

CAREGIVERS' PREFERENCES FOR INSTITUTIONAL INFORMATION AND SUPPORT
DURING THE GERIATRIC LONG-TERM ADMISSION PROCESS

by

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CHAPTER 1

Introduction

Admission of a family member to a long-term care facility is often a stressful time, especially when dealing with a large, bureaucratic facility. The elderly individual and the family, even the institution, have major adjustments to make. The hospitalization of one member disrupts the family unit (Van Dyke, 1980) as the balance of responsibility shifts, and a new equilibrium in providing care is sought (Brody & Spark, 1966). Many families express frustration and anger during the time of transition of an older person from home to institution. Family members of institutionalized elders seem to feel that more could be done to make the transition easier for them as well as for their relatives (Chenoweth & Spencer, 1986).

Past research has shown that families do need help in learning to assume responsible roles towards their institutionalized relatives, yet society does not prepare them for these new responsibilities (Stafford, 1976). Contrary to a common myth, families do not "dump" their relatives into a nursing home and leave them in the care of the employees (Springer & Brubaker, 1984). Instead, they tend to remain interested and involved in the care of their relatives, even if this becomes a draining and tedious affair.

Contemporary families may need support at the time of a crisis more than in the past because of certain historical changes that have occurred in our society. Demographic changes have reduced the number of descendants to whom elderly persons or their caregivers

can turn for help, so these "kin resources" are now often over-extended (Treas, 1977). Elderly persons are better educated, and are therefore expecting a higher standard of living throughout their lives (Shanas, 1979). A transformation in our economy has decreased parents' power to insure care and support by their children as they age (Treas, 1977). At one time, families were expected to see to the economic needs of their elderly members, but now there are government programs available to assist in the support of older members (Shanas, 1979). The family was once the primary source of care for the aged and the sick, but now there are more nursing homes and chronic disease hospitals to provide these services. Families were also the major providers of emotional support, but now there are trained social workers to intervene in the time of crisis (Shanas, 1979). Despite these changes the family is still the preferred and the primary source of support of aged persons in American society (Shanas, 1979). These changes can be confusing because family roles and norms are less clear, and there are more options from which individual members can choose when considering the kind of care most appropriate for an elderly member.

An additional and noteworthy family circumstance that may complicate family caregiving to older members is the changing role of women. Traditionally, women have been the care providers to sick and elderly family members. Now that there are more women working outside of the home, they are more likely to have responsibilities and obligations that compete with traditional duties

associated with caring for aging parents (Shanas, 1960). Women often feel "sandwiched" between caring for their own families, both young and old, and meeting job responsibilities (Brody, 1981).

Human service professionals must endeavor to strengthen existing family ties by providing the services and information that families need to continue supportive relationships with their elderly members, and to deal effectively with institutionalization of their relatives, when necessary. Providing appropriate information and support to families at the time of the admission of a member to a long-term care facility may ease some of the role strain felt by contemporary families.

One form of support, for example, would be for nursing homes to develop services to help families find appropriate roles within the long-term care system (Stafford, 1976). The family could be given the task of bringing the relative a favorite food on a specific day each week, or asked to speak as an advocate of long-term care facilities at a local civic meeting. Both younger and male family members could be encouraged to become involved, thereby creating an increased sense of family caregiving rather than overburdening the traditional female caregiver. The sense of involvement might help reduce the family's guilt and anxiety, and allow all members different opportunities to develop and continue active support to the relative. Programs such as these would help families move through their particular problems and more quickly reach a comfortable equilibrium in the balance of care to be provided by the family and by the facility to the elderly person (Brody & Spark, 1966).

Nursing home staff often see the patient's relatives as obstacles to the delivery of services (Van Dyke, 1980). Staff members need to understand the importance of maintaining a relationship between the relatives and the patient after admission. The family has much first-hand information about the patient that could help the staff provide better care. The time spent by family members in visiting the relative, if properly directed, could free staff for more demanding tasks and add to the overall quality of care provided. A change in staff attitude could lead to cooperative services that might diffuse some of the frustration and anger often expressed (Stafford, 1976).

Family satisfaction is also becoming more important to administrators of hospitals and long-term facilities because of competition for patients in the health care market (Abramowitz, Cote, & Berry, 1987). One way to attract clients might be to develop programs that assure families of the quality of care provided to both patients and their families.

There are potential problems in providing such services. It is challenging to be able to incorporate the heterogeneity of today's families, and to meet their diverse needs during the long-term care admission process. Caregivers do react differently to problems and vary in their abilities to manage them. Further, all caregivers do not see the same aspects of the long-term care situation as problematic. As stated by Zarit and associates (Zarit, Todd & Zarit, 1986) in summing up this observation, the variability in the caregivers' reactions is of major importance in planning interventions to alleviate their stress.

Families who admit elderly members to long-term care facilities face major adjustments. More than in previous times, they need information and support to help them adapt to the shift in the balance of care for their relatives. Staff and administration of long-term facilities are also recognizing the need for cooperative endeavors that facilitate the continuation of family ties. There is, however, little research data to substantiate what kinds of programs and services need to be developed. Gerontological research must continue to ask what programs and services provide the most helpful support to families at the time of the admission of an elderly member to a long-term care facility.

The time of admission is a critical time for families. They feel guilt and anxiety over making the decision to place their relatives into a long-term care facility. They may face negative reactions from friends or other family members because they have not continued to provide in-home care. Families may also encounter resistance from the elderly person who does not want to leave familiar surroundings and enter a new way of life.

The purpose of this research is to probe about the supports and services that families consider helpful and not helpful at the time of admission. It will also seek to determine the extent that families of long-term care patients actually utilize the services that are available from the facility, and why they may choose not to use them. It is hoped that their answers will help determine ideal types of support and services for families during the time of the admission of a family member to a long-term care facility.

CHAPTER 2

Literature Review

Weber's Theory on Organizations

A contrast can be made between a long-term care facility, which is a formal organization, and the family, an informal organization. In 1974, Max Weber, in his theory on organizations, established that formal organizations were able to maximize the use of technical knowledge, and, therefore, were more effective in task completion than informal organizations, which he called primary groups. Formal organizations were also larger, which allowed for specialization of tasks. They could better concentrate on smaller areas of action. This concentration and the repeated practice of the assigned tasks naturally allowed the formal organization to become the expert at that task (Dobrof & Litwak, 1977).

Weber also posited that primary groups rely on face-to-face contact of the whole group for communication, and the coordination of task accomplishment. On the other hand, formal groups maintain their distance and rely on the written word to communicate (Dobrof & Litwak, 1977). In a long-term care situation, the staff, for example, may feel the need to keep the family outside and uninvolved with the patient in order to carry out their tasks more efficiently. Written policies or memos convey this line of thinking to other shifts without the topic ever being openly discussed. It becomes the accepted manner in which a facility operates, and accounts

for the overzealous staff, and the air of high professionalism that is often displayed. Family, on the other hand, see these actions as staff who are cold and impersonal. This difference in communication patterns may be one element that produces guilt and the feeling of abandonment among the relatives of patients in long-term care facilities (Dobrof & Litwak, 1977).

Weber defined two types of tasks that need to be performed. Uniform tasks are those that are repetitive, require experts, and require a group to gather specialized resources, such as personnel, finances, or equipment. Nonuniform tasks involve affection, continual proximity, common lifestyles, and long-term commitment (Litwak, 1985). These are tasks often centered around emotional and social needs (Rathbone-McCuan, Hooyman, & Fortune, 1985).

In most health care transitions, there are nonuniform tasks, such as meal preparation by the family, that are relinquished to the facility. To meet more specialized demands and feed greater numbers of people, this becomes a uniform task, and more efficiently handled by the institution. Nonuniform tasks that are less appropriate to routinize, and that better meet the idiosyncratic needs of the patient are left to the family. As a family agrees to this arrangement, it is actually experiencing the partnership between the primary group and the institution (Dobroff & Litwak, 1977).

Economics is another factor in this comparison. Large scale organizations are more effective than primary groups in accomplishing specialized tasks because they have the ability to coordinate

a larger work force (Dobrof & Litwak, 1977). Nursing homes, for example, can provide around the clock care for a patient at a much more efficient rate than the family because they have more staff at their disposal.

Litwak's Alternative Theory

An alternative theory, formulated by Eugene Litwak in the early 1960s, took a broader perspective. This theory included the concepts of shared functions and a balance of coordination. The Weberian formulation suggesting that formal organizations are best able to get the maximum use of technical knowledge becomes the point of departure for Litwak's concepts.

Shared functions. The idea of shared functions suggests that many times technical knowledge is not crucial because it does not make a difference in the situation (Dobrof & Litwak, 1977). For example, on a week-end when the laundry staff is off duty and a patient has soiled all of the available bed lines, the family could either take them home to be washed or purchase new ones. Speed, flexibility, and commitment to the individual are important for efficiently handling this situation. The primary group or the family, as noted earlier, would be more flexible and faster in providing the needed care.

Usually there are two reasons that a person is admitted to a long-term care facility. First, the medical demands are heavy, often requiring twenty-four hour care. Second, the resources of the family have become depleted. The caregiver simply may not be able to take

any more emotional or physical strain, or, financially, the burden of care has affected the economic welfare of the family (Dobrof & Litwak, 1977). These reasons, although making a good defense for the placement of the patient, do not eliminate the need for nonuniform tasks. The aged person still has individualized needs that can best be handled by the primary group. Examples of these are preferred foods, special laundry, and contact with the community at large. Because organizations are set up to handle technical knowledge or large scale resources, they are not as adept at meeting personalized needs.

Balance theory of coordination. The balance theory of coordination posits that generally the same group should not try to handle both types of tasks. Neither group should be dominated by the other, and there is a need for both formal and primary groups to be present. Their activities should be closely coordinated, however, if the patient is to get the maximum quality of care. Balance theory suggests that there is an arbitrary point of distance that allows the balance of efficient cooperation to be maintained. If this occurs then both technical and nontechnical needs are more likely to be met (Dobrof & Litwak, 1977).

At any time the primary group and the formal group may be too far apart or too close together. If brought too close together, conflict may result causing both groups to lose the ability to effectively perform the tasks best suited for them. Their linkage must be close, but not too close. Otherwise, their contradictory

characteristics will negatively influence each other (Dobrof & Litwak, 1977). For example, sometimes institutions must use aggressive outreach programs to involve families who do not keep in contact with their hospitalized relatives. Other situations might call for procedures to remove the family members from the facility if their presence becomes overbearing, and inhibits the necessary care provided by trained staff.

The administration and staff in long-term care facilities must recognize the need for both technical and nontechnical tasks in providing care to hospitalized elderly persons. They should not push for the patient's isolation from their kin nor a complete merger of the family with the staff. There are shared functions between staff and family that cover a large range of activities. The development of policies within the facility, and informative programs for the families, would help to maintain a workable distance and enhance both the quality of care provided to the patient, and the relationship between the family and the administration.

Transition to Long-Term Care

Context of the transition. When an elderly person is admitted to a long-term care facility, family members usually have experienced a major crisis. Their energy, patience, and coping skills are at a low point. They are often dealing with a lot of emotional issues. The primary caregiver in the family is almost always in conflict with the family member who is being admitted (Bernheim & Lehman, 1985). Although the stress levels vary in each family, there seems

to be a limit to the continual in-home care that a family can provide without being negatively affected.

For years research has focused on either adult children or aged individuals without including the family context. Now special needs exist within the contemporary family that have been created by changing demographic trends; for example, changes in the role of the woman in the family, and the fact that elderly people are surviving longer usually resulting in increased dependency as they age. Caregiving experiences are normative to the modern family with frail elderly members, but until recent years have been ignored by research endeavors (Rathbone-McCuan, Hooyman, & Fortune, 1985). Caregiving solutions need to be found that maximize the appropriate and essential interdependency and independence for all family members (Rathborne-McCuan, Hooyman, & Fortune, 1985).

Long-term care experiences. Families vary in what they expect of a facility concerning the care and treatment that their family members will receive. These expectations are colored by fears as well as by immediate needs for reassurance and relief from the caregiving situation. Expectations are also governed by their level of education and sophistication about long-term care facilities. Also, the image of how the relative will be treated is often formed by media presentations that are sometimes misleading and inadequate (Bernheim & Lehman, 1985).

The guilt and frustration expressed by these families is well-documented. Joint decisions about who is responsible for what tasks in the care of the relative still must be made. The "shared

responsibility" between families and institutions is not yet defined, and remains a critical issue. Finding an appropriate balance of caregiving is a major challenge for practitioners, policymakers, and families (Rathbone-McCuan, Hooyman, & Fortune, 1985). Families are not retreating from caregiving responsibilities, but instead are struggling to find an acceptable and functional equilibrium with the long-term facility that they select for their relatives.

Research is needed to determine whether interventions can minimize the stress for specific family groups who attempt to provide care to their elders. Some work is being done on such topics as day care for Alzheimer's disease patients and support groups for families of dependent elders (Hartford & Parsons, 1982). These studies show that families are better able to deal with their caregiving responsibilities if they utilize respite care and receive adequate information. The challenge remains to reform policies and programs to strengthen family support, and to determine what approaches help families increase their effectiveness in managing the caregiving role as the elderly member makes the transition from living in the home to an institution (Rathbone-McCuan, Hooyman, & Fortune, 1985).

Support for Families in Transition

General benefits of support. Support is needed by all people, especially when experiencing stressful situations. For the purpose of this research, support is defined as the physical, emotional, spiritual, and financial elements that help sustain a person in difficult times (Springer & Brubaker, 1984). People develop a sense

of well-being from supportive relationships. These supportive relationships enable the individual to respond to the challenges and strains of everyday life. Evidence shows that persons who perceive themselves as having a support network are emotionally and physically healthier than those who feel they do not (Springer & Brubaker, 1984).

Support is especially important to persons in transition. It eases anxiety and fear about leaving a situation that is familiar and comfortable, and starting a new phase of life. Therefore, to support the caregiver faced with the placement of a relative into a long-term care facility is appropriate because it helps the caregiver remain involved thus facilitating the transition. Caregivers with adequate support feel less burdened, and more effective in their roles (Springer & Brubaker, 1984; Zarit, Reever, & Bach-Peterson, 1980). Understanding the value of support, especially during a transition, undergirds the rationale as confirmed by Mace and Rabins (1981) for developing supportive programs for families who are going through the stressful transition of admitting a family member to a long-term care facility.

Formal and informal support. There are basically two kinds of support that families receive: formal and informal. This concept is analogous to Weber's concept of formal and informal organizations. Formal support systems are those community services, agencies, and institutions designed to assume some of the caregiving tasks for older adults (Brody, 1979). The informal support network includes involved family, friends, and neighbors who provide assistance in

a less structured and more personal manner (Springer & Brubaker, 1984). Both forms of support are important and complementary. Each provides a type of support that the other cannot, and usually a caregiver needs a mixture to enhance the individual caregiving role (Shanas & Sussman, 1977).

Formal support systems usually supplement family caregiving. They serve to strengthen the family's ability to respond to the needs of the elderly person. Included are medical and legal care, nutrition, mental health services, financial assistance programs, and support groups (Springer & Brubaker, 1984).

Although the formal support system offers a range of services that the family's informal network may not be able to provide, it may not respond to the social and emotional needs of the individual (Atchley, 1983). A social worker cannot share the personal history, experiences, and memories of the informal support network, but would be more supportive than a nonexistent or abusive family. Public services, such as state operated long-term care facilities, must also be cost-effective to survive, and may not be able to provide highly specialized services for individual family situations. There are necessarily forms to be completed and definite procedures in a bureaucratic system that can confuse or even turn away families who seek help from the formal system. Often there is a high turnover rate for personnel in formal or social services that requires the family to readjust, thereby placing additional strain on a family already burdened with the stresses of caregiving (Atchley, 1983).

Informal support networks, on the other hand, offer a different

type of assistance to the burdened family. There are four separate aspects of informal support. One aspect is that informal support is on-going, and deals with long-term burdens and stress. However, informal support may only provide intermittent or short-term support to deal with an acute need or crisis (Caplan, 1974). Informal support may be instrumental and actually provide any needed physical assistance. Or, finally, informal support may be expressive, providing companionship or emotional strength during a crisis (Springer & Brubaker, 1984).

Support and long-term care. Admission to a long-term care facility is a time of particular stress on a family and on the elderly person. There is a definite shift in the responsibility for providing care from the informal atmosphere of the primary family to the more formal long-term care facility. Supports of differing types can help caregivers deal effectively with the transition, and continue to be involved with the care of the elderly family member after admission. What seems to be lacking is specific research that would help long-term care facilities design and implement services and programs to support families and their existing networks at the time of admission, making this transition easier for the family, the elder, and also for the facility. It is critical that families receive assistance to develop skills and gain information to help them continue their involvement in the caregiving system because they are already an important part of it (Springer & Brubaker, 1984). Families who are comfortable with the transition to an institution will be

better sources of support to elderly members who must adjust to the new living arrangements than those who display guilt and anxiety.

Linkage Between Families and Facilities

There is both practical significance and theoretical relevance in positing a linking model that places the knowledgeable family representative in an intermediary position between the elderly person and the institution (Shanas & Sussman, 1981). In this linking role the family can communicate, educate, and facilitate on behalf of the elder, and the institution can remain in control of various services such as the acquisition of financial assistance and health care.

Usually one member of the family assumes the primary responsibility for providing care to the frail elderly member. That person usually is most involved with both the care before admission, and the long-term care admission process. Also, it is usually the primary caregiver who remains most involved with the elder after admission, despite how difficult that becomes. This person serves unofficially as well as officially as the primary link between the elder and the family, the elder and the facility, and the family and the facility (Brody & Spark, 1966).

Elders facing placement in a long-term care facility need a primary linkage. They often have a harder time dealing with formal organizations than younger family members because of failing physical abilities, failing mental capacities, and an increasing unfamiliarity with modern bureaucracy. In looking to the future, with demographic changes such as the decrease in family size and the

increased mobility of family members, it is even speculated that elders of the twenty-first century will be in search of a relative to look after them and to take appropriate actions on their behalf (Shanas & Sussman, 1981). Thus, one can see the potential importance of a linkage between the family member and the institution.

Both the family and the formal organization must operate on a principle of shared functions in the care of the elderly person. The elderly person needs the family, or the primary group, to help handle unpredictable events and situations with many components that arise in a long-term care facility. Any specific need of the individual is best met through the family. The family usually takes the first responsibility in providing care, and is effective to the best of its ability. The formal organization is contacted second, and depends on the family for knowledge of the elder's existing resources. It is usually the primary caregiver who conveys both how the family will use the formal system, and the family's abilities to solve the problems brought on by placement (Shanas & Sussman, 1981). The formal organization is best utilized when expertise is needed to handle situations and events that are beyond the capabilities of the family. For example, consider the case of a caregiving spouse of a bed-fast individual who suddenly is hospitalized for a serious heart attack. Both of their sons live in distant states, and are unable to attend to the physical needs of their parents. It may be more appropriate that the invalid parent be placed temporarily into a long-term care facility than for either son to assume the caregiver's role. The

son's emotional support for both parents should be encouraged, and can, in fact, be continued via telephone conversations. Both formal and informal support systems are operating together for the benefit of the parents, and are still within the realms of their expertise and abilities.

To increase the quality of care for the elderly person, a symbiotic relationship between the elderly person, the family, and the long-term care facility is needed. All parts must be integrated because each segment needs the other. The responsibilities delegated to each segment, however, are more difficult to define (Shanas & Sussman, 1981). Long-term care facilities are in desperate need of scientific investigation as organizations. It is not at all clear how these facilities deal with families, patients, and community interests, as well as meet their other responsibilities (Shanas & Sussman, 1981).

Search for the Ideal

Family-as-partner concept. Research has begun to search for an ideal system that would accept and accommodate the needs of the family and the facility during the stressful time of admission. In the past, hospitals and long-term care facilities have done little more than increase the guilt and anxiety of the family members by concerning themselves with the patient, and ignoring the family's needs (Hirst & Metcalf, 1986). A new attitude and a new kind of health care professional might improve the caregiving situation. It is time that the facility and the family collaborate in the treatment and care of the patient. Facilities must begin to treat the

family as a partner and ally in the overall care plan of the elder (Hatfield, 1979).

Services could be extended to the family as well as to the patient, thus including the family-as-partner concept. The past lack of interest and acceptance of this concept has resulted in a lower involvement by families in patient care, and thus probably a lower quality of care. It has left some very negative stereotypes of the treatment patients receive in long-term care facilities (Smith & Bengston, 1979). If more facilities were to plan family orientations and educational services, the public as well as involved families might have a better understanding of the aging process and the care that institutions can provide. Additional information to the families might also reduce their guilt about placement of an elderly member, and help them recognize their limitations before emotional and physical resources are depleted (Smith & Bengston, 1979).

Long-term care facility administrators need to recognize that families are important to the total care of the patient. In accepting this attitude, they need to develop services and programs to help families achieve the proper perspective on their role within the facility, and in the treatment plan for the patients. If institutions were to foster increased family involvement, this would maximize the value of the informal support system, the family, and give support to the formal service, the facility (Olsen, 1980).

Components of educational support. Recent studies have recognized several components of a family education program that seem to be most helpful to families as they seek to continue their

involvement with the care of their relatives. First, families need more knowledge about the normal aging process and any specific health problem that their relatives might have (Hatfield, 1979; Olsen, 1980). This would include the type of disorder as well as the extent of the impairment, and what to expect in the future (Hirst & Metcalf, 1986). Second, families need to know what their role is within the institutional setting (Hirst & Metcalf, 1986). Most families admitting an elder to a long-term care facility are entering the bureaucratic service system for the first time. They need to become familiar with its rules, regulations, and the general limits with which they are now expected to comply (Hirst & Metcalf, 1986; Olsen, 1980). Just as important in this shift in the balance of responsibility, family members need to know how the facility expects them to act in relation to the care of their relatives (Olsen, 1980). This may include, for example, the desire to know how to better visit with elderly family members if impairment has progressed to a confused and disoriented state (Hirst & Metcalf, 1986). Third, the family members should be allowed to talk and to express their feelings. They may need help in coping with some of the emotions that they are experiencing. At any rate, they need to know that these feelings are appropriate and normal for families to be having at this time (Hatfield, 1979; Hirst & Metcalf, 1986; Olsen, 1980). Finally, families want to know that their relatives are being cared for in the best possible way (Hatfield, 1979; Hirst & Metcalf, 1986). Families have usually invested a considerable amount of time, energy, and resources in taking care of their relative to the best of

their abilities at home. When this is no longer a viable option, the families need to be reassured that their relatives are still receiving the best possible care.

Additional needs. Families seem to be satisfied when there are shared functions of care, and when there is a balance in the coordination of tasks (Smith & Bengston, 1979). Institutions should encourage the families of their patients to be involved in their care within the guidelines of the facility. Families should be made to feel welcomed and comfortable there. By this sharing of responsibility for patients, the quality of the care provided can only increase.

Unfortunately, most long-term care facilities do not offer such programs. When steps are taken to include families, it is from the facility point of view, and the families are seldom asked what their preferences for support really are. In addition to this, nowhere has this researcher been able to find what families want at the critical time of admission. The components of an educational program that were previously described, while apparently excellent and all encompassing, are not aimed specifically at the support and information needs of the family at the time of admission.

Summary

Weber's organization theory has helped gerontologists recognize that for elders residing in long-term care facilities formal organizations are more effective in the performance of tasks requiring extensive, specialized knowledge. Routine or uniform tasks in institutions, such as meal preparation or health services, should be left to the formal organization. This actually frees the family

to respond to the social and emotional needs of the individual, for which, indeed, it is best suited (Litwak & Figueria, 1968). Litwak further recognized the need to share the caregiving tasks between each group and to balance their performance for the best results. Flexibility in the coordination of these activities is important so the equilibrium of care will not be disrupted.

It is also important to recognize the role of the primary caregiver who links the institution and the family with the elderly person. The process of admission to a long-term care facility is stressful. If adequate support and information are provided by the facility to this person, a high level of family involvement will probably be maintained. Support at this critical time would most likely ease the family's anxiety, decrease any sense of guilt, and foster future involvement in the care of the relative.

Staff needs to be aware of the changes in the contemporary family system, and adapt their patterns of support accordingly (Dobrof & Litwak, 1977). Policies that have been in effect within a facility for a long time may no longer be satisfactory. Maintaining communication and exchanges today requires the art of communicating over long distances and across class lines. Striving to find new ways, or accepting different ways, permits the autonomy of each family. This message of acceptance may decrease the anxiety, and lighten the dilemma of a particular family.

Few long-term care facilities take the needs of the individual into account (Litwak & Figueria, 1968), but the continuous exchange between theory and practice will eventually lead to the development

of principles that will be of greater use to us all (Dobrof & Litwak, 1977) as we seek ways to support the family as it admits a member to a long-term care facility.

CHAPTER 3

Methods

Design

The facility that cooperated with this research project (see Appendix A) is Piedmont Geriatric Hospital. It is a psychogeriatric facility with approximately 200 residents who are at least age 65, have a diagnosis of some type of mental impairment, and who have no major physical impairment upon admission. Because this is a state operated facility, patients may be admitted on a voluntary or involuntary status, meaning that in some cases, the court system may direct placement into the facility rather than a family requesting it. The facility serves a 22-county and 5-city catchment area in Southside Virginia. This includes both a very rural population and metropolitan areas such as Richmond.

To collect data for this project, telephone interviews were conducted with 20 primary caregivers of patients at Piedmont Geriatric Hospital. Additional interviews followed with other involved family members who were willing to participate.

The following criteria for sample selection were used: (a) the caregiver is a relative who was providing care and support to the patient before the admission, (b) the patient was admitted in the months of May, June, July, August, and September, 1987, and was still a patient at Piedmont Geriatric Hospital, and (c) the patient received a primary diagnosis of dementia.

Caregivers were selected first from September, the month with the least amount of time between the admission and the interview

in order to optimize recall of the support needed, then from each preceding month, respectively, until 20 family units were obtained.

The hospital director made the first contact by letter (see Appendix B) with the selected primary caregivers to inform them of the interview as well as to establish credibility for the project (Frey, 1983). One person returned this letter, asking to be omitted from the project. This name was dropped from the sample and a letter was sent to the next eligible caregiver. Thus the response rate is 95.2%. Upon receiving the telephone call from the project director, all caregivers were asked for their consent to continue with the interview, and no one refused to participate. The project director signed and has on file a record of each permission (see Appendix C).

Each interview followed the guidelines of the questionnaire (see Appendix D), and lasted approximately thirty minutes. The information was collected and coded so that the data could not be associated with any particular caregiver. Letters thanking the participants were sent out as the interviews were completed (see Appendix B).

There were two reasons for limiting the interviews to families with relatives who have a diagnosis of dementia. First, approximately 75% of the patients in Piedmont Geriatric Hospital have a diagnosis of some type of dementia (B. Fowlkes, personal communication, October 21, 1987). These include undifferentiated or chronic dementia, alcohol-related dementia, senile-onset dementia, degenerative dementia of the Alzheimer's type, and other classifiable dementias including types of delerium, delusions, and depression. It is estimated that

this same percentage carries over to nursing homes, and other kinds of long-term care facilities. Therefore, the primary reason for this sample selection criterion was that the results would be more generalizable from a long-term, mental health facility to other long-term care facilities.

Questionnaire

The questionnaire contains both open-ended and structured questions, and was developed: (a) to describe both the patient and the primary caregiver (Information about the patient was taken from the hospital records prior to the interviews, (b) to probe about the supports and services that respondents consider helpful and not helpful at the time of admission, (c) to determine the extent of utilization of available services by respondents, (d) to determine the reasons for not using the resources available for support, and (e) to probe for ideal types of support for families at the time of the admission of a family member to a long-term care facility.

Specific questions were developed from several sources since there was no instrument already designed for the purpose of this research. First, health care related questionnaires were reviewed (York & Calsyn, 1977; Holden & Lewine, 1982; Abramowitz et al., 1987) to find areas that might be associated with the long-term admission process, and family reactions to the delivery of such services. Questions were evaluated for appropriateness and clarity. Second, health care professionals were interviewed including a long-term

care facility director, an admissions director, and the director of psycho-social services from a long-term care facility. Their responses were helpful in simplifying the terminology used as well as adding to the list of questions considered important to the planning and implementation of intervention programs. Finally, faculty members at VPI & SU who had completed descriptive research, especially those familiar with telephone survey methods, were consulted. Their input improved the format and face validity of the questionnaire.

A pilot study was conducted to further test the questionnaire. First, it was reviewed by professionals in both the areas of academic research and long-term health care. Second, telephone calls were made to five persons in similar caregiving situations to test the actual administration of the survey. No significant changes were made in either format or content as a result of the pilot effort.

It was anticipated that the design of the questionnaire would facilitate personalized responses, and give families an opportunity to expand upon their insights into the admission process since they represent a vital resource in the care of the patient. Their answers were expected to yield potential guidelines to help facilities plan services to support families at the time of admission (Holden & Lewine, 1982).

Six long-term care personnel who are involved in the admission process were also asked to complete parts of the questionnaire so that their perceptions of the services offered by the facility could be compared with the responses of the family caregivers.

Data Analysis

Qualitative data analysis techniques were applied to identify themes and patterns of responses (Kerlinger, 1973). Results are expressed in terms of percentages and illustrated by tables. Descriptions of both the patient and the family caregiver are included. The level of both physical and mental impairment of the patient was recorded to determine if either affected the family's involvement in care after admission.

Interrelationships among the following areas of inquiry were examined: (a) family involvement prior to admission, (b) family visits to the patient after placement, (c) willingness of families to participate in educational and informative programs, (d) information and support families receive from the facility, and (e) mental and physical status of the patient (York & Calsyn, 1977). Responses were tabulated and coded into categories to determine any trends, and to support previous findings in the literature.

The results of this research were expected to show that families who were involved with their relative prior to admission to a long-term care facility would continue to be involved, even if the visits became more difficult due to increased impairments or discomfort with the facility. It was also expected that families would say facilities offered very little to them in terms of information and education at the time of admission. When support services were offered, it was anticipated that families would underutilize them.

Limitations

Certain limitations of this research project must be recognized. First, it was a purposive study designed to gather information on a specific subject. Second, the sample size was small. If a wider population could have been surveyed, result could have been further examined for the possibility that these findings express a cultural phenomenon. For example, the majority of the long-term care patients in this study were Black, and national statistics show that there are more Caucasians than Blacks residing in nursing homes (American Association of Retired Persons (AARP), 1985). Statistics also cite a lower educational level for Black adults (AARP, 1985), and in this research, some Black caregivers had very high levels of education. This may not hold true for the total hospital population, but, clearly, whether there is a relationship between these factors needs further investigation.

CHAPTER 4

Results, Discussion and Implications

Results

The typical patient in this study is a Black female, aged 74, who is widowed but still has supportive family members. She is alert and cooperative, but exhibits partial disorientation, especially to place and time. She is ambulatory, but does require assistance with her activities of daily living. She is in no major physical distress; however, she has a chronic illness listed in her medical history.

The age range of the sample was from 65 to 85 years with 5 patients who were age 76. There were 8 Caucasians and 12 Black persons. The females outnumbered the males by 15 to 5. Additional variations showed that 11 were widowed, 4 were still married, 3 were divorced, and 2 were single (See Tables 1 and 2).

Insert Tables 1 and 2 about here

A comparison of the sample to the total population of the hospital (Table 1) yielded different data. The total number of patients in the facility was 196. Of these, there were 110 females and 86 males; 85 were Caucasian and 111 were Black. The average age for the total population was 76 years (W. Pierce, personal communication, December 3, 1987). Approximately 65% of the patients had some family member who was involved with their care (B. Fowlkes, personal communication, December 1, 1987).

Table 1

Demographic Characteristics of Sample as Compared to Population

Variable	Sample		Total Facility	
	n	%	n	%
Age, Years				
65-69	5	25		
70-74	5	25		
75-79	6	30		
80-84	3	15		
85 and up	1	5		
Mean	74.15		76.00	
Gender				
Male	5	25	86	43.8
Female	15	75	110	56.1
Race				
Black	12	60	111	56.6
White	8	40	85	43.4
Marital Status				
Married	4	20		
Widowed	11	55		
Divorced	3	15		
Single	2	10		

Table 2

Patients' Mental and Physical Status

Variable	N.	%
Mental Status		
Totally Oriented	3	15
Totally Disoriented	6	30
Partially Disoriented	11	55
Other Mental Characteristics ^a		
Alert	9	45
Cooperative	12	60
Poor Memory	7	35
Physical Status		
Ambulatory	11	55
Walks With Help	3	15
Bedridden	1	5
No Documentation	5	25
Other Physical Characteristics ^a		
No Major Distress	11	55
Chronic Illness Recorded	18	90
Needs Help With Activities of Daily Living (ADL)	8	40

^aN's exceed 20 because more than one condition can apply

The typical caregiver in this study is a female, usually the daughter, aged 51. She has a high school education, is employed full-time away from home, and does not want to reveal her income. The impaired elder has lived with her prior to hospitalization, and she received no significant support or assistance from other family members in providing care to the elder.

In the total sample of respondents, the age range was 28 to 75 years with 3 caregivers who were age 40. There were 15 females and 7 males. Their relationships to the patient varied, showing 6 daughters, 3 sons, 3 spouses, 2 nieces, 2 brothers, a cousin, a sister, a daughter-in-law, a nephew, a granddaughter, and an adopted daughter. Eleven were employed full-time, 3 were employed part-time, 4 were unemployed, and 4 were retired. They reported a great variation in income, from none to over \$100,000.00 per year. Educational levels also ranged from not completing high school to post-graduate work. Nine caregivers had lived with the elderly person for whom they were responsible, but the distance varied up to one caregiver living over seven hundred miles away. Although 13 felt they had no support in caring for their relatives, 5 felt they had limited support, and 4 believed they had adequate support from other family members (See Table 3).

Insert Table 3 about here

Table 3
Characteristics of Caregivers

Variable	n	Variable	n
Age, years		Support From Others	
20-29	1	None	13
30-39	3	Supported	4
40-49	6	Limited Support	5
50-59	5	Annual Income	
60-69	3	None	1
70-79	3	Social Security Only	3
Missing	1	Less than \$8,000	2
Mean	51.19	\$10,000-\$15,000	3
Gender		\$35,000	3
Male	7	\$70,000-\$80,000	2
Female	15	Over \$100,000	1
Relationship to Patient		No Answer	7
Son	3	Employment	
Daughter	6	Full-time	11
Spouse	3	Part-time	3
Nephew	1	Unemployed	4
Niece	2	Retired	4
Cousin	1	Distance Lived from Patient Prior to Admission	
Sister	1	With patient	9
Brother	2	Less than 1 mile	3
Daughter-in-law	1	1-5 miles	3
Granddaughter	1	6-100 miles	3
Other	1	101-200 miles	2
Education		About 700 miles	1
0-12 years	4	Missing	1
12 Years	7		
13-15 Years	2		
16 Years	5		
Over 16 Years	3		
Missing	1		

To compare the perceptions of primary caregivers with other family involved with the patient, additional telephone interviews were conducted within three family units. These included (a) a brother/sister pair, (b) two sons of a primary caregiver who was a nephew of the patient, and (c) a woman who had been raised in foster care by the patient and was considered part of the natural family. Responses from (a) and (c) confirmed the responses from the primary caregiver. Information from (b) revealed only that they gave support to their father and had very little knowledge about the patient. The responses from this set of interviews (b) were not calculated with the responses of the primary caregivers and extended family members. Therefore, the total sample (n = 22) represented in the discussion of results and in tables reflects the responses of 20 primary caregivers and two additional extended family members.

The majority of family caregivers feel that the long-term care facility encourages them to remain involved with their relatives. The most frequent comments referred to the helpful, kind, and cooperative attitude of staff members who had been encountered. Other examples of this encouragement were the staff notifying them of upcoming meetings and conferences that pertained to the family member, on-going communication by telephone and letter that updated the caregiver on the patient's condition, and the specific verbal acknowledgment that visits were important to the patient, thus encouraging the family to make an effort to come often.

Most caregivers had daily, weekly, or at least several times a month contact with the relative prior to hospitalization. Although most were social visits, during these times they also shopped, cleaned, and drove the elder to conduct personal business. Recognizing that distance was a factor for some, the caregivers were typically in close contact with their relative prior to admission to the long-term care facility.

The interviews also revealed that this involvement continued after institutionalization. The primary caregivers, however, were divided as to whether they attended planned conferences with facility staff to discuss their relatives. Approximately one-half explained that they could not attend these meetings because the times conflicted with their work schedules. The other half made necessary travel arrangements, and came to the conference as they were scheduled. One family member had requested that the time of the conference be changed, the facility had met this request, and the relative was able to attend. This type of flexibility to coordinate activities that involve both staff and family members represents what Litwak's theory encouraged to develop a partnership with the family, and to maintain an equilibrium in the provision of care.

When asked what would be the most helpful information or support to receive at the time of the admission of the family member to the long-term care facility, one-half of the respondents replied nothing was needed. Although this particular question was asked in a number

of different ways to elicit a response, caregivers did not seem to be able to verbalize an answer or focus on their own needs during the admission process. This satisfaction with the status quo may be a reflection of our society's willingness to accept the advice and recommendations of the medical profession as absolute and unquestionable. It may also reflect the strong emphasis on family involvement by this particular facility. Practitioners must continue to be aware of the ethnic and cultural differences, however, that could inhibit a family from voicing their real concerns or asking for a different way of handling a situation.

Other caregivers, although satisfied with the support and information received from the facility, commented on a lack of helpfulness from the general health care delivery system. These statements included both their need for the relative to be admitted sooner, and for help with the admission decision.

The caregivers were asked to evaluate a list of possible ways a long-term care facility could assist the family during the admission process. If they had used the service, they were asked to rate their degree of satisfaction. If they had not used the service, they were asked how useful they felt the service might have been to them during the admission process. The primary caregivers were generally satisfied with the information and support received. Some items on the list were not explained by the admissions staff to the caregivers, and the caregivers did not think these items were important. Examples of these are the location of visitors' parking

spaces, local restaurants, and chaplain services. However, three areas of unavailable support that caregivers felt might have been helpful are noted as possible exceptions. These are a complete tour of the facility, a list of activities with which the patient could be involved, and a support group for families of long-term care patients. Detailed results are provided in Table 4.

Insert Table 4 about here

Table 5 presents the responses of facility nurses and social workers to the question about the types of information they provide to families of newly admitted patients. In comparing their perceptions of support with those of family caregivers as indicated in Table 4, it is interesting to note that families felt they received more assistance than the staff felt they gave. Perhaps some of the information that the staff routinely gives out to families is not perceived as part of the admissions process, but is indeed useful and helpful as the family begins the partnership with the facility. Another possible explanation is what the morale of the admissions staff may be low, and the administration might bolster this by recognizing the good job that families think the staff is doing.

It is also noted that the nursing staff responsible for admissions felt that they gave out a wider range of information than the social workers who were also involved. Explanations for this could stem from the fact that the nurses are located on the same unit where the patient lives, and the family has more immediate contact with the nurses. Social workers tend to refer questions

Table 4

Respondents' Use of Information and Support Services Offered by
Facility and Associated Satisfaction or Perceived Usefulness

Service	Used By Respondent					
	Yes			No		
	Satisfaction			Perceived Usefulness		
	1	2	3	1	2	3
	Low		High	Low		High
Chaplain Services			7	11		3
Social Workers			20	1		
Facility Tour			6	6		9
Activity List			4	3	3	9
Financial Information	2		11	2	1	4
How To Visit			8	7	3	9
Medical Information			15	2	1	4
Diagnosis		2	12	3		4
Privacy		1	2	7		1
Visiting Hours			14	4		1
Who/How To Call		1	18			1
Support Group	1			9	4	6
Hospital Rules			9	5		3
Visitor Parking	7			10	1	2
Local Restaurants			2	11	1	7

that the family might have regarding diagnosis and treatment to the medical staff. Nurses are also available on a 24-hour basis, and the social workers are primarily available on an eight-hour shift. Again, this perception could reflect the morale within each department, and might well be examined further by the facility.

Insert Table 5 about here

Discussion

Several points of interest surface with a closer examination of the data. First, most of the caregivers felt little more could be done to assist them at the time of admission. It seems these caregivers had difficulty focusing on their own needs during this time. This observation is supported by such comments as:

"I didn't need anything. It's not me that's sick." (SISTER)

"I want help for him, not for me." (NIECE)

Respondents displayed the tendency to ignore their own needs in favor of attending to the concerns of the patient making the transition to long-term care.

A progressive philosophy held by the administrators of the facility has encouraged a focus on outreach and education. Often students from other institutions have internships at Piedmont to learn more about the management of mental health problems in elderly persons. In 1983, Piedmont Geriatric Institute, a subdivision of the hospital, was created to provide training to staff in nursing homes and adult homes statewide. This atmosphere may help to explain

Table 5

Provision of Information by Admission Staff to Family Caregivers

Service	Nurses (n=2)		Social Workers (n=4)	
	n	%	n	%
Chaplain	2	100	1	25
Social Workers	2	100	4	100
Tour	1	50	1	25
Activity List	2	100	3	75
Financial Information	1	50	4	100
How to Visit	2	100	3	75
Medical Information	2	100	2	50
Diagnosis	2	100	1	25
Privacy	1	50	0	
Visiting Hours	2	100	3	75
How/Who to Call	2	100	4	100
Support Group	0		0	
Hospital Rules	2	100	2	50
Visitor Parking	1	50	0	
Local Restaurants	2	100	1	25

Note. Entries show the number and percentage who said they provided the information.

the satisfaction expressed by family caregivers with the information and support provided by the long-term care facility during the admission process, a factor often not reflected in current literature. This administrative philosophy does, however, provide an excellent example of Weber and Litwak's concept of shared caregiving responsibilities and the balance of coordination which results in high family satisfaction and continued involvement.

In general, then, the families were satisfied with the services and information that were made available to them by the long-term facility at the time of admission. The single service from the list that was not available to families of patients at Piedmont and that needs further explanation, relates to the support group for family members. The staff wished to ascertain the extent of interest in support groups. The results reveal that the distance the relative lived from the facility, rather than the actual need, made this service seem more or less feasible to the respondents. If a relative lived a considerable distance or relied on others for transportation, then this option was rejected as not useful. On the other hand, if support groups could be offered at a location closer to the caregiver's home, perhaps this service would be more appealing. Those family members who had some previous involvement with a support group also tended to favor this as an option for support at the time of admission of a relative.

Race is another variable that may partially account for findings which are different from those in previous research. Nationally, only 3% of all Black elderly reside in institutions whereas

approximately 5% of white elderly do (AARP, 1985). Whites also make up a much larger percentage of elderly admissions to mental health facilities than persons from other races (U.S. Department of Health and Human Services, (DHHS), 1987). It is noted, however, that admissions for elderly minority persons are highest in state and county operated mental facilities (DHHS, 1987). Since Piedmont is a state facility, this may account for the fact that nearly 57% of the total population is Black.

Admission to a long-term care facility is usually a last resort for both Black and white families. Most minority elders remain in the community, and care is provided by families and friends. However, as the number of frail elderly people continues to increase, so does the burden of care on families. Admissions from all races are more likely to occur, and both white and nonwhite families typically remain involved in supporting institutionalized elders (AARP, 1985).

As Weber and Litwak have pointed out regarding long-term care facilities, efforts to encourage family and staff interaction will yield a higher quality patient care. In facilities that have a higher white than nonwhite staffing ratio, there are more chances for ethnic differences to interfere with the development of the family-as-partner concept. Care needs to be taken with both the dissemination of patient-related information and, for example, the atmosphere in which conferences are held, so that families feel comfortable and understand the roles that are expected of them. People whose social backgrounds lead to middle-class jobs approach aging with greater resources in terms of knowledge and income than

those less fortunate (Atchley, 1983). These differences need to be taken into account when providing any family with support and information.

Other comments reflected some dissatisfaction with the overall health-care system, and did not pertain specifically to the time of admission. These comments are noteworthy, however, because they do voice a way that families need additional information and support with the entire placement process. Examples of these comments are:

"I felt I needed everybody's help, but especially from the health care people. There was some confusion because they took her off her medicine. Then we had the problems."
(COUSIN)

"It was very stressful. I didn't know what to do, and the family didn't want to be bothered. There were too many referrals. It seemed we just went back and forth. I needed emotional support because I had to deal with my own anger and especially hers. She was in between qualifications for nursing homes and adult homes, and we went back and forth. My frustration built to the point I was afraid I would abuse her. She wouldn't even bathe. There was no bond between us because I had lived so far away."
(GRANDDAUGHTER)

"The admission was not easy. The family had known her condition long before the health care people would take any action. If she was admitted earlier, she wouldn't have caused so much humiliation and embarrassment to the family."
(SISTER)

"It would have been helpful for a social worker to explain the options for the best care for her."
(DAUGHTER)

"It would have helped if the people at (an acute care hospital) would have been better informed, and given us more information and options for her care."
(DAUGHTER)

One caregiver reflected two separate problems:

"I needed to have her admitted sooner. There is such a high turnover in the staff that they never seem to get to know her." (SPOUSE)

Implications

Professionals in the health care field need to continue to provide information and support to families at the time they admit a relative to a long-term care facility. When these supports are in place, the families continue to remain involved with the care of the relative. In some cases in this study, the family caregivers actually reported more interaction with the relative after admission than prior to hospitalization. This continued involvement supports current literature affirming families do not "dump" their relatives into long-term care facilities and leave them, but rather seek alternatives to providing the best possible care in their circumstances.

It appears, however, that often these families are so involved in the process of admission that they do not have the time and energy to think about their own needs. Professionals should be aware of these unspoken needs, and still attempt to alleviate the stress and emotional turmoil that may be affecting these families. One way to do this would be to increase the information flow between long-term care facilities and those agencies with which the family first comes in contact such as acute-care hospitals and community services. This might increase the family's awareness of various options and restrictions to providing the necessary care to their relative.

This research also indicates that while a caregiver often cannot recognize a personal need for support, if adequate services and information are routinely provided, the caregiver utilizes them, and perceives the facility as encouraging and supportive. This is one way to improve the sometimes negative image that long-term care facilities carry.

Another area of concern for health care professionals needs to be the dissemination of information to the caregivers. Practitioners must seek new and more flexible ways to establish and maintain contact with the contemporary family. A majority of the caregivers in this study were employed full-time away from home. Although they continued to visit and remain in contact with both the relative and the staff of the facility, the majority of caregivers could not attend the conferences and meetings that were scheduled with the intent of family and staff interaction. This no doubt results in a loss of information about the patient for the staff as well as a potential loss of support and information for the family. It seems that the involved family, the patient, and the staff would benefit if meetings could be arranged at a more convenient time, or the information delivered in a more creative manner. An example of this would be to record any relevant information from the facility on audio cassettes for the employed caregiver to listen to enroute to work.

Administrators in long-term facilities need to be aware of the extra demands these suggestions for innovation and flexibility may place on already overextended staff. Compensation could be offered

by way of flexible work hours or extra time earned for week-end or night meetings. To insure a workable and satisfactory relationship between staff and family caregivers, all parties involved need to hear the praise and favorable comments that sometimes do not get related to appropriate persons when a problem has been worked out or an unpleasant task has been performed. These extra efforts would go a long way towards cementing a positive caregiving relationship, and generally improving the image of long-term care facilities.

CHAPTER 5

Summary and Conclusion

This study was designed to determine what types of information and support families wanted at the time they admitted their relatives to a long-term care facility. Twenty family units were interviewed by telephone, including both the primary caregiver and, where appropriate, other significant, involved family members. It was found that half of the families felt they wanted no additional information or support other than what they had received, and that the families were basically satisfied with the facility's admission process. The majority of the families felt that the institution also encouraged their continued involvement with their relatives after admission. These findings support Weber and Litwak's theories that when a balance of responsibility is developed, and caregiving tasks are shared between the family and the facility, both parties are satisfied. The results also support Litwak's theory that when the primary caregiver feels supported and informed, a high level of family involvement is maintained after the admission to a formal organization such as a long-term care facility.

Researchers and practitioners need to be aware, however, that the admission process is often a stressful time, and that family members may be so involved that they do not focus on their own needs, but rather on the needs of the elderly patient. Support services and information should continue to be provided on an individualized basis throughout the admission period, considering such factors as

ethnic differences, whether the caregiver is employed full-time, and the distance the caregiver lives from the facility.

This information should suggest new variables to be investigated in future research, and new ideas for effective interventions with families who are admitting a member to a long-term care facility. The results should be of interest to facility administrators, to direct care staff such as social workers, admissions personnel and chaplains, and to families with frail elders. Both in-service training programs for staff in long-term care facilities and additional interventions with families should help maximize the assistance and support available during the stressful process of admission, therefore continuing and strengthening the necessary link between families and institutions.

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APPENDIX A
Approval of Joint Project



COMMONWEALTH of VIRGINIA

PIEDMONT GERIATRIC HOSPITAL
HWY. 360-460
BURKEVILLE, VIRGINIA 23922

August 26, 1987

Department of Mental Health
and Mental Retardation

Dr. Rosemary Blieszner
Department of Family and Child Development
Wallace Annex
Virginia Tech
Blacksburg, Virginia 24061

Dear Dr. Blieszner:

Re: Approval of Joint Project between Piedmont Geriatric
Hospital and VPI&SU (Thesis by Beverly Bass)

It is my understanding that Beverly Bass will head a project as part of her thesis to determine what family caregivers expect from long-term care facilities in terms of information and support services at the time of admission. This is to inform the thesis committee that Beverly has the cooperation of Piedmont Hospital and access to the necessary patient information and records.

Should you need additional information, please let me know. We look forward to working with Beverly on this project.

Sincerely,

W. R. Pierce, Jr.
Director

WRP/py

/cc: B. Bass

APPENDIX B
Communication With Families



COMMONWEALTH of VIRGINIA

PIEDMONT GERIATRIC HOSPITAL
HWY. 360-460
BURKEVILLE, VIRGINIA 23922

Department of Mental Health
and Mental Retardation

Name
Address

Dear _____,

You have been selected from families who have relatives at Piedmont to be a part of a project conducted by a graduate student from Virginia Tech. The purpose of this study is to see what kinds of information and support families want at the time they admit a family member to a long-term care hospital. Because you have gone through this recently, we think you will have some helpful information to give. We will use this information to plan future services and programs to help families through this often difficult time.

Please expect a call from Beverly Bass, the project director, in the near future. We hope you will be able to make time for this, and cooperate with this project.

Thank you very much.

Sincerely,

Willard R. Pierce
Director
Piedmont Geriatric Hospital

VIRGINIA TECH

Department of Family and Child Development
College of Human Resources

Wallace Annex
Blacksburg, Virginia 24061-8299
(703) 961-4794 or 4795

Name
Address

Dear _____,

Thank you for taking the time to talk with me about admitting your relative to Piedmont. The information you were able to share was really helpful and useful. We will now take what you have experienced together with the experiences of other families, and identify the types of support and information that should be provided at the time of admission.

We could not possibly guess at the answers. Your personal experience will help our understanding of this often stressful process of admitting a relative to a long-term care facility. We sincerely thank you, and appreciate your time and information.

Sincerely,

Beverly Bass
Project Director

Rosemary Blieszner, Ph.D.
Associate Professor
Gerontology and Family Studies

APPENDIX C
Consent Statement

FAMILY CAREGIVERS RESEARCH PROJECT--CONSENT STATEMENT

(To be signed by project director for each telephone interview)

I certify that I have explained the nature of the project to the primary caregiver listed below, and have answered any questions that were asked. It is further understood that the caregiver gave a verbal consent for the telephone interview.

name of caregiver

date

project director

APPENDIX D
Questionnaire

QUESTIONNAIRE

Hello, is this the _____ residence?

If wrong number, terminate the call with something like
"Sorry to have bothered you."

May I speak with _____ ?

This is Beverly Bass calling from Virginia Tech. I am conducting a project with Piedmont Geriatric Hospital in Burkeville to find out what kinds of support or assistance or information families want from hospitals when they admit a family member. Did you receive a letter from Mr. Pierce, the Hospital director, earlier this month telling you that I would be calling about this project?

If yes, proceed with the introduction.

If no, say something like sorry, then explain the project, tell them that you would like for them to be a part of it, and continue.

Because you have recently admitted a family member to a long-term care facility, I'm sure you could give us some helpful information. We will use ideas from people like you to plan future programs and services to help others through the admission process.

This interview will take about thirty minutes. I want to also tell you that anything you tell me will be kept confidential. Please feel free to ask questions at any time, and you may withhold your answer on any question if you wish. Is it okay to continue?

CHARACTERISTICS OF THE PATIENT (taken from record)

1. Name
2. Age
3. Gender (M/F)
4. Marital status
5. Diagnosis
6. Patient classification (level of impairment)
 - Mental
 - Physical

CHARACTERISTICS OF THE PRIMARY CAREGIVER

First I want to ask you some questions about yourself.

1. Age today:
2. Gender (M/F)
3. Race (a) white (b) black (c) other _____
4. Relationship (a) spouse (b) son (c) daughter (d) other _____
5. Approximate income for the total household?
6. Education: number years completed:
7. Employment (Tell me all that apply.)
 - a. full time (30 or more hours)
 - b. part time (less than 30 hours)
 - c. not employed outside home
 - d. retired
8. How far did you live from your _____ before hospitalization?

The next group of questions will be about your caregiving responsibilities with _____.

9. Do others in your family share the responsibility for caring for your _____?

If yes, list each person and give examples of kinds of support (for example, listening to you, help with tasks, share expenses).

13. Do you think the hospital encourages or discourages your involvement with the care _____ is receiving?

Would you give examples of these?

14. If you could have any kind of service or support, what would have been the most helpful at the time you were admitting _____ to the hospital? Who would this have come from?

15. Have you attended any conferences or special events at the hospital since _____ was admitted? If yes, which ones?

16. Other. . .

Thank you very much for taking your time to think about and answer these questions. Because you have been so involved in this process of admitting a family member to an institution, you have given us some helpful information. We hope we can use this to help the hospital work better in the future with other families like yours.

Would you like for me to send you a copy of the results? I could put your name and address on a separate sheet of paper, and send them to you when the project is completed.

Thanks again for your cooperation. Good-bye.

**The vita has been removed from
the scanned document**

CAREGIVERS' PREFERENCES FOR INSTITUTIONAL INFORMATION AND SUPPORT
DURING THE GERIATRIC LONG-TERM ADMISSION PROCESS

by

Beverly Bass Hines

Committee Chair: Rosemary Blieszner
Family and Child Development

(ABSTRACT)

The focus of this study was to determine what types of information and support families wanted at the time they admitted a relative to a long-term care facility. Twenty families were interviewed by telephone, including both the primary caregiver and, where appropriate caregiving family members. It was found that half of the families felt they wanted no additional information or support than they had received, and that they were basically satisfied with the facility's admission process. The majority of the families felt that the institution also encouraged their continued involvement with their relatives after admission.

The results suggest that researchers and practitioners need to be aware, however, that the admission process is often a stressful time, and that family members may be so involved in making long-term care arrangements that they do not focus on their own needs, but only on those of the elderly patient. Support services and information should be provided on an individual basis, considering such

factors as whether the caregiver is employed full-time and the distance the caregiver lives from the facility.