCORDING TO AMOUNT OF HELP NEEDED (N = 30).

	With No Help		With Some Help		Completely Unable To	
ADL	N	%	N	%	N	%
use telephone	3	10	13	43.3	14	46.7
get places out of walking distance	2	6.7	21	70	4	23.3
do shopping	1	3.3	5	16.7	24	80
prepare own meal	0	0	10	33.3	20	66.7
do housework	0	0	8	26.7	22	73.3
take own medicine	0	0	10	33.3	20	66.7
handle money	1	3.3	3	10	26	86.7
eat	19	63.3	10	33.3	1	3.3
dress and undress	14	46.7	13	43.3	3	10
take care of own appearance	11	36.7	14	46.7	5	16.7
walk	23	76.7	5	16.7	2	6.7
get in and out of bed	24	80	4	13.3	2	6.7
take bath or shower	6	20	16	53.3	8	26.7

TABLE 4.13. DISTRIBUTION OF SM AND IM SCORES ON OMFAQ ACTIVITIES OF DAILY LIVING PERFORMANCE SCALE (N = 60).

	Supportive Family Member		Impaired Family Member	
Performance	N	%	N	%
good ADL performance	25	83.3	0	0
mildly impaired ADL performance	2	6.7	0	0
moderately impaired ADL performance	2	6.7	10	33.3
severely impaired ADL performance	1	3.3	12	40
completely impaired ADL performance	0	0	8	26.7
TOTAL	30	100	30	100

tion is astonishing: SMs with low ADL competence have higher management ability [R = 0.41; $p < 0.024$]. On closer consideration, the reason for this finding becomes apparent. SM management ability is largely a measure of support the SM was able to mobilize (see scale construction, p. 73). Caregivers with low ADL competence must have mobilized considerable amounts of support to be able to continue in their principal caregiver role.

The individual's overall functioning is summarized by adding the functional ratings of each of the five areas (social resources, economic resources, mental health, physical health, and ADL performance) to form a Cumulative Impairment Score (CIS) with low CIS ratings indicating good overall functioning and high ratings indicating significant impairment. When comparing the CIS ratings of this sample to the three Duke University samples (Community, OARS Clinic and Institutional study populations), the SMs in this study were slightly more impaired than the Duke Community sample and the IMs were slightly less impaired than the Duke Institutional sample (Pfeiffer, undated report).

TABLE 4.14. CUMULATIVE IMPAIRMENT SCORE (CIS) BREAKDOWN FOR SMs, IMs, AND THREE DUKE SAMPLES.

	Present Study				Three Duke Studies					
	SM		IM		Community		Clinic		Institution	
CIS	N	%	N	%	N	%	N	%	N	%
low impairment 15-17	25	83.3	6	20	870	88	37	47	11	14
high impairment 18-30	5	16.7	24	80	115	12	41	53	65	86
TOTAL	30		30		985		78		76	

There was no statistically significant relationship between SM CIS ratings and the behavioral or attitudinal variables. IM CIS ratings showed no significant correlation with SM management ability, SM mutuality, and IM morale, while they did influence SM morale and IM and SM tension. Whenever IM CIS ratings were higher, SM morale was lower [$R = 0.41$; $p < 0.011$]. Whenever IM CIS ratings were higher, SM tension was higher [$R = 0.39$; $p < 0.016$] and so was IM tension [$R = 0.40$; $p < 0.013$].

In Table 4.15, the significant statistical correlations between the social, demographic and impairment variables, and the attitudinal and behavioral variables will be summarized.

In the preceding part of this chapter, the social demographic, and health characteristics of the sample were presented. Working hypotheses relating these variables to attitudinal and behavioral measures were tested and reported. In the next section the lives of these families living with senile brain disease will be described.

TABLE 4.15. STATISTICALLY SIGNIFICANT CORRELATIONS OF SM AND IM DEMOGRAPHIC, SOCIAL, AND HEALTH CHARACTERISTICS ACCORDING TO SM AND IM ATTITUDINAL AND BEHAVIORAL VARIABLES (N = 60).

SM Management Ability	SM Mutuality	SM Attitude to Institutionalization	SM Morale	SM Tension		IM Morale	IM Tension
					SM sex		
					SM age		
					SM social resources		
					SM economic resources		
			$R = 0.46$ $p < .013$	$R = 0.39$ $p < .038$	SM mental health		
	$R = 0.53$ $p < .003$			$R = 0.42$ $p < .027$	SM physical health		$R = 0.42$ $p < .020$
$R = 0.41$ $p < .024$					SM ADL		
					SM CIS		
					religion		
					spouses: child/parent		
			$t = 4.22$ $p < .000$		IM sex		$t = 2.50$ $p < 0.18$
					IM age		
$R = 0.55$ $p < .002$	$R = 0.55$ $p < .001$		$R = 0.40$ $p < .032$	$R = 0.61$ $p < .000$	IM social resources	$R = 0.43$ $p < .015$	$R = 0.53$ $p < .003$
					IM mental health		
				$R = 0.37$ $p < .045$	IM physical health		
					IM ADL		
			$R = 0.41$ $p < .011$	$R = 0.39$ $p < .016$	IM CIS		$R = 0.40$ $p < .013$
					IM SBDFI		

III. LIVING WITH SENILE BRAIN DISEASE

Description of the Senile Brain Diseased Persons' Behavioral Problems and Characteristics, Their Caregivers' Perceptions of These Problems, and Their Management Strategies

In the open-ended interviews, the SMs spoke to a wide range of IM problems. But the mere fact of a problem's existence did not determine its impact upon a given family's life. While some family members considered a certain behavior the prime problem in handling the IM, other family members hardly acknowledged the behavior's existence. After presenting the frequencies of these problems in Table 4.16, the author will use descriptive data to illustrate the problem situations and the range of strategies these 30 families used in managing them.

Table 4.16 shows the frequency of various types of problems and the extent to which they are perceived as primary, major, or minor sources of stress by the caregiver. Except for a greater tendency to view loss of former self, aggressiveness, restlessness, and physical decline as a primary source of stress and a tendency not to give primary importance to the IM's poor judgment, disorientation to time, speech difficulties, and danger to self, there was little consistency as to which aspect of the impaired person's behavior was experienced as most stressful.

Whenever "loss of self" affected salient features of the earlier IM-SM relationship, the impact of this type of

TABLE 4.16. IM BEHAVIORAL PROBLEMS AND CHARACTERISTICS ACCORDING TO SM PERCEPTION OF THEIR SERIOUSNESS AS A MANAGEMENT PROBLEM AND TO FREQUENCY OF OCCURRENCE (N = 30).

Behavioral Problems and Characteristics	Primary Problem		Major Problem		Minor Problem		Total Number of IMs with This Problem	
	N	%	N	%	N	%	N	%
loss of prior self	5	17	18	60	3	10	26	87
aggressive, abusive	5	17	7	23	2	7	14	47
anxious, restless	4	13	11	37	6	20	21	70
physical decline	3	10	9	30	7	23	19	63
lack of interest, "vegetates"	2	7	18	60	4	13	24	80
demands constant attention, presence	2	7	16	53	2	7	20	67
perseverations, repeating	2	7	13	43	7	23	22	73
dependency	1	3	17	57	12	40	30	100
discontent, unhappy	1	3	14	47	1	3	16	53
unesthetic, unclean	1	3	10	33	2	7	13	43
strange, bizarre behavior	1	3	9	30	2	7	12	40
unable to rally help for SM	1	3	8	27	19	63	28	93
dangerous to surrounding	1	3	5	17	3	10	9	30
wanders	1	3	4	13	3	10	8	27
poor judgment	0	0	13	43	11	37	24	80
disoriented to time	0	0	9	30	16	53	25	83
dangerous to self	0	0	7	23	6	20	13	43
aphasic	0	0	7	23	2	7	9	30
confuses, does not recognize people	0	0	6	20	13	43	19	63
money "hang-up"	0	0	4	13	3	10	7	23
paranoid ideation	0	0	4	13	1	3	5	17

decline weighed heavily upon the supportive family member. On the other hand, whenever this loss did not affect areas central to the former relationship, the caregivers tended either simply to acknowledge or to overlook the deficit. For example, Mrs. Gans, a woman in her 70's with an intelligent and expressive face, motioned toward her sleeping husband explaining, "He was a very intellectual man, well read - I could ask him anything I didn't know. Now he asks me questions. It is such a terrible feeling, such a gnawing feeling. I can't talk myself out of it. There is no communication. I would like to communicate with him like I used to." And then there is Mr. Bary; full of concern, he watches his wife who is aimlessly rearranging piles of underwear. "The neighbors first told me that she doesn't understand. We never used to talk that much and anyway, I would know what she means. Now she can't follow a conversation at all; she can't put things together. It is her moods that bother me, for this (inability to converse) I can pitch in."

Most family members were very upset by <u>aggressive or abusive behavior</u>. "We have been married close to 60 years and everything was fine, when he started losing his mind. I suppose I resent being told off all the time. And that I - I don't want to say it out loud - 'that I am the shits'. I just feel so tired and so worn out that I feel I can't take care of him anymore, and I don't want to." Another elderly wife reported agitatedly,"I put my Social Security money in a safe deposit box and sent the key to my sister, so I have some cash when I need it. But he said that if I ever did such another dirty deal that he'd smash my head in. That's the way he talks when he is angry, and I am afraid. I don't know where you could go for help." Mrs. Gold is a gentle appearing old lady with a most charming smile. If she doesn't like the food the nurse feeds her, she spits it into her face, and being catheterized, she tears off the nurse's wig, cursing her "filthy nigger". Her son reacts with embarrassment, "I never realized my mother even knew these words", explaining to the nurses how his mother did not mean to insult them, but several nurses had quit because of this behavior.

Many family members find it difficult to tolerate anxious and restless behavior. In some cases psycho-pharmaca are effective in controlling anxiety, but adverse reactions are not infrequent. "For months he was looking forward to the trip, but when we were in the plane, he was fighting the seat belt. We gave him Valium and it didn't help, and we gave him a drink and that made it worse. And then in Germany - it was terrible . . . On the way home I had given him Mellaril. We had a stopover and all of a sudden he went berserk at the airport. He was running all over the place. The stewardesses came and the police came and it took four fellows to hold him down. Then they didn't want to let us fly on to San Francisco . . . it was the environmental push.

At home his restlessness became a terrible problem, especially at night. He never found his way back to bed. If he had to go to the bathroom, he would go to any corner. I followed him and tried to get him back to bed. That was every night about four or five times and I was really worn out and then I had to do something. It was hard on me, but I had to do something, otherwise I couldn't have gone on. I tied his blanket on the post like you tie a child in a crib. On both sides. I pushed the bed against the wall. I had the blanket underneath the mattress and tied it so that he could not get out. And he stayed in bed. He would wet anyhow. From then on I slept and he slept and I was able to handle him, to take care of him."

Another elderly wife feels that her husband's anxiety and restlessness make her life intolerable. "Last evening I counted; he called 24 times within about an hour and a half. I go back and forth, back and forth. He wants me there, right next to him, but I have work to do or I talk with someone on the phone. He is always afraid and he screams. The only thing that helps is to take him for a ride in the car. It calms him down."

The implications of particular stresses stemming from the IM's physical decline centered on the hardships of handling a severely physically disabled person in the home. Most families were very resourceful in finding solutions to handling incontinence of bladder (e.g. they would know when to place the IM on the toilet or use padding at night), lack of mobility, and disease regimen. Fifteen families had no hired help for nursing care or supervision, four families had help for three to eight hours per week, five families for 12 to 24 hours per week, and six families had hired help with nursing care and supervision for over 40 weekly hours. The general availability of help to the SM is described in more detail on p. 98.

Most family members were very distressed when speaking of the impaired person's lack of interest, or "vegetating". They conveyed a sense of sad frustration. "He doesn't want to do anything, he doesn't care for television, he doesn't want to read the paper, he doesn't care for music. He used to play solitary - he won't play solitary. He just sits and vegetates, that's all." Another family member speaks of her husband who has Alzheimer's Disease. "But if you try to keep their incentive up, I think that is a big help. Only it seems that he doesn't want to do it, like exercises and stuff. I try and I say, come on let's do it. But he just - even when it first started - he doesn't do it. So I have given up on that. I always think of something to do, but he is accustomed to just sitting around. I think it would be horrible to sit there like he does, day in and day out with the television."

Constant demands for attention and presence of the other terribly upset several family members, while others accepted it with equanimity. "My mother follows me around the house and it drives me up the walls. I hide in the bathroom. I tell her that I need some quiet and peace and she gets angry. I feel like my head is ready to explode." On the other hand there is Mrs. Bruno, who pats her husband's hand while talking. "I take him with me wherever I go now. He is afraid. If I am taking a bath I have to leave the door open, because if it is closed - he doesn't say - he knocks, knocks, knocks. 'I am here honey; I am coming!' Now I just leave the door open for everything. I cannot leave him alone. How could I?"

As can be seen from the preceding examples, family members are resourceful in developing techniques for handling the impaired family member. They had also devised several strategies to handle <u>perseverations or repeating</u>. Often they ignore the behavior, sometimes they try to divert the impaired person's attention; in some instances timing of information giving is used. "When I hear this over and over again, I just try not to react, not to listen; sometimes I scream, but it doesn't help anyway." Mrs. Quint was strained. "He gets these ideas in his head and I recognize it and try to put another thought in his head about something else. Sometimes he takes it and forgets that idea; other times, like with fire, I haven't been very successful - he still sees it too much on the news and I am not fast enough to change the channel. Two nights ago, it was terrible. He was a fireman. He was in a fire. It was a fire and he wanted to get out of bed and he wanted to jump out of the window. And that went on for a whole hour and finally, he had his clothes off and he was perspiring in the middle of the night. After persuading him, talking to him, I gave him some valium; finally he calmed down."

Mr. Duncan spoke to how much his mother's constant repeating bothered him. "Next Sunday I am taking her to the opera, but I won't tell her before Saturday. She would incessantly ask 'are we going today?'"

Family members reacted differently to the impaired person's complete <u>dependency</u> upon them. Mrs. Gans was sad and depressed. "He depends on me for every little thing. I think he is going back. He wants to be a child again. I feel sorry for him and I mother him, because he is just like a little boy. I bathe him; he stands and I wash him. And I do everything a mother is supposed to do. He wants a glass of water; he will ask me for it, and I will tell him to go to the refrigerator to get it. And he says 'forget about it.' It is sad to see a man like that."

Mrs. Bruno perceived her husband's dependency upon her in a very different light. "Of course it is hard, but I feel that somebody needs me. Whoever needed me before? Not even he. I didn't have any children to say 'my children need me'. My little dog needs me. Thank God. And now my husband needs me."

Family members dealt with their impaired person's unhappiness with responses ranging from active intervention to sad resignation and avoidance. "When she starts getting her moods, it is terrible. And I have tried and tried to find what to do, but there is nothing. Walking, riding the bus, washing dishes, nothing. She just wants to sit there. That's all. That's what has me worried; what can you do to occupy her mind when she gets these moods? There's nothing. Then pretty soon after they (her moods) change with no reason at all. Just change around and she will be all smiles again." Another daughter stated, "The hardest thing about it for me is to see him change from a man who was always a happy man, a very kind, happy, and gentle man. He still is kind in his way and he still is gentle, but he is not happy anymore. There is never a smile. You see him sitting there with his glowering look thinking about all the little slights and wrongs that he imagines were done to him. There is no way of pleasing or appeasing dad now."

Unesthetic behavior or an impaired perons's refusal to take a bath were usually upsetting to the caregiver. Some SMs handled the problem by "manipulation", others by "convincing" either with kindness or with anger. Some SMs looked for outside help and still others decided to try and accommodate to the problem or ignore it. "My mother-in-law used to be so particular. Her underwear was snow white and now I cannot get her brassier off to put it into the washing machine. She will not give it to me. She will wear it and wear it, so I just sneak her clothes while she is asleep, wash them, and put them exactly back into place." Several wives talked about convincing their husbands to take a bath with hugs and kind words after "screaming" had made the husbands only more obstinate. Others gave up. "He doesn't like to take a bath. Now you see he wouldn't bathe this morning. I said it's okay by me. I said 'do you want clean clothes?' and he said 'I don't think that's necessary'. Once he went three weeks without taking a bath, but I just can't fight him." Mrs. Elliot decided to deal with the problem by acquiescing. "My father's habit of spitting really bothers me. I have to wash the dishes in the sink, but I am wasting my breath telling him not to spit in there." Mr. Low complained only about one thing in caring for his wife. "She keeps all the food in her mouth and then spits it out. The doctor says it is only a bad habit, but now if people invite us, we don't go; it is unesthetic."

Strange behavior, as opposed to unesthetic behavior, was often tolerated with simple acceptance or with humor as long as it was not disruptive. Mr. Bary: "My wife spends a lot of her time moving things from one drawer to the other; fix it up, take it out, lose it, find it. And that is all right - it gives me a little free time and she gets some enjoyment out of it." Mr. Bosworth is bothered by plastic tablecloths. "For half an hour he would just tackle that tablecloth, trying to pick out the flowers and tearing it. The people on television are real to him. Sometimes he starts fighting with them. At times I laugh and he laughs with me; it is sort of amusing, but then there are times I cry." Mr. Madrid eats any food within his field of vision. "The other night he ate ten bananas with the peels; I forgot to cover them." His family resorts to bitter, cynical humor when talking about his bizarre behaviors.

The IM's inability to rally help became a major problem whenever the caregiver was seriously impaired himself, or social resources were scarce. Mrs. Franklin, in her late 60's, lived with her 87-year-old mother in a run down apartment house in the ghetto. They had no family in the area and the friends they referred to with fondness were persons the daughter met on some bench downtown and who had never visited their home. "I don't expect any help from anybody. My help is at the end of my arm. That's where my help is. Up here in my two hands as long as I can keep going. One day I got sick and it paralyzed me from the hips down and I couldn't get out of bed. Mother wasn't able to call me an ambulance and she wasn't able to call the police for help. So I wouldn't be able to depend on her for any kind of help." But unavailability of help was also a major concern to her mother, one of the less cognitively impaired IMs. "I worry every day because my daughter is sick and I don't know what is going to happen to her when I am gone. She will be left alone and I don't know how she is going to get good care like she gives me. And if she can't take care of me, I don't know whether I have to go to a home. I might have to go to a home, but I don't know of any good place."

In the face of dangerous behavior to surroundings or self, many families displayed great ingenuity in rearranging the environment. For some caregivers, safety became the overriding concern governing their lives; others surprisingly chose to ignore possible dangers and when questioned, responded with the common remark, "I guess, I should be worried". Still other caregivers decided to take calculated risks, hoping for the best. "He takes the stove apart. I have the knobs off so he cannot turn it on, but he has already succeeded to turn on a burner without the knob. I cannot leave him alone. He always turns on the water too. The hot water faucet is turned off automatically so that he would not get hurt. Otherwise I just lock the doors. If I have to leave for half an hour, I just barricade him into his reclining chair; there he is safe for a short time." Mr. Wolf had a habit of lighting matches to see where he was. "I take the matches away from him, but no matter how many you take, he manages to find more. I am afraid when he strikes one it might pop and fall on the floor. He would never know it. He also opens the front door; he might let the dogs out or get hit over the head. But I can't watch him all the time; you just learn to hope that he and the house will still be there." Mrs. Bruno's response, when asked about her husband's smoking was, "I am frightened to death. I don't move. I don't do anything but watch him. I just follow him with the ashtray."

Weighing and comparing the price of close supervision to possible danger seemed also to determine a caregiver's way of dealing with the IM's tendency to wander. While Mrs. Green decided not only to lock the doors but also to sleep on a couch next to the front door so that her husband should not "escape" at night, Mrs. Wolf was content to leave a piece of paper with her husband's address in his pocket. "The police look and would bring him back; it has happened."

Most families found effective ways to handle an impaired person's poor judgment. "My mother refused to pay the utility bills. She was simply not going to pay them. So I took over. I got her financial affairs in order and found out where her money was . . . My stepfather had hidden the car keys. She really had not driven for a long time, but she continued to harbor the illusion that she could drive and had been driving. Slowly I got her to agree to sell the car."

With warmth and an understanding smile, a young woman reports, "Father used to do what pleased him all his life. So why shouldn't he in his old age? He brings his girlfriends home. In his normal state he would have never done this. He never had wanted mother and me to know. As long as he was in control of his faculties, he was careful and discrete, but then he would ask for them and wanted everyone gathered around him. It is hard for me to take; they are stupid and primitive women, but I can understand it from his point of view."

Disorientation to time became either a major problem in managing the impaired person, or was used by the caregiver as a strategy to gain some freedom. Mr. Corwin was weary. "My father is still disoriented about time. He called me at 3:30 in the morning, wondering why I hadn't come and he felt that the night was three days long. Especially around holidays or weekends he gets confused with time and calls during the night. I give him dinner and he goes to bed; by ten o'clock he will be up and dressed. He goes to the door, puts his fingers in the door, stands there in the dark waiting for 14 hours. He cannot tell night or day." Mrs. Wolf takes advantage of her husband's inability to tell time. "Whenever I want to leave, I just put a big sign next to his coffee mug 'I went shopping', and even if I am out for several hours, he doesn't know the difference." And another wife would tell her husband that she would be back in an hour - "That gives me two to three hours break".

Most caregivers learned to understand the IM in spite of the aphasia, though the lack of exchange and meaningful communication was often considered painful. "I think he understands me; yes, he does. The particular difficult part of this is that it's hard to understand my husband. But I am learning to do that. Some things he names different. When he wants to smoke, he says, 'give me a plate'. And I tell him that I understand, but that I want him to say the right word, but he only knows 'a plate, a plate'. Perhaps speech therapy could help him." And another wife, "It is so hard that I cannot talk with him anymore. There's no more communication. No understanding. Emotionally there is also (a response) from his side, but not with words or thoughts. But if I am happy, he is very happy too and if I am sad he starts crying. That's very special."

The meaning the family member attached to an impaired person's <u>inability to recognize people</u>, or to confuse them, seemed to determine the severity of the problem experienced by the caregiver. Mrs. Hugo was unable to distinguish her relatives and sometimes related to her son as if he were her dead father. "It took me a long time to accept it and to understand what was happening. Something was changing with mother and when it finally did strike me, it was a real shock. Now it doesn't bother me. Perhaps senility isn't all that bad for the person himself. I thought about it a lot. I wonder if it is maybe like being in a dream where you can't quite get things sorted out. That might be awfully annoying. But many of the things may be worse for the person watching it than for the one it is actually happening to." On the other hand, Mrs. Moraga cried when relating, "He does not even recognize our daughter. Whenever she comes he says 'I don't have a daughter, get out of my house'. It is terrible."

An impaired person's concern with money turned often into a serious source of conflict, though while in some other families it was handled with ease. Mr. Corwin senior was preoccupied with his financial situation and his son was irritated. "He thinks I took all his money and he is a prisoner. He used to carry a lot of money or at least flash it in the day care center. They told me several times that he had to be stopped from treating everyone, from showing off. He was a gambler and he didn't change. So I gave him two more dollars this week and he can pay for his girlfriend which is fine. But how much coffee can you drink? He doesn't need any more money, but he was furious with me. He said, 'I am a starving rat sitting next to you eating breakfast'". Mrs. Bruno used a different strategy. "He used to love these 20-dollar bills. He still goes for them. He goes through my purse. God help me if I have a 20-dollar bill; it disappears fast. But I feel so sorry for him. Poor guy, he was used to keeping money, managing money, and now I have control. Let him keep those bills; he will never spend the money."

A conflict around money was a major focus of ideas of reference in four out of the five paranoid cases. After the impaired person grew unable to handle his financial affairs, the SM took over, which the IM resented. Mrs. Wolf related, "I had to take his bank (deposit) box away from him and put the papers in a different box - our marriage papers and house papers and business papers - because he was always losing the key; that was the beginning of the bad. He kept losing keys, hiding, putting away, and we could never find a thing. We couldn't find the bank deposit book, not for months. Then we'd find it. He hid it again and that kept us in turmoil for a whole year. Bank books and keys - that is why he says that I took everything away from him. I had to because he was so senile that somebody had to do something." While in most situations the IM's accusations seemed unfounded, in other situations a grain of truth might have added to the concerns. When paranoid ideas were directed toward the caregiver, they were mostly handled by the SM "being upset" or brushing them off. Hallucinatory paranoid ideas not directed toward the family (e.g. seeing animals, fire) were usually effectively dealt with by the caregiver's ability to remain calm and willing to stay close to the impaired, frightened person. In one case, major tranquilizers were very helpful.

Report of Activities the Senile Brain Diseased Person Engages in and Enjoys

All nine impaired persons attending the day care program at the Jewish Home for the Aged enjoyed and were eagerly looking forward to the time they could spend there. Even those IMs who were very impaired and "vegetating" at home became active in day care and showed a remarkable change in affect, as observed by the investigator at the day care center and attested to by the family members. Ninety-two year-old Mrs. Fried had a mild cognitive impairment and her face was shining when talking about day care. "That's the most wonderful thing that I go to the home. They call for me, I go in the bus, I sit there in the wheelchair, and when I get there they wheel you into the home. And when you go where they play music, or for your meals, they come with a wheelchair and they take you. It is wonderful. I tell you, what they do in the home for people - it's a wonder. Anybody who has money and who wants to give, should give to the home. It's a blessing." Mr. Corwin described the change day care has made for his father. "Going out to the home and socializing has been fantastic for him. So it is hard to say that he is impaired when before he probably had more mental powers than now. Now he is more sociable. When he had the powers he didn't use them. We couldn't imagine the change; we can now actually sit around the table and talk. This constant stimulation at the home - people talking, like family, people he likes. He likes younger people, especially the ones who pay attention to him. There he gets plenty of attention."

Visiting with friends and relatives was both a source of pleasure and a source of pain for many families. Most impaired persons enjoyed visitors and enjoyed going on visits and most family members made a concerted effort to keep the impaired person's social contacts alive. Often they were successful; friends and relatives continued to visit and to invite, but at times there was bitterness and disappointment. The reports of several family members sounded very similar to Mrs. Daly's. "He was a president of a lodge and he had a lot of friends. But when you are sick nobody wants to be with you. They don't come over. He used to take care of everyone and nobody comes up and says 'I'll take him out for a ride'. Not even my son-in-law or brother-in-law will do that. And I have nephews and they don't come either. They have no time."

Going for drives was an activity many impaired persons greatly enjoyed and family members used car or bus rides as a frequent strategy to share a pleasurable experience, or to divert and calm an anxious, upset IM. Television music, dance, and talk shows (with Lawrence Welk as the prime choice) and animal movies were a favorite entertainment for many impaired persons. In some families the caregiver kept the television turned on to support the illusion of some IM mental involvement. The only physical activity the impaired members engaged in was going on walks, which many did enjoy. One only mildly impaired women went regularly to swim at age 86. Half of the impaired sample enjoyed listening to music.

One woman, who could no longer grasp the function of a toilet, was still able to relate to music.

For one-third of the cognitively impaired sample "going out to eat" was a favorite treat. Mrs. Arguello suffered from severe heart disease. She was in her late 70's and living with her 83-year-old disoriented and extremely forgetful husband on $450 a month. But they still managed to go out. "With two other couples we go out for dinner. My husband just asked 'when are we going again?' We were there Saturday night; we go again a week from Saturday. He just loves it. And he looks forward to it." Although an impaired person's perceptual decline or table manners made it difficult on the family member, dining out was a worthwhile activity. "We go out to lunch. We mix our activities a little bit to break the monotony. It gets a little embarrassing for me because I have to keep showing him where the fork is and what to do with a glass. It does embarrass you a little bit, but I pay no attention to it."

Reading the newspaper or a book seemed a "social habit" more than an active mental activity with all but the only mildly cognitively impaired persons. The IMs with more severe cognitive impairment would only turn pages automatically or gaze at them. Not so with playing cards, which seemed an astonishing finding. Mr. Green's cognitive functioning has been severely impaired for the last two to three years. "My husband does not remember if he eats or what time of the day it is, he doesn't recognize the neighborhood we lived in for 20 years, but sometimes he plays not badly bridge. At times he would not remember what he did. Like tomorrow I have a couple coming. The wife plays bridge and the husband plays chess. He will play chess with my husband. And he (my husband) plays pretty good chess; that is unbelievable. He plays with me Canasta and he beats me quite often. I have to fill the time when I am with him. Playing bridge is a God-given game for people who would like to forget about their problems. You need so much concentration that you forget about other things. It is mental therapy."

The Arguellos also played cards. "We go to different homes to play bridge. And then we have a four couple and we play every other Saturday night and my husband loves it. He plays gin. He never wins because he can't remember the cards, but I don't care; he just enjoys it.

The impaired persons' activities are summarized in Table 4.17, which also indicates the frequency with which given activities were reported as an important source of enjoyment.

Description of the Family Members' Problems Resulting from the Caregiving Situation and Their Management Strategies

Headaches, nervousness, tiredness, and aggrevation of high blood pressure were the main health problems family members complained of as related to the caregiving situation.

TABLE 4.17. ACTIVITIES IMs ENGAGE IN ACCORDING TO FREQUENCY AND ENJOYMENT (N = 30).

	Engage in Regularly		Engage in Sometimes		Source of Enjoyment	
Activities	N	%	N	%	N	%
visiting	13	43	12	40	20	67
going for a drive	12	40	12	40	20	67
watching television	19	63	9	30	18	60
going for walks	14	47	8	27	18	60
listening to music	8	27	11	37	15	50
going out to eat	5	17	6	20	11	37
reading newspaper	10	33	5	17	10	33
group activities (day care)	10	33	2	7	10	33
helping in household	5	17	7	23	9	30
playing card games	3	10	4	13	7	23
reading books	2	7	4	13	5	17
playing solitary	1	3	1	3	1	3

The loss of the impaired person as a companion or valued human being was the second frequent prime problem in the caregivers' lives. Feeling "tied down" was a major complaint and a heavy burden regardless of the quality of the relationship or the severity of the IM impairment. Most family members did manage to get some relief by "taking time off", but seldom was it sufficient to ease the physical and psychological strain. Seventy-three percent of all caregivers reacted at times with feelings of helplessness, hopelessness, guilt and resentment, and three considered these emotions their prime problem resulting from the situation. All family members worried about the future. Concerns focused mainly upon their own capacity to continue with the care of the impaired person. These concerns are compounded by the impact of inflation. Lack of privacy was a more serious problem whenever the impaired person was a parent living with a child's family. Several IMs resented their children for not including them in all of their social activities, which in return became a major problem for the caregiver. The IM's effect on other family members became a serious problem whenever a child was concerned. One couple was very worried about grandmother's impact upon their adolescent daughter, and two SMs were extremely upset about their husbands' deterioration adversely affecting their children.

The caregiver's conflict with a family member other than the impaired person was a major problem for 26 percent of the sample. In one instance the conflict centered around money, while nearly all the other conflicts resulted from "unfairness in sharing the burden of care". This was often aggravated by the impaired person's (usually the parent's) response as Mrs. Ulloa agitatedly described, "My blood pressure goes up; it just isn't right. We are three children and we all supposedly love our mother and we should all do the right thing and it shouldn't only be one person. My older brother never once said 'do you need someone to help you?' Not once did he send me flowers or a little note to make me feel good. Well I never say anything to mother about my blood pressure; I never take a pill in front of her. But my brother always tells her how sick he is. For every little ache or pain she feels for him, but with me, it's just nothing. She never becomes angry and irritated with my brothers no matter how seldom they come to see her. If I only do the slightest thing wrong, she is furious."

Sixty percent of the caregivers perceived lack of free time or time for themselves as a major problem. While disturbed night sleep was a major problem for 43 percent, only one family member considered this her prime problem resulting from the caregiving situation. Caring for the IM conflicted with other valued commitments such as work, study, travel, or physical activity for 60 percent of the SMs. Seventy-three percent of the caregivers complained of not getting enough rest.

The impaired person's conflict with family members, other than the caregiver, was perceived as a major problem in four cases. One example was Mrs. Ousagua, who became very distraught about her impaired husband's resentment of her daughter and her family, with whom they were living. He would curse the children, accuse them of stealing, and insult the daughter's guests, which developed into a major problem for the entire household.

While the impaired person's lack of appreciation or gratefulness was a major problem for 40 percent of the caregivers and was the cause of great unhappiness at times, not one family member considered this as the prime problem. Twenty-three percent of the caregivers considered social isolation as a major problem and most of them had to contend with some impairments of their own in addition to caring for the IM. Mrs. Ash described social isolation as both a function of her husband's disease, but also of old age. She and her husband had moved a few months prior to the interview to live with their daughter, so that their isolation might also have been caused by a new environment. "It is difficult to take him to people. He doesn't hear anything and it confuses him. He knows maybe that he doesn't know. And it bothers him. He doesn't complain about it, but it makes it hard to take him out, although he likes people and likes to see people. In the middle of a visit he would probably want to go. He got out of the habit of seeing people. We just don't go anymore and I cannot leave him alone. Now if there was somebody here, it would break the monotony and the loneliness. Age and this disease - it is hard. I don't know, your life changes whether you want it or not; you can't help it. You have to accept it and take it."

The family members' problems of living with senile brain disease are summarized in Table 4.18, which shows that

TABLE 4.18. SM PROBLEMS IN LIVING WITH SENILE BRAIN DISEASE ACCORDING TO SM PERCEPTION OF THEIR SERIOUSNESS FOR SM'S OWN LIFE AND TO FREQUENCY OF OCCURRENCE (N = 30).

Problems	Primary Problem		Major Problem		Minor Problem		Total Number of SMs with this Problem	
	N	%	N	%	N	%	N	%
SM health problems related to IM care	4	13	16	53	3	10	23	76
loss of IM as companion	4	13	13	43	11	37	28	93
being "tied down"	3	10	17	57	6	20	26	87
feeling helpless, hopeless, guilty, resentful	3	10	16	53	3	10	22	73
worry for the future	2	7	23	76	5	17	30	100
lack of privacy	2	7	8	27	15	50	25	83
effect on other family members	2	7	7	23	17	57	26	87
conflict with family member other than IM	2	7	6	20	1	3	9	30
lack of free time, time for self	1	3	17	57	8	27	26	87
disturbed night sleep	1	3	12	40	6	20	19	63
IM care conflicts with other valued commitment	1	3	11	37	6	20	18	60
not enough rest	1	3	8	27	13	43	22	73
IM conflict with family member other than SM	1	3	3	10	0	0	4	13
IM lack of appreciation, gratefulness	0	0	12	40	3	10	15	50
social isolation	0	0	7	23	5	17	12	40

80 percent of the SMs consider worry for the future the primary or major problem. Two-thirds perceive their own health problems related to the caregiving situation, being "tied down", and feeling helpless or resentful primary or major problems. Family conflict occurs in about 40 percent of the families and is usually a major problem, while lack of privacy, though frequent, is tolerated well in half the cases. Caregivers perceived three to 20 major IM problems (mean - 12, mode - 10) and two to 15 (mean - 8, mode - 9) own major problems resulting from the caregiving situation. The major factors alleviating the strain and burden of the caregiving situation are summarized in Table 4.19.

TABLE 4.19. AVAILABILITY OF HELPING FACTORS TO FAMILY MEMBERS AND WHETHER THEY ARE PERCEIVED AS ALLEVIATING STRAIN (N = 30).

Helping Factors	Alleviates Strain	Available
getting out of the house	23 (77%)	28 (93%)
hours of hired nursing	14 (47%)	15 (50%)
relatives taking over	9 (30%)	13 (43%)
day care	8 (27%)	9 (30%)
vacation	6 (20%)	6 (20%)
going to work	5 (17%)	8 (27%)
friends taking over	1 (3%)	4 (13%)

Description of the Family Members' Problems Resulting from the Boundary Zone

The Lewinian term, boundary zone, describes the impact of the wider social world upon the life space. Inflation was the families' most frequent concern resulting from their social reality. Most of them lived on fixed incomes and although their resourcefulness in making ends meet was remarkable, inflation was a major realistic threat. Considering the nine percent increase in prices between 1974 and 1975, older families lost two percent in real income despite the automatic increase in Social Security payments (Brotman, 1977b). Affording hired help was already a serious difficulty for 63 percent of the sample in the present and rising prices added to this vital concern. Many caregivers could not have managed their IM's care physically without several hours of hired nursing care. For most of them, paid help was the only respite, the only time they could "get out of the house" and "take a breath".

Finding reliable and good help was a major problem for nearly half of the families studied. Mr. Gold's description can stand for many. "I was told that I wouldn't be able to care for my mother, not that it would be difficult, but that it wasn't possible. I would never get the nurses. And it is really hard. In the beginning I was very particular, but I have learnt fast. It is nearly impossible to find good nurses. So I have come down with my expectations. The only thing that matters now is that the care is good. And even there I am sometimes afraid it could be better. But at least I hope she is as well cared for as she could be in a nursing home. In the beginning I, for instance, didn't want anyone who smoked in the house, but I quickly learnt that such demands are not possible. Now the nurses are doing quite a good job, but I am completely at their mercy. If they don't show up, I can't go to work . . . and it costs a fortune - I work nights and weekends to afford the nurses."

In addition to the question of nursing care, the difficulty of getting other useful professional help and advice was a major problem for nearly half the sample. A frequent complaint of families with severe physical problems was the lack of availability and accessibility to medical care, especially at night and on weekends. Inadequate professional intervention was a further source of unhappiness. "When they first diagnosed Alzheimer's they scared the hell out of her. They were talking about sending her to a home. I couldn't bring nobody to the house no more. She'd get ready to fly out of the door because she was afraid somebody was going to take her away. Now, the Social Services, they should be in the vegetable business. All they do is look to see what bin to put her in - 'rotten', 'more rotten, 'most rotten'. That's no good, that's not helping people." And another example: "I brought my husband to the hospital, but the doctor said 'we don't keep our beds for old men who had strokes and are confused; we keep our beds for sick people'. The two doctors I have seen recently told me I should just divorce my husband. How would I live? Then it certainly would be doing a dirty deal, because everything would have to be divided. They told me lots of times that I should call the police to come and get him. That I had a crazy man on my hands. But what would they do? They would take him to the hospital for three days and then they would send him right back, and then he would really have something to be angry about. You see, but that's professional help."

While on the one hand inadequate professional services became a major problem to the families, good professional services, on the other hand, were a major help and relief. In many instances they were instrumental in keeping the impaired person in the home and the situation for the family tolerable. Many caregivers acknowledged gratefully the services of agencies, individual physicians, nurses, and aids.

A great concern of family members was their inability to afford a good and appropriate institution. For few this was the major reason to continue shouldering the burden of care; for most caregivers the cost of institutional care was a worry for the future, should institutionalization become unavoidable. The availability of an appropriate institution was a problem for only 20 percent of the sample. The actual lack of good institutions, appropriate to the care of the senile brain diseased person, is much larger than reflected in this figure. This may be explained by the fact that the Jewish families considered the Jewish Home for the Aged a resource available to them, as long as they were able to afford it.

Forty-three percent of the family members considered "crime in the streets" a large problem. Most of them were old people, who were afraid to leave the house after dark. Their friends were usually as old and as afraid as they were. For some this resulted in long lonely evenings, especially in winter when the "self-imposed curfew" descended as early as five in the afternoon.

Caregivers also mentioned "indifference of the social environment" and difficulties in utilizing services as sources of hardship. In Table 4.20 the problems described in this section are summarized.

The problems families in this sample faced were similar to those described in the literature. As in Sainbury and Grad's (1970) research, the physical health of the closest relative was frequently affected. While the families in this sample considered sleep disturbance not as intolerable a problem as did the families studied by Sanford (1975), the fairly high tolerance for urinary incontinence and dangerous behavior he describes parallels this study's findings. As in Isaac's research (1971), the impaired persons in this study, who never expressed appreciation or gratitude, were most burdensome to their caregivers. The severe restrictions

TABLE 4.20. BOUNDARY ZONE DIFFICULTIES MENTIONED BY THE SM (N = 30).

Difficulties	N	%
inflation	22	73
difficulty to afford hired help	19	63
difficulty to find hired help	14	47
difficulty to get adequate professional service	14	47
crime in the streets	13	43
difficulty to afford good and appropriate institution	12	40
difficulty to find good and appropriate institution	6	20
indifference of social environment	6	20
difficulty in utilizing services	4	13

on all aspects of life, as well as the families' resilience, dignity, and devotion to their impaired family members were findings common to the three above cited British studies and the present research.

IV. THE INTERRELATIONSHIP OF IM AND SM BEHAVIORAL AND ATTITUDINAL VARIABLES

After describing life with senile brain disease in the preceding section, attention in this last section will again be turned toward the question of "what makes a difference?" in these families' morale and tension levels and the caregivers' management ability, perceived mutuality, and attitude toward institutionalization. The investigator assumed that these behavioral and attitudinal variables might influence one another in addition to the influence of the sample's social, demographic, and health characteristics upon them (as presented in pp. 89-113).

In order to partially answer research questions 3 to 6 (see p. 16), working hypotheses were tested which related (1) the IM's morale and tension to the caregiver's attitudinal and behavioral variables; (2) the SM's mutuality, management ability, morale, and tension to one another; and (3) the SM's attitude toward institutionalization to IM and SM morale and tension, as well as to SM mutuality and management ability. The statistical findings are presented in 4.21 - 4.23.

The higher the SM's mutuality and management ability, the better was the impaired person's morale and the lower his/her tension level. High IM morale was correlated with high SM morale and high IM tension with high SM tension.

High mutuality correlated with high management ability,

TABLE 4.21. IM MORALE AND IM TENSION ACCORDING TO SM MUTUALITY, SM MANAGEMENT ABILITY, SM MORALE, AND SM TENSION (N = 60).

	IM Morale		IM Tension	
	Pearson R	Significance	Pearson R	Significance
SM mutuality	0.55	0.001	0.69	0.001
SM management ability	0.39	0.017	0.76	0.001
SM morale	0.29	0.057*	0.75	0.001
SM tension	0.66	0.001	0.69	0.001

*For this study, $p < .05$ was considered the lowest level of statistical significance acceptable which makes this correlation only marginally significant.

TABLE 4.22. THE INTERRELATIONSHIP OF SM MUTUALITY, SM MANAGEMENT ABILITY, SM MORALE, AND SM TENSION (N = 30).

	SM Mutuality		SM Management		SM Morale		SM Tension	
	R	Sig	R	Sig	R	Sig	R	Sig
SM mutuality	-	-	0.63	0.001	0.58	0.001	0.58	0.001
SM management ability	-	-	-	-	0.57	0.001	0.58	0.001
SM morale	-	-	-	-	-	-	0.53	0.001
SM tension	-	-	-	-	-	-	-	-

TABLE 4.23. SM ATTITUDE TOWARD INSTITUTIONALIZATION ACCORDING TO SM AND IM MORALE AND TENSION AND SM MUTUALITY AND MANAGEMENT ABILITY.

	SM Attitude Toward Institutionalization	
	Pearson R	Significance
SM mutuality	0.90	0.000
SM management ability	0.56	0.001
SM morale	0.42	0.032
IM morale	0.61	0.000
SM tension	0.71	0.000
IM tension	0.59	0.001

high SM morale and low SM tension levels. High SM management ability correlated with high SM morale and low SM tension levels and high SM morale correlated with low SM tension levels.

Research question (6), asking about the factors which influence a family to continue home care for a senile brain diseased person, or to consider institutionalization, is of major importance in the planning of services. As demonstrated in section II of this chapter, none of the social, demographic, or health (impairment) characteristics of the study population make a statistically significant difference in the above considerations, while all of the attitudinal and behavioral variables measured do seem to influence the decision to institutionalize an impaired family member.

The higher the mutuality, the more unlikely the caregiver was to even consider institutionalization as a possible alternative to home care. This applies also to high SM management ability, high SM and IM morale. The higher the SM and IM tension levels, the more likely were the caregivers willing to consider or seek ways to institutionalize their IMs. The implications of these findings will be discussed in the following chapter.

SUMMARY

In this chapter the author first presented a typology of mutuality, arrived at by qualitative data analysis. She then described the social, demographic, and health characteristics of the sample and reported their significance in regard to the attitudinal and behavioral variables measured. In the third section of this chapter, the problems families face in living with senile brain disease were described and illustrated with case material. Lastly, working hypotheses interrelating the caregivers' management ability, mutuality, and attitude toward institutionalization and the IMs' and SMs' morale and tension were tested and reported. In the final chapter the implications of these findings for service to these families and further research will be discussed.

CHAPTER V

DISCUSSION AND IMPLICATIONS

MAJOR FINDINGS AND THEIR IMPLICATIONS FOR NURSING INTERVENTION, SERVICES, AND EDUCATION OF HEALTH PROFESSIONALS

A wide array of problems resulting from the disease itself, the caregiving situation, and the wider social context (e.g. lack of appropriate support and respite services, inflation, etc.) confront an old person and his family in the presence of senile brain disease. (For a detailed description of these problems see pp. 115-146.) The three variables which emerged from this study as crucial for these families' quality of life were: mutuality, management ability, and tension. While morale (life satisfaction or happiness) was an important variable, it seemed secondary to the above mentioned three variables and thus less crucial in determining these families' lives.

The findings of the study support the importance of the Lewinian concepts (need, tension, valence, life space, boundary zone, and time perspective) chosen to explain and predict attitudes and behavior of families living with senile brain disease. These concepts can also be used as a conceptual frame and guideline for assessment of these families, as well as for health related interventions: need, valence, and tension influence the burden these families carry; life space and boundary zone influence these families' management ability, and need, valence and time perspective influence the quality of the dyadic relationship, which defined as mutuality, was a crucial variable found in this research.

While not one of the impairment measures from either the impaired person or the caregiver determined a family's ability to continue home care, the tension resulting from the disease and the caregiving situation did. The author therefore suggests the use of tension (the Lewinian term denotes the number and kind of the impaired person's unmet needs; and the number and kind of the caregiver's highly valued unmet needs) as the criterion guiding intervention and not the level or kind of impairment *per se*. This is in agreement with other research (Kraus, Spasoff, Beattie, Holden, Lawson, Rodenburg, and Woodcock, 1976), which found "excessive burden on family members" more important than the specific health problems or diagnoses in seeking admission to long-term care institutions.

The other two criteria determining a family's ability to continue home care were the level of a family's mutuality and their ability to manage. In a paper summarizing two recent Detroit area studies which examined (1) the circumstances associated with nursing home utilization and (2) a 10-year agency experience providing supportive services to the independent elderly, Barney (1977) reported on a mutual support system of older couples. As individuals declined both in vigor and resourcefulness, they exchanged functions and continued their familiar life, more or less unchanged, long after either one could have carried on alone. Barney's "mutuality" and its effect on management parallels the externally reinforced mutuality identified in this study. The author was unable to find an example of internally reinforced mutuality in the research literature. In this study mutuality, management ability, tension, and morale from both the impaired person and the caregiver were interrelated.

In this dissertation two major typologies emerged. The first, set forth in Chapter IV (pp. 77-88), describes a range of dyadic interaction leading to what the author has described as types of mutuality. Mutuality, tension, and the families' management ability were combined in a typology of family types. This typology (see p. 158) is predictive of families' capacity to care for a person with senile brain disease at home. The following equation describes the interrelationships of these variables along with the role that can be played by nursing intervention in maximizing the family's capacity to care for a severely disabled old person:

$$\begin{array}{l}\text{Capacity to}\\ \text{care for a}\\ \text{senile brain}\\ \text{diseased person}\\ \text{in the home}\end{array} = \left[\frac{\text{Management Ability + Mutuality}}{\text{Tension}}\right] \cdot \left[\begin{array}{l}\text{Nursing}\\ \text{Intervention}\end{array}\right]$$

Whenever the numerator of management ability and mutuality do not outweigh the denominator tension, families reach a precarious balance, which is likely to develop into crisis or a state of feeling overwhelmed. Appropriate intervention will be geared either toward meeting some of these families' unmet needs and thereby reducing the tension, and/or toward increasing these families' management abilities. After these interventions, it might in certain cases even be possible for families to regain mutuality, destroyed by the overwhelming burden of the caregiving situation. Nursing intervention might enable the caregiver to redefine his reality and perceive mutuality and meaning once tension is reduced and management strategies improved.

The major areas of tension for these families amenable to intervention were: the supportive family member's health problems related to the caregiving situation, being "tied down", and the caregiver's lack of free time and feelings of resentment, helplessness, hopelessness, and guilt. Health visiting services for preventive, maintenance, and curative home care for both the cognitively impaired person and his/her caregiver would answer a large need. Special attention should be paid to such stress related diseases as high blood pressure, tension headaches, obesity, and cardiovascular problems.

For temporarily relieving caregivers, a wide array of services are needed: (1) a free or low-cost "granny-sitter" service; (2) low-cost comprehensive day care services ready to accommodate individuals who are both mentally and physically impaired (including the incontinent individual and the person with a tendency to wander or to aggressive behavior). Day care must include transportation services and be available for at least two full days per week to be effective in relieving strain. (3) Respite services enabling the caregiver to take a "vacation". Live-in non-professional low-cost assistance would ideally leave the senile brain diseased person in his/her accustomed environment (and prevent disrupting his/her precarious balance by a residential move), while enabling the caregiver to get some rest and replenish energies. Most family members in this study desperately wanted to visit relatives or friends, or take a trip - "just for some time off". In a study specifically designed to prevent institutionalization, Nielsen, Blenkner, Bloom, Downs, and Beggs (1972) found that home aid service was most successful in preventing admission to long-term care institutions in situations where the family was potentially able and willing to care for an older person. Another alternative to live-in respite services would be low-cost beds in long-term care institutions allocated to short-term care with the explicit objective of granting the caregivers temporary relief.

Whenever the above alternatives are not effective or desired by the caregiver to reduce the family's tension, these families deserve the prerogative of choice with appropriate institutions providing good nursing care. Kraus *et* al. (1976) describe such facilities as requiring a specific design which permits confused patients to wander without getting lost - circular hallways giving access to enclosed gardens would promote a sense of freedom with maximum mobility. Psychiatric consultation should be available to such facilities and they should offer various levels of services ranging from assistance in daily living to complete infirmary care. Structured programs with suitable activities for the patients should also be offered.

Such institutions must be available and financially accessible to be a possible alternative to home care. No one should be made to feel guilty for their "failure" to keep a person with senile brain disease at home. Many caregivers in this study felt guilty whenever considering institutionalization a possible alternative. Whenever a family does decide to institutionalize an impaired person, a professional placement service is needed to assist the familes in placing their relative in an institution most suitable to the individual's and the family's needs.

The third most frequent problem of families in this study (after care related health problems and being "tied down") was the occurrence of feelings of resentment, helplessness, hopelessness, and guilt. Family members could reduce the frequency of such feeling states and the amount of distress they occasion by the use of several possible services: (1) A professional nurse consultant in the home offering practical suggestions to improve management strategies (e.g. how to handle restless or aggressive behavior, plan physical care more efficiently, etc.), thereby giving the family members more control over their lives. (2) a non-judgmental listener helping the caregiver to work through his/her emotional reactions to the loss of the impaired person and the impact of the care situation and arrive at a modus vivendi or course of action most compatible with the impaired person's and the caregiver's needs. (3) A self help group of family members offering mutual support. The San Francisco Survival Task Force is an excellent example of the value of peer support for these families. Many of the very specific needs of this population group (e.g. legal advice or financial planning, especially in cases of presenile dementia, when the main bread winner is stricken by catastrophic, irreversible, non-fatal disease) could be answered by services offered through "self help" organizations.

Most families in this study were very resourceful and innovative in handling the problems created by the impact of the disease. By virtue of sample selection, these families were "survivors". Only because of their unusual resourcefulness and ability to manage in adverse situations, as well as their motivation, borne often out of high mutuality, they could have continued with the home care of their severely impaired relatives. These "survivor" families can teach health professionals and other families specific management strategies to handle a senile brain diseased person in the home (e.g. taking him or her for drives, managing incontinence, etc.).

In the following paragraphs the author will describe the family typology predictive of families' capacity to care for a senile braing diseased person in the home. This typology includes four types of two-family situations each, describing varying family capacity and varying need for nursing intervention.

Type A ("managing together") had high management ability and high mutuality. While in the one family situation, tension was high and services were needed to meet some of the unmet needs and thus improve the ratio of tension to management and mutuality, other families, the "lucky ones" had low tension and did not need services. Type B ("managing separately/alone") families had high management ability, low mutuality, and while in one family situation tension was high, in another tension was low. After reducing tension in the first family situation, intervention in both these family types would be geared toward increasing mutuality (e.g. freeing family members' time and energy for them to be able to regain lost mutuality, helping caregivers redefine situations). Type C ("muddling together") families had low management ability, high mutuality, and while in one family situation tension was high, in the other tension was low. The main level for intervention in this group was developing these families' management strategies. Type D ("muddling separately/alone") families had low management ability and low mutuality. In one situation family tension was high and in the other tension was low. Most of the families in this group wanted to institutionalize the impaired person and only extraordinary measures of intervention could have restored a situation where home care was tolerable. This typology of "families' capacity for home care and needs for services" can be generalized to other caregiving situations (e.g. families living with chronically ill members, with mentally ill, with handicapped children, etc.).

When considering the wider social context, there is undoubtedly a need for a health care system which permits early detection and preventive measures, regardless of income level. As shown in other research, older persons (and those close to them) may typically fail to perceive decline or may mask it by adjusting their life style to changes in capacity and resources (Barney, 1977). A public health system built upon neighborhood clinics with a professional nurse responsible for the preventive, maintenance, and curative care of several hundred families in her catchment area and the necessary back-up of a professional health team, is one possible solution. It is also conceivable to create additional resources for these families by redefining irreversible cognitive change in the aged from a medical to a social problem. Voluntary organizations and community groups have a large potential for serving these families and might be as qualified as the health professionals to alleviate these families' strain. Anonymous (1976) describes in the Japanese health care system an example of successful cooperation between public health nursing and voluntary organizations.

Under a health care system responsive to these families' needs, tension could be alleviated and management abilities increased long before problems grow to overwhelming proportions. The situation in the present health care system usually brings these families to the attention of health professionals only when the situation has so deteriorated that institutionalization becomes the only feasible solution for the family.

Aside from a basic reorganization of the health care system, the other precondition for improved services to these families is the education of health professionals. As described in the section on labeling (pp. 63-64), many conscientious health professionals have great difficulty distinguishing between acute brain syndromes and the irreversible chronic dementias, which tends to have disastrous effects for the mislabeled individuals.

Health professionals must become aware of the importance of cognitive change as the prime symptom signaling that something went wrong with an old person's health or social system. They must also learn to distinguish between reversible and irreversible brain syndromes and relinquish their attitude of "therapeutic nihilism" in regard to "senility". Only then will education regarding the specific problems of a senile brain diseased person and his family enable health professionals to help these families answer some of their unmet needs and increase their ability to manage in the face of mental and physical decline.

STUDY LIMITATIONS

Limitations of this study are primarily related to the study sample and the measures developed from the research data. One must have some reservations about generalizing to other populations of families in caregiving situations because of the small nonrandom sample. Nevertheless, the multiple sources of sample acquisition and the wide range of social and demographic characteristics of the study population improves the generalizability. It appears appropriate to generalize the findings to other urban, Caucasian families caring for a senile brain diseased person. The measures of tension, management ability, morale, and mutuality were developed from sets of items chosen for their face validity (see pp. 70-73). No tests of reliability and validity were done for these measures.

IMPLICATIONS FOR FURTHER RESEARCH

There are four areas in which further research is implicated by this study:

1. Basic methodological research is needed to clarify the concepts of tension, management ability, and mutuality and to construct scales measuring these variables. Tension, management, and mutuality scales will then have to be standardized and their reliability and validity established.
2. Little is known about the capacity of families to cope with different types of impairment and disabilities. Research regarding the family impact of single versus multiple and mental versus physical disability is needed. The family impact of the inability to cope with a caregiving burden must also be studied.

   To the present, researchers of families in caregiving situations, including this author, studied the family impact at given points of the illness and caregiving trajectory. This was done regardless of the length of the illness, the age of the impaired person and caregiver at the time of disease onset, or the point in the life cycle of the impaired individual, the caregiver, and the entire family. Studies are needed which would include different types and lengths of impairments, different age groups over time, and families at different points in the family life cycle. Such a cross sequential design will provide knowledge on the development of family coping over time in relation to the length of the caregiving situation, the kind of impairment, and the point on the individual and family life cycle.

3. Evaluative program research is needed. Services such as "granny sitters", live-in home aides to provide families some respite and vacation, and professional nursing intervention must be evaluated as to their impact upon the family. (The development of outcome measures to evaluate the impact of services is a large undeveloped area of research in itself.) Evaluative research should focus upon the different treatment components toward determining what service is best, for what individual or family, with what specific problem, under which set of circumstances, and from whose perspective.
4. Families caring for old and impaired kin are universal. But attitudes toward the aged, the physically and mentally impaired, as well as toward dependency and caregiving are largely influenced by a given culture. Cross cultural research on

caregiving situations and family coping is necessary to shed light on these phenomena.

SUMMARY

Life with senile brain disease was studied by interviewing 30 impaired persons and their 30 caregivers living in one household. The impaired persons' and their caregiving family members' physical health, mental health, social resources, economic resources, and performance level for activities on daily living were assessed by the OARS Multidimensional Functional Assessment Questionnaire. Through focused interviews and participant observation, the investigator also assessed the problems these families were facing in the presence of senile brain disease, their tension level, management strategies, mutuality, and morale.

The three variables which emerged from this exploratory study as crucial for these familes' quality of life and their ability to continue with the home care of the severely impaired kin were mutuality, management ability, and tension. While none of the senile brain diseased person's or the caregiver's social, demographic, or health/impairment characteristics determined a family's attitude toward institutionalization, the caregiver's perceived tension resulting from the caregiving situation and the disease, his/her ability to manage and the perception of mutuality made a significant difference. The lower the perceived tension and the higher a family's mutuality and management ability, the less likely were they to consider institutionalization.

Several implications for health service were derived from the study: (1) the need to educate health care professionals to recognize the prime importance of cognitive decline in old age, assess its source, and distinguish between acute reversible and chronic irreversible brain syndromes; (2) the need to reorganize the health care system and its financing so that families coping with physical and mental decline could receive support before a breaking point is reached; and (3) the development of programs specifically designed to alleviate the family impact of caring for a severely impaired kin.

This study suggested the need for research in four major areas: (1) methological research to establish the armamentaria necessary to measure family impact; (2) added knowledge on the development of family coping over time in relation to the length of the caregiving situation, the kind of impairment, and the point on the individual and family life cycle; (3) evaluative program research in regard to services for families living with senile brain disease; and (4) cross cultural research on families in caregiving situations.

AN AFTERTHOUGHT

"Pneumonia, the friend of the aged is dead". Perhaps more urgent even than the education of health care professionals, the provision of more and better services, and the quest of new knowledge, is an open discussion and reconsideration of our value system. The ethical dilemmas facing mankind in regard to the "survival of the unfittest" will have to be faced. Is there a time where our need to "do something" with continued medical intervention becomes grotesque? We will have to weigh the implications and arrive at some consensus, for when to choose the path of active intervention under all circumstances and when to agree with Kohelet, who said in Ecclesiastes 2300 years ago:

> To every thing there is a season, and a time to
> every purpose under heaven;
> A time to be born and a time to die;
> A time to plant and a time to up-root that which
> is planted.

BIBLIOGRAPHY

Agate, J. Special hazards of illness in later life. In I. Rossman (Ed.), *Clinical Geriatrics*. Philadelphia: Lippincott, 1971, pp. 461-472.

Anderson, W. F., and Davidson, R. Concomitant physical states. In J. G. Howells (Ed.), *Modern perspectives in the psychiatry of old age*. New York: Brunner/Mazel, 1975, pp. 84-106.

Anonymous. Death of a mind. *The Lancet*, 1950, Saturday, May 27, *6613*.

Anonymous. In Japan: health care for all and a 'demographic miracle'. *Hospital Practice*, 1976, *11*(1), 157.

Arie, T. Day care in geriatric psychiatry. *Gerontologia Clinics*, 1975, *17*(1), 31-39.

Barnes, J. A. Effects of reality orientation on memory loss, confusion, and disorientation in geriatric patients. *Gerontologist*, 1974, *14*(2), 139-142.

Barney, J. L. The prerogative of choice in long-term care. *Gerontologist*, 1977, *17*(4), 309-314.

Barns, E. K., Sack, A., and Shore, H. Guidelines to treatment approaches, modalities and methods for use with the aged. *Gerontologist*, 1973, *13*(4), 513-527.

Berezin, M. A. Partial grief in family members and others who care for the elderly patient. *Journal of Geriatric Psychiatry*, Fall, 1970, *4*(1), 53-64.

Berezin, M. A. Psychodynamic considerations of aging and the aged: an overview. *American Journal of Psychiatry*, 1972, *128*(12), 1483-1491.

Berry, R. G. Pathology of dementia. In J. G. Howells (Ed.), *Modern perspectives in the psychiatry of old age*. New York: Brunner/Mazel, 1975, pp. 51-83.

Botwinick, J. Intellectual abilities. In J. E. Birren and K. W. Schaie (Eds.), *Handbook of the psychology of aging*. New York: Van Nostrand Reinhold, 1977, pp. 580-605.

Bowers, M. B., Anderson, G. K., Blomeier, E. C., and Pelz, K. Brain syndrome and behavior in geriatric remotivation groups. *Journal of Gerontology*, July 1967, *22*(3), 348-352.

Brody, E. M., Kleban, M. H., Lawton, M. P., and Silerman, H. Excess disabilities of mentally-impaired aged: impact of individualized treatment. *Gerontologist*, 1971, *11*(2, pt. I), 124-132.

Brody, E. M., Cole, C., and Moss, M. Individualizing therapy for the mentally impaired aged. *Social Casework*, October 1973, *54*(10), 435-461.

Brody, E. M., Kleban, M. H., Lawton, M. P., and Moss, M. A longitudinal look at excess disabilities in the mentally impaired aged. *Journal of Gerontology*, 1974, *29*(1), 79-84.

Brody, S. J. Comprehensive health care for the elderly: An analysis. The continuum of medical, health, and social services for the aged. *The Gerontologist*, Winter 1973, *13*(4), 412-418.

Brotman, H. B. Population projections: Part I. Tomorrow's older population (to 2000). *The Gerontologist*, June 1977a, *17*(3), 203-209.

Brotman, H. B. Income and poverty in the older population in 1975. *Gerontologist*, 1977b, *17*(1), 23-26.

Burnside, I. M. Group work among the aged. *Nursing Outlook*, 1969, *17*(6), 68-71.

Burnside, I. M. Group work with the aged: Selected literature. *Gerontologist*, Fall 1970a, *10*, 241-246.

Burnside, I. M. Clocks and calendars. *American Journal of Nursing*, 1970b, *70*(1), 117-119.

Burnside, I. M. Long-term group work with the hospitalized aged. *Gerontologist*, 1971, *11*(3, Pt. 1), 213-218.

Burnside, I. M. Touching is talking. *American Journal of Nursing*, 1973, *73*(12), 2060-2063.

Burnside, I. M. Group therapy with regressed aged people. In I. M. Burnside (Ed.), *Nursing and the Aged*. New York: McGraw-Hill, 1976.

Butler, R. N. *Why Survive? Being Old in America*. New York: Harper and Row, 1975.

Caird, F. I. Computerized tomography (Emiscan) in brain failure in old age. *Age and Aging*, 1977, *6*, Supplement, 50-51.

Calkins, K. Shouldering a burden. *Omega*, 1972, *3*, 23-36.

Carp, F. M. Senility or garden-variety maladjustment? *Journal of Gerontology*, 1969, *24*(2), 203-208.

Cartwright, D. Lewinian theory as a contemporary systematic framework. In S. Koch (Ed.), *Psychology: a study of science*. Vol. 2. New York: McGraw-Hill, 1959, pp. 7-91.

Cath, S. H. The institutionalization of a parent - a nadir of life. *Journal of Geriatric Psychiatry*, 1972, *5*(1), 25-46.

Chatfield, W. F. Economic and sociological factors influencing life satisfaction of the aged. *Journal of Gerontology*, 1977, *32*(5), 593-599.

Ciompi, L. The frequency of senile psycho-organic deterioration in various psychiatric conditions. In C. Muller and L. Ciompi (Eds.), *Senile Dementia*. Bern, Switzerland: Hans Huber, 1968, pp. 55-59.

Cohen, E. S. Editorial: the unseen plague out of the closet. *Gerontologist*, 1977, *17*(4), 295.

Corsellis, J. A. N. Observations on the neuropathology of dementia. *Age and Aging*, 1977, *6*, Supplement, 20-29.

Corso, J. F. Auditory perception and communication. In J. E. Birren and K. W. Schaie (Eds.), *Handbook of the Psychology of Aging*. New York: Van Nostrand Reinhold, 1977, pp. 535-553.

Dawson-Butterworth, K. The chemotherapeutics of geriatric sedation. *Journal of the American Geriatrics Society*, 1970, *18*(2), 97-114.

Donahue, W. Living in the four-generational family. In W. Donahue, J. L. Kornbluh, and L. Power (Eds.), *Living in the Multigenerational Family*. Michigan: University of Michigan and Wayne State University, Institute for Gerontology, 1969.

Ebersole, P. P. Group work with the aged: A survey of the literature. In I. M. Burnside (Ed.), *Nursing and the Aged*. New York: McGraw Hill, 1976, pp. 182-196.

Eisdorfer, C. and Stotsky, B. A. Intervention, treatment, and rehabilitation of psychiatric disorders. In J. E. Birren and K. W. Schaie (Eds.), *Handbook of the Psychology of Aging*. New York: Van Nostrand Reinhold, 1977, pp. 724-748.

Eisdorfer, C. and Wilkie, F. Stress, disease, aging and behavior. In J. E. Birren and K. W. Schaie (Eds.), *Handbook of the Psychology of Aging*. New York: Van Nostrand Reinhold, 1977, pp. 251-275.

Engen, T. Taste and smell. In J. E. Birren and K. W. Schaie (Eds.), *Handbook of the Psychology of Aging*. New York: Van Nostrand Reinhold, 1977, pp. 554-561.

Essen-Moller, E. Individual traits and morbidity in a Swedish rural population. *Acta Psychiatrica Scandinavica*, Supplementum 100, 1956.

Farndale, J. *The day hospital movement in Great Britain*. New York: Pergamon Press, 1961.

Fillenbaum, G. Reliability and validity of the OARS Multidimensional Functional Assessment Questionnaire. In E. Pfeiffer (Ed.), *Multidimensional functional assessment: the OARS methodology*, Durham, N.C.: Center for the Study of Aging and Human Development, 1975, pp. 39-50.

Foley, J. M. Differential diagnosis of the organic mental disorders in elderly patients. In C. M. Gaitz (Ed.), *Aging and the Brain*. New York: Plenum Press, 1972, pp. 153-161.

Fozard, J. L. and Thomas, J. C. Psychology of aging. In J. G. Howells (Ed.), *Modern Perspectives in the Psychiatry of Old Age*. New York: Brunner/Mazel, 1975, pp. 107-169.

Fozard, J. W., Wolf, E., Bell, B., McFarland, R. A. and Podolsky, S. Visual perception and communication. In J. E. Birren and K. W. Schaie (Eds.), *Handbook of the Psychology of Aging*. New York: Van Nostrand Reinhold, 1977, pp. 497-534.

Goldfarb, A. I. Group therapy with the old and aged. In H. I. Kaplan (Ed.), *Comprehensive Group Psychotherapy*. Baltimore: Williams and Wilkins, 1971.

Goldfarb, A. I. Multidimensional treatment approaches. In C. M. Gaitz (Ed.), *Aging and the Brain*. New York: Plenum Press, 1972, pp. 179-191.

Goldfarb, A. I., Hochstadt, N. J., Jacobsen, J. H., and Weinstein, E. A. Hyperbaric oxygen treatment of organic mental syndrome in aged persons. *Journal of Gerontology*, 1972, *27*, 212-217.

Götestam, K. G. and Melin, L. Improving well-being for patients with senile dementia by minor changes in the ward environment. Paper presented at the WHO Symposium, Stockholm, June, 1976.

Gottesman, L. E., Quarterman, C. E., and Cohn, G. M. Psychologial treatment of the aged. In C. Eisdorfer and M. P. Lawton (Eds.), *The Psychology of Adult Development and Aging*. Washington, D.C.: American Psychological Association, 1973, pp. 378-427.

Grosicki, J. P. Effect of operant conditioning on modification of incontinence in neuropsychiatric geriatric patients. *Nursing Research*, July-August, 1968, *17*, 304-311.

Gruenberg, E. M., Hagnell, O., Öjesjö, L., and Mittelman, M. The rising prevalence of chronic brain syndrome in the elderly. Paper presented at the Society, Stress and Disease Aging and Old Age Symposium, Stockholm, June, 1976.

Gunner-Svensson, F. and Jensen, K. Frequency of mental disorders in old age. Examples of comparability of epidemiological investigations in relation to utility in planning. *Acta Psychiatrica Scandinavica*, 1976, *53* (Fasc. 4), 283-297.

Hagnell, O. *A prospective study of the incidence of mental disorder*. Lund, Nordstedts: Scandinavia University Books, 1966.

Hagnell, O. Disease expectancy and incidence of mental illness among the aged. *Acta Psychiatrica Scandinavica*, 1970, *46*(Supplementum 219), 83-89.

Harris, C. S. and Ivory, P. B. C. B. An outcome evaluation of reality orientation therapy with geriatric patients in a state mental hospital. *Gerontologist*, 1976, *16*(6), 496-503.

Hauser, P. M. Aging and world-wide population change. In R. H. Binstock and E. Shanas (Eds.), *Handbook of Aging and the Social Sciences*. New York: Van Nostrand Reinhold, 1976, pp. 58-86.

Hennessey, M. J. Music and group work with the aged. In I. M. Burnside (Ed.), *Nursing and the aged*. New York: McGraw-Hill, 1976, pp. 255-269.

Ireland, M. Starting reality orientation and remotivation. *Nursing Homes*, April 1972, *21*, 10-11.

Isaacs, B. Geriatric patients: Do their families care? *British Medical Journal*, 1971, *4*(5782), 282-286.

Isaacs, B., Gunn, J., McKechan, A., McMillan, I. and Neville, I. The concept of pre-death. *Lancet*, May 29, 1971, *7709*, 1115-1119.

Isaacs, B., Livingstone, M., and Neville, I. *Survival of the Unfittest*. London: Routledge and Kegan Paul, 1972.

Jacobs, E. A., Winter, P. M., Alvis, H. J., and Small, H. M. Hyperoxygenation effect on cognitive function in the aged. *New England Journal of Medicine*, 1969, *281*(14) 753-757.

Jarvik, M. E. A survey of drug effects upon cognitive activities of the aged. In C. Eisdorfer and W. E. Fann (Eds.), *Psychopharmacology and Aging*. New York: Plenum Press, pp. 129-144.

Jury, M. and Jury, D. *Gramp*. New York: Grossman, Viking Press, 1976.

Kane, R. L. and Kane, R. A. *Long-term Care in Six Countries: Implications for the United States*. Fogarty International Center Proceedings No. 33. Washington: DHEW Publication No. (NIH) 76-1207, 1976.

Kaneko, Z. Care in Japan. In J. G. Howells (Ed.), *Modern Perspectives in the Psychiatry of Old Age*. New York: Brunner/Mazel, 1975, pp. 519-530.

Kaplan, J. The family in aging. *Gerontologist*, 1975, *15*(5), part 1, 385.

Kastenbaum, R. and Slater, P. E. Effects of wine on the interpersonal behavior of geriatric patients; an exploratory study. In R. Kastenbaum (Ed.), *New Thoughts on Old Age*. New York: Springer, 1964, 191-204.

Kay, D. W. K. Epidemiological aspects of organic brain disease in the aged. In C. M. Gaitz (Ed.), Aging and the Brain. New York-London: Plenum Press, 1972, pp. 15-27.

Kay, D. W. K., Beamish, P., and Roth, M. Old age mental disorders in Newcastle upon Tyne. Part I: A study of prevalence. British Journal of Psychiatry, 1964a, 110 (465), 146-158.

Kay, D. W. K., Beamish, P., and Roth, M. Old age mental disorders in Newscastle upon Tyne. Part II: A study of possible social and medical causes. British Journal of Psychiatry, 1964b, 110(468), 668-682.

Kenshalo, D. R. Age changes in touch, vibration, temperature, kinesthesis, and pain. In J. E. Birren and K. W. Schaie (Eds.), Handbook of the Psychology of Aging. New York: Van Nostrand Reinhold, 1977, 562-579.

Kerlinger, F. N. Foundations of behavioral research (2nd ed.). New York: Holt, Rinehart and Winston, 1973.

Kiloh, L. G. Pseudo-dementia. Acta Psychiatrica Scandinavica, 1961, 37, 336-351.

Kinsbourne, M. Cognitive decline with advancing age: An interpretation. In W. L. Smith and M. Kinsbourne (Eds.), Aging and Dementia. New York: Spectrum, 1977, pp. 217-235.

Kleban, M. H., Lawton, M. P., Brody, E. M., and Moss, M. Behavioral observations of mentally impaired aged: those who decline and those who do not. Journal of Gerontology, 1976, 31(3), 333-339.

Kral, V. A. Confusional states. In J. G. Howells (Ed.), Modern Perspectives in the Psychiatry of Old Age. New York: Brunner/Mazel, 1975, pp. 356-362.

Kraus, A. S., Spasoff, R. A., Beattie, E. J., Holden, D. E. W., Lawson, J. S., Rodenburg, M., and Woodcock, G. M. Elderly applicants to long-term care institutions. II. The application process; placement and care needs. Journal of the American Geriatrics Society, 1976, 24 (4), 165-172.

Labouvie Vief, G. Toward optimizing cognitive compenence in later life. Educational Gerontology, 1976, 1, 75-92.

Laurie, W. F. Multi-dimensional functional assessment: the Duke OARS methodology basic research and a practical application. Center Reports on Advances in Research, 1977, 1(2).

Lauter, H. and Meyer, J. E. Clinical and nosological concepts of senile dementia. In Ch. Müller and L. Ciompi (Eds.), Senile Dementia. Bern, Switzerland: Hans Huber, 1968, pp. 13-26.

Lawton, M. P. and Nahemow, L. Ecology and the aging process. In C. Eisdorfer and M. P. Lawton (Eds.), The Psychology of Adult Development and Aging. Washington, D.C.: American Psychological Association, 1973, pp. 619-674.

Letcher, P., Peterson, L., and Scarbrough, D. Reality orientation: A historical study of patient progress. Journal of Hospital and Community Psychiatry, 1974, 25, 801-803.

Lewin, K. Resolving social conflicts. New York: Harper and Brothers, 1948.

Lewin, K. Field theory in social science. New York: Harper and Row, 1951.

Libow, L. S. Pseudo-senility: Acute and reversible organic brain syndromes. Journal of the American Geriatric Society, 1973, 21, 112-120.

Linden, M. Group psychotherapy with institutionalized senile women: Study in gerontologic human relations. International Journal of Group Psychotherapy, 1953, 3, 150-170.

Linden, M. Geriatrics in the Field of Group Psychotherapy. New York: International Universities Press, 1956.

Lindsley, O. R. Geriatric behavioral prosthetics. In R. Kastenbaum (Ed.), New Thoughts on Old Age. New York: Springer, 1964.

Lurie, E. E. and Chiriboga, D. Final report on day care program, Jewish Home for the Aged. Unpublished Manuscript, University of California, San Francisco, Department of Human Development and Aging, December 1975.

Madsen, K. B. Theories on motivation (4th ed.). Kent(Ohio): Kent State University Press, 1968.

Malamud, N. Neuropathology of organic brain syndromes associated with aging. In C. M. Gaitz (Ed.), Aging and the Brain. New York: Plenum Press, 1972, pp. 63-87.

McClannahan, L. E. and Risley, T. R. Design of living environments for nursing home residents: Increasing participation in recreation activities. Journal of Applied Behavior Analysis, 1975, 8, 261-268.

Miller, E. Dementia as an accelerated aging of the nervous system: Some psychological and methodological considerations. Age and Aging, November 1974, 3(4), 196-202.

Miller, E. The management of dementia: A review of some possibilities. British Journal of Social and Clinical Psychology, 1977, Part I, 16, 77-83.

Nielsen, J. Geronto-psychiatric period-prevalence investigation in a geographically delimited population. Acta Psychiatrica Scandinavica, 1962, 38, 307-330.

Nielsen, M., Blenkner, M., Bloom, M., Downs, T., and Beggs, H. Older persons after hospitalization: A controlled study of home aide service. American Journal of Public Health, 1972, 62, 1094-1101.

Osler, W. O. The Principles and Practice of Medicine (5th ed.). New York: D. Appleton, 1904.

Palmore, E. and Luikart, C. Health and social factors related to life satisfaction. Journal of Health and Social Behavior, 1972, 13, 68-80.

Pfeiffer, E. Multidimensional functional assessment: the OARS methodology. Durham, N.C.: Center for the Study of Aging and Human Development, 1975a.

Pfeiffer, E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. Journal of the American Geriatrics Society, 1975b, 23(10), 433-441.

Pfeiffer, E. A short psychiatric evaluation schedule: a new 15-item monotonic scale indicative of functional psychiatric disorder. Paper presented at the Annual Scientific Meeting of the Gerontological Society, Louisville, Kentucky, October 26-30, 1975c.

Pfeiffer, E. Report to the community on Durham's elderly by the Older Americans Resources and Services Program (OARS) of the Duke University Center for the Study of Aging and Human Development. Undated report.

Pfeiffer, E. A. Psychopathology and social pathology. In J. E. Birren and K. W. Schaie (Eds.), *Handbook of the Psychology of Aging*. New York: Van Nostrand Reinhold, 1977, 650-671.

Plath, D. W. Japanese psychology through Japanese literature. Cares of career and careers of caretaking. *The Journal of Nervous and Mental Disease*, 1973, *157*(5), 346-357.

Post, F. Dementia, depression and pseudodementia. In D. F. Benson and D. Blumer (Eds.), *Psychiatric Aspects of Neurological Diseases*. New York: Grune and Stratton, 1975.

Powell, C. The use and abuse of drugs in brain failure. *Age and Aging*, 1977, *6*, Supplement, 83-90.

Rabbitt, P. Changes in problem solving ability in old age. In J. E. Birren and K. W. Schaie (Eds.), *Handbook of Psychology of Aging*. New York: Van Nostrand Reinhold, 1977, pp. 606-625.

Rathbone-McCuan, E. Geriatric day care - a family perspecgive. *Gerontologist*, 1976, *16*(6), 517-521.

Riley, M. W. and Foner, A. *Aging and Society. Volume I: An Inventory of Research Findings*. New York: Russell Sage Foundation, 1968.

Robinson, B. and Thurner, M. *Parental care-taking: A family-cycle transition*. Paper presented at the 29th Annual Scientific Meeting of the Gerontological Society, New York, October 13-17, 1976.

Robinson, R. A. Differential diagnosis and assessment in brain failure. *Age and Aging*, 1977, *6*, Supplement, 42-49.

Rosenmayr, L. and Köckeis, E. *Umwelt und Familie Alter Menschen*. Berlin: Luchterhand, 1965.

Rosow, I. *Social Integration of the Aged*. New York: Free Press, 1967.

Sainsbury, P. and Grad de Alacron, J. The effects of community care on the family. *Journal of Geriatric Psychiatry*, Fall, 1970, *4*(1), 23-41.

Sanford, J. R. A. Tolerance of debility in elderly dependents by supporters at home: Its significance for hospital practice. *British Medical Journal*, 1975, *3*, 471-473.

Savitsky, E. and Sharkey, H. Study of family interaction in the aged. Journal of Geriatric Psychiatry, 1972, 5(1), 3-19.

Schaie, K. W. A field-theory approach to age changes in cognitive behavior. Vita Humana, 1962, 5(3), 129-141.

Schaie, K. W. and Gribben, K. Adult development and aging. Annual Review of Psychology, 1975, 26, 65-96.

Shanas, E. Family-kin networks and aging in cross-cultural perspective. Journal of Marriage and the Family, 1973, 35(3), 505-511.

Shanas, E., Townsend, P., Wedderburn, D., Friis, H., Milhøj, P., and Stehouwer, S. Old People in Three Industrial Societies. New York: Atherton Press, 1968.

Sheldon, J. H. The Social Medicine of Old Age. Report of an Inquiry in Wolverhampton. London: Oxford University Press, 1948.

Sherwin, I. and Seltzer, B. Senile and pre-senile dementia: A clinical overview. In K. Nandy and I. Sherwin (Eds.) The Aging Brain and Senile Dementia. New York and London: Plenum Press, 1976.

Silver, A. Group psychotherapy with senile geriatric patients. Geriatrics, 1950, 5, 147-150.

Simon, A. and Malamud, N. Comparison of clinical and neuropathological findings in geriatric mental illness. In Psychiatric Disorders in the Aged. Manchester: Geigy, 1965, 322.

Sommer, R. Personal Space. Englewood Cliffs, N.J.: Prentice Hall, 1969.

Soyer, D. Helping the family to live with itself. Journal of Geriatric Psychiatry, 1972, 5(1), 52-65.

Spark, G. M. and Brody, E. M. The aged are family members. Family Process, 1970, 9(2), 195-210.

Spreitzer, E. and Snyder, E. Correlates of life satisfaction among the aged. Journal of Gerontology, 1974, 29, 454-458.

Sturrock, A. V. and Kastenbaum, R. Beer and TLC. American Journal of Nursing, 1967, 67(1), 100-103.

Sussman, M. B. The family life of old people. In R. H. Binstock and E. Shanas (Eds.), *Handbook of Aging and the Social Sciences*. New York: Van Nostrand Reinhold, 1976, 218-243.

Taulbee, L. R. Reality orientation and the aged. In I. M. Burnside (Ed.), *Nursing and the Aged*, New York: McGraw Hill, 1976, 245-254.

Taulbee, L. R. and Folsom, J. C. Reality orientation for geriatric patients. *Hospital and Community Psychiatry*, 1966, *17*, 133-135.

Terry, R. D. and Wisniewski, H. M. Ultrastructure of senile dementia and of experimental analogs. In C. M. Gaitz (Ed.), *Aging and the Brain*. New York: Plenum Press, 1972, 89-116.

Thompson, L. W. Effects of hyperbaric oxygen on behavioral functioning in elderly persons with intellectual impairment. In S. Gerson and A. Raskin (Eds.), *Aging Vol. 2: Genesis and Treatment of Psychologic Disorders in the Elderly*. New York: Raven Press, 1975, 169-177.

Tomlison, B. E. Morphological changes and dementia in old age. In W. L. Smith and M. Kinsbourne (Eds.), *Aging and Dementia*. New York: Spectrum, 1977, 25-56.

Tomlison, B. E., Blessed, G., and Roth, M. Observations on the brains of demented old people. *Journal of Neurological Science*, 1970, *11*, 205-242.

Treas, J. Family support systems for the aged: Some social and demographic considerations. *Gerontologist*, 1977, *17*(6), 486-491.

Verwoerdt, A. *Clinical Geropsychiatry*. Baltimore: Williams and Wilkins, 1976.

Vital Health Statistics. Chronic conditions and impairments of nursing home residents. DHEW Publication (HSM) 73-1704, 1973.

Wang, H. S. Dementia of old age. In W. L. Smith and M. Kinsbourne (Eds.), *Aging and Dementia*. New York: Spectrum, 1977, 1-24.

Weihl, H., Nathan, T., Avner, U., Finkelstein, N., and Getter, N. *Investigation of the Family Life, Living Conditions and Needs of the Non-Institutionalized Urban Jewish Aged 65+ in Israel*. State of Israel, Ministry of Social Welfare, 1970.

Weissert, W. G. Two models of geriatric care: Findings from a comparative study. Gerontologist, 1976, 16(5), 420-427.

Wershow, H. J. A pilot study comparing certain characteristics of black and white patients in proprietary nursing homes in Birmingham and rural Alabama. Technical, Training, and Research Division of the National Center on Black Aged, 1974.

Wershow, H. J. Reality orientation for gerontologists: some thoughts about senility. Gerontologist, 1977, 17(4), 297-302.

APPENDIX I

THE SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE (SPMSQ)

RELIABILITY AND VALIDITY OF THE OARS MULTIDIMENSIONAL FUNCTIONAL ASSESSMENT QUESTIONNAIRE (OMFAQ)

> We have developed a series of instruments, each based on experience with its predecessors, culminating in the Multidimensional Functional Assessment Questionnaire . . . The OARS instruments were specifically designed to assess level of functioning in each of five areas: . . . Careful attention was paid to item selection. Items were chosen for their relevance, and because they fulfilled at least one of a number of criteria:
>
> 1. reliability and validity were already known, or
> 2. we were willing to determine it;
> 3. local or national comparison standards were available;
> 4. the item was relevant to present theory and findings, or
> 5. the item was required because of accepted professional standards.
>
> . . . All the questionnaires have been pre-tested to ensure that those to whom they may be administered can understand them and those who will be using them can rate them . . .. Unlike the other questionnaires, which were particularly designed for the elderly, additional items make this questionnaire suitable for persons aged 18 and over. Because it has only recently been developed, little data is available on this questionnaire. Its manner of construction, however, ensures its validity, and it is sufficiently like the others that its reliability can be expected to be comparable to theirs (Fillenbaum, 1975, pp. 39-40).

APPENDIX II

RELIABILITY AND VALIDITY OF THE OARS MULTIDIMENSIONAL FUNCTIONAL ASSESSMENT QUESTIONNAIRE (OMFAQ)

THE SHORT PORTABLE MENTAL STATUS QUESTIONNAIRE (SPMSQ)

The Short Portable Mental Status Questionnaire (SPMSQ) has been developed and standardized on a community population of approximately 1,000 persons 65 years and older. The validity of the tool (does it test for senile brain disease and does a particular error score, modified for educational level and race, serve as a quantitatively accurate indicator of organic impairment?) was established in several ways. The strikingly different distributions of error scores for three study populations, the Duke Survey community population and two non-random populations of elderly, 143 subjects referred for evaluation to the OARS Clinic at the Duke University Center for the Study of Aging and Human Development and 102 institutionalized subjects in Durham, North Carolina, lend face validity to the SPMSQ as a measure of organic impairment.

Further validity studies relied on a comparison of SPMSQ results from individuals with their clinical psychiatric diagnoses. In a sample of 133 subjects seen in the OARS Clinic there was 92 percent congruence between the SPMSQ score and clinical diagnosis when the SPMSQ indicated definite impairment. There was 82 percent agreement between the SPMSQ score and clinical diagnosis, when the SPMSQ showed no or only mild impairment. As part of a larger validity study of the mental health section of the multidimensional assessment instrument (OMFAQ), 80 subjects' SPMSQ scores were compared with their clinical diagnoses. The researchers reported that 88 percent of those scoring in the range of moderate to severe impairment on the SPMSQ had been given a diagnosis of organic brain syndrome.

SPMSQ Reliability Studies: The SPMSQ was administered twice at four-week intervals to two groups of aged 65 and over (N = 30, N = 29). Test-retest correlations were 0.82 and 0.83 for the two groups. Responses to individual questions and the total error score remained stable, indicating no significant practice or short-term time effect.

APPENDIX III

CONSENT FORM

University of California
San Francisco
Consent to Act as a Research Subject
Cognitive Impairment Study

Approval Number:
930106-01

Miriam Hirschfeld, the investigator, has explained this study to me. I understand this study has two main purposes: (1) to study how people over age 60 perceive a change in their mental functioning and how one of their family members perceives it; (2) to identify some of the things the older person or the family member does, which are particularly helpful to them to adjusting to such a change.

I understand this study involves my answering a questionnaire and a series of interviews over approximately a two-week period of time. I also understand, as Ms. Hirschfeld and I talk during these interviews, that some of the questions may touch upon painful experiences and may be upsetting to me. I understand that sharing my experiences through talking with Ms. Hirschfeld, may or may not provide any comfort to me directly and that there will be no benefit to me personally. It is hoped that the findings from this study may benefit older people and their families in the future.

My refusal or later withdrawal would be without any jeopardy to my future care. I realize that I will not receive any money, or other tangible material gain, by participating in this study.

I understand that all interviews will be tape-recorded. Ms. Hirschfeld has assured me that the tapes, and any material from the tapes or the questionnaire, will be handled in a manner to ensure confidentiality; any publications resulting from this study will include the necessary precautions to protect my identity.

________________ (date)

__________________________ (signature)

APPENDIX IV

CODING DOCUMENT: IMPAIRED MEMBER

CODING DOCUMENT: IMPAIRED MEMBER

CARD I

Column

1-2 Family number

#

3 Impaired member code

1

4-5 Relationship of R to supportive member 1

01	Wife
02	Husband
03	Father
04	Mother
05	Father-in-law
06	Mother-in-law
07	Sister
08	Brother
10	Other
09	Not codable

6-7 Relationship of R to supportive member 2

01	Wife
02	Husband
03	Father
04	Mother
05	Father-in-law
06	Mother-in-law
07	Sister
08	Brother
10	Other
09	None

8 Sex

1	Male
2	Female

9 Blank

CARD I

Short Portable MSQ

Column

10 Date

1 Correct
2 Incorrect

11 Day of week

1 Correct
2 Incorrect

12 Address

1 Correct
2 Incorrect

13 Telephone number

1 Correct
2 Incorrect

14 Age

1 Correct
2 Incorrect

15 When born

1 Correct
2 Incorrect

16 President of U.S.

1 Correct
2 Incorrect

17 Last president

1 Correct
2 Incorrect

18 Mother's maiden name

1 Correct
2 Incorrect

CARD I

Short Portable MSQ

Column

19 Subtract 3 from 20...

1 Correct
2 Incorrect

20-21 Number of errors on MSQ

##

22 Religion

1 Jewish
2 Protestant
3 Catholic
4 Other
9 No information

23-24 Age

Real age

25 Length of stay in U.S.

1 Born - age 15
2 16-30
3 31-50
4 51+
9 No information

26 Refugee (left country of origin not by free choice)

1 Yes
2 No

27 Proficiency in English

1 Good
2 Fair
3 Poor
9 Not codable

28-29 Years of education

##

CARD I

Column

30 Marital status

1 Married to first spouse
2 Married to 2(+) spouse
3 Widowed
4 Divorced, separated
5 Single, never married
9 Missing information

Household Composition

31 Spouse

1 Yes
2 No

32 Daughter

1 Yes
2 No

33 Son

1 Yes
2 No

34 Daughter-in-law

1 Yes
2 No

35 Son-in-law

1 Yes
2 No

36 Daughter's friend

1 Yes
2 No

37 Son's friend

1 Yes
2 No

CARD I

Household Composition

Column

38 Sibling

1 Yes
2 No

39 Grandchild

1 Yes
2 No

40 Other

1 Yes
2 No

Relatives

41 Number of living siblings

#

42 Number of (living) children with present spouse; or widowed R

#

43 Number of children from prior marriage

#

44 Number of spouse's children from prior marriage

#

45 Number of R's children who died

#

46 Blank

47 Confidant

1 Spouse
2 Child
3 Other relative

CARD I

Column

47 Confidant (cont'd)

4 Friend
5 None
9 Not codable

48 Confidant's accessibility

1 Resides in same household
2 In San Francisco area
3 Distant
9 Not codable

49 Lonely (R subjective)

1 Hardly ever
2 Sometimes
3 Often
9 Not codable

50 Available help

1 Someone who would take care of Subject indefinitely (as long as needed)
2 Someone who would take care of Subject for a short time (a few weeks to six months)
3 Someone who would help the Subject now and then (taking him to the doctor or fixing lunch, etc.)
4 No help available
9 Not codable

Social Contacts: Frequency/Intensity

51 With SM1

1 High
2 Moderate
3 Low
0 Not applicable

52 With SM2

1 High
2 Moderate
3 Low
0 Not applicable

CARD I

Social Contacts: Frequency/Intensity

Column

53 Relatives

1 High
2 Moderate
3 Low
0 Not applicable

54 Friends (1:1, small groups, hired help)

1 High
2 Moderate
3 Low
0 Not applicable

55 Social activity (club, day-care)

1 High
2 Moderate
3 Low
0 Not applicable

Social Contacts: Satisfaction

56 With SM1

1 Predominantly satisfied
2 Neutral
3 Dissatisfied
0 Not applicable
9 Not codable

57 With SM2

1 Predominantly satisfied
2 Neutral
3 Dissatisfied
0 Not applicable
9 Not codable

58 Relatives

1 Predominantly satisfied
2 Neutral
3 Dissatisfied
0 Not applicable
9 Not codable

CARD I

Social Contacts: Satisfaction

Column

59 Friends or hired help

1 Predominantly satisfied
2 Neutral
3 Dissatisfied
0 Not applicable
9 Not codable

60 Social activity

1 Predominantly satisfied
2 Neutral
3 Dissatisfied
0 Not applicable
9 Not codable

61 Day care

Number of days/week

62 Mobility

1 Leaves house independently
2 Leaves house only accompanied
3 House-bound

63 Blank

64 Social resources rating scale (OARS)

1 Excellent social resources. Social relationships are very satisfying and extensive; at least one person would take care of him/her indefinitely.

2 Good social resources. Social relationships are fairly satisfying and adequate and at least one person would take care of him/her indefinitely. OR Social relationships are very satisfying and extensive; and only short term help is available.

3 Mildly socially impaired. Social relationships are unsatisfactory, of poor quality, few; but at least one person would take care of him/her indefinitely. OR Social relationships are fairly satisfactory, adequate; and only short term help is available.

CARD I

Column

64 Social resources rating scale (OARS)

4 Moderately socially impaired. Social relationships are unsatisfactory, of poor quality, few; and only short term care is available. OR Social relationships are at least adequate or satisfactory; but help would only be available now and then.

5 Severely socially impaired. Social relationships are unsatisfactory, of poor quality, few; and help would only be available now and then. OR Social relationships are at least satisfactory or adequate; but help is not even available now and then.

6 Totally socially impaired. Social relationships are unsatisfactory, of poor quality, few; and help is not even available now and then.

65 Occupation (the kind of work done most during life)

1 Higher executive, major professional
2 Business manager, medium sized business owner, lesser professional
3 Administrative personnel, small business owner, semi-professionals
4 Clerical and sales workers, technicians
5 Skilled manual employees
6 Semi-skilled
7 Unskilled
8 Housewife
9 Not codable

66-67 Income, own or common

		Yearly	Monthly
01	A.	0 - $499	(0 - $41)
02	B.	$500 - $999	($42 - $83)
03	C.	$1,000 - $1,999	($84 - $166)
04	D.	$2,000 - $2,999	($167 - $249)
05	E.	$3,000 - $3,999	($250 - $333)
06	F.	$4,000 - $4,999	($334 - $416)
07	G.	$5,000 - $6,999	($417 - $583)
08	H.	$7,000 - $9,999	($584 - $833)
09	I.	$10,000 - $14,999	($834 - $1249)
10	J.	$15,000 - $19,999	($1250 - $1666)

CARD I

Column

66-67 Income, own or common (continued)

		Yearly	Monthly
11	K.	$20,000 - $29,999	($1667 - $2499)
12	L.	$30,000 - $39,999	($2500 - $3333)
13	M.	$40,000 or more	($3334 or more)
99	No information		

68 Assets and financial resources sufficient to meet emergencies (R's view)

1 Yes
2 Depends
3 No
9 Not codable

69 Meet payments (R subjective)

1 No problem
2 Barely
3 Cannot

70 Financial situation compared to others (R subjective)

1 Better
2 Same
3 Worse

71 Resources meet needs (R subjective)

1 Very well
2 Fairly
3 Poorly
9 Not codable

72 Enough to buy little extras (R subjective)

1 Yes
2 No
9 Not codable

73 Enough for needs in future (R subjective)

1 Yes
2 Don't know
3 No
9 Not codable

CARD I

Column

74 Economic resources scale (OARS)

1	Economic resources are excellent. Income is ample; Subject has reserves.
2	Economic resources are satisfactory. Income is ample; Subject has no reserves. OR Income is adequate; Subject has reserves.
3	Economic resources are mildly impaired. Income is adequate; Subject has no reserves. OR Income is somewhat inadequate; Subject has reserves.
4	Economic resources are moderately impaired. Income is somewhat inadequate; Subject has no reserves.
5	Economic resources are severely impaired. Income is totally inadequate; Subject may or may not have reserves.
6	Economic resources are completely impaired. Subject is destitute, completely without income or reserves.

75 Blank

76 Worry (R subjective)

3	Very often
2	Fairly often
1	Hardly ever

77 Find life (R subjective)

1	Exciting
2	Routine
3	Dull

78 Life satisfaction (R subjective)

1	Good
2	Fair
3	Poor

CARD I

Column

79 Emotional health (R subjective)

- 1 Excellent
- 2 Good
- 3 Fair
- 4 Poor

80 Card number

- 1

CARD II

1-2 Family number

- ##

3 Impaired member code

- 1

4 Emotional health compared to five years ago (R subjective)

- 1 Better
- 2 Same
- 3 Worse

5-6 Short Psychiatric Evaluation Schedule sum of capital responses

- ##

7 Self

- 1 Intact
- 2 Blurred
- 3 Eroded

R seems to interviewer

8 Bothered, upset

- 1 Yes
- 2 No

9 Euphoric, jovial

- 1 Yes
- 2 No

CARD II

<u>Column</u>

10 Depressed

1 Yes
2 No

11 Joking inappropriately

1 Yes
2 No

12 Singing inappropriately

1 Yes
2 No

13 Angry, agressive

1 Yes
2 No

14 Anxious

1 Yes
2 No

15 Restless

1 Yes
2 No

16 Pacing

1 Yes
2 No

17 Tense

1 Yes
2 No

18 Satisfied

1 Yes
2 No

19 Bland

1 Yes
2 No

CARD II

Column

20 Regretful, sad

1 Yes
2 No

21 Tearful, but not sad

1 Yes
2 No

22 Suspicious

1 Yes
2 No

23 Paranoid

1 Yes
2 No

24 Bizarre, inappropriate

1 Yes
2 No

25 Somnolent, stuporous

1 Yes
2 No

26 Alert and interested

1 Yes
2 No

27 Pleasant and cooperative

1 Yes
2 No

28 Feeling useless, dull, "nothing"

1 Yes
2 No

29 Blank

CARD II

Column

30 Life/death attitude

- 1 Wants to live
- 2 Evades or denies
- 3 Wants to die

31 Mental health rating scale (OARS)

- 1 *Outstanding mental health*. Intellectually alert and clearly enjoying life. Manages routine and major problems in his life with ease and is free from any psychiatric symptoms.

- 2 *Good mental health*. Handles both routine and major problems in his life satisfactorily and is intellectually intact and free of psychiatric symptoms.

- 3 *Mildly mentally impaired*. Has mild psychiatric symptoms and/or mild intellectual impairment. Continues to handle routine, though not major, problems in his life satisfactorily.

- 4 *Moderately mentally impaired*. Has definite psychiatric symptoms, and/or moderate intellectual impairment. Able to make routine, commonsense decisions, but unable to handle major problems in his life.

- 5 *Severely mentally impaired*. Has severe psychiatric symptoms and/or severe intellectual impairment, which interfere with routine judgments and decision making in every day life.

- 6 *Completely mentally impaired*. Grossly psychotic or completely impaired intellectually. Requires either intermittent or constant supervision because of clearly abnormal or potentially harmful behavior.

32 Blank

33 Hospitalized in last six months

- 1 No
- 2 Once
- 3 More than once

CARD II

<u>Column</u>

34 Unable to carry out usual activities because of physical problem

1 Never
2 Week or less
3 Week - one month
4 More

35 Takes prescribed "life sustaining medication" (e.g. heart, BP, diabetes, thyroid)

3 Regularly
2 For short period
1 None

36 Takes psycho-pharmaca

3 Regularly
2 Now and then
1 Never

37 Adverse reactions to psycho-pharmaca

2 Yes
1 No

38 Takes other medication (e.g. pain medication, ant-acid, laxative...)

3 Regularly
2 Now and then
1 Hardly ever

39 Takes vitamins

2 Yes
1 No

40 Eyesight

1 Good
2 Fair
3 Poor

41 Hearing

1 Good
2 Fair
3 Poor

CARD II

<u>Column</u>

42 Smoking

2 Yes
1 No

43 Alcohol a problem

2 Yes
1 No

44 Sports

1 Yes
2 No

45 R rating own present health (subjective)

1 Excellent
2 Good
3 Fair
4 Poor

46 Compared to five years ago (R subjective)

1 Better
2 Same
3 Worse

47 Health trouble standing in way of doing things (R subjective)

1 Not at all
2 A little
3 A great deal

48 Physical health scale (OARS)

1 <u>In excellent physical health</u>. Engages in vigorous physical activity, either regularly or at least from time to time.

2 <u>In good physical health</u>. No significant illnesses or disabilities. Only routine medical care such as annual check ups required.

3 <u>Mildly physically impaired</u>. Has only minor illnesses and/or disabilities which might benefit from medical treatment or corrective measures.

CARD II

Column

48 Physical health scale (OARS)

4 Moderately physically impaired. Has one or more diseases or disabilities which are either painful or which require substantial medical treatment.

5 Severely physically impaired. Has one or more illnesses or disabilities which are either severely painful or life threatening, or which require extensive medical treatment.

6 Totally physically impaired. Confined to bed and requiring full time medical assistance or nursing care to maintain vital bodily functions.

49 Blank

Instrumental ADL

50 Can you use the telephone...

1 Without help, including looking up numbers and dialing
2 With some help (can answer phone or dial operator in an emergency, but need a special phone or help in getting the number or dialing)
3 Or are you completely unable to use the telephone?
9 Not answered

51 Can you get to places out of walking distance...

1 Without help (can travel alone on buses, taxis, or drive your own car)
2 With some help (need someone to help you or go with you when traveling)
3 Are you unable to travel unless emergency arrangements are made for a specialized vehicle like an ambulance?
9 Not answered

52 Can you go shopping for groceries or clothes (ASSUMING S HAS TRANSPORTATION)...

1 Without help (taking care of all shopping needs yourself, assuming you had transportation)
2 With some help (need someone to go with you on all shopping trips)
3 Or are you completely unable to do any shopping?
9 Not answered

CARD II

<u>Column</u>

53 You prepare your own meals...

1 Without help (plan and cook full meals yourself)
2 With some help (can prepare some things but unable to cook full meals yourself)
3 Or are you completely unable to prepare any meals?
9 Not answered

54 You do your housework...

1 Without help (can scrub floors, etc.)
2 With some help (can do light housework but need help with heavy work)
3 Or are you completely unable to do any housework?
9 Not answered

55 You take your own medicine...

1 Without help (in the right doses at the right time)
2 With some help (able to take medicine if someone prepares it for you and/or reminds you to take it)
3 Or are you completely unable to take your medicine?
9 Not answered

56 You handle your own money...

1 Without help (write checks, pay bills, etc.)
2 With some help (manage day-to-day buying but need help with managing your checkbook and paying your bills)
3 Or are you completely unable to handle money?
9 Not answered

Physical ADL

57 You eat...

1 Without help (able to feed yourself completely)
2 With some help (need help with cutting, etc.)
3 Or are you completely unable to feed yourself?
9 Not answered

CARD II

<u>Column</u>

58 You dress and undress yourself...

1 Without help (able to pick out clothes, dress and undress yourself)
2 With some help
3 Or are you completely unable to dress and undress yourself?
9 Not answered

59 You take care of your own appearance, for example combing your hair and (for men) shaving...

1 Without help
2 With some help
3 Or are you completely unable to maintain your appearance yourself?
9 Not answered

60 You walk...

1 Without help (except from a cane)
2 With some help from a person or with the use of of a walker, or crutches, etc.
3 Or are you completely unable to walk?
9 Not answered

61 You get in and out of bed...

1 Without any help or aids
2 With some help (either from a person or with the aid of some device)
3 Or are you totally dependent on someone else to lift you?
9 Not answered

62 You take a bath or shower...

1 Without help
2 With some help (need help getting in and out of the tub, or need special attachments on the tub)
3 Or are you completely unable to bathe yourself?
9 Not answered

63 You ever have trouble getting to the bathroom on time?

1 No
2 Yes
3 Have a catheter or colostomy
9 Not answered

CARD II

Column

64 How often do you wet or soil yourself (either day or night)?

1 Once or twice a week
2 Three times a week or more
9 Not answered
0 Not at all

65 ADL rating scale (OARS)

1 Excellent ADL capacity. Can perform all of the Activities of Daily Living without assistance and with ease.

2 Good ADL capacity. Can perform all of the Activities of Daily Living without assistance.

3 Mildly impaired ADL capacity. Can perform all but one to three of the Activities of Daily Living. Some help is required with one to three, but not necessarily every day. Can get through any single day without help. Is able to prepare his/her own meals.

4 Moderately impaired ADL capacity. Regularly requires assistance with at least four Activities of Daily Living but is able to get through any single day without help. Or regularly requires help with meal preparation.

5 Severely impaired ADL capacity. Needs help each day but not necessarily throughout the day or night with many of the Activities of Daily Living.

6 Completely impaired ADL capacity. Needs help throughout the day and/or night to carry out the Activities of Daily Living.

66-67 Cumulative Impairment Score (sum of five ratings)

##

68 Amount of nursing care and/or supervision needed

1 None
2 Occasionally
3 Few hours daily

CARD II

Column

68 Amount of nursing care and/or supervision needed

- 4 Can be left for several hours
- 5 24-hour supervision

69 Nursing care provided by

- 1 None provided
- 2 Family occasionally
- 3 Family less than 8 hrs/day with occasional hired help
- 4 Family less than 8 hrs/day with daily hired help
- 5 Family more than 8 hrs/day with occasional hired help
- 6 Family more than 8 hrs/day with daily hired help
- 7 Family more than 8 hrs/day without hired help

70 Times of hired help/week for R's personal care

#

71-72 Hours of hired help/week

##

73 Blank

74 Attachment of R to SM1

- 1 Love and devotion
- 2 Warm feelings, attachment
- 3 Neutral
- 4 Ambivalent
- 5 Resentment
- 6 Hate

75 Attachment of R to SM2

- 1 Love and devotion
- 2 Warm feelings, attachment
- 3 Neutral
- 4 Ambivalent
- 5 Resentment
- 6 Hate

CARD II

Column

76 R's perception of Family Life Space, of "my family"

- 1 Very positive
- 2 Positive
- 3 Neutral
- 4 Negative
- 5 Very negative

77 Blank

78 Wanders

- 1 No
- 2 Has gotten lost
- 3 Takes off

79 Blank

80 Card number

- 2

CARD III

1-2 Family number

- #

3 Impaired member code

- 1

Needs (R's perception and/or inferred from observation and interview data)

4 Giving love, closeness

- 1 Met
- 2 Partly met
- 3 Unmet
- 9 Not codable

5 Receiving love

- 1 Met
- 2 Partly met
- 3 Unmet
- 9 Not codable

CARD III

Column

6 Mutuality, matching needs with SM

1 Met
2 Partly met
3 Unmet
9 Not codable

7 Trust

1 Met
2 Partly met
3 Unmet
9 Not codable

8 Privacy

1 Met
2 Partly met
3 Unmet
9 Not codable

9 Mental stimulation

1 Met
2 Partly met
3 Unmet
9 Not codable

10 Being appreciated

1 Met
2 Partly met
3 Unmet
9 Not codable

11 Getting 'kavod'

1 Met
2 Partly met
3 Unmet
9 Not codable

12 Belonging

1 Met
2 Partly met
3 Unmet
9 Not codable

CARD III

<u>Column</u>

13 Defense against loneliness

1 Met
2 Partly met
3 Unmet
9 Not codable

14 Physical activity

1 Met
2 Partly met
3 Unmet
9 Not codable

15 Activity (work, 'play')

1 Met
2 Partly met
3 Unmet
9 Not codable

16 Freedom of movement

1 Met
2 Partly met
3 Unmet
9 Not codable

17 Socializing

1 Met
2 Partly met
3 Unmet
9 Not codable

Activities R engages in

42 Watching TV

1 Regularly
2 Sometimes
3 Hardly ever
0 Not answered

43 Plays solitaire

1 Regularly
2 Sometimes
3 Hardly ever
0 Not answered

CARD III

Column

44 Cards, chess...

1 Regularly
2 Sometimes
3 Hardly ever
0 Not answered

45 Reads paper

1 Regularly
2 Sometimes
3 Hardly ever
0 Not answered

46 Reads books

1 Regularly
2 Sometimes
3 Hardly ever
0 Not answered

47 'Visiting'

1 Regularly
2 Sometimes
3 Hardly ever
0 Not answered

48 Goes for walks

1 Regularly
2 Sometimes
3 Hardly ever
0 Not answered

49 Goes for drives

1 Regularly
2 Sometimes
3 Hardly ever
0 Not answered

50 Goes out for meals

1 Regularly
2 Sometimes
3 Hardly ever
0 Not answered

CARD III

Column	Activities R engages in		
51	Group activities		
		1	Regularly
		2	Sometimes
		3	Hardly ever
		0	Not answered
52	Enjoys music		
		1	Regularly
		2	Sometimes
		3	Hardly ever
		0	Not answered
53	Helps in household		
		1	Regularly
		2	Sometimes
		3	Hardly ever
		0	Not answered
	Activities R enjoys		
59	Watching TV		
		1	Yes
		2	No
		0	Not applicable
60	Solitaire		
		1	Yes
		2	No
		0	Not applicable
61	Cards, chess...		
		1	Yes
		2	No
		0	Not applicable
62	Reading paper		
		1	Yes
		2	No
		0	Not applicable

CARD III

Column   Activities R enjoys

63   Reading books

1 Yes
2 No
0 Not applicable

64   'Visiting'

1 Yes
2 No
0 Not applicable

65   Walks

1 Yes
2 No
0 Not applicable

66   Drives

1 Yes
2 No
0 Not applicable

67   Going out to eat

1 Yes
2 No
0 Not applicable

68   Group activities

1 Yes
2 No
0 Not applicable

69   Music

1 Yes
2 No
0 Not applicable

70   Helping in household

1 Yes
2 No
0 Not applicable

CARD III

<u>Column</u>

76 Speech

1 Clear
2 Motoric aphasia
3 Sensory aphasia
4 Completely unable to communicate verbally

80 Card number

3

APPENDIX V

CODING DOCUMENT: SUPPORTIVE FAMILY MEMBER

CODING DOCUMENT: FAMILY MEMBER

CARD IV

Column

1-2 Family number

#

3 Family member R

2 Supportive member 1
3 Supportive member 2
4 Supportive member 3

4-5 Relationship of R to IM

01 Husband
02 Wife
03 Son
04 Daughter
05 Son-in-law
06 Daughter-in-law
07 Child's live-in friend
08 Sibling
10 Other relative
11 Other

6 Sex

1 Male
2 Female

7 Blank

8-9 Short Portable MSQ # of errors

##

10 Religion

1 Jewish
2 Protestant
3 Catholic
4 Other
9 No information

CARD IV

Column

11-12 Age

Real age

13 Length of stay in U.S.

1	Born - age 15
2	16-30
3	31-50
4	51+
9	No information

14 Refugee (left country of origin not by free choice)

1	Yes
2	No

15 Proficiency in English

1	Good
2	Fair
3	Poor

16-17 Years of education

##

18 Status

1	Married to first spouse
2	Married to 2(+) spouse
3	Widowed
4	Divorced, separated
5	Single, never married
6	Living with friend (mate)
9	Missing information

19 Living arrangement

1	R and IM in common household
2	R living in IM's household
3	IM moved in with R before impairment
4	IM moved in with R after impairment
5	Other

Relatives

20 Number of living siblings

#

CARD IV

<u>Column</u>

21 Number of living children

#

22 Number of children who died

#

23 Blank

24 Confidant

1	Spouse (mate)
2	Child
3	Sibling
4	Other relative
5	Friend
6	None
9	Not codable

25 Confidant's accessibility

1	Resides in same house
2	Lives in San Francisco area
3	Distant
9	Not codable, none

26 Lonely

1	Hardly ever
2	Sometimes
3	Often
9	Not codable

27 Available help

1	Someone who would take care of Subject indefinitely (as long as needed)
2	Someone who would take care of Subject for a short time (a few weeks to six months)
3	Someone who would help the Subject now and then (taking him to the doctor or fixing lunch, etc.)
4	No help available
9	Not codable

CARD IV

Column

Social relationships: frequency/intensity

28 With IM

1 High
2 Moderate
3 Low
0 Not applicable

29 Nuclear family

1 High
2 Moderate
3 Low
0 Not applicable

30 Relatives

1 High
2 Moderate
3 Low
0 Not applicable

31 Friends (1:1, small groups)

1 High
2 Moderate
3 Low
0 Not applicable

32 Social activity (club...)

1 High
2 Moderate
3 Low
0 Not applicable

Social relationships: satisfaction

33 With IM

1 Predominantly satisfied
2 Neutral or ambivalent
3 Dissatisfied
0 Not applicable
9 Not codable

CARD IV

Column Social relationships: satifaction

34 Nuclear family

1 Predominantly satisfied
2 Neutral or ambivalent
3 Dissatisfied
0 Not applicable
9 Not codable

35 Relatives

1 Predominantly satisfied
2 Neutral or ambivalent
3 Dissatisfied
0 Not applicable
9 Not codable

36 Friends

1 Predominantly satisfied
2 Neutral or ambivalent
3 Dissatisfied
0 Not applicable
9 Not codable

37 Social activities

1 Predominantly satisfied
2 Neutral or ambivalent
3 Dissatisfied
0 Not applicable
9 Not codable

38 Blank

39 Social resources rating scale (OARS)

1 Excellent social resources. Social relationships are very satisfying and extensive; at least one person would take care of him/her indefinitely.

2 Good social resources. Social relationships are fairly satisfying and adequate and at least one person would take care of him/her indefinitely. OR Social relationships are very satisfying and extensive; and only short term help is available.

CARD IV

Column

39 Social resources rating scale (OARS)

3 Mildly socially impaired. Social relationships are unsatisfactory, of poor quality, few; but at least one person would take care of him/her indefinitely. OR Social relationships are fairly satisfactory, adequate; and only short term help is available.

4 Moderately socially impaired. Social relationships are unsatisfactory, of poor quality, few; and only short term care is available. OR Social relationships are at least adequate or satisfactory; but help would only be available now and then.

5 Severely socially impaired. Social relationships are unsatisfactory, of poor quality, few; and help would only be available now and then. OR Social relationships are at least satisfactory or adequate; but help is not even available now and then.

6 Totally socially impaired. Social relationships are unsatisfactory, of poor quality, few; and help is not even available now and then.

40 Work situation

1 Employed full time
2 Employed part time
3 Retired
4 Student
5 Other
9 Not codable

41
1 Carries major household work and responsibility
2 Shares work and responsibility with other member of household
3 Carries hardly any household work and responsibility
9 Not codable

42 Has hired help with household chores

1 Yes
2 No

CARD IV

Column

43 Instrumental help available

1 Readily available
2 Some
3 Hardly any

44 Emotional support available

1 To a high degree
2 Some
3 Hardly any
9 Not codable

45 Occupation (the kind of work done most during life)

1 Higher executive, major professional
2 Business manager, medium sized business owner, lesser professional
3 Administrative personnel, small business owner, semi-professionals
4 Clerical and sales workers, technicians
5 Skilled manual employees
6 Semi-skilled
7 Unskilled
8 Housewife
9 Not codable

46-47 Income

		Yearly	Monthly
01	A.	0 - $499	(0 - $41)
02	B.	$500 - $999	($42 - $83)
03	C.	$1,000 - $1,999	($84 - $166)
04	D.	$2,000 - $2,999	($167 - $249)
05	E.	$3,000 - $3,999	($250 - $333)
06	F.	$4,000 - $4,999	($334 - $416)
07	G.	$5,000 - $6,999	($417 - $583)
08	H.	$7,000 - $9,999	($584 - $833)
09	I.	$10,000 - $14,999	($834 - $1,249)
10	J.	$15,000 - $19,999	($1,250 - $1,666)
11	K.	$20,000 - $29,999	($1,667 - $2,499)
12	L.	$30,000 - $39,000	($2,500 - $3,333)
13	M.	$40,000 or more	($3,334 or more)

99 No information

CARD IV

Column

48 IM has additional own income

1 Yes
2 No
3 Common income

49 Number of people living on this income (at least 50% of their income)

#

50 Assets and financial resources sufficient to meet emergencies (R's view)

1 Yes
2 'Depends'
3 No
9 Not codable

51 Meet payments

1 No problem
2 Barely
3 Cannot

52 Financial situation compared to others

1 Better
2 Same
3 Worse

53 Meet needs

1 Very well
2 Fairly
3 Poorly
9 Not codable

54 Enough to buy little extras

1 Yes
2 No
9 Not codable

55 Enough for needs in future

1 Yes
2 Don't know
3 No
9 Not codable

CARD IV

Column

56 Economic resources scale (OARS)

1 Economic resources are excellent. Income is ample; Subject has reserves.

2 Economic resources are satisfactory. Income is ample; Subject has no reserves. OR Income is adequate; Subject has reserves.

3 Economic resources are mildly impaired. Income is adequate; Subject has no reserves. OR Income is somewhat inadequate; Subject has reserves.

4 Economic resources are moderately impaired. Income is somewhat inadequate; Subject has no reserves.

5 Economic resources are severely impaired. Income is totally inadequate; Subject may or may not have reserves.

6 Economic resources are completely impaired. Subject is destitute, completely without income or reserves.

57 Blank

58 Worry

3 Very often
2 Fairly often
1 Hardly ever

59 Find life

1 Exciting
2 Routine
3 Dull

60 Life satisfaction

1 Good
2 Fair
3 Poor

CARD IV

<u>Column</u>

Short Psychiatric Evaluation Schedule

61-62 Sum of capital letter responses

#

63 Emotional health (subjective)

1 Excellent
2 Good
3 Fair
4 Poor

64 Compared to five years ago

1 Better
2 Same
3 Worse

65 Mental health rating scale (OARS)

1 <u>Outstanding mental health</u>. Intellectually alert and clearly enjoying life. Manages routine and major problems in his life with ease and is free from any psychiatric symptoms.

2 <u>Good mental health</u>. Handles both routine and major problems in his life satisfactorily and is intellectually intact and free of psychiatric symptoms.

3 <u>Mildly mentally impaired</u>. Has mild psychiatric symptoms and/or mild intellectual impairment. Continues to handle routine, though not major, problems in his life satisfactorily.

4 <u>Moderately mentally impaired</u>. Has definite psychiatric symptoms, and/or moderate intellectual impairment. Able to make routine, common-sense decisions, but unable to handle major problems in his life.

5 <u>Severely mentally impaired</u>. Has severe psychiatric symptoms and/or severe intellectual impairment, which interfere with routine judgments and decision making in every day life.

CARD IV

<u>Column</u>

65 Mental health rating scale (OARS)

6 <u>Completely mentally impaired</u>. Grossly psychotic or completely impaired intellectually. Requires either intermittent or constant supervision because of clearly abnormal or potentially harmful behavior.

66 Blank

67 Hospitalized in last six months

1 No
2 Once
3 More than once

68 Unable to carry out usual activities because of physical problem

1 Never
2 Week or less
3 Week - one month
4 More

69 Prescribed "life sustaining medication" (e.g. heart, BP, diabetes, thyroid...)

3 Regularly
2 For short periods
1 None

70 Tranquilizers, sleeping pills

3 Regularly
2 Now and then
1 Never

71 Other non-prescription medicine (e.g. pain medication, ant-acid, laxative...)

3 Regularly
2 Now and then
1 Hardly ever

72 Vitamins

2 Yes
1 No

CARD IV

Column

73 Eyesight

- 1 Good
- 2 Fair
- 3 Poor

74 Hearing

- 1 Good
- 2 Fair
- 3 Poor

75 Smoking

- 2 Yes
- 1 No

76 Alcohol a problem

- 2 Yes
- 1 No

77 Sports

- 1 Yes
- 2 No

78 R rating own present health

- 1 Excellent
- 2 Good
- 3 Fair
- 4 Poor

79 Compared to five years ago

- 1 Better
- 2 Same
- 3 Worse

80 Card number

- 4

CARD V

Column

1-2 Family number

#

3 R

2 Supportive member 1
3 Supportive member 2
4 Supportive member 3

4 Blank

5 Health trouble standing in way of doing things

1 Not at all
2 A little
3 A great deal

6 Physical health scale (OARS)

1 In excellent physical health. Engages in vigorous physical activity, either regularly or at least from time to time.

2 In good physical health. No significant illnesses or disabilities. Only routine medical care such as annual check-ups required.

3 Mildly physically impaired. Has only minor illnesses and/or disabilities which might benefit from medical treatment or corrective measures.

4 Moderately physically impaired. Has one or more diseases or disabilities which are either painful or which require substantial medical treatment.

5 Severely physically impaired. Has one or more illnesses or disabilities which are either severely painful or life threatening, or which require extensive medical treatment.

6 Totally physically impaired. Confined to bed and requiring full time medical assistance or nursing care to maintain vital bodily functions.

7 Drives own car

1 Yes
2 No

CARD V

Column

8 ADL scale (OARS)

1 Excellent ADL capacity. Can perform all of the Activities of Daily Living without assistance and with ease.

2 Good ADL capacity. Can perform all of the Activities of Daily Living without assistance.

3 Mildly impaired ADL capacity. Can perform all but one to three of the Activities of Daily Living. Some help is required with one to three, but not necessarily every day. Can get through any single day without help. Is able to prepare his/her own meals.

4 Moderately impaired ADL capacity. Regularly requires assistance with at least four Activities of Daily Living but is able to get through any single day without help. Or regularly requires help with meal preparation.

5 Severely impaired ADL capacity. Needs help each day but not necessarily throughout the day or night with many of the Activities of Daily Living.

6 Completely impaired ADL capacity. Needs help throughout the day and/or night to carry out the Activities of Daily Living.

9-10 Cumulative Impairment Score (sum of the five ratings)

#

11-12 Cumulative Impairment Score of IM and R combined (added)

#

Physical environment changes (made because of IM)

13 Sleeping arrangements

1 Yes
2 No

14 Doors locked, adjusted

1 Yes
2 No

CARD V

Column

15 Stairs adjusted, glide

1 Yes
2 No

16 Safety changes (i.e. rails in bathroom...)

1 Yes
2 No

Factors alleviating stress

19 Day-care

1 Yes
2 No
0 Not applicable

20 Hours of hired nursing

1 Yes
2 No
0 Not applicable

21 Going to work

1 Yes
2 No
0 Not applicable

22 Relatives taking over

1 Yes
2 No
0 Not applicable

23 Friends taking over

1 Yes
2 No
0 Not applicable

24 Vacation

1 Yes
2 No
0 Not applicable

CARD V

<u>Column</u>

25 Getting out of the house

1 Yes
2 No
0 Not applicable

Boundary zone (as perceived by R)

30 Difficulty to get hired help

1 Mentioned
2 Not mentioned

31 Difficulty to afford hired help

1 Mentioned
2 Not mentioned

32 Difficulty to find appropriate institution

1 Mentioned
2 Not mentioned

33 Difficulty to afford appropriate institution

1 Mentioned
2 Not mentioned

34 Crime in the streets

1 Mentioned
2 Not mentioned

35 Inflation

1 Mentioned
2 Not mentioned

36 Difficulty to get medical care, advice

1 Mentioned
2 Not mentioned

37 Difficulty to utilize services

1 Mentioned
2 Not mentioned

CARD V

Column

38 Indifference of social environment

1 Mentioned
2 Not mentioned

Major problem for R (mentioned as)

43 Disturbed sleep (night)

1 Yes
2 No
0 Not applicable

44 Not enough rest

1 Yes
2 No
0 Not applicable

45 Tied down (cannot leave home, 'take off')

1 Yes
2 No
0 Not applicable

46 Privacy (unable to 'close door')

1 Yes
2 No
0 Not applicable

47 Free time (no time to 'play', for self)

1 Yes
2 No
0 Not applicable

48 Social isolation

1 Yes
2 No
0 Not applicable

49 Loss of other because of impairment

1 Yes
2 No
0 Not applicable

CARD V

<u>Column</u> Major problem for R (mentioned as)

50 Conflict with other valued commitment (e.g. work)

1 Yes
2 No
0 Not applicable

51 Conflict with family member other than IM

1 Yes
2 No
0 Not applicable

52 IM conflict with family member other than R

1 Yes
2 No
0 Not applicable

53 Lack of appreciation, 'thanklessness' by IM

1 Yes
2 No
0 Not applicable

54 Health problems (related to care of IM)

1 Yes
2 No
0 Not applicable

55 Conflict around money

1 Yes
2 No
0 Not applicable

56 Feeling of helplessness and/or ambivalence and/or hopelessness and/or guilt and/or resentment

1 Yes
2 No
0 Not applicable

57 Inability to get help

1 Yes
2 No
0 Not applicable

CARD V

Column Major problem for R (mentioned as)

58 Worry for future

1 Yes
2 No
0 Not applicable

59 Effect on other family members (children...)

1 Yes
2 No
0 Not applicable

60 Dependency of IM

1 Yes
2 No
0 Not applicable

61 Sibling conflict (i.e. shared burden, shared love)

1 Yes
2 No
0 Not applicable

64-65 Most important - prime problem

# of column

66-67 Number of problems perceived as major by R

#

Major problem of IM for R

68 Wanders off

1 Yes
2 No
0 Not applicable

69 Dangerous to surrounding

1 Yes
2 No
0 Not applicable

CARD V

Column	Major problem of IM for R
70	Dangerous to self
	1 Yes 2 No 0 Not applicable
71	Aggressive, abusive
	1 Yes 2 No 0 Not applicable
72	Unesthetic, refuses bath, eating habits
	1 Yes 2 No 0 Not applicable
73	Loss of prior 'self'
	1 Yes 2 No 0 Not applicable
74	Demands constant attention
	1 Yes 2 No 0 Not applicable
75	Restlessness, anxiety
	1 Yes 2 No 0 Not applicable
76	Paranoid
	1 Yes 2 No 0 Not applicable
77	Unable to make self understood, speech impediment
	1 Yes 2 No 0 Not applicable

CARD V

Column Major problem of IM for R

78 "Money hang-up"

1 Yes
2 No
0 Not applicable

79 Confuses, does not recognize people

1 Yes
2 No
0 Not applicable

80 Card number

5

CARD VI

1-2 Subject number

#

4 Blank

Major problem of IM for R

5 Disorientation to time

1 Yes
2 No
0 Not applicable

6 Constant repeating, perseverations

1 Yes
2 No
0 Not applicable

7 Poor judgment

1 Yes
2 No
0 Not applicable

8 Bizarre behavior

1 Yes
2 No
0 Not applicable

CARD VI

<u>Column</u> Major problem of IM for R

9 Physical decline

- 1 Yes
- 2 No
- 0 Not applicable

10 Discontent with R

- 1 Yes
- 2 No
- 0 Not applicable

11 IM's inability to rally help for R

- 1 Yes
- 2 No
- 0 Not applicable

12 Dependency

- 1 Yes
- 2 No
- 0 Not applicable

13 Lack of interest, "vegetates"

- 1 Yes
- 2 No
- 0 Not applicable

16-17 Prime problem

# of column

18-19 Number of problems

#

20 Blank

21 Onset - can describe specific events related to onset

- 1 Yes
- 2 No

CARD VI

Column

22 Variables to R's obligation toward IM's care

1 Continuing love and affection - R still receives emotional satisfaction from relationship

2 Repayment for all IM did, was - R receives emotional satisfaction from being able to care for IM

3 Out of duty - reluctant to place IM in good home against wishes

4 Lack fo acceptable choice - would place in good home irrespective of IM's wishes

5 Unable to continue care for IM at home - in process of institutionalization

23 Attachment of R to IM - in present

1 Love and devotion
2 Warm feelings, attachment
3 Neutral
4 Ambivalent
5 Resentment
6 Hate

24 R's perception of past relationship - history toward IM

1 Highly satisfactory
2 Got along well
3 Neutral (parallel living)
4 Significant resentment, ambivalence
5 Much serious conflict, dislike
9 Not codable

25 Quality of R's obligation to IM's care in terms of gain:loss

1 Considerable gain - imagined release from obligation felt as essential loss ($1 + 1 > 2$)

2 Some gain - imagined release from obligation felt as certain loss ($1 + 1 = 2$)

3 Neutral ($1 + 1 = 1$)

4 Some loss - imagined release from obligation felt as some gain ($1 + 1 < 1$)

CARD VI

Column

25 Quality of R's obligation to IM's care in terms of gain:loss

5 Loss - R pays 'high price' - imagined release from obligation felt as relief (1 + 1 = -1)

26 R's attitude toward institutionalization of IM

1 Unwilling to even consider institutionalization for the future

2 Considering institutionalization as the last resort for the future

3 Considering institutionalization under certain circumstances ("not for now")

4 Institutionalization desired, no steps taken

5 In process of institutionalization

Factors that R considers would lead to institutionalization

27 Decline in IM's physical state

1 Yes
2 No

28 IM becoming 'senile'

1 Yes
2 No

29 IM becoming incontinent

1 Yes
2 No

30 R's impairment or death

1 Yes
2 No

31 Too much strain on R

1 Yes
2 No

CARD VI

Column

32 Inability to find or afford necessary help

1 Yes
2 No

33 R no longer recognized by IM

1 Yes
2 No

37 R planning own institutionalization together with IM

1 Yes
2 No

38 R's attitude toward safety hazards

1 R seemingly unconcerned
2 R takes calculated risks
3 R preoccupied with possible dangers - guides most of everyday life
0 No "objective" danger

39 Blank

40 Religion - considers religion a source of support

1 Yes
2 No

41 Family rituals

1 Holidays, birthdays, anniversaries
2 Others
3 None

42 R handling anger, aggression

1 R blows up, feels relief
2 R blows up, feels guilty
3 Low level - chronic nagging
4 Turns predominantly inward
5 Doesn't seem to experience
9 Not codable

CARD VI

Column

43 Future

1 R perceives as positive
2 R perceives as 'hanging on'
3 R perceives as a threat
9 Not codable

44 Blank

Needs (R's perception)

45 Time for oneself

1 Met
2 Partly met
3 Unmet
9 Not codable

46 Rest, sleep

1 Met
2 Partly met
3 Unmet
9 Not codable

47 Giving love, closeness

1 Met
2 Partly met
3 Unmet
9 Not codable

48 Receiving love, closeness

1 Met
2 Partly met
3 Unmet
9 Not codable

49 Mutuality, matching needs with IM

1 Met
2 Partly met
3 Unmet
9 Not codable

CARD VI

Column

50 Privacy

1 Met
2 Partly met
3 Unmet
9 Not codable

51 Mental stimulation

1 Met
2 Partly met
3 Unmet
9 Not codable

52 Being appreciated

1 Met
2 Partly met
3 Unmet
9 Not codable

53 Belonging to

1 Met
2 Partly met
3 Unmet
9 Not codable

54 Defense against loneliness

1 Met
2 Partly met
3 Unmet
9 Not codable

55 Physical activity

1 Met
2 Partly met
3 Unmet
9 Not codable

56 Outside activity (work, study, play)

1 Met
2 Partly met
3 Unmet
9 Not codable

CARD VI

Column

57 Freedom of movement

1 Met
2 Partly met
3 Unmet
9 Not codable

58 Socializing

1 Met
2 Partly met
3 Unmet
9 Not codable

R's valence of needs

64 Time for oneself

1 High
2 Medium
3 Low
9 Not codable

65 Rest, sleep

1 High
2 Medium
3 Low
9 Not codable

66 Giving love, closeness

1 High
2 Medium
3 Low
9 Not codable

67 Receiving love, closeness

1 High
2 Medium
3 Low
9 Not codable

68 Mutuality, matching needs with IM

1 High
2 Medium
3 Low
9 Not codable

CARD VI

<u>Column</u> R's valence of needs

69 Privacy

1 High
2 Medium
3 Low
9 Not codable

70 Mental stimulation

1 High
2 Medium
3 Low
9 Not codable

71 Being appreciated

1 High
2 Medium
3 Low
9 Not codable

72 Belonging to

1 High
2 Medium
3 Low
9 Not codable

73 Defense against loneliness

1 High
2 Medium
3 Low
9 Not codable

74 Physical activity

1 High
2 Medium
3 Low
9 Not codable

75 Outside activity

1 High
2 Medium
3 Low
9 Not codable

CARD VI

Column R's valence of needs

76 Freedom of movement

1 High
2 Medium
3 Low
9 Not codable

77 Socializing

1 High
2 Medium
3 Low
9 Not codable

79 R's perception of Family Life Space, of "my family"

1 Very positive
2 Postive
3 Neutral
4 Negative
5 Very negative

80 Card number

6

CARD VII

1-2 Family number

##

3 R

2 Supportive member 1

R appears to interviewer

4 Bothered, upset

1 Very
2 Somewhat
3 Hardly
4 Not at all

CARD VII

Column R appears to interviewer

5 Worried

- 1 Very
- 2 Somewhat
- 3 Hardly
- 4 Not at all

6 Contented

- 1 Very
- 2 Somewhat
- 3 Hardly
- 4 Not at all

7 Frustrated

- 1 Very
- 2 Somewhat
- 3 Hardly
- 4 Not at all

8 Resentful

- 1 Very
- 2 Somewhat
- 3 Hardly
- 4 Not at all

9 Satisfied

- 1 Very
- 2 Somewhat
- 3 Hardly
- 4 Not at all

10 Unhappy

- 1 Very
- 2 Somewhat
- 3 Hardly
- 4 Not at all

11 Tense

- 1 Very
- 2 Somewhat
- 3 Hardly
- 4 Not at all

CARD VII

<u>Column</u> R appears to interviewer

12 Bored

1 Very
2 Somewhat
3 Hardly
4 Not at all

13 Lonely

1 Very
2 Somewhat
3 Hardly
4 Not at all

14 Feeling guilty

1 Very
2 Somewhat
3 Hardly
4 Not at all

15 Anxious

1 Very
2 Somewhat
3 Hardly
4 Not at all

16 Suspicious

1 Very
2 Somewhat
3 Hardly
4 Not at all

17 Alert and interested

1 Very
2 Somewhat
3 Hardly
4 Not at all

18 Pleasant and cooperative

1 Very
2 Somewhat
3 Hardly
4 Not at all

CARD VII

<u>Column</u> R appears to interviewer

19 Angry, aggressive

1 Very
2 Somewhat
3 Hardly
4 Not at all

20 Depressed

1 Very
2 Somewhat
3 Hardly
4 Not at all

21 Regretful, sad

1 Very
2 Somewhat
3 Hardly
4 Not at all

22 Exasperated

1 Very
2 Somewhat
3 Hardly
4 Not at all

23 Discouraged

1 Very
2 Somewhat
3 Hardly
4 Not at all

24 Confident

1 Very
2 Somewhat
3 Hardly
4 Not at all

CARD VII

Column

50 Ascribed Management Rating Scale

1 Excellent management ability. Manages own life and care of IM with ease; R and IM are comfortable with their life style

2 Good management ability. Manages own life and care of IM with effort, but to both of their satisfaction

3 Mildly impaired management ability. Has difficulty managing own life and/or care of IM, is able to find sufficient practical and/or emotional support

4 Moderately impaired management ability. Has difficulty managing own life and/or care of IM and is unable to find sufficient practical and/or emotional support

5 Severely impaired management ability. Manages "somehow", but very unhappy and/or care of IM is lacking

6 Completely impaired management ability. Feels overwhelmed, extremely distraught and care of IM is lacking

80 Card Number

7