ELDERLY NURSING HOME PATIENTS AND THEIR FAMILIES: PROGRAMMATIC AND SOCIAL ISSUES

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ABSTRACT

ELDERLY NURSING HOME PATIENTS AND THEIR FAMILIES: PROGRAMMATIC AND SOCIAL ISSUES

By

Jonathan Lind York

A review of the literature revealed that families generally remain involved in the lives of their older relatives and that such phenomena as "dumping" of the elderly into institutions are empirically invalid. Nevertheless, further investigation has shown that families are rarely utilized as treatment resources for elderly relatives who have been placed in nursing homes, and that families often act as a negative factor in their relative's care.

The present research was undertaken in order to examine the factors crucial to productive involvement of families in the lives of nursing home patients. Extensive personal interviews were conducted with the significant relatives of 76 nursing home patients in the Lansing, Michigan area. Through this interview, a comprehensive picture of the family was compiled, covering to the nursing home placement process, pre-placement involvement,

visiting practices, available support systems, feelings of guilt concerning institutionalization, expressed programmatic needs, and demographics. In addition, other instruments measured the behavioral and physical functioning levels of each patient on several scales.

Data analysis focused on descriptive statistics, correlation matrices, and a cluster analysis of variables. Results revealed that families were unaware of and made very little use of alternatives to nursing home placement; however, placement was not seen as a "dumping" reaction, but as a final response to a difficult situation. Furthermore, a large proportion of families were willing to take part in any programs to help them communicate better with their relative and to serve as a more positive treatment resource. Visiting is even more problematic for relatives of mentally impaired patients; these families not only enjoy their visiting less but seem to visit more out of guilt feelings than out of desire to see the patient. Programs are needed to train families to visit more productively; those families who were more active on visits tended to enjoy visits more no matter what the condition of their relative.

In addition, support mechanisms for families were found to be inadequate. Only 33% of the families felt support from the physician in dealing with their relative's emotional and psychosocial needs, and those who did draw

this type of support tended to both feel less guilty and be less willing to be involved in programs. Physician support did not correlate with either quantity or quality of visiting.

Based upon the results and their interpretation, several suggestions were made for program development in both nursing homes and other social service agencies.

ELDERLY NURSING HOME PATIENTS AND THEIR FAMILIES: PROGRAMMATIC AND SOCIAL ISSUES

By

Jonathan Lind York

A THESIS

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To Kathy, who sticks with me,

To Jacob, who came in the middle,

and

To my mother, who was there from the start.

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A great debt is owed to Bob Calsyn, my committee chairman and friend, who may have refused to OK my first draft verbatim but never refused to advise, counsel, and support. Also, to Louis Tornatzky and George W. Fairweather, for serving on my committee and for helping me on my way in Ecological Psychology.

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TABLE OF CONTENTS

LIST OF TABLES

CHAPTER I

INTRODUCTION

The Quality of Life in Nursing Homes: The Problem of Resources

There are currently over one million older Americans living in almost 23,000 nursing homes in this country. Although this represents only 5% of the total population over 65, a more significant fact is that one-fourth of all persons over age 75 will enter a nursing home sometime in their lives (Lubin, 1975). In addition, with the vast increases of older Americans projected in the last quarter of the twentieth century, the total number needing nursing home care is bound to grow astronomically. In fact, some researchers have projected as high as 25 or 30% of the population, the number older than 65 by the year 2000 (Graber, 1976). If utilization rates remain the same, this will place two or three times as many people in nursing homes as there are today. Even if medical advances and development of strong alternatives to institutionalization can cut utilization in half, there will still be vast numbers in need of nursing home care.

This vast number of institutionalized elderly is not a problem in itself, as most of the residents in nursing homes need some sort of professional care in a protective and therapeutic environment. What has become a major problem is the fact that a large proportion of these people are living in nursing homes which are marginally, if at all, geared toward providing for a decent quality of life for their patients. This country originally allowed the proprietary profit-making nursing home industry to grow and to flourish in an atmosphere of disregard, unhampered by any but the most rudimentary controls. Shocking revelations of health and safety hazards, along with several horrible disasters (Mendelson, 1974), brought the first round of governmental regulation, controlling such important aspects as nutrition, fire safety, cleanliness, etc.

Unfortunately, the improvement of these areas may serve as a necessary condition for upgrading the quality of life in nursing homes, but it is far from sufficient. Regulations have failed thus far to attack the more global problem of quality of care and quality of life, and in failing have therefore left it up to each nursing home to maintain its own standards. Moreover, the emphasis of governmental bodies on "bricks and mortar" regulations has shifted the focus of both nursing homes and the public from the crucial question of what kind of lives our elderly citizens can lead in nursing homes (Shore, 1975).

It has thus been left to a handful of researchers and social scientists to attempt to measure the quality of life in nursing homes (Andrews & Withey, 1974; Goldman, 1973) and to attempt to make improvements (Coons, 1973; Donahue, 1964; Goldman, 1975). Several major steps have been made in improving the general quality of life among the institutionalized elderly; foremost among these are the development of reality orientation techniques (Folsom, 1968); milieu therapy (Gattesman, 1973); remotivation therapy (Pullinger & Sholly, n.d.); resocialization (Kunkel, 1970). In addition, new research is produced regularly on methods of structuring living environments for the elderly in institutions to improve functioning (McClannahan, 1973; Jones, 1975).

Nevertheless, it is an unfortunate fact that almost all of the innovative treatment and rehabilitation techniques being used to improve institutional care got their start in and are yet limited to a select handful of high-powered geriatric centers or state hospitals. Facilities such as the Philadelphia Geriatric Center, the Institute of Gerontology at Ann Arbor, the Tuscaloosa Veteran's Administration Hospital all have far greater resources in both staff and physical plant than the proprietary nursing homes which care for over 80% of our nation's elderly (Brody, 1973). Indeed, it is this disparity in resources between the forerunners in

geriatric care and the local nursing home which may account for the enormous lag in diffusion of progressive treatment techniques and environmental changes.

The minority of gerontologists who have attempted to create programmatic improvements in the "average" proprietary nursing home setting have almost universally cited the paucity of resources as the major impediment (Wershaw, 1976). These nursing homes operate at the minimal standards as set and reimbursed by government, and thus make the minimal expenses necessary to meet regulations. For example, while in a nonprofit, high expense geriatric center the activity program may be run by one or more occupational therapists, in a proprietary nursing home it could be directed by a nineteen-year-old ex-nurse's aide.

Proprietary and small nonprofit nursing homes have traditionally been most inadequately prepared in three major areas: staffing, rehabilitative services, and physical plant.

1. Staffing--The weaknesses of nursing home staff are those of both quantity and quality. Inadequate number of staff is most often a direct result of the fact that nursing homes operate with between 70% and 80% of their patients paid for by state Medicaid funds (Brody, 1973), and thus staffing levels and amount of reimbursement for staff is a state prerogative. In other words, the

state will reimburse the nursing home for staff as long as it maintains the minimal regulated levels; there is no incentive for increasing beyond this. Staff quality is also in great part a result of the fiscal policies--nursing home wages are the lowest in any health care profession, and, for aides, are rarely above minimum wage levels. Thus, for nonprofessional staff (aides, orderlies, housekeepers), wages for a very difficult and demanding job are no higher than those for much easier jobs on the outside; most of these staff members are forced by economic necessity to move to any higher paying job available, which contributes to the enormous turnover rate in these positions--as high as 90% per year (Schwartz, 1974). For professional nurses, lower wages contribute to high turnover and difficulty in securing top quality staff, but added to this is the fact that nursing homes are considered the lowest-status jobs in health care. Because of the dual stigmata attached to "chronic care" and working with the elderly, it is extremely difficult to lure top quality nurses into the field. Finally, weaknesses in staff quality are in a large part the result of inadequate preparation, training, and supervision. York, Calsyn, and Fergus (1975) found that only 15% of the nursing home staff in the Lansing area reported any formal training in working with the elderly. Also, supervision by physicians and gerontological nurses was nonexistent.

2. Rehabilitative services, such as occupational and physical therapy, speech and hearing therapy, and mental health diagnosis, consultation and therapy are also lacking in nursing homes, largely because of the paucity of funds to support them. Nursing care is emphasized as primary, although Sottesman and Bourestom (1974) found that only 2.1% of residents' time was spent in medical or nursing activities and 55% doing absolutely nothing. Thus, even though nursing homes are modeled after general hospital settings in treating the older person as a "patient" to whom things must be "done," there are few resources available to carry out these treatment tasks and to even begin to fulfill this role (Brody, 1973).

3. Physical plant resources of nursing homes are also far from adequate. Built on a strict cost per square footage formula, most nursing homes have a minimum of space for any but the most traditional uses: dining, sleeping, personal hygiene, and usually one lounge or activity area (Butler & Lewis, 1973). This has been perceived by Butler and Lewis (1973) as a special problem for those nursing home patients who have been released from state mental hospitals, which have relatively a wealth of resources.

Aged Patients and Their Families

At the same time that researchers and social planners lament this paucity of resources, the most potentially powerful resource available to the patient lies fallow or, worse, works against his well-being. This resource is the patient's family.

Before examining some of the potentials of the family in the rehabilitation of the aged patient, it is necessary to dispute several of the myths which seem to lend hopelessness to involving family members with nursing home patients. The first of these can be termed the myth of family uninvolvement, or as it is called by Spark and Brody (1970), "the myth of separation of the aged." Shanas (1963) has attacked this "alienation theory," which holds that old people who live along or apart from their children are neglected by their children. She cites evidence that ties between older people and their families continue (Shanas, 1960), and that families behave responsibly in relating to their older members' needs (Shanas, 1968). In addition, she has found that families regularly perform household tasks for their older relatives and often house their relatives with them in times of crisis (Shanas, 1968). Townsend (1963) studied family structure and its effects on the likelihood of admission to a Home for the Aged (not nursing home) in Britain, and found that over 45% of the older

persons samples had moved in with family until circumstances forced their institutionalization. In addition, these circumstances were found to be of a real and severe nature, such as illness of the child, loss of home forcing moves to smaller accommodations, etc.

The World Health Organization has addressed this issue of separation and alienation thus:

> Wherever careful studies have been carried out in the industrialized countries, the lasting devotion of children for their parents has been amply demonstrated. The great majority of old people are in regular contact with their children, relatives, or friends. All the same, industrial and urban development increases social and geographical mobility, and a small portion of the aged are, as a result, left with few human contacts, particularly in large cities. . . . There is also a marginal group, a still larger number of aged people whose survival in the community is precarious and bought at the cost of hardship to relatives or friends.
>
> . . . A number of investigators have shown that the three-generation family is very much alive even in the heart of great cities, and that the human relationships which it fosters are preferred by a high proportion of young people no less than old ones. (WHO, 1959, pp. 6, 7)

The conclusion which can be drawn from much of the evidence is that most older persons continue to have contact with their children and other relatives throughout their aging years. Although much has been made of the isolated nuclear family as the prevalent family structure of the last half of the twentieth century, this concept is giving way among empirical evidence to a broader view of the nuclear family operating within a network of kin relationships (Sussman & Burchinal, 1962).

Another prevalent myth regarding older persons and their families relates closely to the above myth of segregation: this is the view that older people in institutions are "dumped" there by their families. Camp (1965) states that "the dumping syndrome . . . is observed constantly by the admitting officer of every type of facility to which admission of aged persons is sought: the description of the patient . . . has a miraculous way of adapting itself to coincide with the admission criteria of the receiving facility." However, Spark and Brody (1970) dispute this popular assumption: "The stereotypes of families 'dumping' their aged is a myth. . . . When families place their older members, they are often elderly and ill themselves, have exhausted all other alternatives and have endured enormous social, psychological and economic stress in the process."

Data concerning family response to illness tends to further destroy the "dumping" myth. Shanas (1960), in a study of 2,507 older persons, concluded that "as parental needs in the health area become greater, as nursing care or special diets are needed, or as household chores become burdensome for the older person, the majority of children assume these responsibilities." In this study, while 76% of the older people with children and 86% of the children felt that the best place for an older person to live was in his own home, this contrasted

with the finding that 44% of the "very sick" old were taken into their childrens' homes. Furthermore, over 35% of the "not sick" old were living with one or more of their children (Shanas, 1960). Thus, it seems that families are more likely to adapt their lifestyles to accommodate a sick or needy older relative rather than automatically place that person into an institution; consequently, placement often occurs only after other alternatives have been tried and exhausted.

Further evidence refuting the "dumping theory" is provided by a study by Miller and Harris (1965) of 90 patients and families. They found that six months prior to placement, 42% of the patients lived in a family constellation with either children or relatives, whereas immediately prior to placement 54% lived in a similar family structure. They conclude: "This exemplifies the family's attempt to bring the deteriorating elderly person within the family once again as his medical, psychiatric, and social disability mounts. Such a phase of shifting family relationships is common during the period of crisis for the patient and family prior to placement" (p. 849).

Frequent observation of the increased dependency of older people on their families has led to another misconception, that of role reversals creating a "second childhood." This is often conceptualized as the reversal

of the child's early dependence on the parents, now manifesting as the parent's dependence on the child. While this may be true in a physical sense, most family theorists (Spark & Brody, 1970; Blenkner, 1965; Sussman, 1965) have felt that it is not the rule in a psychological sense. Rather than seeing the son or daughter as taking on the "parental" role with the older parent, Blenkner (1965) proposes a further stage of development for the adult child which fits this perceived role reversal. This stage, which she calls "filial maturity," represents the normative transition from the Freudian stage of genital maturity to old age. She states, " . . . while it is true that the filial crisis marks childhood's end, the son or daughter does not thereby take on a parental role to his parent. He takes on a filial role, which involves being depended on and therefore being dependable insofar as his parent is concerned" (Blenkner, 1965). Thus, the normal conception of role reversal, which implies weakness on the part of the older parent and a sort of turning of the tables on the part of the child, must give way to the concept of filial maturity, which implies acceptance of responsibility and understanding of both his and his parent's needs by the child (Spark & Brody, 1970).

Indeed, in reviewing the literature on each of the above myths, one becomes aware of the fact that it

is observation of the pathological or abnormal families which has created the myth in the first place. One possible explanation for this may be that it is these troubled families which receive a great deal of attention from the authorities, both in government and in social science research. Contrary to the prevalent view that the family structure and harmony may easily break down with the aging problems of parents, Spark and Brody (1970) state:

> The family behavior . . . is part of the natural continuity of past relationships from which it flows, not a sudden idiosyncratic departure from previous relationship patterns. . . . The prospect of institutional placement may constitute a crucible in which family patterns are revealed in full strength. The behavior of families seen represents the entire spectrum from "health" to pathology. When severe relationship problems have historical roots in the younger family, pathology may be evidenced by the manner in which the family deals with the prospect of placement.

As will be seen later, there is a distinct difference between the pathology arising thus and the normative crises around institutionalization of an older family member, and therefore distinctly different treatment methodologies and goals are indicated.

Families and Institutionalization

Refutation of the above myths as they relate to the general "nonpathological" population can establish that older people do indeed have their families as available resources. A further review of the literature

and current research efforts reveal that this resource is (1) strained and often exhausted by the crisis of institutionalization and (2) very rarely tapped in a productive manner at the time of placement.

In a large-scale study of 514 patients being placed in nursing homes from Veteran's Administration hospitals, Linn and Gurel (1972) attempted to study the families' attitudes toward placement. Families who were more opposed to nursing home placement and judged as having a more negative attitude toward this type of care tended to be those who had less close ties to their relative while he was hospitalized. The authors hypothesize that this type of family "has not only adjusted to the patient's absence, but, more importantly, having increasingly given over to the hospital the responsibility for the patient's welfare, it is now opposed to an action which would return that responsibility to the family" (p. 222). This hypothesis is suspect in its final statement, as there is little reason to believe that nursing home care puts any more demands on family responsibility than hospital care. The finding is significant, however, in another light: assuming that eliminating opposition to placement may create maximized family participation and cooperation, it may be possible to lessen this opposition by greater involvement of the family at the earlier hospital level of care.

Linn and Surel (1972) also found in the same study that families of patients with greater psychiatric impairment were more opposed to nursing home placement; the authors attribute this to the families' perception that nursing homes cannot provide adequate care. Interestingly enough, there were no significant differences in opposition to placement by different types of key relatives, i.e. wife, child, sibling, and no differences based on age or physical diagnosis of the patient. The authors finally conclude that there are no simple predictors of opposition, but that there is a definite need for early intervention to forestall as many of the negative effects of this opposition as possible.

In a separate study of the factors influencing change in attitudes toward the home after placement, Linn and Surel (1969) studied the attitudes of 80 wives of nursing home patients. The major factors influencing both positive and negative attitude changes were the families' perceived judgments of the characteristics of the homes; the highest correlation was with quality of meals, and then with quality of staff. They conclude that meal quality can be symbolic for the overall impression of the home, but more importantly, that families' judgments of nursing home care are based on superficial factors. The major significance of this finding relates to the relatively unsophisticated method

by which people choose nursing homes. This may be a result of the fact that most families at the time of nursing home placement are in a crisis situation, are at the end of their rope after trying other failed alternatives, and are seeking to find any means to rationalize their basically uneducated choice of home.

Further research has concentrated on the ability and willingness of the family to become involved in treatment plans for their older relative. Baer, Morin, and Gaitz (1970) examined the family resources of 87 elderly psychiatric patients admitted to a screening and diagnostic center. Their major thrust was to establish the parameters of family contributions, both actual and potential, to the future treatment of the elderly person. By comparing ratings of family resources in attitude and capability with number of treatment tasks undertaken by the family, the authors found that "family attitude was substantially more positive in the group of patients who suffered from organic brain syndrome (OBS) associated with aging, compared to groups of patients who had long-term disturbances such as alcoholism or functional psychosis" (p. 348). They noted this more positive attitude especially in the degree of concern that the family member showed for the patient and the depth of that family member's attachment. Also, families of patients with OBS visited significantly more often.

This is possibly because the families could perceive OBS as a medical illness, despite its psychological manifestations, and thus could avoid the stigmata generally attached to mental illness.

The implications of this study are significant for working with nursing home patients and their families. Families tend to remain involved with older patients, as shown above in many studies; however, it is not so certain that families will remain involved with older patients with severe psychiatric difficulties. Baer, Morin, and Gaitz's study has suggested that the explanation of psychiatric disorder by medical (physical) causes may be crucial in eliciting or maintaining family interest. Especially in a nursing home, where the greatest proportion of psychiatric and behavioral dysfunction is a result of organic brain syndrome, this finding may be utilized. The immediate implication of this study is the need for family education: if the family understands the causes and effects of OBS, it may thus be more willing to remain patient and involved with the older person. OBS behavior looks, to the layman, as bizarre as psychotic behavior, and indeed it is; however, educating the family as to its etiology and prognosis can help them rationalize as inevitable and, thus, "beyond the patient's control."

Maintaining family involvement is crucial to the success of almost any treatment program with mental health implications. Zwerling and Mendelsohn (1965) examined the family's role in a day hospitalization treatment program for mental patients. They found that "the mere expression of willingness to participate in a program of family therapy, and the mere appearance of family members for the first two scheduled sessions, without regard to what is done in these sessions, are significantly related to the improvement in the patient at the time of discharge . . ." (p. 57). In addition, the authors reported a significantly more accepting family response toward those patients who were in their first episode of mental illness, a finding which closely parallels the more positive attitude of families toward OBS patients found by Baer, Morin, and Gaitz (1970) above. Zwerling and Mendolsohn conclude that a mental illness in an individual "is a manifestation of profound disequilibrium in the family unit. The capacity of the family to re-equilibriate from its disturbed state . . . seems to us the underlying force; . . . to the extent to which this capacity exists, recovery can be expected" (p. 62). This finding once again can be extended to the nursing home patient and his family: the more quickly that the family is able to come to an equilibrium after the stressful placement of a relative, the more it will be able to assist this relative through

the traumatic early separation period. Often the extrusion of the relative from the home is a welcome relief to the family, and the first reaction is to regroup totally excluding the older patient. Somehow the nursing home must facilitate early involvement of the family members in order to avoid this type of situation.

Family Programs in Nursing Homes

As shown above, the research indicates that families are available for involvement and that early involvement of families can facilitate higher functioning in patients; nevertheless, there have been only limited attempts to either delineate the actual factors related to family involvement or to establish family programs in geriatric facilities.

The first major type of family program to have evolved are those which emphasize information-giving and exchange. An example of this is the staff-resident program at Drexel Home in Chicago (Shore, 1964); this program emphasizes the financial aspects of nursing home care, the overall treatment goals and approaches of the home, the religious programming, and the rules and regulations of the home. The primary benefit of this type of program is that it promotes cooperation between the family and the nursing home along the above parameters. Shore has recognized, however, that it is not so simple for a family program to remain purely informational.

Because relatives are being asked to share in the processes of the home, there is most often a need for individualized attention. Questions arise about specific patient behaviors and physical or mental health problems, and as Shore has found, it is crucial to recognize and answer these concerns.

In response to this need, Lazarus and Schmidt (1971) have developed a more individualized program of family interviewing. Rather than formalizing contacts with the family only in a crisis situation, staff members were trained to conduct regular short sessions with family members focused around the family's needs and concerns. The authors found that ordinary nursing home line staff (primarily R.N.'s and nurses' aides) could establish good rapport with the families and, moreover, could initiate a productive exchange of treatment goals and methods.

Often, however, the individualized form of information-sharing and education program can reveal deep-seated family problems in need of further intervention. In this case, the treatment of choice would be some sort of family therapy, either with or without the older relative involved (Brody & Spark, 1966). Unfortunately, as Howells (1975) notes, it is often difficult to get family therapists to work with family groups around crises in the latter part of life. This may in part be

due to the general therapeutic nihilism surrounding the elderly (Butler & Lewis, 1973) or to the more specific myth concerning the aged and their families as outlined above. Whatever the specific cause, the effect remains that there has been no systematic investigation of the efficacy of family therapy in breaking down some of the maladaptive relationship patterns surrounding the elderly and their families.

It is toward this end that Manaster (1967) developed a family group therapy program at a Chicago Home for the Aged. The program, with 8 to 12 relatives of patients meeting at one time, was designed to be an opportunity "for the participants to look at their own feelings about their parents. . . . Lecturing, information-giving and reassurances were held to a minimum" (pp. 302-303). More specific objectives were to foster an awareness in relatives of the reasons for the patient's behavior and of their own feelings and reactions to the institutionalization and how these affect their relationships. Manaster reports that almost 60% of all the relatives invited responded favorably to taking part in the program; "many relatives began to recognize the basis for some of their anxieties and guilt feelings, and came to the realization that they had not 'dumped' their parents" (p. 304). In addition, he reported that relatives discovered by these therapy sessions that "they were not

alone in their feelings, and that their reactions were not abhorrent and horrible" (p. 305). Finally, an added benefit was the growing awareness on the part of the staff that the resident was not an isolated person but part of a functioning family unit.

While programs such as Manaster's have provided some encouragement that intervention in nursing home patient-family relationships is feasible, they remain both isolated and unsubstantiated instances of actual treatment attempts. It is still impossible to find a systematic and well-researched approach toward solving the problem of family involvement in the lives of nursing home patients. Moreover, none of these few treatment programs have been established from a firm theoretical understanding of the various parameters of this problem, and it is this deficiency that the present study strives to remedy.

The Present Research

The author has been involved for the past two years as coordinator of a comprehensive research project evaluating the effectiveness of mental health consultation and training services to nursing homes (Lynn, Fargus, & York, 1974). In this project it has become evident that nursing homes do not make enough of an effort to facilitate involvement of family members in the lives of their patients. Often, in case consultations about difficult

or problem patients, much of the acting-out behavior was felt to represent in some way anger toward the family for placement or for lack of visiting. Further individualized contacts with family members verified both their worry for their relative and their feelings of unease about visiting. In addition, the nursing home staff often reported that families who complained a lot were those families who seemed to be having the most trouble communicating with their relative.

Recognizing this, a small planning group of staff at one nursing home, led by the author, set up two pilot meetings with some families of their patients; 18 relatives attended the two meetings, about 60% of all invited. The major subjective finding from these meetings was that families were eager to meet as a group and talk about their problems with their relative, and also felt a need to get professional advice on some very specific psychosocial aspects of aging. It also became obvious that for some of these families the intervention may have been too late, as they had already established the unproductive patterns of guilt, martyrdom, or burden-bearing as described by Brody and Spark (1966); in all of these such cases, the relative showed evidence of great mental debilitation. For these families, an intervention before placement or early in the process may have prevented the deterioration of their relationship.

The present research study was aimed at expanding and elaborating some of the subjective findings of these early family meetings. Through a historical examination of the placement process and an investigation of the perceived needs of families of nursing home residents, this study is intended to shed light on appropriate programmatic interventions. Specifically, the following questions will be answered.

1. What factors are involved in placing a relative in a nursing home, and how do these relate to further involvement of the family?

2. What are the needs as perceived by relatives with respect to their involvement with the nursing home?

3. What are the potential points for intervention by either the nursing home or an outside agency in order to facilitate family involvement?

4. What current support mechanisms are utilized by families, and how do these relate to current family involvement?

5. What specific types of intervention would be most appropriate for families of patients at different functioning levels?

6. What are the relationships between family guilt concerning institutionalization of their relative and visiting practices, involvement, and support mechanisms?

CHAPTER II

METHODS

Participants

Participants in the study were all patients at one of three Lansing area nursing homes as of June, 1975. The seventy-six patients and their families were a subset of a random sample of 116 patients assessed in a previous study on mental health intervention in nursing homes (Lynn, Fergus, & York, 1974); patients were excluded because of death or discharge from the home (n=4), lack of any family in the area (n=17), refusal of families to participate (n=10), or family unavailable for interview (n=19). Thus, the final sample consisted of 76 patients and their families who lived within a 25-mile radius of Lansing. The specific family member to be interviewed was defined as that person identified on the patient's chart as "person to contact in emergency."

The three nursing homes chosen were all owned and operated by Provincial House, Inc., a company with a chain of nursing homes and other health care facilities across Michigan. These homes were chosen because of

their similarity to each other in size (about 110 beds), programs, and administrative policies. In addition, it was felt that these three homes were representative of other proprietary nursing homes in Michigan and across the country, with approximately 70% of patients being paid for through public funds (Medicaid, Medicare), with staff-patient ratios meeting both Federal and State standards, and with a similar sex ratio, mean age, and disability level of patients to that reported in much of the literature (Brody, 1973; Gottesman & Bourestom, 1974).

Interview Methods

All interviews with patients' families were conducted by a registered occupational therapist (OTR) with 11 years experience in hospital work including family training. Families were contacted initially by a letter of introduction (Appendix A) after addresses were provided by the nursing home administrators. Following this, the interviewer telephoned all those who had not indicated an unwillingness to participate and scheduled appointments. Interviews took place in all but 9 instances in the home of the interviewee; these others took place in the respondent's office (n=3) or in the interviewer's office at St. Lawrence Hospital (n=6). The formal interview took an average of 45 minutes to administer.

Patient Assessment Methods

All data on patients, as presented below, was collected in conjunction with the Nursing Home Training and Consultation Project at St. Lawrence Hospital CMHC. Ratings were completed by nurses; archival data were gleaned from patient charts by the Project's research assistant.

Measurement of Patient Functioning Level--BOP

The behavioral and physical functioning of patients in the study was measured using two nurses' observational instruments, the Behavior of Older Patients Checklist (BOP) and the Physical Capabilities Checklist (PCC). The BOP (Appendix B) is a 43-item inventory developed specifically for nursing home research (Fergus, York, & Calsyn, 1975). Inter-rater reliability between nurse (R.N.) raters was established by having three pairs of nurses rate 20 patients each; reliabilities measured .92, .91, and .70. The BOP is rationally divided into seven separate scales, as follows:

Cognitive Functioning

This dimension measures the patient's ability to: (1) recall past and present events, (2) identify time, place, and person, and (3) possess sound judgment with regard to daily activities. The internal consistency

for this scale was .92, using Hoyt's analysis of variance technique.

Lack of Social Interaction

The degree to which patients initiate and participate in conversation and activities is measured in this dimension. It thus could also be characterized as an activity scale. The internal consistency was .88.

Verbal Hostility

This dimension measures degree of anger and irritability voiced by the patient. It also taps lying and verbal expressions about people attacking, or cheating him/her. The internal consistency was .86.

Physical Hostility

Both physical violence to objects and people are measured in this dimension. The internal consistency was .79.

Depression

For this scale patients were rated on the degree to which they had verbalized feelings of depression, worthlessness, and thoughts of suicide. The internal consistency was .82.

Psychotic Behavior

This dimension measures delusional, hallucinatory, and other psychotic behaviors which may indicate a need for psychiatric hospitalization. The internal consistency measure was .81.

Messiness

This dimension taps willingness to care for oneself and keep one's appearance as presentable as possible. The internal reliability for this dimension is .74.

Measurement of Patient Physical Functioning--PCC

The Physical Capabilities Checklist (Appendix C) enables nurses to evaluate patients on a five-point scale ranging from total self-sufficiency to total dependency in the following four areas of functioning: self-care (toileting, feeding, bathing, grooming, dressing), sensory capabilities (hearing, speaking, seeing), ambulation, and activity level.

Family Interview

A 45- to 60-minute structured interview with the family of each patient was employed to assess the family variables crucial to this study (Appendix D) including the following areas:

Pre-placement Problems

Questions in this area were designed to elicit information concerning the pre-placement history of the patient and his family and the factors involved in the decision for placement and choice of home. An extensive checklist of 28 items questioned whether certain types of problems existed for the patient prior to placement; in addition, relatives were asked to decide which of these problems were crucial in leading to the decision for institutionalization. Five separate problem scales (see Table 1) were derived from this checklist (Question 7, Appendix D), creating variables in the following areas: physical problems (stroke, illness, broken bones, etc.); sensory problems (speech, hearing, sight); social problems (e.g., death of spouse, poverty, loneliness); emotional problems (e.g., depression, violence, grouchiness); and mental or cognitive problems as would be indicative of organic brain syndrome (e.g., loss of orientation, confusion).

Pre-placement Family Involvement

Further questions were intended to look at the degree of involvement of the family with the elderly relative prior to institutionalization. Included in this was an assessment of the relative's living situation in the two years before going into a nursing home; of special interest was the question concerning whether the

Table 1

Variables Assessed on Family Survey Questionnaire

Variable or Scale	Question Number (s) Appendix D
PROBLEMS BEFORE PLACEMENT	
Physical problems before placement	
loss of ability to walk	7 (c)
loss of use of limb(s)	7 (d)
loss of continence	7 (b)
severe physical illness	7 (n)
stroke	7 (o)
heart attack	7 (p)
broken hip or leg	7 (q)
Sensory problems before placement	
severe impairment of eyesight	7 (e)
severe impairment of hearing	7 (f)
severe impairment of speech	7 (g)
Social problems before placement	
death of spouse	7 (a)
loss of ability to drive	7 (b)
ran out of money	7 (m)
poor nutrition	7 (w)
no more friends	7 (x)
Emotional or psychological problems before placement	
depressed	7 (r)
grouchy	7 (s)
violent	7 (t)
hallucinated	7 (u)
delusional	7 (v)
alcoholic	7 (y)

Table 1--Continued

Variable or Scale	Question Number (s) Appendix D
Cognitive disabilities before placement	
loss of orientation to time	7 (i)
loss of orientation to place	7 (j)
started misidentifying others	7 (k)
loss of memory	7 (l)
general confusion	7 (z)
PRE-PLACEMENT FAMILY INVOLVEMENT	
Prior living situation	3, 4, 5
Alternatives to institutionalization	8
Personal care assistance	6
bathing	
dressing	
feeding	
toileting	
transferring	
Household assistance	6
light chores	
heavy house-cleaning	
laundry	
shopping	
cooking	
medical help	
Prior telephone contact	24 (a)
Prior visits	24 (b)
NURSING HOME CHOICE PROCESS	
People influencing in decision	9
Ultimate decision	10
Factors influencing choice of home	14
Homes visited before choosing	11
Times visited final choice home	12
Did relative visit home too?	13
Relative's acceptance of decision	15
FAMILY VISITING PRACTICES	
Number of visits monthly	16, 2
Taking relative out	23, 23 (a)
Enjoyment of visits	20

Table 1--Continued

Variable or Scale	Question Number (s) Appendix D
FAMILY VISITING PRACTICES (continued)	
Problems on visits	
emotional problems	19 (a)(b)(e)(f)(g)
cognitive problems	19 (c)(d)
Activities on visits	18
SUPPORT SYSTEMS	
Support with physical aspects	21
Support with emotional aspects	22
Most difficult problem to cope with physical, emotional, or mental	29
GUILT	17
PROGRAMMATIC NEEDS	30
MISCELLANEOUS DEMOGRAPHIC VARIABLE	
Marital status of patient	46-pt. chart
Age of patient	45-pt. chart
Sex of patient	pt. chart
Socioeconomic status of patient	31-32
Socioeconomic status of family	37, 38, 39, 40
MISCELLANEOUS DESCRIPTIVE VARIABLES	
Length of stay at nursing home	44-pt. chart
Method of payment	42-pt. chart
Regular psychotropic drugs	pt. chart
Special (PRA) psychotropic drugs	pt. chart
Changes in family concern since placement	25
Changes in family routine since placement	26

family attempted to solve the problem by taking their relative into their home. In addition, the other possible alternatives to institutionalization were presented to the family in an effort to ascertain both awareness of these programs and attempted utilization. Included among these were Visiting Nurses, home health and housekeeping aides, and meals-on-wheels. (For a complete listing, see question 8 in Appendix D.) The final measures of family involvement with their relatives were two variables, one measuring amount of personal care assistance given to the relative before placement and the other the amount of household help. The former variable was a scale constructed from five items in question 6, with an internal consistency of .79; the latter scale comprised the remaining six items in question 6, internal consistency = .81. (See Table 1 for a complete breakdown of these two scales.) In addition to these variables, two others assessed the number of times weekly/monthly that the family had contact with the relative on the phone or visiting prior to placement.

Nursing Home Choice Process

The final area of inquiry in the placement process concerned the process of deciding on institutionalization and choosing a nursing home. This included the amount of influence in the decision held by the physician, by the nursing home administrator, by the other relatives,

by a hospital social worker, and by the patient himself (Question 9, Appendix D). In addition, another question assessed the factors important in the actual choice of a home, including location, availability of bed, quality of staff, care, or programming, and condition of other residents (Question 14); these were supplemented by variables ascertaining how many homes were actually visited before choosing, how many times the chosen home was visited, and whether the elderly relative visited with the family. The final question in this area assessed the family's perception of how their relative accepted the placement in a nursing home. (See Table 1 for complete listing.)

Family Visiting Practices

The second major area of investigation in the family survey assessed the quantity and quality of family visiting to the nursing home patient. Quantity was measured by a self-report of number of visits monthly, as nursing home records are not adequate in this area. (See Question 16, Appendix D.) Also, one question looked at how often the family took the patient out of the home, and another at whether they visited more or less often at time of interview than in the past. Quality was measured by a self-report of the degree of enjoyment of visits (Question 20). Also, a separate question looked

at the types of problems encountered by the families on visits; from this, two scales were extracted, one measuring emotional problems presented by the relative in visiting (internal consistency = .55), the other measuring cognitive-orientation problems (internal consistency = .64). See Table 1 and Question 19, Appendix D, for further explication.

Support Systems

Variables in this area were designed to measure the degree of support the families felt in dealing with the emotional and physical problems of their relatives. To this end, families were asked to rate separately whether they received support from the physician, the nursing home staff, other relatives, a clergyman, or a social worker on both physical and emotional concerns. For later correlational analysis, two variables were created: support from the physician, and support from nursing home staff (combining aides, nurses, and administrator, Questions 21-22, Appendix D). In addition, an open-ended question (29, Appendix D), concerning the problems with which families found it hardest to cope, was coded to separate these into three dichotomous variables--whether they had trouble coping with relative's physical problems, emotional problems, or confusion-related problems. Finally, several of the items from Question 27, concerning problems perceived by the

families, were grouped into a scale of total degree of direct problems with the patient, with a reliability of .63. Table 1 provides a summary of the variables in this support section.

Guilt

The five separate statements in Question 17 were summed to make one scale which measures the families' feelings of guilt regarding the nursing home placement. Internal consistency of this scale was .70.

Programmatic Needs

Questions in this area were designed as a need assessment of the willingness of families to take part in programs in the nursing home. The seven separate programs in Question 30 were summed to make one overall scale of willingness to participate, with internal consistency of .79. In addition, families were asked whether they had actually taken part in any programs like these before; from this, one dichotomous variable was retained, indicating whether the family had met and talked with nursing home staff before placement.

Miscellaneous Variables

Variables in this category are presented in Table 1. Of special interest are two that assess the changes in the families' routine and concern about their relative since placement (Questions 25 and 26). In

addition, amount of psychotropic medication (taken from medical charts), method of payment, and length of stay at the nursing home were also measured.

Scope of the Analysis

The purpose of this study, as stated above, was to examine the factors related to family involvement in nursing homes; thus, the data analysis was carried out on several different levels, from simple frequency count statistics to cluster analytic techniques (Tryon & Bailey, 1970). The frequency distributions and descriptive statistics of many of the variables were of crucial importance to the need assessment aspects of this survey, and thus this was the first level of analysis. Using these results, many of the variables were grouped into scales for simplification of the correlation matrices, and many were eliminated because of inadequate variance or because of limited interest beyond their descriptive qualities. Testing of the major hypotheses was carried out either by correlation or by analysis of variance. Finally, an empirical-V and a preset key cluster analysis were employed for a further study of the interrelationships of the variables.

CHAPTER III

RESULTS

Descriptive Statistics--Needs Assessment

Nursing Home Placement Process

Many of the factors which impinge directly on any programs to be planned can be seen in the descriptive statistics relative to the placement process. One major set of variables measured the families' perceptions of the elderly relatives' problems prior to placement. From these it can be seen that physical problems were by far the most prevalent, with 87% of the sample reporting one or more problems. Cognitive problems were reported in 42% of the cases, emotional problems in 58%, sensory problems in 37%, and social problems (including nutrition, loneliness, etc.) in 47%. Essentially the same order can be seen when an assessment was made of whether the reported problems were determinants of institutionalization. (See Table 2.) The prevalence of physical problems is borne out by the fact that 45

out of 76 patients (59%) had spent time in the hospital directly before nursing home placement, with the average stay being 6.8 weeks.

Table 2

Pre-placement Problems

	Reported in % of Cases	Reported as Determinants of Institutionalization
Physical problems	87%	62%
Emotional-psychological problems	58%	28%
Social problems	47%	34%
Mental (cognitive) problems	42%	24%
Sensory problems	37%	10%

The helping involvement of the families with their older relatives before placement was also assessed here; the proportions of families providing help with 11 separate areas of functioning can be seen in Table 3. In addition to the physical help provided, 30% of the families took the older relative into their home before placement, while all but 6% of the others maintained frequent telephone contact ($\overline{X}$ = 5 calls per week) and all but 4% visited ($\overline{X}$ = 9 visits per month). Although this percentage of family involvement may be inflated somewhat by a sampling procedure which eliminated

geographically distant relatives, it remains an important figure in the light of the fact that only 8% of the original random sample were excluded for this reason.

Table 3

Percentage of Families Providing Help Before Placement in Areas of Need

Help With:	% Providing Regular Help
Shopping	72%
Laundry	69%
Medical affairs	69%
Heavy cleaning	69%
Cooking	58%
Light cleaning	42%
Bathing	32%
Dressing	21%
Toileting	12%
Transferring	10%
Feeding	4%

A third area of needs assessment questioned the families on their awareness of community agencies providing services to the elderly which might have been used before placement, and on whether they actually made use of these alternative services. While some programs had good community awareness, such as Visiting Nurses, which all but five families knew of, other such as home health aides (40% aware), and home housekeeping aides (34% aware) were far from well known. The actual usage figures are

drastically lower, with only one family trying housekeeping or health aides, and with Visiting Nurses having the highest utilization at 20%.

A further area looked at was the actual decision for placement and choice of a nursing home. In 83% of the cases the family's or patient's physician was of some or much importance in the decision to institutionalize, while the patient himself had importance in only 19%. Hospital social workers had influence in 43%, but the nursing home personnel or administrators themselves were influential in only 12%. In only one case did the patient make the ultimate decision to go into a nursing home, while in all others the decision was made for the patient by a family member. This coincides with the fact that only six patients (8%) actually visited the nursing home before placement.

The choice of which nursing home to use is one that is not characterized by a great deal of searching, as 45% of the families did not visit any at all, 12% visited one, 12% visited two, and 31% visited three or more. Only eight families visited more than once to the home they chose, while 39 (51%) did not visit this home at all. Availability of a bed and location of home were the most influential factors cited in choice of home, with 75% emphasizing the influence of availability and

62% location; only 35% looked at the quality of the staff, while a negligible 12% considered the quality of the activity program.

Family Visiting Practices

Quantity of family visiting varied greatly, from a low of one visit per month (n=2) to a high of two visits daily (n=1). Mean number of visits per month was 12, with the modal number being 4, or once weekly (n=9); standard deviation was 10.3. The mean number of times that the families took their relative out of the nursing home was nine times per year; however, 32 (42%) never went out, and the mean was inflated by a modal value of 12, or one excursion per month.

Quality of family visiting was initially assessed by a self-report of enjoyment; here, the distribution was as can be seen in Table 4. Thus, a significant

Table 4

Family Ratings of Enjoyment of Visits

% of Total Visits Enjoyed	n of Families	% of Families
0-10%	14	18.9
10-35%	8	10.8
35-65%	16	21.6
65-90%	9	12.2
90-100%	27	36.5

number of families (approx. 40%) enjoy their visiting less than half the time. In addition, 57% reported some problems with their relative's confusion on visiting, and 83% reported some problems with their relative's moods or emotions. A breakdown of these emotional problems reveals that almost 50% of the patients are sometimes or often grouchy, while 58% seem depressed sometimes or often.

Support Systems

The number of families saying that they got much support in dealing with physical problems was greatest in relation to staff nurses (57% got much support, 31% some), nurse's aides (40% and 22%) and administrators (25% and 25%); surprisingly, while 35% of the families got much help from the patient's physician, a full 51% said they got no help at all. The pattern is similar regarding support in dealing with emotional or psychosocial concerns, although the overall level of support is much lower. Once again, staff or floor nurses are most helpful, with nurses' aides second, and administrators and doctors equal; here, 67% of the families got no help at all from the physician, and 50% got none from the nurses, the top-rated group.

The three variables concerning the toughest things for the families to cope with showed that 37%

had most trouble with problems such as confusion and reduced mental functioning, 30% had most trouble with emotional changes, and only 16% had most trouble coping with their relative's physical illnesses.

Programmatic Needs

Families were questioned as to their interest in and perceived need of several types of possible programs: 67% felt that they would like to meet with staff; 30% would meet with other families; 46% would meet with some type of counselor (22% of these would want to include their relative); 33% would have been interested in meeting with someone to learn about nursing home alternatives; 51% would like to attend classes on aging; and 48% would be interested in getting advice on how to improve visiting. A variable created from the sum of these seven programs indicates that only 17% of the families said they would not be interested in any, while 40% would take part in four or more.

Regarding program usage in the past, the only program with any significant figures was "meeting with staff," which had occurred, informally, in 29% of the cases.

Cluster Analysis of Variables

Cluster analysis (Tryon & Bailey, 1970) is a statistical technique which can be used to create groupings of variables on the basis of their similarities and

differences; by this technique, one can discover the general properties of variables by an objective procedure which groups variables without implying any causative underlying dynamics. Multivariate cluster analysis (V-analysis) involves the removal of successive clusters of items with high intercorrelation from a complete correlation matrix. In this way, the total number of factors which can reproduce the full array of intercorrelations is minimized without loss of generality.

For this study, a cluster analysis was performed using variables describing the resident's history before institutionalization, his placement process, his current functioning, and his and his family's demographic characteristics. Because a subject variable ratio of less than 2:1 was maintained for the first V-analysis, caution must be used in drawing strong inferences from the results. Nevertheless, this may be adequate for forming some tentative conclusions in such an exploratory and needs assessment study.

The original V-analysis produced eight clusters of variables, each grouped around a set of collinear defining variables. The results of this preliminary analysis appear in Appendix E. In order to create a more optimal solution, a preset key cluster analysis was performed; for this technique, the definer variables of each cluster were preset in a manner which would give

logical coherence to each cluster. In addition, several variables with low communalities and one cluster were eliminated. This preset key cluster analysis is presented in Table 5.

The seven clusters in Table 13 represent the seven most significant characteristics or properties which underlie the variables entered. Cluster 1 suggests visiting patterns and activities, specifically the families who visit more are also those who enjoy the visits more and tend to do more physical things on visits, while placing less emphasis on talking.

Cluster 2 represents an independent grouping of all support mechanisms both on physical and emotional issues, from the physician and from the nursing home. Factor loadings suggest that those who get some support tend to get it from all sources. Because of the high intercorrelations of these variables, they were all set as definers in the preset key cluster analysis; nevertheless, no other variables had high enough loadings to fall into this cluster.

Cluster 3 describes the patient with the type of functioning problems which may be a result of organic brain syndrome: messiness in personal hygiene, disorientation to time and place, lack of interest in the surroundings, and, with a weaker loading, sensory impairment. Cluster 4 is a cluster describing more physically

Table 5

V-Analysis Preset Key Cluster Structure

	Variables	Factor Loading
Cluster 1	Visiting Practices	
1.	Total number of visits (D)	.5574
2.	Greater enjoyment of visits	.5526
3.	Do more active things on visits	.5513
4.	Visit more now than at first placement	.5343
5.	Do less verbal things on visits	.4885
Cluster 2	Support	
1.	More support from physician with physical aspects (D)	.7489
2.	More support from physician with emotional aspects (D)	.6699
3.	More support from nursing home staff with physical aspects (D)	.6045
4.	More support from nursing home staff with emotional aspects (D)	.5712
Cluster 3	Organic Brain Syndrome Symptoms	
1.	Messiness (D)	.8574
2.	Impairment of sensorium (D)	.8447
3.	Lack of interaction (D)	.6887
4.	Impairment of sensory abilities	.3721
Cluster 4	Pre-placement History	
1.	More physical problems at placement (D)	.6332
2.	More time in hospital (D)	.6263
3.	Less social problems at placement (D)	.5202
4.	Impairment of ambulation	.4338
5.	Male	.4162
6.	Less emotional problems at placement	.3834
7.	Visited fewer homes before placement	.3763
8.	Less emphasis on staff quality in home choice	.3001

Table 5--Continued

	Variables	Factor Loading
Cluster 5	Psychiatric or Emotional Problems at Present	
	1. More verbally hostile (D)	.9522
	2. More depressed (D)	.5062
	3. Receive more psychotropic drugs on PRN (as needed) basis (D)	.4974
	4. More physically hostile (D)	.4805
	5. Have more emotional problems with family on visits	.3330
Cluster 6	Cognitive Dysfunction	
	1. Presenting more orientation problems on visits (D)	.7998
	2. Family has more difficulty coping with cognitive problems (D)	.6836
	3. More mental problems before placement (D)	.6818
	4. More psychotic behaviors	.4498
	5. Family paid more attention to other residents' condition at admission	.3481
Cluster 7	Pre-placement Living Situations	
	1. Did not live alone (D)	.8381
	2. Had more help from family in household tasks (D)	.7333
	3. Had more help from family in personal care tasks (D)	.5434
	4. Institutionalization helped stabilize family routine more (D)	.4101
	5. Family tried more alternatives (D)	.4001
	6. Lived with a relative (D)	.3701
	7. Lived with another person (D)	.2239

Note. (D) indicates variables which are cluster definers.

impaired patients at placement; these patients had greater physical problems and were also in a hospital, and tended to be nonambulatory and female. In addition, they had less tendency to show social or emotional problems at admission, and their families tended to visit less homes and pay less attention to staff quality in choosing a home. Thus, this cluster can be said to represent the patients for whom placement was for pressing physical problems and thus was less deliberate and planned.

Cluster 5 pictures the acting-out and emotionally troubled patient; variables loading on this cluster describe someone who is both verbally and physically hostile, acts depressed, presents emotional upset to his relatives, and must be given psychotropic drugs on a PRN (as needed) basis.

Cluster 6 is another picture of the mentally impaired patient. Variables here describe a patient who is disoriented when seeing his family and had many orientation and memory problems before admission; because of this, this patient was rated by staff as being a high risk for psychiatric institutionalization as many behaviors appear psychotic. In addition, the family sees coping with these mental problems as their greatest difficulty, and felt that the condition of other residents was an important factor in choosing a nursing home.

The last cluster, Cluster 7, is internally consistent in representing most of the pre-placement variables, such as living arrangements, amount of help gotten from the family, number of alternatives tried, and effects on family routine. The negative loading on the variable describing patients who lived alone clearly suggests that these people got less help than those who moved in with a friend or relative.

The relationship between number of problems of the patient and family quest for support confirmed in the raw correlation matrix below is alluded to in the inter-cluster correlations (Table 6). In the preset key analysis there is a correlation of .49 between Cluster 2 (support mechanisms) and Cluster 6 (mentally impaired patients). The similarity in content between Clusters 3 and 6 is also borne out empirically with an intercorrelation of .60. Finally, the negative correlation (-.30) between Clusters 4 and 6 suggests that mental and physical impairment are exclusive of each other in the families' minds; in other words, the family tends to see the problems of their relative as along one of these lines only.

A more detailed examination of the result of the cluster analysis is provided in the hypothesis testing section which follows.

Table 6

Inter-Cluster Correlations--Preset Key Cluster Analysis

	1	2	3	4	5	6	7
Cluster 1	1.000						
Cluster 2	.0988	1.000					
Cluster 3	.1696	.2809[a]	1.000				
Cluster 4	.1580	-.2313[a]	-.0446	1.000			
Cluster 5	.0549	.1701	.1741	-.1864	1.000		
Cluster 6	-.2439[a]	.4872[b]	.5984[b]	.3030[b]	.1905	1.000	
Cluster 7	-.0323	-.1604	.2724[a]	.0820	.1099	.1491	1.000

Hypothesis Testing

As indicated in the introduction, nine specific hypotheses were made concerning relationships between various variables.

1. The families of more highly impaired patients will have lower quality visiting. Impairment of patients was assessed by the BOP and PCC. The variable concerning enjoyment of visits was seen to correlate significantly in a negative direction with the scales "messiness" and "cognitive functioning" from the BOP, and with the scale "self-care" from the PCC. All of the other BOP scales also correlate negatively with enjoyment, although not at a significant level. (See Table 7.) In addition, orientation problems with visiting correlate positively with the BOP scales, "messiness," "lack of social interaction," "cognitive functioning," and "psychotic behavior," as would be expected. The families' report of emotional problems on visits also correlates significantly with "depression," and "verbal hostility." Also, if the families' report of orientation problems and emotional problems on visiting is considered an indicator of impairment, one can see that enjoyment of visiting decreases significantly as these are present. The correlation between enjoyment and orientation problems is $-.36$ ($p < .001$), and between enjoyment and emotional problems is $-.29$ ($p < .01$).

Table 7

Correlation of Behavioral and Physical Functioning of Patients with Family Quality and Quantity of Visits

	Enjoyment of Visits	Orientation Problems on Visits	Emotional Problems on Visits	Total Number of Visits
Cognitive Functioning Problems	-.242[a]	.612[b]	-.219	.145
Lack of Social Interaction	-.116	.384[b]	-.227[a]	.053
Verbal Hostility	-.172	.064	.334[b]	.123
Physical Hostility	-.082	.160	.080	.055
Depression	-.119	-.092	.378[b]	.072
Psychotic Behavior	-.138	.327[b]	.094	.031
Messiness	-.342[b]	.559[b]	-.192	.028
Self-care Disability	-.239[a]	.449[b]	-.184	.139
Sensory Disability	.002	.185	-.193	.049
Ambulatory Disability	-.066	.106	-.010	.012
Diminishment of Activity Levels	.141	-.073	-.060	.224

[a] $p < .05$; [b] $p < .01$

Thus, as can be seen, 11 of the 33 correlations (see Table 5) relevant to the hypothesis are significant at the .05 level. If the impairment variables were not intercorrelated, the probability that this was a chance finding would be less than .001 (Wilkinson, 1951). However, since the impairment variables are intercorrelated, the value of .001 is inflated. The previously mentioned cluster analysis also provides information relevant to this hypothesis. One impairment cluster (Cluster 6) somewhat related ($r = -.24$) to the visiting cluster (Cluster 1). However, the other impairment cluster (Cluster 3) is not related to the visiting cluster. Thus, while there is some relationship between impairment and quality of visiting, the relationship is not overwhelming.

2. The families of more highly impaired patients will visit less often. Total number of visits does not correlate significantly with any of the impairment measures. Thus, it seems that impairment is related to quality of visits but not quantity.

3. Families with more resources available to aid understanding will have higher quality visiting. Enjoyment of visits is not related significantly to the variables concerning support from physician or from the nursing home staff. There was a significant positive

relationship between emotional problems on visiting and amount of support received from both physician and nursing home in coping with emotional problems; this seems to suggest that those who need the support are those who receive it, although the correlation is not high (Table 8).

4. Families with more resources available to aid understanding will visit more often. No relationship was found here between resources for support and quantity of visiting (Table 8).

5. Families who tried more alternatives to nursing home placement will feel less guilt. No relationship was found ($r = .099$), although this may be influenced by the small variance of the variable assessing alternatives tried (mean = .539; SD = .824).

6. Families of patients with more serious physical problems at admission will feel less guilt. There was no relationship between physical problems and guilt ($r = 0.022$), and no relationship between number of weeks in hospital (as a measure of seriousness of physical illness) and guilt.

7. Families who involved patient in choice of home and decision for placement will feel less guilt. No significant correlation was found between the patient's

Table 8

Correlation of Support in Understanding Relative's Physical and Emotional Problems with Family Quality and Quantity of Visits

	Enjoyment of Visits	Orientation Problems on Visits	Emotional Problems on Visits	Total Number of Visits
Support with Physical Problems from Physician	.049	.079	-.100	.051
Support with Emotional Problems from Physician	-.043	.286[a]	-.224[a]	.052
Support with Physical Problems from Nursing Home	-.034	.237[a]	-.107	.103
Support with Emotional Problems from Nursing Home	-.107	.260[a]	-.053	-.064

[a] $p < .05$

importance in the decision for placement and the families' guilt (r = .102); it was not possible to compute a correlation between guilt and whether the patient visited the homes because of the lack of variance in the latter variable.

8. There will be a significant interaction effect of family guilt and patient impairment with respect to total number of visits, such that

   a. families with high guilt will visit less often to more alert patients than families with low guilt;
   b. families with high guilt will visit more often to totally confused patients than families with low guilt;
   c. families with high guilt will visit more often to partially confused patients than families with low guilt.

For this analysis, the variables guilt and mental impairment were each broken into three groups of equal size, and a two-way analysis of variance was computed with total visits as the dependent variable. No significant main effects were found; a significant interaction of guilt and impairment existed ($F = 3.61$, $p < .01$). Inspection of the cell means in Table 9 reveals that, indeed, families with high guilt did visit less to alert relatives and more to partially alert relatives than

Table 9

Breakdown of Mean Number of Visits Per Month by Family--Guilt and Impairment Level of Patients

		GUILT			
		Low	Medium	High	
IMPAIRMENT (sensorium)	Low	13.3 n = 6	7.0 n = 7	9.8 n = 13	$\bar{X}$ = 9.9 n = 26
	Medium	6.3 n = 7	13.8 n = 10	23.3 n = 6	$\bar{X}$ = 14.0 n = 23
	High	15.5 n = 11	13.9 n = 8	7.5 n = 8	$\bar{X}$ = 12.7 n = 27
		$\bar{X}$ = 12.3 n = 24	$\bar{X}$ = 11.9 n = 25	$\bar{X}$ = 12.1 n = 27	

families with low guilt. However, high guilt families also visited less to highly impaired patients than low guilt families. Thus, the major portion of the hypothesis was proven valid, while this finding concerning high guilt-high impairment interaction ran counter to expectations. It is possible that for families with high guilt visits to highly impaired patients proved too painful; likewise, for these high guilt families, visits to alert patients who could easily confront them with anger or guilt-invoking behavior were also too painful. High guilt families were found to visit more often to partially confused relatives; for these families, guilt may have been the motivating factor in visits, as hypothesized, and the family may have had some underlying feeling that visits would both allay their guilt and help improve the patient.

9. Patients who were involved in the decision for placement and the choice of home will have higher functioning level when measured at present. This hypothesis was tested by looking at the correlations between the variables from the BOP and PCC measuring patient functioning with the variables assessing the patient's input into the decision process. It was found that patients who were judged by their families to be more important in the decision for placement revealed fewer problems in the sensorium (orientation, cognitive

functioning) as assessed by present nurse's ratings ($r = -.270$). Of course, this cannot at all be construed as a causative finding; on the contrary, these patients also had less mental (cognitive) problems at admission ($r = -.227$). The only other significant finding was a positive relationship between patients' input into placement and nurse's rating of verbal hostility; this would make sense as one realizes that those patients who insisted on having some say in the placement process may also tend to have input into their treatment in a nursing home and thus may be perceived by staff as more hostile. Once again it was impossible to compute any correlations with the patient's input into actual choice of home because of the lack of variance in that variable. It is necessary to view these results in a somewhat cautionary light, however, as the probability of this many significant correlations in a matrix of this size by chance alone is .1019 (Wilkinson, 1951), even if there was no interrelationship between the impairment variables. (See Table 10.)

Correlational Analysis

In addition to the summary statistics comprising the needs assessment, and the correlations and analyses of variance in the hypothesis testing situation, a complete correlation matrix was computed and analyzed to look for other significant and meaningful relationships.

Table 10

Correlation of Patient Behavioral and Physical Functioning with Patient's Importance in Placement Decision

	Patient Importance in Placement
Cognitive Functioning Problems	-.270[a]
Lack of Social Interaction	.015
Verbal Hostility	.074
Physical Hostility	.283[a]
Depression	-.111
Psychotic Behavior	.057
Messiness	-.024
Self-care Disability	.153
Sensory Disability	.157
Ambulatory Disability	.205
Diminishment of Activity Levels	.046

[a] $p < .05$

These will be discussed as they group around several of the main conceptual areas investigated in this study.

Factors Influencing Choice of Home

The intercorrelations between all of the possible factors influencing the actual choice of home (Question 14, Appendix D) present an interesting matrix (Table 11). As can be seen, the variable "availability of bed" has no significant correlation with any others, yet tends toward the negative side with all. Then, all the other variables are positively related to each other significantly ($p < .01$) in 6 of 10 instances. Thus it may be that if availability was the major factor, all the others were not present; if availability was not important, people tended to look at all of the other factors.

Another variable assessed how many nursing homes the family actually visited before choosing; this was found to correlate negatively ($r = -.312$, $p < .01$) with the degree of severity of the relative's physical problems before placement; it seems that families of more seriously ill patients may have less time or flexibility in the choice process. On the other side, relatives of patients with more serious social problems tended to visit more homes ($r = 3.16$, $p < .01$). Whether the family actually visited the home finally chosen correlated highly with two factors influencing their choice process: cleanliness

Table 11

Intercorrelations of Factors Influencing Choice of Nursing Home

	Availability of Bed	Location of Home	Quality of Staff	Quality of Physical Care	Cleanliness	Condition of Other Residents
Availability of Bed						
Location of Home	-.155					
Quality of Staff	-.042	.087				
Quality of Physical Care	-.160	.229[a]	.661[b]			
Cleanliness	-.138	.320[b]	.411[b]	.434[b]		
Condition of Other Residents	-.097	.163	.171	.297[b]	.604[b]	

[a] $p < .05$

[b] $p < .01$

of home ($r = .553$, $p < .01$) and the condition of the other residents ($r = .460$, $p < .01$). Then for those who did visit, it seems that the crucial factors in choice tended to be things which were easily assessed by a layman's eyes, rather than professional items such as quality of nursing care, or quality of activity program. In addition, visiting the final home chosen correlated negatively, but not significantly ($r = -.109$) with availability of bed as a major factor: possibly those who visited had more freedom in choice or time for choice, as their relative was less physically ill and immediate availability was not as crucial.

Support Systems--Pre- and Post-Placement

As indicated above, an entire set of variables examined the people who were supportive of and influential with the family in the placement process, and who were of assistance in understanding the patient's physical and emotional problems after placement (see Questions 9, 21, and 22, Appendix D).

The discussion of the frequency distributions of these variables illuminated several interesting gaps in service and support; a further investigation of the correlations of these variables with each other and with other variables elaborates these findings. There were no significant intercorrelations between any of the four

pre-placement variables measuring the importance of the physician, the nursing home staff, the other family members, and the patient himself. Two of these variables correlate significantly with willingness to take part in programs planned for families; people for whom the physician was more influential tended to be less willing to be involved ($r = -.397$, $p < .01$), while people for whom the nursing home was influential tended to be more willing ($r = .290$, $p < .05$).

There is a strong set of interrelationships among the variables measuring physical and emotional support from the nursing home or physician (see Table 12). Families who get one sort of support from one source tend to also get support from other sources; the strongest relationships are between the two kinds of support (with physical and emotional problems) from the physician ($r = .638$, $p < .001$) and from the nursing home ($r = .480$, $p < .01$).

There are also relationships between these variables assessing support with emotional and physical problems and the variables looking at the families' difficulty in coping with mental (cognitive) or emotional problems, and the families' assessment of problems related to cognition on visiting (Questions 19, 27, 29, Appendix D). From the correlations of these variables (Table 13), it can be seen that the strongest positive

Table 12

Correlation of Variables Assessing Support in Placement Decision with Variables Assessing Support After Placement

	1	2	3	4	5	6	7	8
1. Physician Important in Placement								
2. Nursing Home Staff Important in Placement	-.062							
3. Patient Important in Placement	-.095	0.000						
4. Family Members Important in Placement	-.066	.208	.197					
5. Physician Helps Understand Physical Aspects	.389[b]	-.129	-.060	-.227[a]				
6. Physician Helps Understand Emotional Aspects	.151	-.152	-.155	-.177	.638[b]			
7. Nursing Home Staff Help Understand Physical Aspects	.055	.114	-.154	.002	.393[b]	.295[b]		
8. Nursing Home Staff Help Understand Emotional Aspects	-.003	-.043	-.023	.070	.182	.394[b]	.480[b]	

[a] $p < .05$; [b] $p < .01$

Table 13

Correlations of Support Variables with Variables Assessing Problems on Visits and Family Difficulty in Coping

	Orientation Problems on Visits	Difficulty Coping with Cognitive (Mental) Problems	Difficulty Coping with Emotional Problems
Physician Helps Understand Physical Aspects	.079	.330[b]	-.241[a]
Physician Helps Understand Emotional Aspects	.286[b]	.426[b]	-.295[b]
Nursing Home Staff Help Understand Physical Aspects	.237[a]	.253[a]	-.163
Nursing Home Staff Help Understand Emotional Aspects	.260[a]	.129	-.074

[a] $p < .05$

[b] $p < .01$

relationship is that those people who experience coping with mental problems (e.g. orientation, memory) as significant tend to turn to the physician for support on both physical ($r = .330$, $p < .01$) and emotional ($r = .426$, $p < .01$) problems. However, those who have more difficulty with their relative's emotional state tend to turn away from the physician for the same types of support ($r = -.241$, $p < .05$ for physical; $r = -.295$, $p < .01$ for emotional). These people also tend to avoid the nursing home staff as well, although the relationships are not significant.

Patient's Problems Before Placement

Several variables looked at the family's perceptions of their relative's problems before he/she entered a nursing home (Question 7, Appendix D). There was a significant negative correlation ($r = -.316$, $p < .01$) between presence of physical problems and presence of socially related problems (such as loneliness, poverty, poor nutrition, etc.). On the other hand, there was a positive relationship between the presence of mental (cognitive) and emotional problems ($r = .361$, $p < .01$), and between emotional and social problems ($r = .254$, $p < .05$). Beyond these three relationships, all of the other problem areas tended to be quite independent, as can be seen in Table 14.

Table 14

Intercorrelations of Pre-Placement Problems

	Social Problems	Physical Problems	Sensory Problems	Mental Problems	Emotional Problems
Social Problems					
Physical Problems	-.316[b]				
Sensory Problems	.093	-.066			
Mental Problems	-.054	-.069	-.129		
Emotional	.254[a]	-.219	-.139	.361[b]	

[a] $p < .05$

[b] $p < .01$

There are several significant and meaningful relationships between these problem area variables and other variables in the study. First, there is a negative correlation ($r = -.243$, $p < .05$) between the presence of physical problems at placement and whether the family tried to talk to the staff about planning for their relative (Question 30a, Appendix D); this may indicate that the families of more seriously ill patients are less confused about the type of care needed for their relative and feel less need to get involved. The existence of mental or cognitive-related problems before placement correlates highly with the patient's later functioning level and the family's perception of this, which tends to verify that these variables are measuring the same concept: mental problems before placement correlates .508 ($p < .001$) with family report of mental problems on visiting; .472 with the BOP scale "cognitive functioning"; and .472 with the family report of mental problems being hardest to cope with.

Willingness to Take Part in Programs

This important need assessment variable (Question 30, Appendix D) was found to have several interesting relationships with other variables. There was a positive relationship between willingness and the nursing home's importance in the placement process

($r = .290$, $p < .05$); this may indicate that those people who were more reliant on institutional resources for advice may also be more willing to get involved in their relative's treatment. This is supported by the additional finding that there was a significant negative correlation ($r = -.397$, $p < .001$) between reliance on the physician and willingness to take part in programs; possibly these people have assigned the treatment of their relative largely to a third party, the doctor. This may not be totally necessary, as it was shown that there is no relationship between reliance on the physician and actual scope of physical problems. Furthermore, there was a strong positive relationship between level of guilt and willingness to take part in programs ($r = .332$, $p < .01$); this coincides with the above data on reliance on physicians and willingness in that those who tend to rely on the physician more also express less guilt ($r = -.284$, $p < .05$). Thus, while guilt may be a factor in willingness to participate, reliance on physician is both a negative factor in reduced willingness and in reduced guilt. Finally, the length of stay that the relative has had in the nursing home correlates negatively ($r = -.250$, $p < .05$) with willingness to participate and also with guilt ($r = -.268$, $p < .05$); thus the length of stay may also be a factor along with reliance on physician in both reduction of guilt and lack of willingness to participate.

Visiting Quantity and Quality

Total number of visits made was found to correlate positively with greater enjoyment of visits ($r = .308$, $p < .01$), a result which even though it cannot establish a causative direction at least indicates that these two most important factors in family involvement are somewhat linked. In addition total number of visits was also correlated to amount of telephone contact before placement ($r = .281$, $p < .05$) and amount of visiting before ($r = .298$, $p < .01$), which may show that this greater involvement was present even before the relative entered a nursing home. Finally, total visits is related to what families actually do on the visits; those who do physical things, such as walking, combing hair, playing games, etc., tend to visit more ($r = .307$, $p < .01$) while those who just sit and talk visit less ($r = -.272$, $p < .05$).

Enjoyment of visiting did not relate to either of these variables concerning what is done on visits; however, it was highly related to variables which describe the status of the patient. Enjoyment was lower if the family reported that the patient had orientation problems on visiting ($r = -.360$, $p < .01$) and emotional problems on visiting ($r = -.289$, $p < .05$). In addition, enjoyment was lower with more impairment on the BOP scales for messiness ($r = -.342$, $p < .01$) and cognitive impairment ($r = .245$, $p < .05$).

Whether the family ever took the patient out of the nursing home was highly correlated with five variables describing physical disfunctioning: walking impairment ($r = -.387$, $p < .01$); lessened activity ($r = -.290$, $p < .01$); inability for self-care ($r = -.396$, $p < .01$); messiness ($r = -.251$, $p < .05$); and sensory impairment ($r = -.299$, $p < .01$). Also, taking the patient out correlated negatively with greater length of stay ($r = -.349$, $p < .01$), which may be related to the fact that two factors influencing not going out also correlated with length of stay: walking impairment ($r = .310$, $p < .01$) and self-care inability ($r = .345$, $p < .01$).

Finally, the families report of orientation or cognitive problems on visiting was correlated positively with several of the BOP and PCC scales; such as with (all $p < .01$); inability for self-care ($r = .449$); messiness ($r = .559$); cognitive impairment ($r = .612$); psychotic behavior ($r = .327$); and lack of interest in surroundings ($r = .384$). These orientation problems on visiting were highly related also to the families' report of mental condition as being toughest to cope with ($r = .485$, $p < .01$).

CHAPTER IV

DISCUSSION

It is important in any needs assessment study such as this to recognize the limitations of the design and of the statistical techniques used in analysis. Although the subjects were all chosen randomly, it must be remembered that they are a random sample from a quite defined population, the residents and families in three Lansing nursing homes. Thus, generalization to other cities, or other nursing home populations, must be guarded, especially when there may exist gross differences in ethnic makeup, socioeconomic status, etc. In addition, the major statistical techniques employed in this analysis were correlative methods; it is necessary to remember that a correlation can not imply causation and that directionality in this type of correlative finding is not discernible. Nevertheless, several distinct patterns have emerged from this data, especially concerning the need for and design of programs to aid the families of nursing home patients and to facilitate productive involvement of these families in their relative's lives.

Placement and Choice of Home

The first thing that becomes obvious in examining the variables concerning the pre-placement process is that families made little use of alternative services. Other than the Visiting Nurses program, which had almost 100% awareness and 20% usage, the other programs such as home health aides, housekeeping aides, Meals-on-Wheels, etc., were virtually unknown and unused. As more and more demands are heard from health planners, politicians, etc. for developing alternatives to institutionalization for the elderly in order to eliminate or postpone nursing home care, it will become necessary for these programs to find ways of making themselves visible and available. This is more important when considered with the fact that 33% of the families in this survey felt they would have liked more information on alternatives before nursing home placement.

This ties in closely with another issue--the actual choice of nursing home. Data collected indicate that this was most often purely a matter of availability of bed; when availability was not an issue, families were then influenced by location and reputation. There was very little examination of staff quality, and no examination of the quality of the activity programming. Thus, given the fact that nursing home beds are increasing and demand may decrease as alternatives develop, it

becomes important to facilitate a more educated choice of nursing home by the patient's family. This could have two powerful effects: first, to create a competitive market among the private homes where one of the major criteria will be quality of care; second, to ensure that the families are more involved in the placement of their relative from the beginning and in gearing this placement to both of their needs.

It seems, therefore, that one solution to this problem is the creation of a central agency in each area which would be charged primarily with advising and counseling older people and their families concerning proper noninstitutional alternatives and institutional care. In addition, this agency would assist in the referral and admission of the older person to a nursing home when necessary, and serve as a central clearinghouse for nursing home information. Several valuable sourcebooks for nursing home evaluation and selection are available, including those created by Michigan's Citizens for Better Care; this proposed central agency could insure adequate dissemination of this knowledge and, in addition, serve a monitoring function toward nursing homes. It is interesting to note that the Area Agencies on Aging are charged with these general duties as part of their information and referral services; they have, however, been traditionally geared toward assisting the elderly

who are still living in the community, and have stayed largely away from nursing home affairs. Nevertheless, the ideal location for such a nursing home I&R agency remains within the Area Agency; it is necessary, however, to reemphasize and redefine this specific function and to establish the appropriate linkages with nursing homes, hospitals, churches, and any other possible sources of referral.

Family Involvement

Any plan for increasing the therapeutic capability of families in their older relatives' lives must be concerned with the present level of involvement. As was discovered, for the most part families tended to remain involved with their relative after nursing home placement. The average number of visits per family was three weekly, with the modal number being once weekly; only two families visited less than once every two weeks. This tends to reinforce the invalidity of some of the more prevalent viewpoints concerning the "dumping" of the elderly into nursing homes, where they are pushed from their families' minds forever. On the contrary, there was no correlation between number of visits and length of stay in the home, so involvement does not seem to decrease over time.

There was found to be a definite decrease over time, however, in the amount that families took their

relative out of the home. This can be explained by the fact that patient excursions were highly correlated with physical health, and that physical health almost always deteriorates with nursing home patients. Thus, the relative infrequency of excursions with the family is less a sign of disengagement than it is a realistic response to the difficulty of taking the elderly person out.

Other data corroborate the finding that families are willing to remain involved in their relative's lives. Almost 30% of the families took the older relative into their home before deciding on a nursing home placement. As has been shown (Spark & Brody, 1970), this is an extremely disruptive event in a family's history; 46% of all families reported that their household routine had stabilized significantly since placement of their relative. It can be hypothesized that the strain placed upon the family by the intrusion of an older relative is reflected in the families' attitudes toward this relative and is in turn easily sensed by the elderly person. Thus, nursing home placement may often be a great relief for the family and, if not quite so welcome to the relative, at least a respite from the tension of being dependent on his grown children.

The task, therefore, is to create an environment in which the willingness of the family members to remain

involved in the life of their relative can be channeled therapeutically to benefit both parties. It thus becomes important to examine not only the quantity of visiting as a measure of involvement but also the quality of visiting and factors which may directly improve it. This is particularly crucial as it was found that enjoyment of visiting had a high positive correlation with quantity of visiting; it can confidently be postulated that those who felt their visits were of higher quality and more personally satisfying were willing to visit more often.

The first thing that becomes evident is that families of more mentally impaired older people may enjoy their visiting less. Many behaviors concomitant with mental deterioration in the elderly explain this. First, memory losses and cognitive dysfunction tend to cause repetitive speech, wandering thought processes, misidentification of others, disorientation, and even outright delusional ideas. Second, mental deterioration is often accompanied by a decrease in cleanliness and self-maintenance; thus the older person may begin to appear very sloppy, wear inappropriate clothing, and seem to lose all of his past dignity and self-respect. Third, the patient may revert to childish or inappropriate behaviors, extreme emotional lability, or total dependency on staff or relatives.

Thus, it is easy to see why visiting may be an unenjoyable or painful experience for the family member of a mentally impaired patient. Nevertheless, several other potentially damaging factors do not seem to impede enjoyment of visiting; among these are depression, verbal and physical hostility, and psychotic behaviors. This may be explained several ways. The older relatives may not exhibit these behaviors when they are visited by their families; in contrast to mental deterioration, all of these tend to be functional behaviors which can be more or less controlled by the person. In addition, these behaviors may be so long-standing that, as opposed to mental deterioration, they are well integrated into the families' conception of their relative and interactions with him, and are not perceived as age and/or nursing home related.

Nevertheless, mental impairment may indeed decrease the families' enjoyment of visits; however, this impairment does not seem to correlate negatively with the number of visits the family makes. Thus, the problem becomes not so much one of convincing families to visit their relatives as it is of facilitating more productive and enjoyable visits.

One method which can be proposed for working toward this objective is the initiation of family programs in the nursing home. These may range from initial

orientation meetings with staff to family group meetings to classes concerning the process of aging and nursing homes. Questions assessing the families' willingness to take part in such programs revealed that only 17% of the families had no interest at all in getting more involved. Over two-thirds wished to be able to meet with staff, 51% would attend classes on aging and nursing homes, and 47% expressed interest in getting advice on how to make their visiting more productive and enjoyable. A lesser but still considerable amount, 30%, were interested in meeting with other families to share concerns and problems.

What becomes obvious, then, is that a large proportion of families feel a need to become more involved and knowledgeable in their relatives' care, and see formalized programs as one method of attaining this goal. These programs can be structured in several different ways. The most traditional model would consist of classes concerning the aging process. Emphasis would be placed on the physiological and psychosocial changes in aging and how these interact with placement in a nursing home to create the specific types of behaviors which may seem so inexplicable to the family. Because of the prevalence of organic brain syndromes among nursing home patients, a complete explanation of this disorder and its concomitant behavior patterns would be essential.

A second type of family program, possibly serving as a follow-up to the teaching-oriented sessions, would be a training program in nursing home visiting. One of the major problems noted in the interviews was the lack of anything to do on visits; many families felt that they just sat and stared at their relative for an hour twice a week. Training families to visit would be geared toward improving quality and enjoyment of these visits for both parties and toward developing a therapeutic and constructive role for the family. Special emphasis here would be placed on the family's role as a link between the past and the present and how to facilitate that linkage while helping the relative accept his present situation. Combining the techniques of role-playing and simulation with the specific knowledge about psychological functioning of the elderly would serve to clarify the role of the family member; this could be a major step in reversing the destructive guilt-anger cycle seen in so many relationships. The final type of program possible would involve group meetings of families. These meetings would be intended to assist the relatives in gaining support from others in the same position and in being able to discuss their concerns about the nursing home. Combining this type of function with the two above would serve to provide specific information and techniques for the family and support in using these

techniques. In addition, this group of families may develop into or link with an advocacy consumer group such as Citizens for Better Care, which would serve the additional function of monitoring nursing home care. Having nursing home staff members meet regularly with the family groups would also improve the continuity of care provided to the patients by affording a forum for sharing treatment goals and plans.

Support Mechanisms

The programs mentioned above all serve to fill a gap revealed by the data--that of the support the families feel they receive in dealing with the physical and psychosocial problems of their relatives. It was found that very little support is forthcoming from the physician, although this is not surprising given the reluctance of most doctors to work with the elderly and their relative lack of knowledge concerning the processes of aging (Miller, Keller, & Woodruff, 1974). Less than one-third of the respondents felt that they got any help from their relative's physician in understanding psychological changes, and only one-half felt they got any help understanding the physical aspects. Thus, the medical profession is obviously not fulfilling a supportive role when it comes to nursing home care of the elderly and their families.

An encouraging sign was that the nursing home staff was somewhat filling this gap in supportive help for the family. Over 80% of the families got some support from the nurses with physical problems, and almost 50% with emotional problems. Surprisingly, over 50% got physical support and 38% emotional help from the nurse's aides, a group traditionally looked upon as the least knowledgeable and professional in a nursing home.

Thus, it can be seen that for many families the channels of communication with staff are already opened. The task, then, is to facilitate the proper usage of these channels in order to improve the overall quality of nursing home treatment. The willingness of families to be involved in programs to help them with their relatives is related in an interesting manner to the support systems used by the family. Those families who tended to use the physician were less willing to take part, while those who relied more on the nursing home also expressed more willingness. This may be because those families who feel they can get support from the physician are satisfied with this level of support, while those who turn to the nursing home feel a need for still more input. If this hypothesis were true, the mandate would be to educate physicians to meet more of the needs of the families of their nursing home patients. However, this is unreasonable on two counts: from the data, it

can be seen that those who rely on the physician have no higher quality of visiting than the others, so getting support in that direction may not be a purely positive step; second, it is both impractical and unrealistic to expect that physicians would make the necessary changes even if they were proven beneficial. Thus, a more reasonable alternative, given both current knowledge and state of resources, is the facilitation of more contact between nursing home staff and families. A further benefit of this type of support system is opposed to that with the physician is that the nursing home staff have more contact and familiarity with the older patient, and have a much greater actual impact on the quality of his life.

Guilt

Many have hypothesized that guilt is a major factor impinging on all relationships between families and older patients (Kramer, 1964; Friedsam & Dick, 1964). An attempt was made to measure level of guilt in this study by directly questioning the family concerning this area. As is often noted, self-report data of this sort are of questionable validity. Some have suggested that the only response with any validity is a positive response, or, in this case, an admission of guilt; it is impossible to attribute validity with any confidence to a negative or denial response. However, it is even

more difficult to obtain a behavioral measure of guilt, and projective measures, such as the Geriatric Apperception Test (Wolk, 1972) or Szondi (Taylor, 1972) were beyond the scope of this study. Thus, any conclusions concerning this variable should be examined in this cautionary light.

As was seen in the hypothesis testing situations, there was little relationship between guilt and any of the other variables. Families who tried more alternatives to nursing home placement did not, as expected, feel less guilt. This may be explained by the low variance of the variable assessing alternatives tried--most families tried none at all. Thus, if families tend to experience guilt in placing a relative in a nursing home, this guilt may only be related to their failure to try alternatives when there are sufficient alternatives available and accessible. However, there was another slightly negative correlation which indicated that those people who tried taking their relative into their home before placement felt less guilt; in this case, this may be closer to a measure of alternatives tried.

In addition, the expected negative relationship between guilt and severity of physical problems at admission was not evident. Part of this may be explained by the fact almost all patients had some physical problems. What this does indicate, however, is that families feel,

quite justifiably, that mental or psychological problems are as valid as physical problems as a determinant of nursing home placement. Often, in fact, it is much more taxing and difficult for a family to keep a severely confused and ambulatory relative in their home as opposed to one with a more restrictive physical illness.

Another hypothesis concerning guilt which was not borne out was that families who involved their relative more in the decision to go into a nursing home would feel less guilt. The rationale behind this hypothesis was that those families who did have more input from the older relative would be able to justify the placement as having been a decision of the patient. The absence of any correlation tends to negate this. However, it was shown that those families who tended to rely on the physician more for the decision for placement did feel less guilt. This indicates that some families are willing to assign the decision-making process elsewhere, and that those who do are able to feel less guilt about it. It is interesting to note that those families who rely more on the physician and feel less guilt are also less willing to take part in any programs, which could be indicative of a high degree of disengagement from and/or disinterest in their relative's life.

The relationship between guilt, relative's functioning level, and quantity of visiting presents an

interesting picture. It was hypothesized and shown that high guilt families would visit less often to totally confused patients than low guilt families would; this reflects the feeling that visits to very impaired relatives may be too painful for a family feeling a lot of guilt. It was also shown that high guilt families visit less often to totally alert patients; this is probably a result of the fact that most families of alert patients who feel much guilt have their guilt magnified by the patient's reaction, which is most often anger. Thus, visits may be more threatening when the relative is alert and able to express this anger. Finally, with patients who are sometimes alert, sometimes confused, high guilt families actually visited more. For these families, guilt is probably a motivating factor in visiting, with the underlying hope that more visits will create improvement in their relative and relieve their guilt (or the corollary fear, that not visiting creates the confusion, and thus they will feel more guilty).

This interaction between guilt and impairment on quantity of visiting has several implications which relate to the family programs discussed above. First, the fact that higher guilt relates to more visiting for a middle impairment level is encouraging, as it at least reveals that these families are still involved and available for intervention. The task with these families

is to train them to communicate effectively with their relative in order to facilitate his periods of lucidity, and, on the other hand, to use proper methods (e.g., reality orientation) to work with him in confused periods. It is unfortunate, however, that guilt does not have the same effect on families of highly impaired patients, as these patients are also in great need of visiting. Here, as mentioned before, families must get support from staff in the form of explanations of behavior, guides to working with this behavior, assistance in better visiting, etc. For the high guilt families who may visit less to alert residents for fear of confrontation with anger, the preferred intervention may be some sort of family therapy or family counseling. The relative must learn to accept the placement and try to maximize his functioning; the family must become able to allow the relative to express his anger and concerns, and to not always interpret these feelings as a direct or guilt-inducing attack (Brody & Spark, 1966). Unfortunately, intervention with this group is least likely to succeed for two reasons: resources are rarely available for this sort of family therapy; and, if they were, this pattern of guilt-anger-recrimination is most likely a long-standing problem (of possibly 30-50 years duration) and one not likely to be amenable to any therapy in

such a time of duress as nursing home placement with chronic illness (Howells, 1975).

Cluster Analysis

Seven separate clusters were identified on the preset key cluster analysis. The first cluster, labelled "Visiting practices" included variables describing how often families visited, how much they enjoyed visits, and what they did on visits. This cluster points to the fact that families who find things "to do" on visits rather than just sit and talk tend to visit more and have higher quality visiting. The major implication of this is that any family program should probably have a component aimed at teaching the families to visit better; this should be true whether one speaks of family educational programs, group meetings, or even family therapy.

Cluster 2 is the "support" cluster. It indicates that families who get one type of support tend to get others as well. Thus, it seems that there are "high support" families, and "no support" families; family programs must especially try to identify and meet the needs of this latter type.

Clusters 3 and 6, with an intercorrelation of .60, can both be called "Impaired Mental Functioning." These verify the observation that mental deterioration

in the elderly is a broad and most often nonspecific process. The inclusion in these clusters of variables rated by both the family and the staff indicates that these two groups have similar perceptions along this line. Also, the two variables describing family problems in relating to this mental impairment were included in these clusters; not only do the relatives have mental problems, but the families perceive these as their major problem in relating to the older person. Once again, this provides evidence that any family programming must be primarily aimed at families of mentally impaired patients.

Cluster 4, "Physical Impairment," essentially describes the "traditional" nursing home patient: one who has a multiplicity of physical problems, is non-ambulatory, and has few social or emotional problems. The families of these patients had less time or choice during the placement process; interventions with this type of patient's family should be either centered on a nursing home placement bureau, as described above, or in the immediate period after placement. Alternatives to nursing home institutionalization are probably not appropriate for this group.

Cluster 5 describes the "Emotionally Troubled Patient" as distinguished from those patients with mental impairment largely the result of organic conditions.

Patients in this group tend to be both more depressed and more hostile, and this can create a whole different set of problems for the family. It may be for this group and their families that some sort of family therapy, group or individual, would be most appropriate.

Cluster 7, "Pre-Placement History," is an internally consistent set of variables describing the patient's living situation and the family's involvement in his life before placement. Patients who lived with a relative or with another person tended to get help from their families in both personal care and housekeeping-maintenance type of activities. Those who lived along received less help on all dimensions and in addition tried fewer alternatives. The implication of this is that the families of older persons living alone are less involved in their relative's life before placement and thus may be less available for intervention later on. Any family program must attempt to pull these people back into involvement or identify and work with the causes of the separation. Obviously not all families are amenable to productive involvement with their relatives; many relationships may have deteriorated years ago to a point beyond redemption. Nevertheless, the crisis of institutionalization may represent an opportunity for reconciliation which can be approached through family therapy or group programs.

In summary, the cluster analysis is most significant in its revelation of the distinction between patients with physical, mental, and emotional problems. Because of these three tight groupings, it is important to plan separately for each type of patient/family within the common framework of increasing productive family involvement. Also, the cluster structure reveals a common grouping of visiting variables, of family support variables, and of pre-placement history variables. Each of these areas is conceptually relevant in planning for the three types of patient groups.

In addition, a review of the cluster structure and inter-cluster correlation matrix reveals that the problem being assessed in this study is extremely complex and multi-dimensional. Whereas previous studies (Lawton, 1972; Shanas, 1960) have postulated the high interrelationship between physical and mental impairment in the elderly, the cluster analysis presented these clusters as relatively independent. It is possible that families choose to see their relative's problems as existing along only one of these dimensions, or that the variety of variables grouping together in these clusters are able to explain only a small part of the variance. This latter view may be supported by the fact that some important variables such as family guilt failed to fall into any of the clusters; obviously these are variables which may

relate to many different concepts and may only have a small part of their variance explained by any single relationship. The same statement applies to enjoyment of visiting as well; while this crucial variable tends to relate significantly with impairment of the patient, this is indeed a rather small negative correlation and many other small correlations make up the major part of the variance. In conclusion, thus, one of the major results revealed by the cluster analysis is the complexity and variability of the problem of family involvement; future researchers would do well to bear this in mind as they plan programs for families of nursing home patients.

Summary

The major findings and recommendations of this study can be summarized as follows:

1. Alternatives to nursing home placement, when they do exist, are both under-recognized and under-utilized by families. In addition, the nursing home choice process is one characterized by a minimum of systematic decision-making based on critical choices. Thus, it has been recommended that the appropriate community agencies improve or establish nursing home information and referral services.

2. Family involvement, as reflected in quantity of visits, remains high even with severely impaired patients. The quality of these visits, however, decreases directly with greater mental impairment of the patient. Thus, programs must be initiated in nursing homes to train families to visit more productively and to become more active treatment resources for their elderly relative.

3. Families feel very little support in dealing with their relative's physical and emotional problems from the physician. More families tend to turn to nurses or even nurses' aides in the home for this support. Thus, any programs for families should take advantage of this established linkage with nursing home staff as a valuable resource in both coordination and treatment.

4. Cluster analysis results highlight the difficulties of families of mentally impaired patients and lend emphasis to the need for intervention with these families.

5. Guilt is often a motivating factor in visiting for families of patients who are at a middle impairment level. Also, families who feel more guilty tend to express more need and willingness to take part in programs in the home.

APPENDICES

APPENDIX A

LETTER OF INTRODUCTION TO FAMILIES

Appendix A

1201 WEST OAKLAND
LANSING, MICHIGAN 48915

TELEPHONE
AREA CODE 517/372-7900

HOSPITAL
COMMUNITY MENTAL HEALTH CENTER

The Nursing Home Training and Consultation Project has been involved with the three Lansing area Provincial Houses for the past year in an effort to train staff in improving psychosocial aspects of care. In this respect we are vitally interested in the concerns of families and relatives of nursing home residents.

In order to better understand the factors which concern families of patients and to better plan programs for both patients and their relatives, we have initiated an area-wide survey. Your name has been chosen from a list given to us by Provincial House, and we hope that you will consent to help us in this survey. The survey will take about a half-hour of your time and will be conducted at your convenience. Of course, all aspects of this interview will be kept confidential.

Mrs. Carole Howland, of the Nursing Home Project, will be telephoning you shortly to set up a time for her to come and meet with you. If you do not wish to be contacted, or have any questions regarding this survey, please call me at 372-7900, extension 236.

Thank you very much for your cooperation. I am confident that you will find this an enjoyable and interesting experience, and that we will be able to better benefit all patients in nursing homes from the information you provide us.

Sincerely,

Jonathan L. York
Project Director
Nursing Home Training and Consultation Project

JY/clh

APPENDIX B

BEHAVIOR OF OLDER PERSON'S CHECKLIST (BOP)

APPENDIX B

BEHAVIOR OF OLDER PERSON'S CHECKLIST

Resident's Name_____

Rated by_____

Facility_____

Date_____

1.	Cries	Never	Sometimes	Often
2.	Shows no interest in activities around him.	Never	Sometimes	Often
3.	Sits, unless directed into activity	Never	Sometimes	Often
4.	Gets angry or annoyed easily	Never	Sometimes	Often
5.	Hears things that are not there	Never	Sometimes	Often
6.	Does not try to be friendly with others	Never	Sometimes	Often
7.	Becomes easily upset if something doesn't suit him	Never	Sometimes	Often
8.	Refuses to do the ordinary things expected of him	Never	Sometimes	Often
9.	Is irritable and grouchy	Never	Sometimes	Often
10.	Refuses to speak	Never	Sometimes	Often
11.	Does not laugh or smile at funny comments or events	Never	Sometimes	Often
12.	Doesn't start up conversations with others	Never	Sometimes	Often
13.	Says he feels blue or depressed	Never	Sometimes	Often
14.	Sees things that are not there	Never	Sometimes	Often

15. Has to be reminded what to do	Never	Sometimes	Often
16. Sleeps, unless directed into activity	Never	Sometimes	Often
17. Doesn't maintain conversations others start with him	Never	Sometimes	Often
18. Says that he is no good	Never	Sometimes	Often
19. Has difficulty completing even simple tasks on his own	Never	Sometimes	Often
20. Talks, mutters, or mumbles to himself	Never	Sometimes	Often
21. Giggles or smiles to himself without any apparent reason	Never	Sometimes	Often
22. Doesn't keep himself clean	Never	Sometimes	Often
23. Does not dress or feed self though physically able	Never	Sometimes	Often
24. Lies to staff and residents	Never	Sometimes	Often
25. Steals or "pack rats"	Never	Sometimes	Often
26. Uses profanities	Never	Sometimes	Often
27. Verbally threatens staff or residents	Never	Sometimes	Often
28. Is physically destructive (e.g. breaks furniture)	Never	Sometimes	Often
29. Is physically assaultive to staff or other residents	Never	Sometimes	Often
30. Expresses fear or nervousness	Never	Sometimes	Often
31. Demonstrates rapid shift of emotions without control	Never	Sometimes	Often

32. Expresses thoughts of killing self	Never	Sometimes	Often
33. Fears specific object or situation (phobias)	Never	Sometimes	Often
34. Expresses unwarranted concern for physical health	Never	Sometimes	Often
35. Is incontinent despite physical ability	Never	Sometimes	Often
36. Misidentifies others	Never	Sometimes	Often
37. Does not recall events of the last few hours or day	Never	Sometimes	Often
38. Does not recall events of several years ago	Never	Sometimes	Often
39. Is disoriented as to time and place	Never	Sometimes	Often
40. Shows lapses in judgment (e.g. may harm himself if left alone by forgetting to blow out match when lighting cigarette, by taking scalding shower etc. -not intentional harm)	Never	Sometimes	Often
41. Talks unrealistically about plans for future (e.g. plans to go live alone when physically impossible)	Never	Sometimes	Often
42. Falsely believes that people are out to get him, attacking, cheating, or persecuting him	Never	Sometimes	Often
43. Has beliefs about his personal life which are not true (e.g. thinks he is President etc.)	Never	Sometimes	Often

APPENDIX C

PHYSICAL CAPABILITIES CHECKLIST (PCC)

APPENDIX C

PHYSICAL CAPABILITIES CHECKLIST

Resident's Name_____

Rated by_____

Facility_____

Date_____

A. TOILET

____1. Cares for self at toilet completely, no incontinence

____2. Needs to be reminded or needs help in cleaning self, or has rare (weekly at most) accidents

____3. Soiling or wetting while asleep more than once a week

____4. Soiling or wetting while awake more than once a week

____5. No control of bowels or bladder

B.FEEDING

____1. Eats without assistance

____2. Easts with minor assistance, but is tidy and clean

____3. Eats with minor assistance and is untidy, needing help cleaning up

____4. Requires extensive assistance for all meals

____5. Does not feed self at all and is uncooperative with others feeding him

C. DRESSING

____1. Dresses, undresses and selects own clothes-needs no assistance

____2. Needs minor assistance sometimes, but for most part can dress and undress self

____3. Needs some moderate assistance always in dressing and undressing

____4. Needs major assistance, but cooperates with efforts of others to help

____5. Completely unable to dress self and resists efforts of others to help

D. GROOMING (neatness, hair, face, hands, nails, etc.)

____1. Always acceptably groomed without assistance

____2. Needs minor assistance in grooming, and occasional reminders

____3. Needs regular supervision or assistance in grooming

____4. Needs total grooming care, but remains interested in staying well-groomed

____5. Needs total grooming care, but is not interested in maintaining grooming; sometimes resists and negates efforts of others

E. BATHING

____1. Bathes self without help

____2. Bathes self with help getting in and out of tub or shower

____3. Bathes self with lettle assistance. but needs to be reminded and forced to bathe

____4. Needs to be bathed by others, but cooperates

____5. Needs to be bathed by others, but resists and refuses to cooperate

F. AMBULATION

____. Walks unassisted usually

____2. Walks with only arm or railing or cane for support, usually; or walks with walker

____3. Moves self around in wheelcahir, can get in and out alone

____4. Moves self around wheelchair, must be lifted in and out

____5. Must be pushed around in wheelchair

G. ACTIVITY

____1. Gets out of bed and dressed in morning, remains out until bedtime with one nap, at most, during day

____2. Gets out of bed in morning, but naps off and on through day

____3. Gets up only when forced, then spends most of day out of bed

____4. Spends whole day in bed, could be out more often

____5. Spends whole day in bed, too sick to get out

H. EYESIGHT

____1. Normal or better

____2. Slightly impaired; can read, but for limited time periods

____3. Somewhat impaired; can read large print, see movies, etc.

____4. Considerably impaired; umable to see to read, but can distinguish faces etc.

____5. Functionally blind

I HEARING

____1. Normal or better

____2. Slightly impaired; occasionally asks "what", etc.

____3. Somewhat impaired; hears about half of what is said to him, does not hear others conversations well

____4. Considerably impaired; has great difficulty hearing

____. Functionally deaf

J. SPEECH (quality of speech, not content or meaning)

____1. Normal or better

____2. Slightly impaired; at times garbled

____3. Somewhat impaired; one must concentrate hard to understand

____4. Considerably impaired; one can only pick out occasional words ; or person speaks in fragments, only expressing needs, etc.

____5. Mute; or totally imcomprehensible

APPENDIX D

FAMILY INTERVIEW SCHEDULE

St. Lawrence Hospital Community Mental Health Center
Nursing Home Consultation and Training Project

FAMILY SURVEY

Name of Interviewee_____

Date of Interview_____

Place of Interiew_____

Comments of Interviewer:

St. Lawrence Hospital Community Mental Health Center
Nursing Home Consultation and Training Project

FAMILY SURVEY

1. What relation are you to _____?

2. What other close relatives does _____ have?

	NAME	RELATION TO PATIENT	DO THEY LIVE IN LANSING AREA	HOW OFTEN DO THEY VISIT PT?
1.				
2.				
3.				
4.				
5.				
6.				
7.				
8.				
9.				
10.				

3. Is this the first nursing home _____ was in?

a) If no, where else was he (she)? _____

b) Why was he moved to this one?

4. Before_____moved to the first nursing home, was he (she) in a hospital?

   a) If yes, for how long?_____

5. In the two years before_____moved to a nursing home, in which of the following places did he (she) live? Please check (✓) all that apply and then note the length of time lived there.

   Then, please go back over the list and place a "1" in the column beside the last place he lived before moving to a nursing home, and a "2" beside the second-to-last, etc., until all are in order.

	PLACE OF LIVING	LENGTH THERE	ORDER LIVED IN (1= closest to present time)
a)	in own home, alone	_____	_____
b)	in own home, w/another	_____	_____
c)	in own apartment, alone	_____	_____
d)	in own apartment, w/another	_____	_____
e)	in senior citizen's apartment	_____	_____
f)	in your home or apartment	_____	_____
g)	in home or apartment of another relative	_____	_____
h)	in home for the aged or retirement center	_____	_____
i)	in a State Hospital	_____	_____
j)	other, please name_____	_____	_____
k)	other, please name_____	_____	_____
l)	other, please name_____	_____	_____

6. In this period before_____moved to a nursing home, with which of the following activities did you have to help him/her? (Place a check beside all appropriate activities.)

	HELPED WITH	HOW OFTEN/WEEK
bathing	_____	_____
dressing	_____	_____
toileting	_____	_____
feeding	_____	_____
light chores	_____	_____
heavy house-cleaning	_____	_____
laundry	_____	_____
shopping	_____	_____
cooking	_____	_____
medical affairs	_____	_____
transferring	_____	_____
other	_____	_____

7. Many types of problems may have happened to your relative in the six months before he entered a nursing home for the first time.
-Please place a check (✔) in the first column for all those problems which actually did occur to _____ in those six months.
-Please place a check (✔) in the second column for all those problems which you feel were crucial in leading to the decision to place _____ in a nursing home.

PROBLEM LIST	ACTUALLY OCCURRED	LED TO DECISION TO PLACE IN NURSING HOME
a) death of spouse	_____	_____
b) loss of ability to drive	_____	_____
c) loss of ability to walk	_____	_____
d) loss of use of limb(s)	_____	_____
e) severe impairment of eyesight	_____	_____
f) severe impairment of hearing	_____	_____
g) severe impairment of speech	_____	_____
h) loss of continence	_____	_____
i) loss of orientation to time	_____	_____
j) loss of orientation to place	_____	_____
k) started misidentifying others	_____	_____
l) loss of memory	_____	_____
m) ran out of money	_____	_____
n) severe physical illness	_____	_____
o) stroke	_____	_____
p) heart attack	_____	_____
q) broken hip or leg	_____	_____
r) became depressed	_____	_____
s) became grouchy	_____	_____
t) became violent	_____	_____
u) hallucinated	_____	_____
v) became delusional	_____	_____
w) other _____		_____
x) other _____		_____

8. Following is a list of some alternatives which may or may not be appropriate to use instead of nursing home.
   -Place a check (✓) in the first column if you have heard of this alternative?
   -Place a check (✓) in the second column if you tried this with your relative.

NAME	HEARD OF	TRIED	COMMENT
Home health aide	_____	_____	__
Adult Day Care Services	_____	_____	__
Physical therapy	_____	_____	__
Visiting Nurses	_____	_____	__
Housekeeping Aides	_____	_____	__
Meals-onwheels	_____	_____	__
Transportation Services (GLATCH)	_____	_____	__
Health Clinics	_____	_____	__
Community Mental Health Center	_____	_____	__
Other (Please Name)_____	_____	_____	__

9. Below you will see a list of people or organizations who may have been helpful or influential in you decision to move_____to a nursing home? Please indicate whether their input to this decision process was:

	NONE	OF SOME IMPORTANCE	VERY IMPORTANT
the patient himself			
other family members			
your clergyman			
your physician			
the patient's physician			
a hospital social worker			
a Nursing Home Administrator			
another Nursing Home staff member			
friends			
family(s) of another patient			
other, please name			

10. Who made the ultimate decision to place_____in a Nursing Home?

11. How many nursing homes did you visit before choosing?_____

12. How many times did you visit the one you chose?_____

13. Did_____visit with you?

14. How much did the following factors influence your choice of_____?

	NO INFLUENCE	SOME INFUENCE	MUCH INFLUENCE
location of home			
availability of bed			
cost quality of staff			
quality of physical care			
cleanliness			
quality of activity program			
condition of other residents			
other			

15. How did your relative accept the decision for him to go into a nursing home?

*****

16. How often do you visit_____?

a). How much would you say you visit compared to when_____ first went into a nursing home?

more_____

less_____

same_____

17. Following are some statements which amy or may not apply to you. Please circle the appropriate letters as to whether you

SA = strongly agree
A = agree
? = no opinion
D = disagree
SD = strongly disagree

a).	I often visit my relative even though I don't really want to.	SA	A	?	D	SD
b).	I feel guilty when I think of my relative in a nursing home.	SA	A	?	D	SD
c).	I often feel that maybe I should not have put my relative in a nursing home.	SA	A	?	D	SD
d).	I am often ashamed to tell people that my relative is in a nursing home.	SA	A	?	D	SD
e).	If I had it to do over again, I would try morealternatives before a nursing home.	SA	A	?	D	SD

18. What do you usually do when you visit?

19. Would you say that any of these things happen with_____ when you visit?
-Place a check ( ) in the appropriate column

	NEVER OR RARELY	SOMETIMES	OFTEN
is grouch and irritable			
seems depressed			
does not recognize you			
seems disoriented			
complains about nursing home			
complains about illness			
complains about life in general			

20. Do you enjoy your visits? (Check one)

90-100% of the time_____
65-90% of the time_____
35-65% of the time_____
10-35% of the time_____
0-10% of the time_____

21. Please place a check mark ( ) in the appropriate column to indicate how helpful the following people have been in helping you understand your relative's physical concerns since he (she) entered a nursing home?

	NO HELP	SOMEWHAT HELPFUL	VERY HELPFUL
patient's physician			
nursing home administrator			
nurse(s)			
nurse aide(s)			
family of other patient(s)			
clergyman			
social worker			
other (please name)			

22. Please place a check in the appropriate column to indicate how helpful the following people have been in helping you understand your relative's emotional problems since he (she) entered a nusrsing home?

	NO HELP	SOMEWHAT HELPFUL	VERY HELPFUL
patient's physician			
nursing home administrator			
nurse(s)			
nurse aide(s)			
family of other patient(s)			
clergyman			
social worker			
other			

23. Do you ever take_____out of the nursing home?

(a) if yes, how often?_____

24. Before_____first entered a nursing home how often did you:

(a) speak with him (her) on the telephone?_____

(b) visit with him (her)?_____

25. Since _____first moved to a nursing home, has the daily routine in your household been: (check one)

more stable_____
less stable_____
the same_____

26. Has your family talked about and been concerned with_____problems

more_____
less_____
the same_____

27. The families of other patients in nursing homes have mentioned several types of problems which have occurred to them. Please mark in the appropriate column below whether each of these potential problems has been:

	NO PROBLEM	SOMEWHAT OF A PROBLEM	A BIG PROBLEM
a) getting information about patient's physical condition			
b) understanding his mental state			
c) understanding his emotional state			
d) nursing home rules make visiting difficult			
e) we feel guilty about having placed patient in nursing home.			
f) can't communicate with him (her) on visits			
g) patient is angry with us because of placement in nursing home.			

One of our major concerns in doing this interview is to get information which may aid in developing better services for patients and their relatives. Your answers to the following few questions would be most helpful to us in this pursuit.

28. Has there been any aspect of your relative's illness or life in the nursing home for which you have been able to get no help in understanding?

29. What has been the most difficult aspect of your relative's aging process for you to cope with.

30. Below are listed some possible programs for families of patients in nursing homes. Which of the following services did you use, would have used when your relative entered the nursing home, or would still use now. Please check the most appropriate.

	USED BEFORE OR USE NOW	WOULD HAVE UTILIZED AT ADMISSION	WOULD UTILIZE NOW
a) meet with nursing home staff to discuss relative's emotional and physical adjustment to the home.	_____	_____	_____
b) meet with families of other patients to share concerns and problems	_____	_____	_____
c) talk over problems with counselor	_____	_____	_____
d) talk over problems with counselor and relative	_____	_____	_____
e) meet with someone who could explain alternatives to nursing home placement	_____	_____	_____
f) attend several informal classes concerning the psychological and social aspects of aging and nursing homes.	_____	_____	_____
g) get advice on how to improve your visiting to make relative happier.	_____	_____	_____
h) other _____	_____	_____	_____

*****

31. What was your relative's occupation?

32. What was his (her) highest level of education?

33. How many children did he (she) have?

34. Was he(she) ever a heavy drinker?

35. Was he(she) ever under psychiatric care? If yes, please explain.

36. What is your marital status?

37. What is your occupation?

38. What is your level of education?

39. What is your spouse's occupation?

40. What is your spouse's level of education?

OTHER PATIENT DATA (FROM MEDICAL CHART)

42. Method of payment at present_____

43. Method of payment at admission_____

44. Length of time at this home_____

45. Age_____

46. Marital status_____

APPENDIX E

SCORING KEY FOR FAMILY INTERVIEW

Column	Variable	Code
1	Place of Interview PLACEINT	1 = home 2 = St Lawrence 3 = office 4 = other Blank = missing (9)
2	Relation of Interviewee RELATINT	3 = spouse 2 = child, brother, sister 1 = other Blank = missing (9)
3	Other Relatives in Area RELATLAN	3 = spouse 2 = child, sibling 1 = other 0 = none Blank = missing (9)
4	Other Relatives Not in Area RELATOUT	3 = spouse or less 2 = child, sibling, or less 1 = other 0 = none Blank = missing (9)
5-6	Visits by Other Relatives VISITREL	___visits total/month Blank = missing (99)
7	Is This the First Nursing Home? FIRSTNH	0 = no 1 = yes Blank = missing (9)
8-9	How Long In Hospital HOSPITWK	___# weeks (use 4 wks = 1 month) Blank = missing (99)
10-11	Last Place of Living PLACLAST	1 = in own home, alone 2 = in own home, w/another 3 = in own apartment, alone 4 = in own apartment, w/another 5 = in senior citizen's apartment 6 = in your home or apartment 7 = in home or apartment of another relative 8 = in home for the aged or retirement center 9 = in a state hospital 10 = other Blank = missing (99)

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
12-13	2nd to Last Place of Living PLACLAS2	use same codes as cols 10-11
14-15	3rd to Last Place of Living PLACLAS3	use same codes as cols 10-11
16	Was Moving in With Relative Last Place? RELALAST	0 = no 1 = yes Blank = missing (9)
17	Helped with Bathing BATHHELP	0 = no 1 = yes
18	Helped with Dressing DRESSHELP	"
19	Helped with Toileting TOILHELP	"
20	Helped with Feeding FEEDHELP	"
21	Helped with Light Chores LITEHELP	"
22	Helped with Heavy House Cleaning HOUSHELP	"
23	Helped with Laundry LAUNHELP	"
24	Helped with Shopping SHOPHELP	"
25	Helped with Cooking COOKHELP	"
26	Helped with Medical Affairs MEDHELP	"
27	Helped with Transferring TRANHELP	"
HOW OFTEN HELPED WITH		
28	Bathing NUMBATH	____times/wk
29	Dressing NUMDRESS	"

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
30	Toileting NUMTOIL	___times/wk
31	Feeding NUMFEED	"
32	Light Chores NUMLITE	"
33	Heavy House Cleaning NUMHOUS	"
34	Laundry NUMLAUN	"
35	Shopping NUMSHOP	"
36	Cooking NUMCOOK	"
37	Medical Affairs NUMMED	"
38	Transferring NUMTRAN	" (1 = 1 time/week or less)
	DID THESE OCCUR:	
39	Death of Spouse P1	0 = no 1 = yes
40	Loss of Ability to Drive P2	"
41	Loss of Ability to Walk P3	"
42	Loss of Use of Limb(s) P4	"
43	Severe Impairment of Eyesight P5	"
44	Severe Impairment of Hearing P6	"
45	Severe Impairment of Speech P7	"
46	Loss of Continence P8	"
47	Loss of Orientation to Time P9	"
48	Loss of Orientation to Place P10	"
49	Started Misidentifying Others P11	"

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
50	Loss of Memory P12	0 = no 1 = yes
51	Ran Out of Money	"
52	Severe Physical Illness P14	"
53	Stroke P15	"
54	Heart Attack P16	"
55	Broken Hip or Leg P17	"
56	Became Depressed P18	"
57	Became Grouchy P19	"
58	Became Violent P20	"
59	Hallucinated P21	"
60	Became Delusional P22	"
61	Alcoholism P23	"
62	Social P24	
63	Mental P25	
	DID THESE LEAD TO PLACEMENT:	
64	Death of Spouse PP1	0 = no 1 = yes
65	Loss of Ability to Drive PP2	"
66	Loss of Ability to Walk PP3	"
67	Loss of Use of Limb(s) PP4	"
68	Severe Impairment of Eyesight PP5	"
69	Severe Impairment of Hearing PP6	"
70	Severe Impairment of Speech PP7	"
71	Loss of Continence PP8	"
72	Loss of Orientation to Time PP9	"
73	Loss of Orientation to Place PP10	"

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
74	Started Misidentifying Others PP11	0 = no 1 = yes
75	Loss of Memory PP12	"
76-78	ID#	
80	Card # = 1	

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
	DID THESE LEAD TO PLACEMENT (cont):	
1	Ran our of Money PP13	0 = no 1 = yes
2	Severe Physical Illness PP14	"
3	Stroke PP15	"
4	Heart Attack PP16	"
5	Broken Hip or Leg PP17	"
6	Became Depressed PP18	"
7	Became Grouchy PP19	"
8	Became Violent PP20	"
9	Hallucinated PP21	"
10	Became Delusional PP22	"
11	Alcoholism PP23	"
12	Social PP24	"
13	Mental PP25	"
	HAVE YOU HEARD OF:	
14	Home Health Aide HEALAID	0 = no 1 = yes
15	Adult Day Care Services DAYCARE	"
16	Physical Therapy PHYTHER	"
17	Visiting Nurses VNA	"
18	Housekeeping Aides HOUSAID	"
19	Meals on Wheels MOW	"
20	Transportation Services (GLATCH) GLATCH	"

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
21	Health Clinics PUBHEAL	0 = no 1 = yes
22	Community Mental Health Center CMHC	"
	HAVE YOU TRIED:	
23	Home Health Aide HEALAIDT	0 = no 1 = yes
24	Adult Day Care Services DAYCARET	"
25	Physical Therapy PHYTHERT	"
26	Visiting Nurses VNAT	"
27	Housekeeping Aides HOUSAIDT	"
28	Meals on Wheels MOWT	"
29	Transportation Services (GLATCH) GLATCHT	"
30	Health Clinics PUBHEALT	"
31	Community Mental Health Center CMHCT	"
	IMPORTANCE OF IN DECISION:	
32	Patient PATIMPOR	0 = none 1 = some 2 = much
33	Other Family FAMIMPOR	same as col 32
34	Clergyman CLERIMPOR	"
35	Physician MDIMPOR	"

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
36	Hospital Social Worker MSWIMPOR	0 = none 1 = some 2 = much
37	Nursing Home Administration ADMIMPOR	"
38	Nursing Home Staff Member STAFIMPO	"
39	Friends FRIMPOR	"
40	Family of Another Patient PTFAIMPO	"
41	Who Made Ultimate Decision? ULTDECI	1 = interviewee 2 = another relative 3 = patient 4 = other Blank = missing (9)
42-43	How Many Homes Visited? HOMVISIT	___# Blank = missing (99)
44-45	How Many Visits to Home Chosen? VISITCHO	___# Blank = missing (99)
46	Did _____ visit with you? VISITWI	0 = no 1 = yes
	INFLUENCE OF FOLLOWING FACTORS:	
47	Location LOCAT	0 = none 1 = some 2 = much Blank = missing (9)
48	Availability AVAIL	same as col 47
49	Staff Quality STAFQUAL	same as 47
50	Quality of Physical Care PHYSQUAL	"
51	Cleanliness CLEAN	"

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
52	Quality of Activity Program ACTIQUAL	0 = none 1 = some 2 = much Blanks = missing (9)
53	Condition of Other Residents CONDIT	"
54	Cost COST	"
55-56	How Often do you Visit? OFTVISI	___# per month (use 4 wks = 1 month) Blank = missing (99)
57	Visiting Compared to at First COMPVIS	0 = less 1 = same 2 = more
58	Visit Though Don't Want to GUILT1	5 = SA 4 = A 3 = ? 2 = D 1 = SD Blank = missing (9)
59	Think of Relative in Home GUILT2	same as col 58
60	Should Not Have Put in Home GUILT3	"
61	Ashamed to Tell GUILT4	"
62	Try More Alternatives GUILT5	"
	DO ANY OF THESE HAPPEN:	
63	Is Grouchy and Irritable GROUCH	0 = never 1 = sometimes 2 = often Blank = missing (9)
64	Seems Depressed DEPRESS	same as col 63
65	Does Not Recognize you NOTRECOG	same as col 63

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
66	Seems Disoriented DISORI	0 = never 1 = sometimes 2 = often Blank = missing (9)
67	Complains About Nursing Home COMPNH	"
68	Complains About Illness COMPILL	"
69	Complains about Life COMPLIFE	"
70	Do You Enjoy Your Visits ENJVIS	5 = 90 - 100% 4 = 65 - 90% 3 = 35 - 65% 2 = 10 - 35% 1 = 0 - 10% Blank = missing (9)
	HELPFUL W/PHYSICAL PROBLEMS:	
71	Patient's Physicain HPMD	0 = none 1 = some 2 = much
72	Nursing Home Administrator HPADMIN	same as 71
73	Nurse HPRN	same as 71
74	Nurse Aide HPNA	"
75	Family of Other Patients HPFAMS	"
76-78	Patient ID #	
80	Card # = 2	

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
	HELPFUL W/PHYSICAL PROBLEMS (cont)	
1	Clergyman HPCLERGY	0 = none 1 = some 2 = much
2	Social Worker HPMSW	same as col 1
	HELPFUL W/EMOTIONAL PROBLEMS	
3	Patient's Physician HEMD	0 = none 1 = some 2 = much
4	Nursing Home Administrator HEADMIN	same as col 3
5	Nurse HERN	"
6	Nurse's Aide HENA	"
7	Family of Other Patient HEFAMS	"
8	Clergyman HECLERGY	"
9	Social Worker HEMSW	"
10-11	Do You Ever Take Patient Out? PTOUT	____# times per year (use 12 mos = 1 year 4 wks - 1 mo) Blank = missing (99)
12-13	How Often Speak With On Phone? PHONE	___#/month (use 4 wks = 1 mo.) Blank = missing (99)
14-15	How Often Visit Before? VISITBEF	___#/month (use 4 wks = 1 mo) Blank = missing (99)
16	Routine In Household ROUTINE	0 = less stable 1 = same 2 = more stable Blank = missing (9)

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
17	Concern W/Problems CONCERN	0 = less 1 = same 2 = more
	ARE ANY OF THESE PROBLEMS:	
18	Getting Information GETINFO	0 = no problem 1 = somewhat 2 = big problem Blank = missing (9)
19	Understanding Mental State UNMENTAL	same as col 18
20	Understand Emotional State UNEMOT	"
21	Rules Make Visiting Difficult RULESVIS	"
22	Feel Guilty FEELGUIL	"
23	Can't Communicate NOCOMMUN	"
24	Patient is Angry PTANGRY	"
	USED BEFORE OR NOW:	
25	Meet W/Nursing Home Staff PROG1BEF	0 = no 1 = yes
26	Meet W/Families PROG2BEF	same as col 25
27	Talk W/Counselor PROG3BEF	"
28	Talk W/Counselor & Patient PROG4BEF	"
29	Get Alternatives PROG5BEF	"
30	Attend Classes PROG6BEF	"
31	Get Advice on Visiting PROG7BEF	"

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
	WOULD UTILIZE AT ADMISSION OR NOW:	
32	Meet With Staff PROG1WLD	0 = no 1 = yes
33	Meet W/Families PROG2WLD	same as 32
34	Talk W/Counselor PROG3WLD	"
35	Talk W/Counselor and Patient PROG4WLD	"
36	Get Alternatives PROG5WLD	"
37	Attend Classes PROG6WLD	"
38	Get Advice on Visiting PROG7WLD	"
39	Relative's Occupation RELOCCUP	use attached categories, Blank = missing (9) 8 = housewife
40	Relative's Education RELEDUC	1 = graduate, professional 2 = standard college grad 3 = partial college 4 = high school grads 5 = partial high school 6 = junior high school (7th-9th) 7 = less than 7 years of school Blank = missing (9)
41-42	How Many Children NOCHILD	# Blank = missing (99)
43	Heavy Drinker? DRINK	0 = no 1 = yes
44	Psychiatric Care PSYCH	0 = no 1 = yes
45	Respondent's Marital Status RESMARIT	1 = married 2 = widowed 3 = divorced 4 = separated 5 = single Blank = missing (9)

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
46	Respondent's Occupation RESOCCUP	___use attached categories 8 = housewife Blank = missing (9)
47	Respondent's Education RESEDUC	1 = graduate, professional 2 = standard college grad 3 = partial college 4 = high school grads 5 = partial high school 6 = junior high school (7th-9th) 7 = less than 7 years of school Blank = missing (9)
48	Spouse's Occupation SPOOCCUP	___use attached categories 8 = housewife Blank = missing (9)
49	Spouse's Education SPOEDUC	1 = graduate, professional 2 = standard college grad 3 = partial college 4 = high school grads 5 = partial high school 6 = junior high school (7th-9th) 7 = less than 7 years of school Blank = missing (9)
50	Confusion P26	0 = no 1 = yes
51	Nutrition P27	0 = no 1 = yes
52	Confusion PP26	"
53	Nutrition PP27	"
54	Reason for Move from 1st N.H. REASMOVE	1 = more care 2 = location, opening 3 = better care 4 = other Blank = missing (9)
55	How Patient Accepted Move PTACCEPT	5 = fully accept 4 = resigned ok 3 = unalert, no emotion 2 = wanted to come home 1 = totally opposed Blank = missing (9)

CODING SHEET - FAMILY INTERVIEW

Column	Variable	Code
56-57	What Do You Do On Visits-Primary DOVISIT1	01 = talk, play cards 02 = read (books, mail) 03 = watch TV 04 = physical things - visits, walks rides 05 = be w/other pts also 06 = do things to - feed. clean, etc 07 = take things 08 = do things for - laundry 09 = nothing - can't do Blank = missing (99)
58-59	What Do You Do on Visits -secondary DOVISIT2	same as cols 56-57
60	No Help In Understanding NOUNDER	1 = physical 2 = poor communication 3 = dissatisfied 4 = more therapy/activity 5 = patient's mental state 6 = other Blank = missing (9) 7 = NONE
61	Most Difficult to Cope With DIFFCOPE	1 = mental (confusion, depress) 2 = physical 3 = personality 4 = dependency 5 = coping w/death 6 = other Blank = missing (9) 7 = NONE
76-78	ID#	
80	Card # = 3	

APPENDIX F

EMPIRICAL V-ANALYSIS KEY CLUSTER STRUCTURE

APPENDIX F

EMPIRICAL V-ANALYSIS KEY CLUSTER STRUCTURE

Variables	Factor Loading
Cluster 1	
Do verbal things on visits (D)	.9457
Do active things on visits (D)	-.9392
Emotional support from MD	-.4116
Physical support from MD	-.3148
Total number of visits	-.3075
Cluster 2	
Self-care disability (D)	.8594
Messiness (D)	.8335
Impairment of sensorium (D)	.7827
Lack of interaction (D)	.7318
Sensory impairment	.4593
Impairment of ambulation	.4150
Lower activity level	.4003
More psychotic behaviors	.3916
Family takes patient out less	.3203
Cluster 3	
Placed because of physical problems (D)	.8724
Had more physical problems at admission (D)	.8016
Placed because of social problems	-.6375
Had more social problems at admission (D)	-.5028
In hospital longer before admission	.4166
Had more emotional problems at admission	-.3728
Male	.3609
Placed because of emotional problems	-.3115
Cluster 4	
Chose home because of cleanliness (D)	.8503
Chose home because of condition of other residents (D)	.7181
Visited home more before choosing (D)	.6812
Family more willing to take part in programs no	.4012
Visited more homes before choosing	.3931
Enjoy visits with relative more	-.3514
Chose home because of location	.2681

Cluster 5	
More verbally hostile (D)	.8377
More depressed (D)	.6277
Have more emotional problems on visits	.4873
Receives more psychotropic drugs on PRN basis	.4511
More physically hostile	.3993
More sensory problems at admission	-.2765
Cluster 6	
More cognitive problems at admission (D)	.8543
Placed because of cognitive problems (D)	.7301
More orientation problems on visiting (D)	.6777
Family has most difficulty coping with mental problems	.5828
Family is more concerned now	-.4165
Lower activity level for pt. (D)	-.3677
Patient is widowed	.2719
First nursing home placement	.2567
Cluster 7	
Had more help from family in household tasks (D)	.7653
Lived alone (D)	-.6959
Lived with family last	.5275
Had more help from family in personal care tasks	.5248
Lived with someone else	.4408
Routine of family more stable now	.3743
Family tried more alternatives	.3071
Cluster 8	
Chose home because of staff quality (D)	.8206
Chose home because of quality of physical care (D)	.8161
Family aware of more alternatives	.3457
Family gets emotional help from nursing home	.3089
M.D. important in placement decision	-.2492

Note: (D) denotes variables which are cluster definers.

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