FACTORS INFLUENCING THE DISCHARGE PLAN FOR TERMINAL PATIENTS: WHERE ALTERNATIVES EXIST—HOME VS. INSTITUTION

Heidi Mandel

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ABSTRACT

FACTORS INFLUENCING THE DISCHARGE PLAN FOR TERMINAL PATIENTS WHERE ALTERNATIVES EXIST - HOME VS. INSTITUTION

Heidi Mandel

The major objective of this research was to investigate factors involved in discharge planning for terminal patients and their families where alternatives exist - home vs. institution. This was an exploratory-descriptive survey, utilizing questionnaires and telephone interviews. The respondents were 86 trained social workers from acute care hospitals and hospice units within hospitals. Data collected were analyzed quantitatively and qualitatively.

The social workers who responded came from hospitals within one state, and from hospices across the country. Sampling was a two-stage process, with hospitals and hospices selected in the first stage, and social workers in the second.

The major research aims were:

1. Identify the parameters of discharge plans for terminal patients, including those factors already suggested in the literature as being involved in discharge planning.

2. Specify the relative importance among factors that social workers consider in their formulation of discharge plans for terminal patients.

3. Compare differences in worker reactions to discharge planning
as between the hospital and hospice settings.

Most social workers felt terminal patients needed nursing services upon discharge, and doctors and nurses were important team members in discharge planning. Hospice workers were more likely than hospital workers to take patients' needs and home conditions into account. Hospice workers recognized patients' spiritual needs and considered religious personnel to be significant team members.

Hospital workers saw their patients as more hopeful, while hospice workers perceived their patients to be more accepting of prognosis. Although most social workers felt patients and families needed counseling around death and dying, hospice workers especially noted the need for bereavement counseling. They were more likely than hospital workers to consider the family attitude of leaving the decision of disposition to the patient.

All hospice workers and many hospital workers had personal experience with family and terminal illness. Most workers preferred sending patients home to die, rather than to an institution. Plans to send patients home generated workers' feelings of competence and empathy toward their work, while plans to send patients to institutions provoked feelings of sadness, guilt, and frustration. Generally, workers believed patients were aware of their prognosis, despite their feelings that the patients were not formally told by their physicians.

Principal factors influencing discharge planning were found to be the family's desire to have the patient home, financial conditions, and the patient's desire to go home.
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CHAPTER 1

RESEARCH PROBLEM

A literature is developing around the needs of terminal patients and their families, as well as the roles and services of the health care personnel in the field of terminal care. The social work contribution to this literature reflects the goal of helping dying patients and their families formulate ways of achieving optimal physical and social well-being. But little of the research done has examined the actual services social workers provide for the terminally ill. This study investigates one of the services that medical social workers provide terminal patients and their families; the service of formulating a discharge plan.

The need for discharge planning has increased during recent years. This development is partly related to public controls having entered the health field. The escalated costs of medical care and public programs have led to legislation mandating review committees such as the Professional Standards Review Organization or PSRO (Public Law 92-603—Amendments to the Social Security Act, 1972). The Professional Standards Review Organization requires of the health care system that: (1) each hospitalization be necessary, (2) the appropriate services be offered, (3) patients be discharged with appropriate follow-up plans ensuring efficient use of the hospital bed.
system and the provision of appropriate resources following hospitalization, and (4) sanctions be imposed if the above conditions are not met.

In order to meet these conditions, plans for discharge must be a multidisciplinary effort. However, because internal and external social and psychological factors are major determinants of the practicality and success of the discharge plan, social workers in health care settings provide the major professional assessment and intervention with the patient, family, and community in discharge planning. For example, readiness on the part of the patient and family to accept the treatment plan, and willingness and ability to assume appropriate responsibility for carrying it out, would seem to be key elements to a "successful" discharge. The social worker assists in marshaling patients' and families' internal and external resources to reach this objective, while working toward the long-term goal of improved health and social functioning.

Discharge planning is a process that is composed of the following components: needs assessment, treatment plan, resource evaluation, and resource mobilization. To accomplish this process, social workers have become sensitive to several operational guidelines. First, they are concerned with the length of time a patient stays in the acute care hospital. They do not want patients to have over-extended stays for social, rather than medical reasons. Early problem identification of patients with "high social risk" (Rehr, Berkman and Rosenberg, 1980) will increase efficiency of intervention. Second, health care should include appropriate and
sufficient medical, nursing, and rehabilitative or restorative services. But these will not be effective unless social and psychological impairments are diagnosed and treated simultaneously. The process of discharge planning demands a close and cooperative team approach with members of the medical and paramedical team.

Another aspect of the complexity associated with assessing the effectiveness of discharge plans has to do with professional values (Davidson, 1978). When, in the process of discharge plan formulation, social workers are pressured by the hospital administration to help patients leave as quickly as possible, they may doubt the degree to which they are individualizing their patients. Meyer (1970) states that individualization differentiates people and that this has been a traditional social work principle. This study seeks to examine, among other things, the degree to which discharge plans for terminal patients and their families are individualized.

The function of discharge planning takes on heightened significance for terminal patients and their families. Terminal illness creates a state of extreme personal crisis and disequilibrium for the patient and family, and also presents difficulties for the medical staff. Everyone involved must confront their own feelings about dying and death. When little in the way of aggressive medical treatment can be offered in terminal care, the physician often relinquishes management of the patient and family to others. The discharge plan requires from the social worker a high degree of knowledge of the physical limitations and emotional coping abilities of the patient and family, responsibility and respect
toward the patient and family in helping them decide where the 
patient is going to die, creativity in planning for an environ-
ment that will support and protect the patient's and family's 
autonomy and dignity in the time remaining, and sensitivity in 
planning for the family's maintenance, as survivors, in economic, 
social and emotional terms. Terminal care crosses every speciali-
zation in an acute care hospital, so that all social workers 
experience dying patients and their families. Terminal illness 
also presents itself in other health care settings and social 
agencies.

Social work has a commitment to acquire knowledge about its 
services and their effectiveness. Bartlett (1970) observes that 
the greater part of social work "knowledge" lies in actual practice, 
and is unrecognized to a large extent because it has not been sys-
tematically codified and tested for general use. In order to gain 
scientific knowledge about discharge plans it is imperative to 
fully and accurately describe them and to study the factors that 
influence the development of such plans. This is not a simple 
process. Discharge plans represent the end-product of a dynamic 
assessment and series of treatments. They tend to include a host of 
factors that have been tailored to each patient and family situation.

This study investigates the nature of discharge plans for 
terminal patients in hospitals. The research will generate a compre-
hensive listing of the variables considered in discharge plans and 
describe the factors that influence social workers and other pro-
fessionals in the discharge planning process. In addition, the study
I will provide a foundation for future research to evaluate the effectiveness of discharge plans. There are at least three different ways to evaluate plans: (1) through dimensions of the patient; (2) conditions of the family during the terminal period, and (3) long-range consequences on the surviving family members. These evaluative foci are not necessarily correlated. For example, one type of discharge plan may increase the patient's self-esteem but decrease levels of esteem or functioning among other members of the family.

Previous research on discharge planning has revealed a relationship between the timing of referral and the length of in-hospital stay for patients (Berkman and Rehr, 1972; Schrager et al., 1978). The latter authors found three additional factors that play a part in delaying or impeding the process of discharge planning: (1) lack of appropriate extended care beds; (2) limited cooperation of the medical staff in the necessary paperwork; and (3) change in the medical condition of the patient (Schrager et al., 1978). Lindenberg and Coulton (1980) in a study describing the posthospital needs of patients and the extent to which these needs were met subsequent to discharge, found that for a large percentage of needs, family or friends provided the planned services. The needs that these authors defined as part of discharge planning were: follow-up medical supervision; shelter; nursing care; health education; physical therapy; occupational therapy; assistance to patients with psychosocial problems associated with illness; assistance to families with psychosocial problems associated with illness; assistance with
personal care; nutritional services; homemaker services; vocational rehabilitation; medical equipment; environmental modification; transportation; financial planning; legal services; meaningful individual and social activity; and coordination of services.

Although much has been written on the nature of social work interventions with terminal patients and their families (Prichard et al., 1977, and others), there is little research on what social workers feel is important in the formulation of discharge plans for the terminal patient and his family. What needs to be investigated are the factors that affect the formulation of the plan and their relative importance. Schrager et al. (1978) suggest more study of the factors affecting discharge planning, and they note a need to identify factors both within and outside of the social worker's control. Lindenberg and Coulton (1980) believe that their research implies that for many categories of patient need, fewer than 60 percent of patients had their needs adequately met one month after discharge. Also implied was that dependence on family and friends to meet these needs would take its toll on the performance of healthy family functioning.

A number of factors that bear upon planning for discharge have been suggested in the literature on the needs of terminal patients and their families. The present study will document similarities and differences among social workers in their formulations of discharge plans for the terminal patient in the hospital. For example, one variable to be examined is the designated location for dying: home or institution. Although this variable is crude, it is an
important one with some clearcut implications for the terminally ill. The following factors will be explored in terms of their relationship to the discharge planning process: (1) timing of referral; (2) lack of appropriate extended care beds; (3) change in condition of the patient; (4) limited cooperation of medical staff in necessary paperwork; (5) patient's desire to go home; (6) family's need for continuing psychological, social, economic and other support following patient discharge; (9) patient and family's financial resources; (10) adaptability of patient's home environment to meet his needs; (11) patient's need for continuing medical, nursing, rehabilitative, clinical, dietary care and transportation upon discharge; and (12) social worker's perceived role autonomy with hospital administration and medical staff.

New models of terminal care, such as the hospice that deals exclusively with terminal patients and their families, have come into existence and require investigation of their services. It is fruitful to include hospice social workers in this study as a comparison with hospital social workers, since, perhaps as a result of specialization or different philosophy, hospice workers have discovered a different way of intervening and giving services to terminal patients and their families.

Among the various models of hospice (classified according to how their in-patient component is developed) is one in which the in-patient program is housed in an institution, such as an acute care hospital, and there exists no coordinated home care program. Consequently social workers within this type of hospice also must
formulate discharge plans for their terminal patients.

This research on discharge planning for the terminal patient will collect data about discharge planning from two settings: the acute care hospitals and hospice units within existing hospitals. The study, being exploratory-descriptive in nature, has the following aims:

1. Identify the parameters of discharge plans for terminal patients.
2. Examine with empirical data those factors already suggested in the literature as included in discharge planning.
3. Specify the relative importance among factors that social workers consider in the formulation of discharge plans for terminal patients.
4. Compare differences in discharge planning between the hospital and hospice setting.
5. Formulate useful hypotheses about the behavior prescribed in the discharge planning process, which may be tested in further research.
Discharge Planning:

Despite the complexity of the task and social work's traditional commitment to this function, hospital discharge planning was not explicitly defined until its recent emergence as a crucial factor in hospitals' compliance with governmental regulations and financial survival. In 1974 the American Hospital Association defined discharge planning as a centralized and coordinated program developed to ensure continuity of care for patients. The process involved identification of those patients needing services, assessment of patient and family needs upon discharge, knowledge of and use of a wide variety of community resources, including the patient's home, and evaluation of the most appropriate place for the patient to go upon discharge. In short, the Association states, "The key word is coordination: the establishment of a focal point at which the contributions of each department or service are brought together to identify the posthospitalization needs of the patient and the resources, for both care and financing, to meet those needs. The discharge planning program should ensure understanding of the alternatives, participation of the patient and family in the decision and timely completion of arrangements to carry out the accepted
plan.)* Although the Association views discharge planning as primarily an administrative task which could be undertaken by any one of several professions, social work throughout its history has long retained the discharge planning function. (Bartlett, 1957; Berkman and Rehr, 1970).

The Joint Commission on Accreditation of Hospitals presents discharge planning in its relationship with the utilization review regulations. In its manual it states, "Discharge planning shall be initiated as early as a determination of the need for such activity can be made, in order to facilitate discharge at that point in time when an acute level of care is no longer required... The utilization review may specify the situations in which non-physician health care professionals are permitted to initiate discharge planning..." (Joint Commission on Accreditation of Hospitals, 1978).

From a social work perspective, Rossen (1977) defines discharge planning as that professional service that helps patients and families cope with their illness, move through the hospital system, and return to the community with appropriate supports. It involves the assessment of individual needs, formulation of a plan, and implementation of the plan to ensure the continuing care and well being of the patient and family. Stein supports the social work leadership role in discharge planning. He believes, "Sound discharge planning of patients, concerned with a person's future way of life,

frequently calls for the greatest of professional security and skill in helping other health professionals to delineate the patient's need and in aiding individuals and their families in their decision reaching process" (Stein, 1975).

One issue of discharge planning that is important for social work practice, that this study addresses, is which patients need discharge planning. Ideally all patients should either be given the benefits of social services or should at the minimum have the option of calling upon social service for discharge planning (Ratliff, 1981). When social workers do their own casefinding, rather than wait for referrals from other health personnel, it is useful to use a screening mechanism in order to identify patients and families that are at high-risk in terms of social or physical stress. (Rehr, Berkman, and Rosenberg, 1980). This research addresses terminal patients and their families, which all authors agree is a target population in desperate need of discharge planning.

Medical social workers often confront bureaucratic constraints on their professional autonomy in discharge planning (Teague, 1971). According to Toren (1969) the main threat to professional autonomy is interference by the organization with the application of knowledge or with the delivery of service. Studies by Billingsley (1964) and Scott (1969) demonstrate conflicts that professionals encounter in their work within a bureaucratic structure and conclude that these conflicts are quite real for social workers. The need of hospitals to comply with regulations regarding financial reimbursement creates pressure for early discharge for patients. This pressure
may clash with the social worker's role of promoting client self-determination and right to quality health care as a consumer. Levy (1975) describes the conflict that social workers feel when confronted with an agency directive that they feel violates their professional ethics. And Davidson (1978) exemplifies this by stating, "...social workers, when constrained to assist patients to select one of several equally bad discharge plans because they must leave the hospital, experience what Levy (1975) suggested" (Davidson, 1978).

Discharge planning for comprehensive patient care requires a multidisciplinary approach in which obstacles to effective practice can surface. Among the members of the medical team there exist differences in knowledge, values, skills and goals which produce different conceptual orientations to people, needs, and interventions. In collaboration, what is needed are feelings and attitudes of mutual respect and knowledge of one another's functions and competence. This study pays attention to interprofessional practice in discharge planning as it relates to the work of the social worker. One of the newest conceptual frameworks pertaining to discharge planning and the multidisciplinary approach was developed by McKeehan (1981). To paraphrase, she defines discharge planning as a process of activities in which team collaboration exists to help the patient leave the hospital. Her framework describes the scope, process, and the development of a model of discharge planning. However, her principal thesis is that the tasks of discharge planning should be under the auspices of nursing, and not social service. Rehr et al.
(1974) describe the issues and conflicts of interprofessional collaboration, such as who should be considered the leader and when, who should be part of the medical team, what should the team accomplish in terms of activities and working relationships, but few clear guidelines have been formulated for the role of the social worker as a member of the medical team in working with terminal patients and families in discharge planning.

There are a variety of factors involved in the process of discharge planning. One of these, timing of referral, has been researched by several studies, notably Berkman and Rehr (1972) and Schrager et al. (1978). The results indicate that this factor is a crucial element in determining the effectiveness of discharge planning. Both studies implied that early referral tends to result in shorter hospital stays. This finding leads the authors to believe that early referral enables the social worker to offer the full range of comprehensive services needed by the patient and his family. The authors feel that an effective plan is one begun early in the admission, that is, whether the case is picked up by independent care-finding or by referral from health personnel. Timing of referral as related to discharge planning has been explored by several hospital task forces (American Hospital Association, 1974; Greater Detroit Health Care, 1977), and other authors (Clark, 1969; Barham, 1974; Fitzpatrick, 1968). Early referral is suggested by Ryder, Elkin, and Doten (1971).

The American Hospital Association (1974) enumerates the factors to be included in the formulation of the discharge plan, such as:
(1) physicians services--frequency and kind and where these services be given; (2) nursing services--frequency, continuity of availability, level of needed competence; (3) rehabilitation services--modalities, frequency, type of equipment, level of supervision required, level of professional skill needed and setting; (4) clinical laboratory and radiology--kind and frequency; (5) nutrition--kind and amount of dietary guidance and supervision needed, frequency or review; (6) social services--kind and frequency of counseling; (7) transportation frequency, distance, kind of conveyance, costs and financial feasibility; (8) financial resources--availability of coverage, sources of payment for special needs, family resources and needs for assistance.

Also in the assessment, the plan should include the patient's and family's attitude toward the illness, the decision of where to go upon discharge, and an evaluation of the home environment. La Bianca and Cubelli (1977) underline these factors as important in building social work knowledge for the task of discharge planning. Lindenberg and Coulton (1980) list these same factors in their study describing the posthospital needs of patients and the extent to which these needs were met subsequent to discharge.

Lindenberg and Coulton (1980) attempted to determine the effectiveness of discharge planning for patients with cardio-vascular, cancer, orthopedic, and cerebrovascular problems in the Cleveland area. The findings reported that for a large percentage of needs, one month following discharge, family or friends provided the planned services. The categories of need that did not have the service planned were: shelter; vocational rehabilitation; environmental modifi-
cation; and meaningful activities. The authors claim that healthy family functioning may be impeded by the dependence of the patient on the family to meet his needs. The authors also found that social workers were not using community resources for follow-up care, either because the resources were inadequate, or they did not exist to meet the needs of patients. A recent study was conducted by the Greater New York Hospital Association (1981) whose purpose was to find out how well discharge planning programs are able to predict where a person will be six months after discharge. As part of the study, follow-up interviews were conducted with the patients three months after discharge to identify any patient needs that had not been met due to poor discharge planning. The findings showed that patients were readmitted to hospitals within three months, and many patients reported a significant decline in the level of care after discharge. It appears necessary, therefore, to develop guidelines and indicators for defining a "successful" and effective discharge plan for the terminal patient.

Schrager et al. (1978) found three factors which played a part in delaying or impeding the discharge planning process: (1) lack of appropriate extended care beds; (2) limited cooperation of medical staff in the necessary paperwork; and (3) change in the medical condition of the patient. Hung (1976) found delay and procrastination by the family toward initiating placement applications in discharge planning in her study of brain tumor patients and their families.
Needs of the Terminal Patient and His Family:

Sociological work on the dying patient and his family finds that the dying individual is defined as a deviant. He loses his social value and becomes "marginal." There is a lack of norms for his behavior with others (Glaser and Straus, 1964, 1968; Sudnow, 1967; Schneidman, 1976). Studies document evidence of emotional resistance to interactions with the dying (Parsons, 1966; Crane, 1970; Kalish, 1966). Studies have also shown that during the terminal stage, physicians have great difficulty confronting their dying patients and communicating with them about their illness and prognosis, as well as with their families (Dovemuehle, 1965; Quint, 1967; Lasagna, 1968; Feifel, 1959; Verwoerdt, 1966; Bulgar, 1963; Friedman, 1970; Thomas, 1972). Studies on nurses' interaction with terminal patients also give evidence of the same difficulty with communication (Glaser and Straus, 1964; 1968; Sudnow, 1967; Quint, 1967; Lewis, 1969; Martinson, 1978; Nursing 75, 1975). Mount (1976) has gathered data indicating that patients want to know their diagnosis and prognosis, but that this usually does not happen. Saunders (1965) calls attention to the fact that hospital staffs generally make an effort to keep the patients in ignorance about their diagnosis and prognosis. Thus, the terminal patient in the hospital frequently feels depressed, isolated and guilty about being a burden on his environment. His environment gives him messages which lower his feelings of competence, dignity and self-esteem.

Professional literature from the fields of social work, medicine, and psychology, views death and dying as a period of crisis
in the life cycle of the individual. The experience of dying taxes one's existing coping strategies and strengths since it is beyond the realm of traditional problem-solving methods (Pattison, 1967; Hinton, 1967; Pearson, 1969; Schoenberg et al., 1972; Norton, 1963; Weisman, 1972, 1974; Shneidman, 1973, 1976; Goldstein, 1973; Feifel, 1965; White, 1973). Studies demonstrate that dying patients are well aware that they are dying, despite the fact that they may not chose to discuss it openly (Hinton, 1963, 1974; Witzel, 1975; McIntosh, 1977; Graeme, 1975; Parkes, 1973; Hackett, 1976, and others). West (1980) has explored the issue of communication with patients and their families and the medical staff and has found that patients are aware of their prognosis even if they have not been formally "told" it. West believes that most patients would welcome the opportunity to discuss their illness with their physicians and family openly.

In the literature, the experience of dying is conditioned by a host of feelings and attitudes. The experience reawakens problems with dependency, passivity, narcissism, identity, anger and competence. The dying patient may fear the unknown and the distintegration of his body. He may feel guilt about being a burden on family and friends and, as a result of rage toward his disease. He must confront grief feelings on many levels, from his home, job, pets and personal belongings, to his close family and significant others. The dying patient may fear death as a punishment and see himself as a failure because of an unfinished need to complete some life task or fulfill an obligation. The dying patient may suffer profound isolation and frustration with himself and others. (Shneidman, 1973, 1976; Weisman,

In the process of discharge planning the social worker must take into account the patient's attitude toward his illness and prognosis because this will have a relation to his communication with his family and his participation in the decision-making of where to go upon discharge.

The psychoanalytic perspective on the experience of dying is concerned with the process in which the patient relinquishes his involvement with the outside work (Freud, 1914; Eissler, 1955). The psychoanalytic treatment of dying patients is aimed at helping them defend against object loss by facilitating the development of a regressive relationship with the therapist. The therapeutic alliance serves as protection against the anxiety and depression. The main therapeutic tool is one of unlimited time given to the patient as a gift of love (Eissler, 1955; Norton, 1963; Joseph, 1962).

Kubler-Ross (1969) in her classic study describes five stages of reactions to dying: (1) Denial; (2) Anger; (3) Bargaining; (4) Depression; and (5) Acceptance. These stages describe a process of realization, with the later stages reflecting greater recognition of the facts of death. Other authors have criticized this classification on the grounds that many patients do not seem to follow the stages. In fairness to Ross, she never claimed that all of her stages must be passed through by every patient. The fact that she termed them "stages" led one to expect a sequence.
One of the reasons this sequence is seldom seen among cancer patients is that the character of the disease is irregular and unpredictable. Thus, the patient faces a number of disappointments each of which must be grieved before the person is ready to move on to the next (Weisman and Worden, 1977). Two studies showed that psychological factors played a significant part in length of time of survival. Weisman and Worden (1975) calculated the average survival time of patients with various types of incurable cancer. They then compared a group of patients who survived longer than average with another group who died in a shorter period. They found that longevity significantly correlated with patients who maintained active and mutually responsive relationships, provided that the intensity of their demands was not so extreme as to alienate people responsible for their care. Shorter survival was found among cancer patients who reflected alienation, deprivation, depression and destructive relationships which extended into their terminal period. Verwoerdt and Elmore (1967) studied thirty terminally ill patients and how they coped; they concluded that those who had least hope died earlier, and patients who were more satisfied with the past were more hopeful and lived longer. From these studies it would seem incumbent upon social workers to counsel patients about their feelings and attitudes toward their illness and the significant persons in their lives in order to help them resolve conflicts and frustrations in the time remaining.

LeShan (1961) believes that the will to live must be strengthened in order to lessen the disease process. He feels that the dying person
needs help to draw upon his inner resources and examine his values and goals. Pattison (1967) and Weisman (1972) view dying as an integrative process which reflects the individual's unique style of living. Weisman's concept of "appropriate death" (1972, 1977) is that the only consolation which can be authentically offered to the dying person is the freedom to die his own death. Weisman believes that the professional staff can help the patient choose his own style of dying and death. Dying patients need to achieve a measure of consciousness, control, competence and protection of their autonomy and identity (Prestage, 1968; Cassem and Stewart, 1975; Beverley, 1976; Kastenbaum, 1974). Thus, one way in which terminal patients can retain a measure of control and participation in the decision-making while they are hospitalized is to assert their own wishes as to where they want to go upon discharge. Whether they choose home or institution reflects their style of living and the style in which they wish to die.

Social Work Practice With Terminal Patients and Their Families

The literature on social work practice with terminal patients and their families stresses what has traditionally been present in the relationship between practitioner and client, namely, the process of listening to, identifying and understanding feelings. (NASW, 1961; Pilsecker, 1975; MacLaurin, 1959; Morrissey, 1963; Weisberg, 1974; Cohen and Dizenhuz, 1977; Daniel, 1973; Krant, Beiser, Adler, and Johnston, 1976). Terminal illness leaves patients and families with profound feelings of helplessness, humiliation and loneliness.
accompanied by physical, emotional and financial suffering. The social worker wants to create an atmosphere of open dialogue with the patient and family and help all involved gain dignity and peace.

At the Tufts Psychosocial Cancer Unit of the New England Medical Center, Krant, Beiser, Adler and Johnston (1976) developed the tasks for social work intervention. These were: establishing a relationship, opening blocked channels of communication, facilitating mourning process, catalyzing interactions with community support systems, fostering individualization, and role rehearsal for the soon-to-be bereaved family members. Smith and McNamara (1977) also suggest similar interventive strategies for meeting the needs of cancer patients and families. Hackett (1976) stresses the need for open communication between the professional staff and the patient and family. Lincoln, Twersky, and Sale (1974) feel that it is essential to involve the doctor and nurse in patient and/or family interviews, and offer to make follow-up home visits for bereavement counseling. They also claim that the social worker has the role to educate the medical team members about his professional perspective in patient care.

Social work interventions generated from an ecological perspective have been developed by Goldstein (1973), Moynihan, (1975), and Wijnberg and Schwartz (1975). These authors view death and dying as a crisis stage in the life cycle which has profound effects on the patient, family and their environmental systems. They believe that social workers can help the patient and family decide on meaningful tasks to keep them close and supportive, as
well as prepare them for the emotional, social and financial strains. Hung (1976) found that avoidance was the dominant pattern of coping interaction between brain tumor patients and their families, but even with this pattern of defense, families were still very receptive to social work interventions. Hung found that families needed the solace in speaking with the social worker and planning around concrete needs.

**Terminal Care:**

Holford (1973) defined terminal care as "...the management of patients in whom the advent of death is felt to be certain and not too far off and for whom medical effort has turned away from therapy and become concentrated on the relief of symptoms and the support of both patient and family" (J.M. Holford, 1972). Saunders (1978), Cade (1963), and Smithers (1960) claim the crucial issue in terminal care is the appropriateness of particular medical and other treatments for the patient when active treatment as such becomes irrelevant. Rather than see terminal care as nothing more can be done, they believe that this kind of care means adequate treatment of the physical distress of dying as well as emotional support for the grief and dignity of the patient. The objective of terminal care often is to overcome the sense of failure which tends to pervade the atmosphere that surrounds the patient.

Despite the statistics that report that increasing numbers of
terminal patients die in hospitals,* the professional literature and personal accounts by dying persons and their families indicate that dying persons want to return home to die. Simpson (1976) and Sampson (1977) claim this is true in their experience as physicians. Gibson (1971) states that there is great benefit and value when elderly people die in their own homes. He believes that the family need much reassurance for their ability to take the patient home and play an active part in his care. Wilkes (1973) found that over one-half of all cancer deaths took place at home, one-third occurred in an acute care hospital, and the rest happened in long-term nursing homes. Smithers (1973) and Gibson (1973) emphasize that dying patients want to die at home with appropriate home care services. Prestage (1968) states that although the dying patients wish to die at home where it is familiar, they are frequently abandoned by those who fear death and whose anxieties create an atmosphere of alienation. The social work literature reports that terminal patients want to die at home, but that this becomes a major drain on the family's emotional coping capacities and financial resources (Archives of the Foundation of Thanatology, 1975; Prichard et al., 1977).

McNulty (1973) states that the consensus of opinion of those attending the 1972 Department of Health and Social Security Symposium on Care of the Dying in Great Britain, was that terminal care should

*Data from the Department of Health, Education, and Welfare show that excluding newborns, an estimated 574,868 persons are discharged dead annually from community hospitals... This is 30.4 percent of all those dying in the United States annually for 1975.
take place at home. Dying persons are becoming more vocal about where they want to die. Studies have shown that where an illness has a foreseeable end, many families wish to look after their relative at home as long as possible (Aitken-Swan, 1959; Wilkes, 1965). McNulty, who has had six years of experience with over 1500 terminal patients and families, states that the problems encountered in terminal care are the following: medical, nursing, social, financial, and emotional. She believes, "There are no absolute criteria to help us decide whether a dying patient can remain at home; each case is individual...The patient's need for home and the familiar surroundings outweigh anything which a hospital can offer. The decision turns on the material circumstances and on the quality of the human relationships within the home" (McNulty, 1978).

**Hospice:**

One of the newest concepts in terminal care is that of hospice. This program seeks to create an atmosphere that neither alienates nor abandons the dying patient and his family. Hospice was defined as, "a program which provides palliative and supportive care for terminally ill patients and their families, either directly or on a consulting basis with the patient's physician or another community agency...Originally a medieval name for a way station for pilgrims and travelers where they could be replenished and cared for; used here for an organized program of care for people going through life's
last station..." (United States Congress, House of Representatives, Committee on Interstate and Foreign Commerce, 1976). The orientation of the hospice philosophy is humanistic in its concern for the well-being of the patient and family. It is holistic in its attention toward the whole person and his family. Hospices draw upon the total armamentarium of medical care through the use of the multidisciplinary team approach. The focus is on the patient and family and the quality of their living, and the rationale for services is that since death and dying is a natural part of life, it can be made easier by the provision of help.

The National Hospice Organization (NHO) was formed in 1977 and is incorporated in Washington, D.C. The purposes of the NHO include the exchange of information between hospice groups, the provision of information about hospice care to the public and the establishment and maintenance of standards of hospice care. Although the NHO has developed a set of standards for hospices, adoption of them by a program is purely voluntary. At present, the NHO does not possess the mechanics, experience or expertise to survey and accredit hospices. It is difficult to say how many hospices exist in the United States because of the problems with definition and data gathering (Cohen, 1979). There has been no federal legislation as yet specifically dealing with hospices, but the Department of Health and Human Services has designated certain hospice programs as pilot projects for the purpose of studying mechanisms of reimbursement for hospice care.

Objectives of hospice care include the following: emphasis on symptom control—that is, not just the physical distress, but the
total psychological, spiritual, social pain of the individual; the
unit of care is the patient and his family; care of the family
extends through the bereavement period; staff offers availability
24 hours/day, seven days a week; the study and teaching of
terminal care to those involved in hospice care as well as those
interested in the needs of the terminally ill and their families.
The emphasis of hospice care is not so much on new technology as
on personal concern in a warm, open, socially supportive environment.

Other characteristics of hospice programs include the follow­
ing: the physician is frequently the team leader, home care and
inpatient components are coordinated by hospice staff to ensure
continuity of care, hospice staff in inpatient units within acute
hospitals are usually only responsible for hospice patients and
families, volunteers are an integral part of hospice care, patients
are admitted on the basis of need, regardless of their ability to pay
or their insurance, patients and family confidentiality is respected,
there exists close staff collaboration and support with patient and
family.

Dr. Saunders (1978) feels that the major thrust in hospice
care is physical symptom control, so that the patient is freed to
deal with spiritual, psychological and social matters. She believes
that medical leadership is a prerequisite of hospice care. The St.
Christopher's Hospice in London, which she describes, is a program
that gives excellent medical and nursing care, while paying close
attention to the needs of the family during and after the terminal
period.
The model of hospice used in this research is the **Institutional-based Hospice** in which the in-patient component is a unit or several beds within a hospital. This study also used the submodel that has no coordinated home care program. Because hospice care aspires to such eminent goals, it deserves serious investigation. Hospice care represents an attempt to meet a current need in our modern health care system. The void exists because acute hospitals are ill-suited to meet the emotional needs of the terminal patient and his family. Such institutions are oriented to cure patients; they want to give efficient rather than individualized optimal care. The proponents of hospice claim that the services they offer are more individualized to the patient and family than those given in the acute hospital.

There appear to be inadequacies in four categories of the existing community health support system which the hospice model of terminal care strives to correct. These components are: (1) **Acute care hospitals**. These are practically and philosophically oriented to the cure of disease. The staff and resources are devoted to helping the patients recover from disease. When disease cannot be cured, the hospital has few resources to enable the patient to live as fully and completely as possible, nor can it give the family the skilled care and support they need to understand and cope with the effects of terminal illness and continuing problems. (2) **Nursing and convalescent homes**. Most nursing homes are not equipped to give attention to the needs of terminal patients, much less to their families. These institutions are designed to primarily provide long
term care for the elderly and to conclude a recuperative period of rehabilitation for certain patients. For terminal patients under age 65, the nursing home environment seems particularly inappropriate. Many rehabilitation programs will not accept terminal patients because they view them as hopeless. (3) Health care professionals. Until very recently, most professionals in the health care field have been trained to preserve life and oriented to the aggressive treatment of disease. When these professionals come face to face with the reality of the dying patient, their fears and biases surface and may interfere with giving empathic, individualized care. (4) Counseling. Both the patient and family need counseling during the terminal stage and following the death in the bereavement period. The patient needs counseling around areas of financial and emotional issues and the family, besides these same needs, have practical concerns to deal with like insurance papers, bills, funeral arrangements. The kind and degree of counseling that the family needs to help them cope with the impending death and carry them through bereavement may not be adequate in current professional practice. Hospice care addresses the needs of the surviving family in an organized way (Zimmerman, 1981).

Hospices seem to be an alternative to the social, medical, and physical environment afforded terminal patients in the traditional acute hospital. Although the two institutional philosophies appear antithetical with regard to terminal care, Dubois (1980) believes that there are definite advantages to establishing a hospice within an existing hospital. In terms of practicality, he states, hospices
are more expensive as separate facilities, and the conversion of hospital beds to hospice is economically justifiable. In addition, hospice personnel can have an educative role with the hospital staff and help to change traditional attitudes and treatment policies. Moreover, many communities cannot afford hospices as separate institutions and it would be more realistic to offer them hospice care within their own community hospital.

This study includes discharge planning as it exists in the hospice programs which are part of acute care hospitals and have no coordinated home care services. The research seeks information on the ways in which hospice care is similar to or different from terminal care in the hospital. The focus is on how social workers in both groups formulate their discharge plans for the terminal patient.
CHAPTER 3

METHODOLOGY

Design:

This study was an exploratory-descriptive survey which sought to define the characteristics of discharge planning for terminal patients and determine the relative importance of factors that social workers considered in the formulation of such plans. Social workers in acute care hospitals and hospices were used as respondents because of their experience with terminal patients and their families. Semi-structured interviews were used to allow for uniformity in responses and flexibility so that respondents could raise issues and share insights.

Sample:

Sampling was a two stage process. In the first stage, different frames of reference were used to select the hospital and hospice samples. In the second stage, the sample of social workers was selected for each of the comparative groups.

The sample of hospitals was limited to those acute care hospitals that allowed for a choice of home vs. institution in their discharge plans. This was done to ensure that all factors involved in the discharge planning process would be included. Sampling was stratified and purposive. There are a total of 149 hospitals in
Missouri (U.S. Bureau of the Census, 1980). The researcher excluded primarily out-patient, psychiatric, rehabilitation, children's, specialized kidney and other hospitals that would not have been appropriate for the study. Nine acute care hospitals were chosen in the city of St. Louis and for reasons of economy and convenience, six were chosen from the County of St. Louis. In addition, one hospital was selected to represent rural areas of the state and one hospital was chosen to represent a smaller city. Table 1 presents the demographic information of the 17 hospitals, based on type of geographic area. The metropolitan city of St. Louis included the hospitals of: Barnes, Jewish, City, Firmin de Loge, Deaconness, Compton Hill, St. Mary's, St. Luke's, and St. Anthony's. The suburban hospitals were: County, Missouri Baptist, St. John's Mercy, Incarnate Word, Lindell, and Lutheran. St. Joseph's Hospital is located in the small city of St. Charles and the University of Missouri Medical Center is in the smaller city of Columbia. Four of the hospitals are teaching hospitals connected to medical schools: St. John's Mercy, St. Louis University Hospital (Firmin de Loge), Barnes, and Jewish. Appendix A lists the hospitals used in the study.

Data in Table 1 shows that the metropolitan hospitals served a geographic population ranging from 500,000 to 2.5 million people. The suburban hospitals served a population ranging from 50,000 to 1 million. The rural medical center served a population of 100,000 and the small city hospital served a population of 150,000. The median family income per annum level for the geographic areas range as follows: from $6,500 to $9,100 for the metropolitan
<table>
<thead>
<tr>
<th>Type of Area</th>
<th>Population Served</th>
<th>Median Family Income Per Annum Level</th>
<th>Ethnicity Of Patient Population (Percent)</th>
<th>Health Insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Metropolitan-City**</td>
<td>500,000-2.5 mil.</td>
<td>$6,500 - $9,100</td>
<td>19-75 24-80 0.8</td>
<td>all categories*</td>
</tr>
<tr>
<td>Suburban***</td>
<td>50,000-1 mil.</td>
<td>$8,400 - $13,400</td>
<td>63-98 1.0-31 0.4</td>
<td>all categories*</td>
</tr>
<tr>
<td>Rural****</td>
<td>50,000</td>
<td>$7,600</td>
<td>98.5 1.5 0</td>
<td>all categories*</td>
</tr>
<tr>
<td>Other city*****</td>
<td>150,000</td>
<td>$15,000</td>
<td>98.5 1.5 0</td>
<td>all categories*</td>
</tr>
</tbody>
</table>

* Categories included: self pay, Blue Cross/Blue Shield, Medicare, Medicaid, Workers' compensation, miscellaneous, other group insurance

** Hospitals included: Barnes, Jewish, City, Firmin de Loge, Deaconness, St. Anthony's, St. Mary's, St. Luke's, and Compton Hill

*** Hospitals included: County, Missouri Baptist, St. John's Mercy, Incarnate Word, Lindell, and Lutheran

**** Hospital included: University of Missouri Medical Center, Columbia, Missouri

*****Hospital included: St. Joseph, St. Charles, Missouri

city; $8,400 to $13,400 for the suburban communities; $7,600 for the rural area; and $15,000 for the smaller city. The categories of health insurance of the patient population included: self pay, Blue Cross/Blue Shield, Medicare, Medicaid, Workers' Compensation, other group insurance, and miscellaneous (such as having no insurance). Only the City Hospital of St. Louis did not have patients who were self pay. With regard to the percentage of ethnicity of the patient population, Table 1 shows that for the metropolitan hospitals the percentage of patients who were white ranged from 19 percent to 75 percent; for the suburban hospitals the percentage ranged from 63 percent to 98 percent; for the small city the percentage of white patients was 98 percent; and for the rural area hospital the percentage was also over 98 percent. For the metropolitan hospitals the percentage of patients who were Black ranged from 24 percent to over 80 percent.

The advantage of having all hospitals from the same state was for the convenience and economy of interviewing the social workers and for defining the range of criteria for selection of the hospitals. The attempt was made to minimize the effects of external variables, such as socioeconomic status, geography, and ethnicity. All forms of health insurance coverage were represented. The sizes of the hospitals varied from 100 to over 500 beds. All admitted patients with all types of diseases, of all ages and religions. None of the hospitals had any special home care programs for terminal patients or any particular linkage with institutions that would have biased the discharge plans toward home or institution.
The population of hospices was limited to include only those programs that were housed in existing hospitals and allowed for discharge planning to home or institution. Also, the attempt was made to use those hospices that did not have coordinated home care programs. This was done to ensure as much comparability with the hospitals. The researcher believed that to include hospices with coordinated home care programs would bias the hospice social workers in the direction of home, since a coordinated home care program makes discharge planning to home much easier. Hospices without coordinated home care must rely on the same kinds of community resources as hospitals when discharge planning for the terminal patient.

Identification of hospices of this model came from the National Hospice Organization Directory as well as from numerous sources (National Hospice Organization, 1978). As a result of restricting the sample of hospices in the United States to those within the model definition, the number was 15. There may have been others in the planning stages that are now functional. Letters were sent to the 15 hospices and all responded. However, two wrote that they did not employ social workers; two communicated that they lacked the time to complete the questionnaires; and three had coordinated home care programs. Appendix B lists the 8 hospices used in the study.

Data in Table 2 shows the following characteristics of the hospices: population served, location, number of beds and categories of health insurance accepted. All hospices admitted the majority of cancer patients. Other diagnostic groups included kidney disease, heart disease and neurological illnesses. The bulk of patients came
from within a 30 mile radius. The hospices served an average population of 500,000. Visiting hours and days were unlimited, with no age restrictions for visitors. All hospices employed volunteers who received orientation and in-service training. Patients' ages ranged from 18 to 65, with no more than half of the patients over 65. Some programs provided overnight accommodations for family members. Data in Table 2 shows that the number of beds ranged from four to twenty-four. The in-patient beds were classified as acute care beds for purposes of third-party reimbursement. Funding and revenues came from Medicare, Medicaid, commercial insurance, self-pay, church support, private foundations, and federal grants. The number of trained social workers at each hospice was two, with one hospice having one worker. Not all social workers worked full-time, five days per week. All participating hospices except for the one in New York and one in Missouri had in-patient units that were separate from the rest of the hospital patients.

Both hospital and hospice terminal patients are attended to by a team of professionals that includes the physician, registered nurse and nursing assistants, social worker, rehabilitation therapists. The hospice team includes the volunteers and clergy as a rule, whereas the hospital team does not. For both the hospital and hospice, administrative personnel and community resources persons were brought into team conferences as the case warranted. Hospices were subjected to the same reviews by the utilization review committees as were hospital patients.

The second stage of sampling involved selecting the social work
<table>
<thead>
<tr>
<th>Name of Hospice</th>
<th>Population Served</th>
<th>Location</th>
<th>Number of Beds****</th>
<th>Health Insurance</th>
</tr>
</thead>
<tbody>
<tr>
<td>El Cajon</td>
<td>50,000</td>
<td>California</td>
<td>4</td>
<td>all categories**</td>
</tr>
<tr>
<td>Lutheran</td>
<td>1 mil. +</td>
<td>Missouri</td>
<td>12</td>
<td>all categories***</td>
</tr>
<tr>
<td>St. Luke's</td>
<td>2 mil. +</td>
<td>Missouri</td>
<td>5</td>
<td>all categories**</td>
</tr>
<tr>
<td>Albert Einstein</td>
<td>500,000 +</td>
<td>New York</td>
<td>approx. 4</td>
<td>all categories**</td>
</tr>
<tr>
<td>Parkwood</td>
<td>1 mil. +</td>
<td>California</td>
<td>14</td>
<td>all categories**</td>
</tr>
<tr>
<td>Pinecrest</td>
<td>225,000</td>
<td>California</td>
<td>24</td>
<td>all categories**</td>
</tr>
<tr>
<td>Methodist</td>
<td>500,000-1 mil.</td>
<td>Indiana</td>
<td>11</td>
<td>all categories**</td>
</tr>
<tr>
<td>Forbes</td>
<td>500,000 +</td>
<td>Pennsylvania</td>
<td>6</td>
<td>all categories**</td>
</tr>
</tbody>
</table>

* Data on ethnicity of patient population not available
** Categories included: self pay, Blue Cross/Blue Shield, Medicare, Medicaid, Workers' Compensation, miscellaneous, other group insurance
*** This hospice was being considered for funding as a pilot project under the federal government at the time of this study
**** Based on 1979 estimates
respondents. The hospital sample was selected purposively from specified quotas. The sizes of the hospital social work staff ranged from two to twenty trained workers. Only those social workers with an MSW were included in the sample. The strategy was as follows: The Directors of Social Work for each of the hospitals were telephoned and the purpose and nature of the study was explained. They were asked if they were willing to participate, and if so, to provide a list of social workers who met the criteria for the study. The correct number of questionnaires was then mailed to each Director, who distributed them. Appendix C shows the letter to each Director that accompanied the questionnaires. The Directors either gathered the questionnaires when completed and returned them, or let each social worker be responsible for sending hers back. There were 120 questionnaires distributed to 120 social workers in the total hospital population. The sample consisted of 71 respondents.

While respondents came from every hospital used in the study, non-respondents came from hospitals having social work staffs with more than ten workers. One rationale to account for this difference may lie in the Director's covert communication to his staff in soliciting their help in completing the questionnaire. Several hospital Directors of large social work staffs, although genuinely interested in cooperating with the purposes and goals of the study, reflected to the researcher that their social workers were extremely busy and hopefully could find the time to assist in the research. Directors of social work staffs having fewer than two workers seemed to express more appreciation that their staff was included in the
study, and thus might have generated more motivation to their workers for assistance.

The sample of hospice social workers was selected in the following manner. Letters explaining the purpose and nature of the study were mailed out to the Directors of the 15 hospices that seemed to fit the model definition. Each letter accompanied a package of five questionnaires (Appendix D), although it was generally known that each hospice had only one or two trained social workers on its staff. Of the 15 hospices, 8 responded with a sample of 15 hospice respondents.

A sub-sample of 44 cases was chosen for follow-up telephone interviews from the returns. The 31 hospital cases were selected from those questionnaires that were either: (1) incomplete; (2) showed ambiguous responses; or (3) contained interesting and thought-provoking ideas and issues. The 13 hospice subsample respondents were selected differently. The researcher attempted to interview all 15 respondents because of the desire to make all the data from this group as meaningful as possible. However, only 13 hospice respondents were interviewed because one worker had left the program and could not be reached, and another worker stated that she had no time for the interview.

Instrument:

The instrument developed (Appendix H) sought to measure the following clusters of factors relating to: (1) the patient; (2) the family; and (3) the environment. Patient factors included the
variables of: patient's desire to go home; change in the condition of the patient; patient's attitude toward dying; patient's need for continuing medical, nursing, rehabilitative, clinical, dietary care and transportation upon discharge; and patient's financial resources. Family factors included the variables of: family's desire to have patient home; family's attitude toward patient; family's financial resources; and family's need for continuing psychological, social, economic and other support following patient discharge. Environmental factors included the variables of: timing of referral; lack of appropriate extended care beds; limited cooperation of medical staff in necessary paperwork; adaptability of patient's home environment to meet his needs; the social worker's perceived role with administration and members of the medical team; and situations encountered in working with terminal patients in discharge planning.

The questionnaire had the following objectives:

1. Identify the parameters of discharge plans for terminal patients. The cluster of factors relating to the patient are found in the sections of: patient's needs upon discharge (Section A and J); patient's attitudes toward dying (Section H and J); patient's financial resources (Section I); patient's desire to go home (Section J); and change in the condition of the patient (Sections J and G). The cluster of factors relating to the family are found in the sections of: family needs upon discharge (Sections C and J); family attitudes toward patient (Sections D and J); family's financial resources (Sections I and J); and family's desire to have patient home (Section J). The cluster of variables relating to the environ-
ment are located in the sections of: timing of referral (Sections E and J); situations (Section G); lack of appropriate extended care beds (Sections G and J); social worker's perceived role with administration and medical team (Sections F, G and J); limited cooperation of medical staff in necessary paperwork (Sections G and J); and adaptability of patient's home environment to meet his needs (Sections B and J).

The open-ended questions in Sections A, B, C, D, E, F, G, H, and I seek to broaden the parameters of discharge plans for terminal patients. Section K asks for the submission of forms that might contain additional information to enlarge the scope of discharge plans.

II. Specify the relative importance among factors that social workers consider in the formulation of discharge plans for terminal patients. This objective sought the information that was emphasized by the social workers. The importance of factors was elicited through responses to ten point scales attached to the factors. The mean scores were rank-ordered for each factor and the number of respondents to each factor was noted. Responses to additional items were qualitatively analyzed and reported as new factors or coded in categories.

III. The questionnaire sought to secure data on the similarities/differences between hospital and hospice social workers with respect to factors. The goal was to explore whether social workers from these different settings agree in specifying the relative importance of factors affecting the formulation of discharge plans for terminal patients.
Telephone Interview:

The follow-up telephone interview was thought necessary because:
(1) The number of cases was rather small and there was a need to make all the data count; and (2) since the subject of death and dying usually produces personal responses, there was a need to obtain and examine the subjective data in order to increase the validity of the study. The flexible use of a semi-structured interview guide (Appendix E) for social workers during interviews was aimed at helping the interviewer focus her attention in advance to a uniform number of subjects in order to raise the likelihood of gathering comparable data from all subjects interviewed. The questions were phrased as similarly as possible in each case and were not biased to extract only certain answers so that the data could remain objective, that is, without the interviewer's contamination. This did not preclude spontaneous productions by the interviewee and comments by the interviewer to stimulate, elaborate and clarify data.

The subjective variables not listed on the questionnaire that the researcher wished to obtain data on pertained to: personal experience with family or friends and terminal illness; personal feelings toward patients who went home or to an institution upon discharge, religious orientation and how it affected coping with death and dying. The interview also asked for the following demographic information: years working in social work; years working with terminal patients; membership in NASW; nature of caseload; and present job as career choice or assignment. Finally the telephone interview was used to obtain from the respondents their general impressions of the
study and their reactions to the questionnaire.

**Data Collection:**

The instrument was mailed to the Directors of Social Work Departments of 17 hospitals and the Directors of 15 hospices. As stated earlier, 7 of the hospices were found to be inappropriate for the study. All of the hospitals responded. The Directors of the hospital and hospice programs distributed the questionnaires to the appropriate social workers. After two weeks, telephone calls were made to those hospitals and hospices from which a few or no questionnaires were received. A cutoff date was arbitrarily established to give a two-month response period, which was deemed sufficient to permit an adequate response rate. Any additional time allotted was judged as unlikely to increase significantly the response rate. In total, 120 questionnaires were distributed to hospital workers and there were 71 respondents. For the hospices, 40 questionnaires were distributed, with 15 respondents. Response rate for hospitals was 59 percent, and for hospices, 100 percent, since all social workers in the appropriate hospice programs responded. As the questionnaires were received, follow-up telephone interviews were scheduled with those social workers whose questionnaires were: (1) incomplete; (2) showed ambiguous responses; and (3) contained interesting and thought-provoking ideas and issues.

All 44 of the social workers telephoned were cooperative. The collection of data was systematized through the use of the semi-structured interview guide (Appendix E). During the interview, once
the initial rapport was established, the tone was informal and conversational.

**Definition of Concepts:**

**Social Work Respondents:** Trained social workers (MSW) who, for at least 25 percent of their time, work with terminal patients in the hospital or hospice and must plan for their discharge.

**Home:** Discharge to a non-institution setting. It can include the patient's address upon admission or a residence to which the patient will go to live with family, friends, or alone.

**Health Care Institution:** A setting that provides long-term skilled nursing and custodial care to in-patient residents.

**Terminal Patients:** Those patients, who, with a variety of illnesses, have in their physician's judgment, from one to six months to live.

**Discharge Plan:** A statement, written by the social worker, that tells where the patient will go upon discharge. It includes the treatment plan for the patient's continued care.

**Hospice:** The list of actual programs in Appendix B. It is a program which deals exclusively with terminal patients and their families. For this study, the hospice is housed in a hospital and has no coordinated home care.

**Data Analysis:**

Two methods of statistical analysis were used: tests of significance of the differences between the means, and rank-order correlations, using the Spearman rank correlation coefficient. Tests of
significance sought to compare the importance hospital and hospice workers attached to all variables. Rank order correlations were performed to elicit the workers' ordering of importance of each variable in its own group. In addition, tests of significance of the differences between the means were performed on all variables to compare two groups of social workers that differed in the number of referenced cases who went home. Referenced cases refers to the last five terminal patients respondents used to complete questions in the questionnaire. Group I responded with "5" referenced cases, while Group II responded with "1" referenced case (Section A, question 2). The rationale for the comparison was based on the following assumption. Social workers, including both hospital and hospice, whose last one referenced case went home, would be more in touch with factors which pointed in the direction of the institution, while workers whose last five referenced cases went home, would be more in touch with factors which pointed in the direction of home.

Factor analysis was performed on all variables to explore whether factors could be correlated with each other and ordered into a concept (factor). However, no underlying factor structure was found to exist, so the results are not discussed.

Attempts were made to improve reliability by writing items and instructions unambiguously so their interpretation was as uniform as possible. Respondents were told to contact the investigator to clarify questions if they felt an item was ambiguous. Validity was principally face validity, taking at face value worker responses. Items used in the instrument were derived from the
content of the literature on discharge planning, social work practice with terminal patients and their families, and models of terminal care.

Analysis of the content of the responses to open-ended questions in the questionnaire and telephone interview was performed and categories were developed for reporting them (Appendixes F and G respectively). New Factors were clustered into Patient, Family, and Environment categories. This qualitative data will be discussed in a later chapter. The analysis was based on the rationale that if a response was clearly different from those stated as items, it was considered a new factor. The telephone interview provided the opportunity to clarify those additional items which were ambiguous.
CHAPTER 4
THE PARAMETERS OF DISCHARGE PLANS
FOR THE TERMINAL PATIENT

Research Question I: Identify the parameters of discharge plans for terminal patients.

This question sought to explore the factors involved in discharge plans for terminal patients in the hospital. Factors from the literature, those previously studied, were clustered according to their relation to: (1) the patient; (2) the family; and (3) the environment. Patient variables included those of: patient's desire to go home; patient's attitude toward dying; change in the condition of the patient; patient's need for continuing medical, nursing, rehabilitative, clinical, dietary care, and transportation upon discharge; and patient's financial resources. Family variables included: family's desire to have patient home; family's financial resources; family's need for continuing psychological, social, economic, and other support following discharge; and family's attitude toward patient. Environmental variables included: timing of referral; lack of appropriate extended care beds; limited cooperation of medical staff in necessary paperwork; adaptability of patient's home to meet his needs; situations encountered in working with terminal patients; and social worker's perceived role in relation to members of the medical team. All factors were found to be included in the parameters.
of discharge planning by the total sample of 86 respondents.

With regard to the important factors social workers considered in their formulation of discharge plans, the following percentages were calculated on the entire sample of 86 respondents. Differences between hospital and hospice social workers are reported in the next chapter.

Data in Table 3 show that over 90 percent of social workers believed patients needed nursing services in discharge planning. Over one-third of the workers felt patients needed assistance with obtaining medical equipment; only 29 percent felt patients needed counseling around death and dying. These findings suggest that social workers rely strongly on their collaboration with nurses in discharge planning. Also, the findings imply that terminal patients are going home, since there is no need for medical equipment if the patient is being discharged to an institution. It appears that counseling around death and dying is not recognized as important a need by the social workers as one would have assumed.

**TABLE 3**

THREE MAIN PATIENTS' NEEDS IN DISCHARGE PLANNING REPORTED BY SOCIAL WORKERS (PERCENTAGE)*

<table>
<thead>
<tr>
<th>Patient Need</th>
<th>Number</th>
<th>Social Workers (Percent)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nursing services</td>
<td>78</td>
<td>90.7</td>
</tr>
<tr>
<td>Medical equipment</td>
<td>32</td>
<td>37.2</td>
</tr>
<tr>
<td>Counseling on death and dying</td>
<td>25</td>
<td>29.1</td>
</tr>
</tbody>
</table>

*Note - Due to overlapping, total does not add to 100
Data in Table 4 show that 47 percent of the social workers believed that their patients felt guilt toward dying during the process of discharge planning. Forty-one percent felt their patients were depressed; and 34 percent felt their patients denied their prognosis. Another 34 percent felt their patients' medical condition was such that they were unable to ascertain the patient's attitude. The finding that social workers felt their patients' predominate attitude toward dying was guilt, seems to contradict a prevailing theme in the literature indicating that dying persons feel isolated and withdrawn. The finding, suggest that patients may need intervention to help them with these guilt feelings.

**TABLE 1**

THREE MAIN PATIENTS' ATTITUDES TOWARD DYING CONSIDERED IN DISCHARGE PLANNING REPORTED BY SOCIAL WORKERS (PERCENTAGE)*

<table>
<thead>
<tr>
<th>Attitude</th>
<th>Number</th>
<th>Social Workers Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guilt</td>
<td>40</td>
<td>47.0</td>
</tr>
<tr>
<td>Depression</td>
<td>36</td>
<td>41.9</td>
</tr>
<tr>
<td>Denial</td>
<td>29</td>
<td>34.0</td>
</tr>
<tr>
<td>Unable to ascertain</td>
<td>29</td>
<td>34.0</td>
</tr>
</tbody>
</table>

*Note – Due to overlapping, total does not add to 100

Data in Table 5 show that over 67 percent of social workers believed that the family needed help with application to nursing homes in discharge planning. Forty-seven percent felt the family needed
counseling on death and dying; and over 31 percent felt the family needed help with obtaining medical supplies. These findings imply that families need counseling to help them cope with the patient in the hospital. Also, the implication is that families feel ambivalent about taking the patient home. Applications to nursing homes appears to be a strong need, according to social workers, while assistance in obtaining medical supplies, presumably for home, is less strong.

TABLE 5

THREE MAIN FAMILY NEEDS IN DISCHARGE PLANNING REPORTED BY SOCIAL WORKERS (PERCENTAGE)*

<table>
<thead>
<tr>
<th>Need</th>
<th>Number</th>
<th>Social Workers Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Counseling around death and dying</td>
<td>40</td>
<td>47.0</td>
</tr>
<tr>
<td>Application to nursing homes</td>
<td>58</td>
<td>67.4</td>
</tr>
<tr>
<td>Assistance with obtaining medical supplies</td>
<td>27</td>
<td>31.3</td>
</tr>
</tbody>
</table>

* Note - Due to overlapping, total does not add to 100

Data in Table 6 show that, according to over 58 percent of social workers, families felt guilt and ambivalence toward the terminal patient, as reflected by the statement, "She's my mother, I can't put her away." Over 54 percent of the social workers felt their families held positive and accepting attitudes toward the patient, while one-
third of the workers felt their families openly rejected the patients. An interpretation from these findings is that families feel both positive and ambivalent feelings toward the terminal patient, but that other factors interfere with the family taking the patient home upon discharge.

**TABLE 6**

**THREE MAIN FAMILY ATTITUDES IN DISCHARGE PLANNING REPORTED BY SOCIAL WORKERS (PERCENTAGE)**

<table>
<thead>
<tr>
<th>Attitude</th>
<th>Number</th>
<th>Social Workers Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;She's my mother, I can't put her away.&quot;</td>
<td>50</td>
<td>58.1</td>
</tr>
<tr>
<td>&quot;I definately want him home.&quot;</td>
<td>47</td>
<td>54.7</td>
</tr>
<tr>
<td>&quot;I think the nursing home will take better care of her.&quot;</td>
<td>29</td>
<td>33.8</td>
</tr>
</tbody>
</table>

*Note - Due to overlapping, total does not add to 100

Data in Table 7 show that 86 percent of social workers felt that the terminal patients who lived alone needed much consideration in discharge planning. This finding confirms that social workers are sensitive to the degree of vulnerability that living alone presents for the terminal patient in terms of physical stress and psychological and social isolation. Over 54 percent of the workers felt attention should be paid to the patient's home if there was no elevator and
only steps in the home. Over 65 percent of the workers felt that the existence of the bathroom and bedroom on different floors of the patient's home required attention in discharge planning. The findings point to a need for careful planning when the physical layout of the home presents stressful conditions to patients who may be weak and have difficulty negotiating steps.

### TABLE 7

**THREE MAIN HOME CONDITIONS IN DISCHARGE PLANNING REPORTED BY SOCIAL WORKERS (PERCENTAGE)**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number</th>
<th>Social Workers Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient lives alone</td>
<td>74</td>
<td>86.0</td>
</tr>
<tr>
<td>Bath and bedroom on different floors</td>
<td>56</td>
<td>65.1</td>
</tr>
<tr>
<td>Steps to apartment</td>
<td>47</td>
<td>54.6</td>
</tr>
</tbody>
</table>

*Note - Due to overlapping, total does not add to 100

Data in Table 8 show that over 83 percent of social workers found a lack of appropriate extended care beds in nursing homes in the community. This finding may explain why applications to nursing homes are so important in discharge planning. It appears that if there is a shortage of beds, then early applications are imperative. Over one-half of the social workers reported that during the course of discharge planning, the patient's condition changed. This finding
may be related to the length of admission, and the change may mean either improvement or deterioration. However, the fact of change implies that the discharge plan must accommodate the new situation. More than one-third of the social workers reported that the utilization review pressured them to help a patient leave the hospital when the appropriate plan was not yet formulated.

TABLE 8
THREE MAIN SITUATIONS ENCOUNTERED IN WORKING WITH TERMINAL PATIENTS REPORTED BY SOCIAL WORKERS (PERCENTAGE)*

<table>
<thead>
<tr>
<th>Situation</th>
<th>Number</th>
<th>Social Workers Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of appropriate care beds when patient is ready for discharge</td>
<td>72</td>
<td>83.7</td>
</tr>
<tr>
<td>Patient's condition changes from time of admission</td>
<td>45</td>
<td>52.3</td>
</tr>
<tr>
<td>Utilization review says patient must leave when appropriate plan is not yet formulated</td>
<td>33</td>
<td>38.4</td>
</tr>
</tbody>
</table>

*Note - Due to overlapping, total does not add to 100

Data in Table 9 show that social workers perceived their role in discharge planning was important with doctors (97 percent), nurses
(over 91 percent), and physical therapists (over 54 percent). These seem to be the key members of the medical team, according to the social workers. In selecting physical therapists as important team members, social workers were again giving evidence of their recognition of the physical weakness and rehabilitative needs of terminal patients.

**TABLE 1**

<table>
<thead>
<tr>
<th>Team Member</th>
<th>Number</th>
<th>Social Workers Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
<td>83</td>
<td>97.0</td>
</tr>
<tr>
<td>Nurses</td>
<td>79</td>
<td>91.9</td>
</tr>
<tr>
<td>Physical therapists</td>
<td>47</td>
<td>54.7</td>
</tr>
</tbody>
</table>

*Note - Due to overlapping, total does not add to 100%

Data in Table 10 show that over 74 percent of social workers felt that Medicare and Medicaid played an important part in assessment of financial resources in discharge planning. Over 58 percent believed that Medicaid alone was important; and over 55 percent reported that Medicaid eligibility was an important financial condition of patient and/or family. The findings underscore the importance of financial conditions in discharge planning. The relation of Medicare and Medicaid to planning for home or institution will be
discussed in a later chapter.

**TABLE 10**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Number</th>
<th>Social Workers Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare and Medicaid</td>
<td>64</td>
<td>74.4</td>
</tr>
<tr>
<td>Medicaid</td>
<td>50</td>
<td>58.1</td>
</tr>
<tr>
<td>Medicare and private insurance</td>
<td>50</td>
<td>58.1</td>
</tr>
<tr>
<td>Medicaid eligible</td>
<td>48</td>
<td>55.8</td>
</tr>
</tbody>
</table>

*Note - Due to overlapping, total does not add to 100*

**TABLE 11**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Number</th>
<th>Social Workers Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient and Family financial resources</td>
<td>44</td>
<td>51.2</td>
</tr>
<tr>
<td>Patient's desire to go home</td>
<td>41</td>
<td>47.7</td>
</tr>
<tr>
<td>Family's desire to have patient home</td>
<td>38</td>
<td>44.2</td>
</tr>
</tbody>
</table>

*Note - Due to overlapping, total does not add to 100*

Data in Table 11 show that over 51 percent of social workers
believed financial factors were of utmost importance in discharge planning, which supported the findings in Table 10. Almost half, or over 47 percent of the workers reported the importance of the patient's desire to go home, and over 44 percent claimed that the family's desire to have patient home was important in discharge planning.

**New Factors:**

The following is the researcher's summary of new factors which were clustered into Patient, Family and Environment categories (Appendix F). New patient factors included those related to needs, attitudes toward dying, and financial conditions. With respect to needs, from 5 to 16 percent of the workers reported the following: the need for a nursing home that was geographically close to the family; spiritual needs; counseling on issues other than death and dying (16 percent); patient-family teaching on the management of the patient in the hospital; increased knowledge of Medicare and Medicaid benefits. Spiritual needs included the desire to talk to a clergy member for forgiveness for real or imagined wrongdoings, comfort from someone and something beyond themselves, guidance about religious issues after death, and understanding from a religious viewpoint, of why they were dying. Counseling on other issues included planning for children's future and marital and parental roles and conflicts.

Social workers noted two additional attitudes that patients felt in relation to dying (Appendix F). Thirteen percent of the workers reported that patients were anxious about discharge, and
two percent of the workers mentioned the desire of their patients to be as self-sufficient and independent as possible, regardless of the level of physical functioning. With respect to the first attitude, patients were fearful about leaving the protective setting of the hospital, regardless of the support they received from their families and community resources. With the second attitude, patients wanted to maintain basic skills in personal care, such as dressing, feeding, ambulation and other simple and complex activities of daily living. These were feelings, not of denial, but of realistic accommodation to the limitations the illness had imposed.

From 2 to 8 percent of the workers reported the following:

patient financial conditions: Medicare and a fixed income, such as social security or disability (8%); and no insurance or funds, so that the social worker was required to apply for public assistance and medicaid, or in the case where the patient was not alert and competent, apply for guardianship through the hospital (2%). In Missouri, once guardianship is legally assumed, the hospital is then responsible for the costs of the hospitalization.

From 1 to 12 percent of the workers added the following:

family needs (Appendix F): increased knowledge about Medicare benefits; counseling on issues other than death and dying, such as marital and parental roles and conflicts; the need for closer involvement with the physician with regard to more open discussions about the patient's illness and prognosis; and the need for staff-family teaching about the management of the patient in the hospital and at home (12%). Both patients and families expressed the desire
for patient management teaching, according to social workers. These findings suggest that patients and families want to learn the ways concrete care is given, such as pain control, personal hygiene, ambulation training, and rehabilitative exercises. It may be that one way to help families give greater reassurance to patients is to allay families' anxiety by teaching them what to do for the patient. If families felt more comfortable about patient care, perhaps they would feel more secure in taking the patient home. Also, with closer involvement of the physician, families might reduce their maladaptive coping mechanisms of avoidance, rejection, and ambivalence.

It appears clear from the findings that, while terminal illness may take paramount importance, those involved are very much concerned with other issues of family life and productive living which require problem-solving and conflict resolution in meaningful ways. How this relates to practice concerns will be discussed in a later chapter.

With regard to family financial conditions, 5 percent of the workers added the situation in which the extended family was willing to contribute to the costs of the hospitalization and home care plans, or placement, upon discharge. In these cases the distinction was made between immediate and extended family.

From 5 to 27 percent of the social workers reported the following home conditions (Appendix F): the availability of transportation for the patient and others to go to and from places relating to medical needs, recreation, economic and family matters (27%); the geographic location of the home in relation to medical
facilities, such as in rural areas; the existence of adequate cooking facilities in the home; the existence of adequate temperature control of the home, whether it be air-conditioning or heating. These factors imply that social workers are sensitive to the patients' needs to maintain their independence, competence, and mobility inside and outside the home.

With respect to members of the medical team in discharge planning, from 1 to 20 percent of the social workers added the following persons (Appendix F): patient (20%); family members; community resource persons; social work supervisor. By involving the patient and family in team collaboration, there is greater likelihood of the opportunity for patient-family-staff teaching of patient management. The scope of definition of medical team was enlarged to include community resource persons from organizations, such as the Visiting Nurse Association and national and local cancer agencies. These community persons were involved because they wanted to be part of the discharge planning process and/or they knew the patient and family from prior admissions. Social workers saw their supervisors as team members in those situations in which they needed more guidance about counseling, and more teaching about community resources and procedures necessary for application for home care, placement or certain insurance or economic benefits. One implication from these findings may be that social workers use their supervisors for support in discussing their feelings about death and dying, since the supervisor is the closest professional to whom they can directly turn for help.
Social workers did not note any other situations which were not covered by the themes of: frustration with community support systems, such as lack of nursing home beds or establishing eligibility for benefits; lack of cooperation with medical staff; pressure from utilization or administration for discharge planning; or change in the medical condition of the patient. There were no new family attitudes discovered by social workers that did not fall into the categories of: acceptance; ambivalence; or rejection.

There were several assessment forms submitted by hospital social workers which they used in their discharge planning. Form I -- Home Health Service Referral Form -- shows the physician's plan for home care which would be covered by Medicare. Form II -- Skilled -- shows the application for nursing homes in which there is space for a social work evaluation under the heading of "Rehabilitation Services." On this form the social worker can also indicate whether or not the patient will require assistance with planning for discharge from the skilled nursing facility. Form III -- Nursing Home Referral -- is an assessment form from one hospital used in applying to nursing homes. This form details the patient's physical needs for care and seems to require close collaboration between social worker and nursing. This form also asks for information from the physical therapist, and is comprehensive in its attention to the need for transportation to the nursing home and preferences for specific nursing homes. There is space for the social work family evaluation and treatment plan for discharge. Form IV -- Social Work Assessment for Long Term Illness Planning -- is a straightforward form which
allows ample space for the assessment and discharge plan. All these forms were used by social workers in the decision-making process of where the patient would go upon discharge. They required that the social workers collaborate with physicians, nurses, physical therapists and others in order to accomplish a complete assessment and treatment plan.

Timing of Referral:

Timing of referral was investigated to support or refute previous research that found it played a part in discharge planning. In addition, the researcher wanted to explore whether timing of referral was related to length of admission. Data in Table 12 show that an overwhelming majority, 86 percent, of social workers felt that timing of referral played a part in discharge planning for the terminal patient. When interviewed, social workers stated that earlier referral had a decided effect on shortening length of admission stays. They felt early intervention generally prevented patient hospitalizations which extended beyond the need for acute medical care because complex discharge planning needs and problems were identified and resolved sooner.

For social workers in Missouri, independent case-finding was relatively new, and they were mainly dependent upon the other health personnel to refer them patients and families. Thus, timing of referral became timing of intervention, since the workers began their assessment as soon as they received the referral. When the patient was referred early in admission, the social worker had enough time to
plan for an appropriate discharge as soon as the patient was medically ready. List 1 presents the reasons why social workers believed timing of referral played a part in discharge planning for the terminal patient. These findings support the previous research by Berkman and Rehr (1972) in which referral at the time of admission resulted in shorter hospital stays, than referral which occurred later in the hospitalization.

TABLE 12

DOES TIMING OF REFERRAL PLAY A PART IN DISCHARGE PLANNING, REPORTED BY SOCIAL WORKERS

<table>
<thead>
<tr>
<th>Timing of Referral</th>
<th>Number of Social Workers</th>
<th>Social Workers Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>74</td>
<td>86.0</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
<td>14.0</td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>100.0</td>
</tr>
</tbody>
</table>
LIST 1

REASONS FOR RELATION BETWEEN TIMING OF REFERRAL AND DISCHARGE PLANNING, REPORTED BY SOCIAL WORKERS

Reasons: 1. Earlier referral means more time to evaluate and assess attitudes and wishes of patient and family with regard to the decision of where patient will go upon discharge.

2. Earlier referral means more time to find appropriate nursing home placement.

3. Earlier referral means more time to develop better worker-patient and/or worker-family relationship.

4. Earlier referral means more time to do necessary paperwork.

5. Does not apply, as all admissions are referred on the day of admission.

6. When certain doctors refer their patients, it means that the patients are nearly medically ready for discharge.

TABLE 13

TIME BETWEEN ADMISSION AND REFERRAL OF LAST TERMINAL PATIENT REPORTED BY SOCIAL WORKERS, BY DISPOSITION

<table>
<thead>
<tr>
<th>Time</th>
<th>Home</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
</tr>
<tr>
<td>same day</td>
<td>11</td>
<td>12.8</td>
</tr>
<tr>
<td>1 - 2 days</td>
<td>20</td>
<td>23.3</td>
</tr>
<tr>
<td>3 - 7 days</td>
<td>23</td>
<td>26.7</td>
</tr>
<tr>
<td>8 - 14 days</td>
<td>23</td>
<td>26.7</td>
</tr>
<tr>
<td>15 - 30 days</td>
<td>5</td>
<td>5.8</td>
</tr>
<tr>
<td>over 30 days</td>
<td>4</td>
<td>4.7</td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>100.0</td>
</tr>
</tbody>
</table>
Table 13 shows that over one-third of the social workers reported that the length of time between admission and referral of their last terminal patient was within two days of admission, regardless of whether the patient went home or to an institution upon discharge. In addition, over one-half of social workers reported that the length of time between admission and referral of their last terminal patient was between 3 and 14 days, or the first two weeks of admission, regardless of disposition outcome. The finding clearly demonstrates that social service intervention took place during the first or second week after admission. This is in contrast to the results of an earlier study of elderly patients by Berkman and Rehr (1970) which found that social service intervention, based upon traditional case referral, usually occurred during the second or third week after admission. The findings give evidence to the fact that terminal patients are referred early in their admission.

Data in Table 14 show that terminal patients who went home or to an institution upon discharge generally had the same length of admission, according to social workers. The majority of social workers reported that their last terminal patients stayed from two weeks to over one month, whether they went home (71 percent) or to an institution (81%) upon discharge. This finding implies that, despite the lack of appropriate extended care beds recognized by social workers, terminal patients who are discharged to the institution are not overstaying their admission for social reasons. The implication is that early intervention by the social worker leads to more
efficient discharge planning whether to home or institution.

<table>
<thead>
<tr>
<th>Length of Hospitalization</th>
<th>Home</th>
<th>Institute</th>
</tr>
</thead>
<tbody>
<tr>
<td>One week or less</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>One - two weeks</td>
<td>24</td>
<td>14</td>
</tr>
<tr>
<td>Two weeks - one month</td>
<td>36</td>
<td>35</td>
</tr>
<tr>
<td>Over one month</td>
<td>25</td>
<td>35</td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>86</td>
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</tbody>
</table>

Home vs. Institution:

The variable, home vs. institution, as the designated location for dying, was examined because of its implications for discharge planning for the terminal patient. The researcher wanted to explore factors which pointed in the direction of home or institution. As previously stated, comparison was made between those social workers both hospital and hospice, whose last one in five referenced cases went home, and those whose last five in five referenced cases went home.

Table 15 indicates that over 74 percent of social workers reported that at least three of their five referenced cases went
home upon discharge. This finding is clearly evidence that a greater
number of terminal patients are going home than to an institution
upon discharge.

**TABLE 5**

PATIENT OUTCOME FOR FIVE REFERENCED CASES,*
REPORTED BY SOCIAL WORKERS (PERCENTAGE)

<table>
<thead>
<tr>
<th>Number of Five Referenced Cases Returning Home</th>
<th>Number of Social Workers</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>14</td>
<td>16.0</td>
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<tr>
<td>4</td>
<td>23</td>
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</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>100.0</td>
</tr>
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</table>

*Those cases upon which the questions were based
TABLE I
RANK-ORDERED MEAN SCORES OF PATIENTS' NEEDS IN DISCHARGE PLANNING, BY REFERENCED GROUP (SCALE 0-9)

<table>
<thead>
<tr>
<th>Group</th>
<th>I (N=14)</th>
<th></th>
<th></th>
<th>II (N=10)</th>
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<th></th>
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<tr>
<td></td>
<td>mean</td>
<td>SD</td>
<td>R</td>
<td>mean</td>
<td>SD</td>
<td>R</td>
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<tr>
<td>24 hr. nursing</td>
<td>6.1</td>
<td>2.8</td>
<td>2.5</td>
<td>6.9</td>
<td>2.4</td>
<td>1 ns</td>
</tr>
<tr>
<td>Medical equipment</td>
<td>5.8</td>
<td>1.9</td>
<td>4</td>
<td>5.8</td>
<td>2.3</td>
<td>3 ns</td>
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<td>2.6</td>
<td>6</td>
<td>5.6</td>
<td>2.4</td>
<td>4.5 ns</td>
</tr>
<tr>
<td>Physicians' services</td>
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<td>3.1</td>
<td>1</td>
<td>4.9</td>
<td>2.1</td>
<td>14 .01**</td>
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<tr>
<td>Nursing (less 40 hrs.)</td>
<td>4.8</td>
<td>2.2</td>
<td>8.5</td>
<td>5.3</td>
<td>3.0</td>
<td>7.5 .05*</td>
</tr>
<tr>
<td>Contacting family</td>
<td>6.1</td>
<td>2.7</td>
<td>2.5</td>
<td>4.8</td>
<td>2.0</td>
<td>16 ns</td>
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<tr>
<td>Diet</td>
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<td>7</td>
<td>4.7</td>
<td>2.0</td>
<td>17 ns</td>
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<td>4.4</td>
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<td>5.0</td>
<td>2.6</td>
<td>11.5 ns</td>
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<tr>
<td>Rehab services</td>
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<td>2.1</td>
<td>8.5</td>
<td>5.0</td>
<td>3.2</td>
<td>11.5 .05*</td>
</tr>
<tr>
<td>Cash assistance</td>
<td>5.6</td>
<td>2.4</td>
<td>5</td>
<td>5.9</td>
<td>3.2</td>
<td>2 ns</td>
</tr>
<tr>
<td>Medication</td>
<td>3.6</td>
<td>2.1</td>
<td>17</td>
<td>4.9</td>
<td>2.5</td>
<td>14 ns</td>
</tr>
<tr>
<td>Insurance</td>
<td>3.7</td>
<td>2.4</td>
<td>16</td>
<td>5.1</td>
<td>2.7</td>
<td>9.5 ns</td>
</tr>
<tr>
<td>Benefits</td>
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<td>1.8</td>
<td>13</td>
<td>4.2</td>
<td>2.5</td>
<td>20 ns</td>
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<tr>
<td>Meal services</td>
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<td>15</td>
<td>3.7</td>
<td>1.8</td>
<td>21 ns</td>
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<td>11.5</td>
<td>4.5</td>
<td>3.5</td>
<td>18.5 ns</td>
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<td>2.2</td>
<td>14</td>
<td>5.3</td>
<td>3.9</td>
<td>7.5 ns</td>
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<tr>
<td>Housing</td>
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<td>2.8</td>
<td>20</td>
<td>5.6</td>
<td>3.7</td>
<td>4.5 ns</td>
</tr>
<tr>
<td>Clinic appointment</td>
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<td>2.3</td>
<td>19</td>
<td>4.9</td>
<td>4.2</td>
<td>14 ns</td>
</tr>
<tr>
<td>Food stamps</td>
<td>2.0</td>
<td>1.1</td>
<td>21</td>
<td>3.1</td>
<td>3.9</td>
<td>9.5 ns</td>
</tr>
<tr>
<td>Legal aid</td>
<td>3.5</td>
<td>3.1</td>
<td>18</td>
<td>5.4</td>
<td>4.1</td>
<td>6 ns</td>
</tr>
<tr>
<td>Budgeting</td>
<td>4.6</td>
<td>4.0</td>
<td>10</td>
<td>4.5</td>
<td>3.9</td>
<td>18.5 ns</td>
</tr>
</tbody>
</table>

r = .14

* p < .05
** p < .01
Of all variables, only patients' needs, as shown in Table 16, was found to be significantly associated with the number of referenced cases who went home upon discharge. Data in Table 16 show the significance of the following patients' needs: physicians' services \( (p < .01) \), nursing services (less than 40 hrs.) \( (p < .05) \), and rehab services \( (p < .05) \). However, there appears to be a low degree of association between social workers' perceptions of their patients' needs and the number of referenced cases who went home \( (r = .14) \). Rankings of patients' needs was very different for each group. Because of the rather low levels of significance, interpretation of these findings might be that disposition outcome was related to needs or features of the patient rather than because different social workers used different criteria in discharge planning. These findings permit speculation, but warrant considerably more investigation.

List 2 presents reasons for change in the implementation of the discharge plan to home, according to social workers. These reasons highlight certain factors that come into play when the decision of home vs. institution is being made, such as: the medical condition of the patient; family's desire to have patient home; patient and family financial resources; patient's desire to go home; cooperation of physician; and patient's rehabilitative needs upon discharge.
LIST 2

REASONS FOR CHANGE IN IMPLEMENTATION OF DISCHARGE PLAN TO HOME, REPORTED BY SOCIAL WORKERS

Reasons: 1. Patient died in the hospital

2. Wife changed her mind because she could not cope with idea of patient dying at home.

3. Patient underwent rapid and great deterioration so that skilled nursing home was indicated.

4. Patient was discharged to rehabilitation facility for additional therapy prior to going home.

5. Family could not come up with the necessary financial resources to pay for home care.

6. Patient desired to go to a hospice.

7. Physician refused to accept plan for home because of family's ambivalence.
Research Question II: Compare the differences/similarities in discharge planning between hospice and hospital settings.

This research sought to investigate whether hospice social workers offered services in discharge planning which were more individualized to the terminal patient and his family than the hospital social workers. The focus was on what factors both groups considered important in their formulation of discharge plans for the terminal patient. Because of the small size of the hospice sample, interpretations of the findings presented should only be made or accepted with some caution. The data were analyzed statistically for significant relationships in the clusters of variables which related to: (1) the Patient; (2) the Family; and (3) the Environment.

Patient Factors:

Significant differences in patients' needs upon discharge were found to be associated with hospice or hospital setting. Data in Table 17 show that the following variables were significantly different: "assistance with obtaining medical equipment" (p < .01), "counseling around death and dying" (p < .001), "physicians' services (p < .001), "nursing (less than 40 hrs.) (p < .01), "special diet"
(p < .05), "assistance with obtaining medication" (p < .001), and "help with private insurance" (p < .01). Mean scores for those variables were significantly higher for hospice workers, indicating that they placed more emphasis on these needs. The findings show that hospice workers consider counseling patients around death and dying more important than hospital workers. Hospital and hospice workers were similar in scoring the lowest means for: budgeting, legal aid, food stamps, clinic appointments, mental health, and housing. There was a high degree of association between social workers' perceptions of patients' needs upon discharge, and setting. (r = .84). Both groups ranked the following patients' needs in relatively the same high order: "24 hr. nursing," "medical equipment," "counseling," "physicians' services," and "nursing (less than 40 hrs.)." These findings suggest that, although hospital and hospice social workers differed significantly in the importance they attached to particular patients' needs, such as "medical equipment," "counseling," "physicians' services," and "nursing (less than 40 hrs.)," both groups placed more emphasis on these needs compared to others.

Data in Table 18 support the finding that hospice workers (73%) consider counseling around death and dying more important than hospital workers (4%). The three main patients' needs stressed by hospital workers were: nursing services (89%), medical equipment (39%), and rehabilitation (32%). The three main patients' needs highlighted by the hospice workers were: nursing (100%), counseling around death and dying (73%), and spiritual (40%). It is interest-
ing to note that hospice workers added spiritual needs as a new factor, while hospital workers did not mention this at all.

In studying patients' attitudes toward dying between hospice and hospital social workers, the following variables were found to be statistically significant, as presented in Table 19: "guilt" \( (p < .001) \), "unable to ascertain" \( (p < .05) \), "denial" \( (p < .05) \), "isolation" \( (p < .01) \), "withdrawal" \( (p < .05) \), and "acceptance" \( (p < .001) \). The mean scores for these variables were significantly higher for hospice workers, indicating that they placed more emphasis on these attitudes. The relationships between "guilt," and "acceptance," and setting were very significant. It can be interpreted from Table 19, that hospital and hospice workers recognize different feelings in their patients in discharge planning \( (r = .24) \). Hospice workers ranked "guilt" as the most important attitude, while hospital workers ranked "hopeful." One explanation for this finding may be the contrasting philosophical orientation of the two settings. Hospital workers may view their patients as more "hopeful" because this becomes integrated from a cure-oriented environment, while hospice workers may tend to view their patients as more "accepting," indicating the open admission of prognosis in this setting. The finding with regard to "guilt" and hospice workers warrants more investigation. In relation to the attitudes of "anger" and "depression," there were no significant differences between settings. Data in Table 20 show that 80 percent of hospice social workers felt that the patient's desire to go home was a very important factor in discharge planning. Only 40 percent of the hospital workers felt
this factor was important. It appears clear from these data, that hospice workers individualize their terminal patients in discharge planning to home or institution. This finding again supported that hospice social workers seem more sensitive to their patients' needs in discharge planning.

There were significant differences in three variables of patients' financial conditions, and setting: "Medicare and private insurance" (p < .05), "Medicare and Medicaid" (p < .05), and "private insurance and private funds" (p < .01) (Table 21). Mean scores for those variables were significantly higher for hospice workers, indicating that they placed more emphasis on these financial conditions. One explanation for the findings may be the various ways that hospice patients cover their medical costs. Medicaid does not provide coverage for hospice services, so that hospice social workers turn to Medicare and private insurance and funds for coverage. Both groups ranked patients' financial conditions in relatively the same order (r = .84), with both ranking "Medicare and private insurance" as most important.

Family Factors:

Variables relating to family needs upon discharge were analyzed in order to determine whether they were associated to any significant degree with setting. Data in Table 22 show that the following variables were found to be very significant: "counseling around death and dying" (p < .001), "bereavement counseling" (p < .001), and "other medical problems" (p < .001). These are key findings and will
be discussed more fully in a later chapter. They clearly indicate that hospice workers believe the families of their terminal patients need counseling—during hospitalization and after the death of the patient. Hospital workers did not feel bereavement counseling was an important family need, as evidenced by the low mean score. Mean scores for those needs were significantly considerably higher for hospice workers, indicating the importance the workers placed on these needs. There was no significant differences found between "application to nursing homes" and setting, and both groups ranked this need very high. There was a high degree of association between social workers' perceptions of family needs upon discharge, and setting (r=.84), indicating that both groups ranked the needs in relatively the same order. Both groups scored low mean ratings for such concrete needs as: "vocational training," "legal aid," "food stamps," "clinic appointments," "housing," "mental health," and "budgeting." These findings were similar to those for patients' needs (Table 17), and imply that social workers do not consider these concrete tasks important in their discharge planning for the terminal patient and family. Possible explanations may be that these concrete needs arise infrequently, or workers have inadequate time to address them.

Data in Table 23 show that the three main family needs stressed by hospital workers were: counseling around death and dying (35%), application to nursing homes (73%), and medical supplies (31%); while the three principal family needs highlighted by hospice workers were: counseling around death and dying (100%), bereavement counseling
(73%), and application to nursing homes (40%). It is of interest to note that few hospital workers felt families needed bereavement counseling (13%). These findings supported the findings from data in Table 22.

Data in Table 24 show that significant differences were found between the following family attitudes toward the patient, and setting: "loving marriage" ($p < .001$), "can't face the thought" ($p < .001$), "live too far away" ($p < .001$), "leave the decision to the patient" ($p < .001$), and "never that close" ($p < .01$). Mean scores for these variables were significantly higher for hospice workers, indicating the emphasis the workers placed on these attitudes. There was no significant difference between the family attitude of leaving the decision of disposition to the family, and setting. The respondents' mean rating for this variable was around midpoint. Again, these findings support the impression that hospice social workers, more than did hospital workers value the patient's wishes of where to go upon discharge. Moreover, the data suggest that hospice workers are considerably more attuned to open and direct expressions of feelings by the family toward the patient in discharge planning, whether positive or negative. Hospice and hospital were similar in their scoring high mean ratings for attitudes which expressed feelings of guilt, for example, "can't put her away" and "never forgive." No significant difference was found between the attitude of "want home," and setting. Both groups ranked this variable extremely high. These findings imply that both hospital and hospice social workers consider it quite important when the family
wants to take the patient home upon discharge, and attest to the critical nature of this factor in decision-making for disposition. Data from Table 20 confirm this. Over 43 percent of hospital workers, and over 46 percent of hospice workers reported that the family's desire to have patient home was one of the three main factors in discharge planning. The correlation between social workers' perceptions of family attitudes and setting was modest (r=.48), so that the practical significance of the rankings for both groups cannot be interpreted.

There were significant differences found in two variables of family's financial conditions, and setting: "private insurance and private funds" (p .01), and "Medicaid eligible" (p .01), as shown in Table 25. Mean scores for these variables were significantly higher for hospice workers, indicating that they placed more emphasis on these financial conditions. Both groups ranked family's financial conditions in relatively the same order (r=.84), with Medicare and private insurance and funds considered very important by both groups. From previous findings in Table 22, it was demonstrated that hospice workers consider the family's medical problems as significantly important in discharge planning. This finding might explain why hospice workers pay attention to the family's medicaid eligibility. Hospice workers may view the family as part of the unit of attention with the patient, and as such, they intervene in ways to help the family with their own problems. Defining the unit of attention as the patient and family is one of the hallmarks of hospice philosophy.
Data in Table 26 show that the three main financial conditions considered by hospital workers were: Medicare and Medicaid (75%), Medicaid (62%), and Medicare and private funds (60%); while the three main financial conditions stressed by hospice workers were: Medicare and Medicaid (73%), private insurance and private funds (67%), and Medicare and private funds (47%). Hospice depends upon payment from Medicare and private insurance and private funds for its services, such as bereavement counseling for example, since Medicaid does not provide coverage.

**Environment Factors:**

In studying the importance hospice and hospital social workers place on environmental factors in discharge planning, several significant differences were found between the variables of patients' home conditions, and setting (Table 27): bathroom and bedroom on different floors (p < .01), steps to apartment (no elevator) (p < .01), inadequate space for equipment (p < .001), equipment already installed (p < .01), and overcrowded (p < .001). Mean scores were significantly higher for hospice workers, indicating the importance they placed on these conditions. No significant difference was found between settings and "living alone." Thus, while the findings suggest that hospice workers seem to give more weight to the physical layout of the patient's home in discharge planning, both groups perceived the patient living alone as most vulnerable and in need of service. Rankings of home conditions were highly correlated for both groups (r = .96). Thus, while hospital and hospice social workers
differed significantly in the importance they attached to particular
home conditions, reported above, both groups were very similar in
the order of importance they placed the conditions.

In studying social workers' perceptions of important team
members in discharge planning, a significant difference was found
between religious personnel, and setting (p< .01), as presented in
Table 28. The mean rating was significantly higher for hospice
workers, indicating the importance they placed on religious personnel
in discharge planning. Hospice workers assigned the highest rank to
religious personnel, again confirming the emphasis they attached to
these team members. Hospital workers gave religious personnel a
relatively low rank. Including the clergy in the medical team is
one of the principal features of the hospice philosophy. Although
another hallmark of the hospice team approach is the use of volun­
teers in discharge planning. Data in Table 28 also show that there
were no significant differences between setting and social workers'
perceptions of the importance of nurses, doctors, and physical
therapists as team members. The correlation between social workers'
perceptions of the importance of team members, and setting was so
close to zero (r=.04), that it indicated the ranking of variables
for both groups was unrelated. Although both groups assigned a
similarly high rank for "nurses" and a similarly low rank for
"administrators," they differed widely in the importance they placed
other team members. The findings again supported the evidence in
Table 18 of the importance social workers ascribe to nursing services
for patients in discharge planning.
Data in Table 29 show that significant differences were found between two situations encountered in working with terminal patients, and setting: patient's condition changes from time of admission ($p < .001$), and physician decides where patient should go upon discharge ($p < .01$). One explanation for the first finding may lie in the nature of hospice philosophy. Hospice workers are very oriented to the physical care of the patient in terms of pain control, physical comfort, and mental alertness. The finding implies that hospice social workers may individualize their patients more than hospital workers, with regard to actual physical condition. One interpretation for the significant difference found between setting and the situation in which the physician decides the disposition, may be the greater involvement of the physician with the patient and family in the hospice program. The hospice concept emphasizes the patient's wishes in deciding where to go upon discharge, and more often than not, the patient wants to return home. With greater involvement of the physician, and consequently more support for the family, perhaps more hospice patients are going home than to an institution. Hospital and hospice social workers were similar in their scoring the lowest means for "limited cooperation of medical staff in necessary paperwork." This finding refutes previous research that found this factor to impede the efficient process of discharge planning, and suggests that doctors are more responsive to completing the paperwork needed to apply for nursing home and home health care. Both groups' mean ratings for the following variables were around midpoint: "utilization review says patient must leave
when appropriate plan is not yet formulated," and "difficulty in establishing eligibility of patient for needed benefits." Both groups scored similarly high means for the variable, "lack of appropriate extended care beds," and no significant difference was found between this variable, and setting. This finding confirms the lack of appropriate nursing home beds for terminal patients, and supports previous research by Schrager et al. (1978) in which the lack of appropriate extended care beds tended to delay the course of discharge planning. It is noteworthy that both hospital and hospice workers assigned the highest rank to this situation, indicating the importance they placed on it in discharge planning for the terminal patient. The correlation between social workers' perceptions of situations encountered in working with terminal patients, and setting was moderate (r=.60), so that the practical significance of the rankings for both groups is difficult to be interpreted.

To summarize the major findings of this section, the researcher found that a greater number of factors relating to the patient, as opposed to factors relating to the family or environment, were found to be significantly associated with setting. Several key findings indicate that hospice workers, more than hospital workers, may individualize their terminal patients and families. Hospice workers were significantly more likely to take into account patients' needs for counseling around death and dying, medical equipment, physicians' services, nursing services (less than 40 hrs. per week), assistance with obtaining medication, help with private insurance, and special
diet. They also showed greater recognition of patients' spiritual needs. Hospice workers perceived their patients as more accepting of their illness, while hospital workers saw their patients as more hopeful. During the course of discharge planning, hospice workers were significantly more likely to consider patients' attitudes about dying, and they were more likely to take into account the patient's desire to go home. With regard to financial factors, hospice workers were significantly more likely to attach importance to patients' and families' private insurance and private funds, than did hospital workers.

Hospice workers were significantly more likely than hospital workers to emphasize the family's needs for counseling around death and dying, bereavement counseling, and other medical problems, and consider the family attitude of leaving the decision of disposition to the patient. Both groups believed the family's desire to take the patient home was a crucial factor in discharge planning. Findings showed that hospice workers were significantly more likely to take the patients' home conditions into account in discharge planning, implying greater recognition to the actual, physical layout of the patient's home environment. Both groups regarded living along as the most vulnerable home condition in need of the utmost consideration in discharge planning. Hospice workers were significantly more likely to perceive religious personnel as important team members.

Findings supported previous research on two environmental factors. Lack of appropriate extended care beds and the change in the
medical condition of the patient, were found to be important in discharge planning. Hospice workers were significantly more likely to encounter the change in medical condition, which might suggest that they are more attuned to how the change may affect the discharge planning. The factor of limited cooperation of medical staff in necessary paperwork, was not found to be important, refuting previous research. Hospice workers were significantly more likely to encounter situations in which the physician decided where the patient would go upon discharge.

Rank correlation coefficients ranged from $r = -0.04$ to $r = 0.96$. The former correlation was between social workers' perceptions of the importance of team members, and setting, and since it was so close to zero, it indicated the ranking of variables for both groups was unrelated. The latter correlation showed that hospital and hospice workers were very similar in the order of importance they placed patients' home conditions. Higher correlations related to patients' needs upon discharge ($r=0.84$), patients' financial conditions ($r=0.84$), family needs upon discharge ($r=0.84$), and family's financial conditions ($r=0.84$), indicating that, for patients and families, hospice and hospital social workers were similar in the order of importance they placed needs upon discharge and financial conditions. One interpretation may be that both groups attach qualitative similarity among these variables for patients and families. In addition, both groups assigned the highest ranks to two environmental situations, "patient living alone" and "lack of appropriate extended care beds,"
indicating how critical they considered these situations in discharge planning for the terminal patient.
### TABLE 17

**RANK-ORDERED MEAN SCORES OF PATIENTS’ NEEDS CONSIDERED IN DISCHARGE PLANNING, BY SETTING (SCALE 0-9)**

<table>
<thead>
<tr>
<th>Setting</th>
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<th>Hospice (N=15)</th>
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<th></th>
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<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>R</td>
<td>Mean</td>
<td>SD</td>
<td>R</td>
</tr>
<tr>
<td>24 hr. nursing</td>
<td>5.9</td>
<td>2.9</td>
<td>1</td>
<td>6.3</td>
<td>2.9</td>
<td>4.5</td>
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<tr>
<td>Medical equipment</td>
<td>5.3</td>
<td>2.4</td>
<td>2</td>
<td>6.9</td>
<td>1.6</td>
<td>2</td>
</tr>
<tr>
<td>Counseling</td>
<td>4.6</td>
<td>2.7</td>
<td>3.5</td>
<td>7.0</td>
<td>1.9</td>
<td>1</td>
</tr>
<tr>
<td>Physicians’ services</td>
<td>4.6</td>
<td>2.3</td>
<td>3.5</td>
<td>6.7</td>
<td>1.9</td>
<td>3</td>
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<tr>
<td>Nursing (less 40 hrs.)</td>
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<td>5</td>
<td>5.8</td>
<td>2.7</td>
<td>6</td>
</tr>
<tr>
<td>Contacting family</td>
<td>3.8</td>
<td>2.9</td>
<td>6</td>
<td>4.6</td>
<td>2.5</td>
<td>9</td>
</tr>
<tr>
<td>Diet</td>
<td>3.5</td>
<td>2.6</td>
<td>7</td>
<td>5.1</td>
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<td>9</td>
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<td>13</td>
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<tr>
<td>Cash assistance</td>
<td>3.8</td>
<td>3.0</td>
<td>9</td>
<td>2.3</td>
<td>3.1</td>
<td>15</td>
</tr>
<tr>
<td>Medication</td>
<td>2.9</td>
<td>2.4</td>
<td>11</td>
<td>6.3</td>
<td>2.6</td>
<td>4.5</td>
</tr>
<tr>
<td>Insurance</td>
<td>3.1</td>
<td>2.4</td>
<td>12.5</td>
<td>5.1</td>
<td>1.8</td>
<td>7.5</td>
</tr>
<tr>
<td>Benefits</td>
<td>3.1</td>
<td>2.7</td>
<td>12.5</td>
<td>3.0</td>
<td>2.5</td>
<td>12</td>
</tr>
<tr>
<td>Meal services</td>
<td>2.4</td>
<td>2.3</td>
<td>14</td>
<td>3.1</td>
<td>2.4</td>
<td>11</td>
</tr>
<tr>
<td>Clinical lab</td>
<td>2.1</td>
<td>2.4</td>
<td>15</td>
<td>1.7</td>
<td>1.5</td>
<td>18</td>
</tr>
<tr>
<td>Mental Health</td>
<td>1.9</td>
<td>2.2</td>
<td>16</td>
<td>2.3</td>
<td>2.7</td>
<td>15</td>
</tr>
<tr>
<td>Housing</td>
<td>1.8</td>
<td>2.4</td>
<td>17</td>
<td>2.3</td>
<td>2.9</td>
<td>15</td>
</tr>
<tr>
<td>Clinic appointments</td>
<td>1.3</td>
<td>2.0</td>
<td>18.5</td>
<td>2.0</td>
<td>3.5</td>
<td>17</td>
</tr>
<tr>
<td>Food stamps</td>
<td>1.3</td>
<td>1.8</td>
<td>18.5</td>
<td>0.7</td>
<td>1.4</td>
<td>21</td>
</tr>
<tr>
<td>Legal aid</td>
<td>1.2</td>
<td>1.9</td>
<td>20</td>
<td>1.6</td>
<td>1.6</td>
<td>19</td>
</tr>
<tr>
<td>Budgeting</td>
<td>0.8</td>
<td>1.5</td>
<td>21</td>
<td>1.4</td>
<td>1.9</td>
<td>20</td>
</tr>
</tbody>
</table>

* p < .05  
** p < .01  
*** p < .001  

r = .84
### TABLE 18

**SUMMARY OF THREE MAIN PATIENTS' NEEDS IN DISCHARGE PLANNING REPORTED BY SOCIAL WORKERS, BY SETTING (PERCENTAGE)**

<table>
<thead>
<tr>
<th>Patient Need</th>
<th>Hospital</th>
<th></th>
<th>Hospice</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
<td>Number</td>
<td>Percent</td>
</tr>
<tr>
<td>Nursing services</td>
<td>63</td>
<td>89.0</td>
<td>15</td>
<td>100.0</td>
</tr>
<tr>
<td>Medical equipment</td>
<td>28</td>
<td>39.0</td>
<td>1</td>
<td>7.0</td>
</tr>
<tr>
<td>Rehabilitation</td>
<td>23</td>
<td>32.0</td>
<td>2</td>
<td>13.0</td>
</tr>
<tr>
<td>Counseling on death and dying</td>
<td>3</td>
<td>4.0</td>
<td>11</td>
<td>73.0</td>
</tr>
<tr>
<td>Spiritual</td>
<td>**</td>
<td></td>
<td>6</td>
<td>40.0</td>
</tr>
</tbody>
</table>

* Note - Due to overlapping, total does not add to 100

**Respondents did not mention this item

### TABLE 19

**RANK-ORDERED MEAN SCORES OF PATIENTS' ATTITUDES TOWARD DYING CONSIDERED IN DISCHARGE PLANNING, BY SETTING (SCALE 0-9)**

<table>
<thead>
<tr>
<th>Attitude</th>
<th>Hospital (N=71)</th>
<th></th>
<th>Hospice (N=15)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>R</td>
<td>Mean</td>
</tr>
<tr>
<td>Guilt</td>
<td>5.7</td>
<td>2.1</td>
<td>3</td>
<td>7.7</td>
</tr>
<tr>
<td>Unable to ascertain</td>
<td>5.7</td>
<td>2.4</td>
<td>3</td>
<td>7.1</td>
</tr>
<tr>
<td>Hopeful</td>
<td>5.8</td>
<td>2.1</td>
<td>1</td>
<td>6.5</td>
</tr>
<tr>
<td>Depression</td>
<td>5.7</td>
<td>2.3</td>
<td>3</td>
<td>5.7</td>
</tr>
<tr>
<td>Denial</td>
<td>5.3</td>
<td>2.5</td>
<td>5</td>
<td>6.7</td>
</tr>
<tr>
<td>Isolation</td>
<td>4.9</td>
<td>2.4</td>
<td>6</td>
<td>6.9</td>
</tr>
<tr>
<td>Withdrawal</td>
<td>4.7</td>
<td>2.4</td>
<td>7</td>
<td>6.1</td>
</tr>
<tr>
<td>Bargaining</td>
<td>4.6</td>
<td>2.4</td>
<td>8</td>
<td>5.8</td>
</tr>
<tr>
<td>Acceptance</td>
<td>4.1</td>
<td>2.2</td>
<td>10</td>
<td>7.1</td>
</tr>
<tr>
<td>Anger</td>
<td>4.3</td>
<td>2.4</td>
<td>9</td>
<td>4.6</td>
</tr>
</tbody>
</table>

*p < .05

**p < .01

***p < .001

r = .24
TABLE 20

SUMMARY OF THREE MAIN FACTORS IN DISCHARGE PLANNING REPORTED BY SOCIAL WORKERS, BY SETTING (PERCENTAGE)*

<table>
<thead>
<tr>
<th></th>
<th>Hospital</th>
<th>Hospice</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
</tr>
<tr>
<td>Patient and family</td>
<td></td>
<td></td>
</tr>
<tr>
<td>financial resources</td>
<td>38</td>
<td>53.5</td>
</tr>
<tr>
<td>Patient's desire to</td>
<td></td>
<td></td>
</tr>
<tr>
<td>go home</td>
<td>29</td>
<td>40.8</td>
</tr>
<tr>
<td>Family's desire to</td>
<td></td>
<td></td>
</tr>
<tr>
<td>have patient home</td>
<td>31</td>
<td>43.6</td>
</tr>
</tbody>
</table>

*Note — Due to overlapping, total does not add to 100

TABLE 21

RANK-ORDERED MEAN SCORES OF PATIENTS' FINANCIAL CONDITIONS CONSIDERED IN DISCHARGE PLANNING, BY SETTING (SCALE 0–9)

<table>
<thead>
<tr>
<th></th>
<th>Hospital (N=71)</th>
<th>Hospice (N=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Medicare and private insurance</td>
<td>6.1</td>
<td>2.2</td>
</tr>
<tr>
<td>Medicaid eligible</td>
<td>5.9</td>
<td>2.3</td>
</tr>
<tr>
<td>Medicare and medicaid</td>
<td>5.8</td>
<td>2.8</td>
</tr>
<tr>
<td>Medicaid</td>
<td>5.5</td>
<td>2.5</td>
</tr>
<tr>
<td>Private insurance and private funds</td>
<td>4.8</td>
<td>2.7</td>
</tr>
</tbody>
</table>

* p \leq .05  
** p \leq .01  
r = .84
<table>
<thead>
<tr>
<th>Need</th>
<th>Hospital (N=71)</th>
<th></th>
<th>Hospice (N=15)</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>R</td>
<td>Mean</td>
<td>SD</td>
<td>R</td>
</tr>
<tr>
<td>Application NHs</td>
<td>6.0</td>
<td>3.0</td>
<td>1</td>
<td>7.2</td>
<td>1.9</td>
<td>3</td>
</tr>
<tr>
<td>Counseling</td>
<td>4.9</td>
<td>2.6</td>
<td>2</td>
<td>8.7</td>
<td>0.7</td>
<td>1</td>
</tr>
<tr>
<td>Medical supplies</td>
<td>4.6</td>
<td>2.5</td>
<td>3</td>
<td>4.7</td>
<td>2.0</td>
<td>6</td>
</tr>
<tr>
<td>Transportation</td>
<td>4.3</td>
<td>2.7</td>
<td>4</td>
<td>4.9</td>
<td>2.6</td>
<td>5</td>
</tr>
<tr>
<td>Bereavement</td>
<td>3.2</td>
<td>2.8</td>
<td>7</td>
<td>7.4</td>
<td>2.1</td>
<td>2</td>
</tr>
<tr>
<td>Insurance</td>
<td>3.6</td>
<td>2.9</td>
<td>6</td>
<td>4.2</td>
<td>2.3</td>
<td>7</td>
</tr>
<tr>
<td>Cash assistance</td>
<td>3.7</td>
<td>3.1</td>
<td>5</td>
<td>3.3</td>
<td>3.2</td>
<td>8</td>
</tr>
<tr>
<td>Benefits</td>
<td>3.1</td>
<td>2.6</td>
<td>8</td>
<td>2.7</td>
<td>1.8</td>
<td>11</td>
</tr>
<tr>
<td>Medical problems</td>
<td>2.5</td>
<td>2.1</td>
<td>9</td>
<td>5.3</td>
<td>2.4</td>
<td>4</td>
</tr>
<tr>
<td>Meal services</td>
<td>2.0</td>
<td>2.4</td>
<td>11</td>
<td>2.9</td>
<td>1.7</td>
<td>9</td>
</tr>
<tr>
<td>Housing</td>
<td>2.1</td>
<td>2.5</td>
<td>10</td>
<td>2.0</td>
<td>2.8</td>
<td>14</td>
</tr>
<tr>
<td>Mental health</td>
<td>1.7</td>
<td>2.2</td>
<td>12</td>
<td>2.2</td>
<td>2.5</td>
<td>12</td>
</tr>
<tr>
<td>Budgeting</td>
<td>1.1</td>
<td>1.9</td>
<td>15.5</td>
<td>2.8</td>
<td>1.8</td>
<td>10</td>
</tr>
<tr>
<td>Clinic</td>
<td>1.2</td>
<td>2.0</td>
<td>14</td>
<td>2.1</td>
<td>2.6</td>
<td>13</td>
</tr>
<tr>
<td>Legal aid</td>
<td>1.3</td>
<td>1.6</td>
<td>13</td>
<td>1.3</td>
<td>1.5</td>
<td>15</td>
</tr>
<tr>
<td>Food stamps</td>
<td>1.1</td>
<td>1.7</td>
<td>15.5</td>
<td>1.0</td>
<td>1.4</td>
<td>16</td>
</tr>
<tr>
<td>Vocational training</td>
<td>0.8</td>
<td>1.5</td>
<td>17</td>
<td>0.5</td>
<td>1.3</td>
<td>17</td>
</tr>
</tbody>
</table>

***p < .001
r = .84
### Table 23

**SUMMARY OF MAIN FAMILY NEEDS IN DISCHARGE PLANNING REPORTED BY SOCIAL WORKERS, BY SETTING (PERCENTAGE)**

<table>
<thead>
<tr>
<th>Need</th>
<th>Hospital</th>
<th></th>
<th>Hospice</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
<td>Number</td>
<td>Percent</td>
</tr>
<tr>
<td>Counseling around death and dying</td>
<td>23</td>
<td>35.0</td>
<td>15</td>
<td>100.0</td>
</tr>
<tr>
<td>Application to nursing homes</td>
<td>52</td>
<td>73.0</td>
<td>6</td>
<td>40.0</td>
</tr>
<tr>
<td>Medical supplies</td>
<td>22</td>
<td>31.0</td>
<td>5</td>
<td>33.0</td>
</tr>
<tr>
<td>Bereavement counseling</td>
<td>9</td>
<td>13.0</td>
<td>11</td>
<td>73.0</td>
</tr>
</tbody>
</table>

*Note - Due to overlapping, total does not add to 100*
TABLE 24
RANK-ORDERED MEAN SCORES OF FAMILY ATTITUDES CONSIDERED IN DISCHARGE PLANNING, BY SETTING (SCALE 0-9)

| Attitude                  | Setting          | Hospital (N=71) | Hospice (N=15) | R     | P
|---------------------------|------------------|----------------|----------------|-------|-----
| "Want home"               |                  | 6.7            | 7.5            | 1     | ns  |
| "Can't put away"          |                  | 6.6            | 7.6            | 2     | ns  |
| "Never forgive"           |                  | 5.4            | 5.6            | 4     | ns  |
| "Can't afford NH"         |                  | 5.5            | 5.6            | 3     | ns  |
| "NH better care"          |                  | 4.9            | 6.6            | 5     | ns  |
| "Loving marriage"         |                  | 4.0            | 6.9            | 8     | .001*** |
| "Decision family"         |                  | 4.1            | 5.4            | 6.5   | .001*** |
| "Can't face thought"      |                  | 3.6            | 6.8            | 10    | .001*** |
| "Live far away"           |                  | 3.7            | 6.6            | 9     | .001*** |
| "Not alert"               |                  | 4.1            | 4.6            | 6.5   | ns  |
| "Decision patient"        |                  | 3.5            | 6.7            | 11.5  | .001*** |
| "Afford to pay"           |                  | 3.5            | 4.7            | 11.5  | ns  |
| "Never close"             |                  | 2.9            | 5.1            | 13    | .01** |

**p < .01
***p < .001

r = .48
### TABLE 25

**RANK-ORDERED MEAN SCORES OF FAMILY'S FINANCIAL CONDITIONS CONSIDERED IN DISCHARGE PLANNING, BY SETTING (SCALE 0-9)**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Hospital (N=71)</th>
<th></th>
<th></th>
<th></th>
<th>Hospice (N=15)</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>R</td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>R</td>
<td>p</td>
</tr>
<tr>
<td>Medicare and private insurance</td>
<td>5.5</td>
<td>2.1</td>
<td>1</td>
<td>7.3</td>
<td>2.2</td>
<td>2</td>
<td>ns</td>
<td></td>
</tr>
<tr>
<td>Private insurance and private funds</td>
<td>5.3</td>
<td>2.8</td>
<td>2</td>
<td>7.5</td>
<td>1.4</td>
<td>1</td>
<td>.01**</td>
<td></td>
</tr>
<tr>
<td>Medicaid eligible</td>
<td>3.8</td>
<td>3.0</td>
<td>3</td>
<td>6.7</td>
<td>2.4</td>
<td>3</td>
<td>.01**</td>
<td></td>
</tr>
<tr>
<td>Medicare and medicaid</td>
<td>3.6</td>
<td>3.2</td>
<td>4</td>
<td>5.3</td>
<td>3.3</td>
<td>4</td>
<td>ns</td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>3.5</td>
<td>2.9</td>
<td>5</td>
<td>5.2</td>
<td>3.3</td>
<td>5</td>
<td>ns</td>
<td></td>
</tr>
</tbody>
</table>

**p < .01

r = .84**

### TABLE 26

**SUMMARY OF THREE MAIN FINANCIAL CONDITIONS IN DISCHARGE PLANNING REPORTED BY SOCIAL WORKERS, BY SETTING (PERCENTAGE)**

<table>
<thead>
<tr>
<th>Condition</th>
<th>Hospital</th>
<th></th>
<th></th>
<th>Hospice</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Percent</td>
<td>Number</td>
<td>Percent</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare and medicaid</td>
<td>53</td>
<td>75.0</td>
<td>11</td>
<td>73.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid</td>
<td>44</td>
<td>62.0</td>
<td>6</td>
<td>40.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicare and private funds</td>
<td>43</td>
<td>60.5</td>
<td>7</td>
<td>47.0</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private insurance and private funds</td>
<td>22</td>
<td>31.0</td>
<td>10</td>
<td>67.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note - Due to overlapping, total does not add to 100
TABLE 27
RANK-ORDERED MEAN SCORES OF PATIENTS' HOME CONDITIONS
CONSIDERED IN DISCHARGE PLANNING, BY SETTING (SCALE 0-9)

<table>
<thead>
<tr>
<th>Condition</th>
<th>Hospital (N=71)</th>
<th></th>
<th>Hospice (N=15)</th>
<th></th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>R</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Lives alone</td>
<td>7.5</td>
<td>2.1</td>
<td>1</td>
<td>8.2</td>
<td>2.2</td>
</tr>
<tr>
<td>Different floors</td>
<td>5.4</td>
<td>2.5</td>
<td>2</td>
<td>7.3</td>
<td>2.1</td>
</tr>
<tr>
<td>Steps</td>
<td>5.3</td>
<td>2.6</td>
<td>3</td>
<td>7.1</td>
<td>2.1</td>
</tr>
<tr>
<td>Space equipment</td>
<td>3.0</td>
<td>2.3</td>
<td>4</td>
<td>5.3</td>
<td>2.4</td>
</tr>
<tr>
<td>Installed</td>
<td>2.7</td>
<td>2.6</td>
<td>5</td>
<td>4.7</td>
<td>3.2</td>
</tr>
<tr>
<td>Overcrowded</td>
<td>2.4</td>
<td>2.4</td>
<td>7</td>
<td>4.1</td>
<td>2.3</td>
</tr>
<tr>
<td>Aide</td>
<td>2.5</td>
<td>2.6</td>
<td>6</td>
<td>3.4</td>
<td>2.8</td>
</tr>
<tr>
<td>Rehab equipment</td>
<td>2.3</td>
<td>2.5</td>
<td>8</td>
<td>3.4</td>
<td>3.3</td>
</tr>
</tbody>
</table>

* p < .05
**p < .01
***p < .001

r = .96
TABLE 28

RANK-ORDERED MEAN SCORES OF SOCIAL WORKERS' PERCEPTIONS OF THEIR ROLE IMPORTANCE WITH TEAM MEMBERS IN DISCHARGE PLANNING, BY SETTING (SCALE 0-9)

<table>
<thead>
<tr>
<th>Team Member</th>
<th>Setting</th>
<th>Hospital (N=71)</th>
<th>Hospice (N=15)</th>
<th>R</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>R</td>
<td>Mean</td>
</tr>
<tr>
<td>Nurses</td>
<td></td>
<td>7.0</td>
<td>1.7</td>
<td>1</td>
<td>7.8</td>
</tr>
<tr>
<td>Doctors</td>
<td></td>
<td>6.6</td>
<td>1.7</td>
<td>2</td>
<td>7.3</td>
</tr>
<tr>
<td>Religious personnel</td>
<td></td>
<td>5.5</td>
<td>3.4</td>
<td>8</td>
<td>9.1</td>
</tr>
<tr>
<td>Physical therapists</td>
<td></td>
<td>6.0</td>
<td>1.9</td>
<td>3</td>
<td>6.1</td>
</tr>
<tr>
<td>Aides</td>
<td></td>
<td>5.9</td>
<td>3.6</td>
<td>4</td>
<td>6.2</td>
</tr>
<tr>
<td>Occupational therapist</td>
<td></td>
<td>5.6</td>
<td>2.9</td>
<td>6.5</td>
<td>7.3</td>
</tr>
<tr>
<td>Volunteers</td>
<td></td>
<td>5.1</td>
<td>4.1</td>
<td>9</td>
<td>7.5</td>
</tr>
<tr>
<td>Dieticians</td>
<td></td>
<td>5.7</td>
<td>3.2</td>
<td>5</td>
<td>5.8</td>
</tr>
<tr>
<td>Speech therapists</td>
<td></td>
<td>5.6</td>
<td>3.3</td>
<td>6.5</td>
<td>7.0</td>
</tr>
<tr>
<td>Administrators</td>
<td></td>
<td>4.6</td>
<td>3.5</td>
<td>10</td>
<td>6.0</td>
</tr>
</tbody>
</table>

**p < .01
r = -.04
RANK-ORDERED MEAN SCORES OF SITUATIONS ENCOUNTERED IN WORKING WITH TERMINAL PATIENTS, BY SETTING (SCALE 0-9)

<table>
<thead>
<tr>
<th>Situation</th>
<th>Hospital (N=71)</th>
<th></th>
<th>Hospice (N=15)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>R</td>
<td>Mean</td>
</tr>
<tr>
<td>Lack of beds</td>
<td>6.9</td>
<td>2.1</td>
<td>1</td>
<td>7.8</td>
</tr>
<tr>
<td>Condition changes</td>
<td>5.3</td>
<td>1.9</td>
<td>2.5</td>
<td>7.5</td>
</tr>
<tr>
<td>Benefits</td>
<td>5.3</td>
<td>2.2</td>
<td>2.5</td>
<td>5.2</td>
</tr>
<tr>
<td>Utilization review</td>
<td>4.8</td>
<td>2.4</td>
<td>4</td>
<td>5.5</td>
</tr>
<tr>
<td>Limited cooperation</td>
<td>4.6</td>
<td>2.9</td>
<td>5</td>
<td>4.6</td>
</tr>
<tr>
<td>Physician decides</td>
<td>3.6</td>
<td>2.3</td>
<td>6</td>
<td>5.5</td>
</tr>
</tbody>
</table>

** p < .01
*** p < .001

r = .60
CHAPTER 6

INTERVIEWS WITH SOCIAL WORKERS

This chapter will discuss the interviews with 44 social workers, 51 percent of the sample. Of these 31 were hospital, and 13 were hospice workers. The goal of each interview was to explore the social worker's feelings toward her work with terminal patients and their families, and gain an understanding of her personal way of coping with death and dying. Certain demographic data were obtained, including experience in social work and specifically with terminal patients, membership in NASW, religion, and whether working with terminal patients was a career choice or a job assignment. Data were also obtained on personal experiences with family or friends in terminal illness, and locale of their death. Social workers' feelings about their last terminal patient who went home or to an institution upon discharge were explored. In addition, the respondents reported what they felt was the single most important factor that made for a good discharge plan, and what was the deciding factor in disposition. Finally the respondents discussed their concerns for improving their practice with terminal patients and their families in discharge planning.

Findings showed that all respondents were female. Data in Table 30 show that over 70 percent of social workers worked in social
work from one to six years, while 84 percent worked with terminal patients from one to six years. This finding clearly indicates that the sample had considerable experience working with terminal patients and their families. Over 74 percent of the hospital workers, and over 84 percent of the hospice workers, chose to work with terminal patients. With regard to caseload, 80 percent of hospital workers had a minority of terminal patients, while over 69 percent of hospice had all terminal patients. Sixty-four percent of hospital workers belonged to NASW, while 53 percent of hospice were members. One-half of the hospital and one-half of the hospice respondents reported to

TABLE 30

NUMBER OF YEARS WORKING IN SOCIAL WORK AND SPECIFICALLY WITH TERMINAL PATIENTS, REPORTED BY INTERVIEWED SOCIAL WORKERS (PERCENTAGE)

<table>
<thead>
<tr>
<th>Number of Years</th>
<th>In Social Work (N=44)</th>
<th>Terminal Patients (N=44)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of Social Workers</td>
<td>Percent Of Sample</td>
</tr>
<tr>
<td>1 - 3</td>
<td>14 31.8</td>
<td>25 56.8</td>
</tr>
<tr>
<td>4 - 6</td>
<td>17 38.7</td>
<td>12 27.3</td>
</tr>
<tr>
<td>7 - 9</td>
<td>6 13.6</td>
<td>3 6.8</td>
</tr>
<tr>
<td>10-12</td>
<td>4 9.1</td>
<td>3 6.8</td>
</tr>
<tr>
<td>13-15</td>
<td>3 6.8</td>
<td>1 2.3</td>
</tr>
<tr>
<td>Total</td>
<td>44 100.0</td>
<td>44 100.0</td>
</tr>
</tbody>
</table>

Mean = 5.6
SD = 3.6

Mean = 4.2
SD = 2.8
be either Catholic or Protestant, and approximately one-half of the workers in each group felt that their religion helped them cope with death and dying.

On the whole, social workers felt the study concerns were "excellent" and "timely." One worker said that the study gave her the opportunity to "really think" about the factors in discharge planning which she had never clarified in terms of priorities. A few workers questioned whether their last five terminal patients was a representative number; one worker felt she would have preferred drawing from her experience with her last ten patients. One hospital respondent felt the questionnaire did not give adequate regard to the "individualistic" nature of discharge planning, in spite of the open-ended questions. Over 79 percent of the social workers had no trouble completing the questionnaire.

With regard to personal experience with family in terminal illness, the findings show that over 54 percent of the hospital workers and 100 percent of the hospice workers reported this experience. Only 25 percent of hospital and 15 percent of hospice respondents had experience with friends in terminal illness. These are very interesting findings. The following personal situations were reported, and although not statistical findings, they appear to warrant attention. These are selected experiences which are generally representative of the interview data. One hospice social worker described her experiences with several family members who died in hospitals or nursing homes. She had been close with these relatives and felt "deeply involved" with them. She felt the institution did not support her relatives' needs
for "sustained emotional help" because of the restrictions in visiting hours, for example.

Another social worker had experiences with her mother dying at home from a long illness with cancer, and her brother dying suddenly from a heart attack. From her experiences, she highlighted how important open communication among the family members is in coping with the dying person at home. She felt that the family must honestly acknowledge the prognosis. Also, she believed she and her family needed bereavement counseling, which they did not receive, to help them cope with the grief and problem-solving tasks associated with the sudden loss of her brother.

Another worker, whose spouse died in the hospital after a long illness, claimed that she had felt very ambivalent about taking her husband home because of the physical demands of his care. She was faced with either leaving her job to care for him, which she could not accept because of the emotional stress and the lack of necessary income, or continuing to work and pay privately for home care which would deplete her savings and income. Of all her concerns, communicating her feelings to her husband was her most difficult task. Because she was a social worker, she was not "reached out" to and suffered without professional counseling. As a result, she and her physician planned to keep her husband in the hospital until he died. She felt this experience had a profound effect on her decision to work in a hospice, because it taught her about the guilt and ambivalence families go through with the dying patient. Working in a hospice afforded her the chance to be in an environment in which the patient
and the family were the unit of attention.

One hospice social worker described her experience with the death of her 21 year old brother who died from lung cancer at home ten years ago. She said he was home because the "family wanted him there," but the physical and emotional demands were a "big strain" on the family. This worker also had experience with an aunt who died from congestive heart failure at home, and a grandfather who died from leukemia at home. She stated that having the deaths at home brought the "reality" closer and thus made it easier to cope with the bereavement period.

Another hospice social worker described a very personal story in which she was inspired to pursue work in a hospice. A close family friend, a nun, became ill with breast cancer. When she was hospitalized and dying, she asked to speak with this worker, who, at the time, was working in child welfare and not finding it rewarding. The worker began visiting the nun daily, and learned a great deal from her about what dying persons needed. She carried this experience into her search for work with terminal patients, and translated it into working in a hospice. According to this social worker, the hospice offers unlimited time with others, in contrast to the hospital where time is regimented and parceled out.

The following typical illustrations came from hospital social workers about their experiences with family in terminal illness.

One worker told of her experience with her mother's death. Her mother developed a rapidly growing bone cancer when this worker was a teenager, and was soon hospitalized. As a result of medication, she
became lethargic and semi-comatose. She died in the hospital after only a few months. The worker said the family was fearful of taking her home and, due to her poor medical condition, preferred that she die in the hospital.

Another social worker claimed that her experiences with family and friends, all of whom had died in the hospital, left her feeling very "alone" with death. She felt that dying at home was a more "personal" experience, and the deciding factor in whether the dying patient goes home is the family's ability to cope with the emotional and physical demands.

A worker whose grandmother died at home from cancer, said that the family was helped by a community cancer organization that supplemented aid to the cost of a home health aide, assisted in finding an appropriate aide, and offered weekly counseling during the terminal period and following the death.

One social worker reported that a close aunt with cancer who lived alone in New York City, was helped to die at home through the efforts of a community cancer agency. Although the aunt did not need financial assistance, she did need support in arranging for the home health aide, and she needed help with obtaining transportation for out-patient chemotherapy and rehabilitative treatments.

Another social worker described her grandmother's death in a nursing home three years ago. The family wanted to take her home, but for lack of financial resources to pay for a home health aide, and adequate space, could not do so.

One experience involved the worker's mother who died at home.
from cancer. Thos mother was an active, alert, independent woman who expressed strong feelings about going home from the hospital. The social worker described the emotional pain and responsibility of caring for her mother, but felt that the experience brought the family closer and helped them realize untapped sources of strength.

Another worker told of her experience with the death of a male friend who died at home from chronic renal disease. He had been cared for by his sister who was a registered nurse. There was a close and loving relationships between the siblings, and the sister felt qualified and emotionally capable of coping with the physical and other stress.

These brief personal accounts of experiences with family and friends in terminal illness highlight some of the key factors in discharge planning for the terminal patient. The hospice workers stressed the family needs of arranging for home care, resolving feelings of guilt and ambivalence toward the dying patient, and evaluating financial resources. Hospice workers felt that dying at home was preferable to dying in the institution, provided the family was given adequate emotional and concrete supportive services during the terminal period and following the death. Generally the experiences did not speak of the multi-disciplinary team efforts in discharge planning or of the input and involvement of the medical staff with the patients or families. The sole exception was the mutual decision by a physician and a wife to keep her husband in the hospital until he died. Hospice social workers emphasized the availability of time and personnel, as notable features of their
Hospital social workers also underscored the needs that families have in discharge planning. Many respondents felt that the family's ability to cope was the deciding factor in disposition. Hospital workers stressed the importance of community resources in providing financial assistance and counseling. Transportation was mentioned as an important need of those patients who lived alone and required outpatient treatments. Also noted as important factors in discharge planning were the patient's desire to return home and resume familial and social roles, the medical condition of the patient and how it might affect the family's ability to plan for home or institution, conditions of the home environment, such as lack of space, and financial resources of the patient and family.

Social workers use coping strategies in their work with terminal patients and families, which are the sum total of their personality, character, experiences, and professional training. Harper (1977) postulated that these coping mechanisms are adaptive and observable through behavior and verbal expression. Harper conceptualized five stages of coping behavior which were based on the length of time social workers worked with terminal patients. The researcher found that coping strategies of social workers seemed related to factors other than length of time at their job. Adaptive coping behavior was assumed from verbal expressions indicating feelings of competence with their job, affection toward the patient and/or family, compassion, self-awareness, and acceptance of death and loss. Maladaptive coping behavior was assumed from verbal expressions indicating intellectuali-
zation and anxiety, feelings of guilt, frustration, depression, and pain.

In discussing their feelings toward their last terminal patient who went home or to an institution upon discharge, the social workers made some interesting observations. Social workers felt competent and helpful with patients and families who were open and honest about the prognosis. The workers felt competent when patients went home, rather than to an institution. They expressed empathy toward families who were struggling to cope with taking the patient home. On the contrary, social workers felt sadness, frustration and guilt toward the patients and families when institution was the final discharge plan. They also felt frustration with uncooperative families, unresponsive or unrealistic patients, and inadequate financial resources.

The following illustrations indicate the predominate feelings of the social workers toward their last terminal patient who went home or to an institution upon discharge.

One worker felt she did a "good job" whenever the family took the patient home. She said that when discharge was to an institution, she felt "very sorry" for the families because the patients died soon after the transfer.

One hospice worker felt "very glad" her patient went home, because he "really wanted to go home." With another patient, this worker felt "sorrow" because the nursing home offered the patient lower quality of care than the hospital. The worker felt "resigned" to a less than adequate plan.
Another worker described a situation in which she felt competent as a member of the medical team in discharge planning. Her patient was very frightened of going home and needed reassurance from the family. The medical team, through teaching of patient management, enabled the family to decide to take the patient home, which was the support the family needed. The family was then able to reassure the patient about his care at home. The worker contributed her psycho-social assessment of patient and family dynamics and treatment plan for continued counseling at home through a community agency.

Several social workers reported that they felt "alienated" and "minimally involved" with patients who were semi-alert. In these situations they tried to help the families resolve guilt toward placement and obtain the best possible nursing home. They were frustrated when the families were resistant to planning for placement.

One respondent said she felt she did a competent job when she helped a patient go to a hospice. Although the family wanted to take the patient home, they lived in a rural area that had inadequate support systems for home care. The family also did not have adequate financial resources to pay for home care or the space for special equipment. The patient was confused, and had various nursing needs for pain control, medication, and rehabilitative needs for physical therapy. As a result, the worker arranged for transfer to a hospice in another state that was geographically close to the family. The family was able to visit and stay over at the hospice.

Another worker felt she did a "poor" job when she transferred a patient to a nursing home that she knew was "dirty...where patients
were not well cared for." But the family insisted on this particular facility for reasons of proximity and familiarity with another family who had used it.

One social worker described a situation involving a man with terminal lung cancer, who denied his illness, and whose wife was very hostile and dependent on him. The worker felt frustrated because both refused counseling in the community. This same worker felt competent when she helped a family resolve their guilt toward placement of an elderly grandfather whom the family could not take care of.

One worker expressed "sadness and discouragement" when her patients were transferred to nursing homes. She felt she was "fulfilling a fear that dying patients have about being abandoned." With her last patient who went home, this worker felt "frustrated at the barrier" between her and the patient and family. Both the patient and family were denying the prognosis, and this bothered the worker although she recognized that they needed the denial to cope.

Another social worker said that going to an institution meant "going there to die." She admitted she felt "angry" at patients who were "demanding" and played the "sick role." She tried to refer patients and families to private therapists in the community for counseling, and she acknowledged the great need for bereavement counseling.

A hospital social worker described her affection for an elderly woman who went to an institution, despite her desire to go home. Because of inadequate financial resources and the persuasion of her
doctor who feared her being alone in her small apartment since she had no family, she was transferred to a "high quality" nursing home. The social worker felt "fortunate" that a bed in this nursing home opened up at the time the patient was ready for discharge. She stated she was "happy to have met her (the patient)," because the patient had the "courage" to speak openly about her feelings toward dying. The worker felt the physician did not "trust" the community resources which might have enabled the woman to go home.

To summarize the personal feelings of social workers toward their last terminal patient, the researcher found that positive feelings of competence, empathy, compassion, and helpfulness were associated with the following factors: patients and families who were realistic and communicative about their feelings toward the illness and prognosis; patients who strongly desired to go home; families who desired to take the patient home; and adequate financial resources. Social workers also reacted positively when there was appropriate input from the medical team in discharge plans to home, since they viewed the institution as a place to die alone and unwanted. Negative personal feelings of frustration, depression, guilt, and sadness were associated with the following factors: inadequate, low quality nursing homes; patients and families who were unrealistic and uncooperative in planning; discharge plans which were not in accordance with the patient's wishes; inadequate financial resources; lack of community support systems; and members of the medical team who were resistant to collaboration and preferred to act unilaterally with the patient or family.
Social workers were asked what they felt was the main factor involved in discharge planning for the terminal patient, and, later in the interview, what they believed was the deciding factor in the decision of home or institution. The researcher wanted to explore respondents' attitudes on possible differences or similarities between the two factors. Data in Table 31 show that interviewed social workers considered the following factors to be relatively equally important in discharge planning: patients' needs upon discharge; financial resources of patient and/or family; patient's desire to go home; and family's ability to cope. These findings support the earlier ones in Table 11. However, over 54 percent of workers felt that the family's ability to cope decided the discharge plan in the direction of home or institution, as shown in Table 32. As previously demonstrated (Table 11), this factor was found to be one of the three main factors in discharge planning. Apparently social workers felt the family, and not the patient, was instrumental in deciding the disposition. In fact, the patient's desire to go home was not considered a deciding factor at all. Only 27 percent of workers reported that the patients' needs influenced the decision of disposition. Even the interviewed hospice social workers did not feel the patient's desire to go home was the deciding factor.
### TABLE 32

**DECIDING FACTOR IN DISCHARGE PLAN TO HOME OR INSTITUTION, REPORTED BY INTERVIEWED SOCIAL WORKERS (PERCENTAGE)**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Number of Social Workers</th>
<th>Percent Of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family's ability to cope</td>
<td>24</td>
<td>54.5</td>
</tr>
<tr>
<td>Patient's needs upon discharge</td>
<td>12</td>
<td>27.3</td>
</tr>
<tr>
<td>Financial resources of patient and/or family</td>
<td>6</td>
<td>13.6</td>
</tr>
<tr>
<td>Family's needs upon discharge</td>
<td>1</td>
<td>2.3</td>
</tr>
<tr>
<td>Recommendation of M.D.</td>
<td>1</td>
<td>2.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>

### TABLE 31

**THE MAIN FACTOR INVOLVED IN DISCHARGE PLANNING, REPORTED BY INTERVIEWED SOCIAL WORKERS (PERCENTAGE)**

<table>
<thead>
<tr>
<th>Factor</th>
<th>Number Of Social Workers</th>
<th>Percent Of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient's needs upon discharge</td>
<td>11</td>
<td>25.0</td>
</tr>
<tr>
<td>Financial resources of patient and/or family</td>
<td>10</td>
<td>22.7</td>
</tr>
<tr>
<td>Patient's desire to go home</td>
<td>9</td>
<td>20.5</td>
</tr>
<tr>
<td>Family's ability to cope</td>
<td>9</td>
<td>20.5</td>
</tr>
<tr>
<td>Availability of community resources</td>
<td>2</td>
<td>4.5</td>
</tr>
<tr>
<td>Cooperation of M.D.</td>
<td>2</td>
<td>4.5</td>
</tr>
<tr>
<td>Family's needs upon discharge</td>
<td>1</td>
<td>2.3</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44</strong></td>
<td><strong>100.0</strong></td>
</tr>
</tbody>
</table>
Practice Concerns:

Social workers had a number of concerns about their practice of discharge planning with terminal patients and their families. One issue repeatedly voiced was that of speaking openly to patients and families about the illness and prognosis. The workers admitted their own anxiety about the subject of death and dying, and questioned how they could talk honestly to their patients when they doubted the patients were ever told of their terminal illness by their physicians. Findings indicate that over 52 percent of the total sample of social workers felt they did not know generally when their patients were informed of their prognosis, as shown in Table 32. When interviewed, most workers claimed they did not feel that their patients were ever informed of their prognosis by the physician. Patients' denial was unlikely, since data in Table 34 show that over 55 percent of the total sample of social workers felt their patients knew they were terminal over one month. That dying patients have an awareness of their condition, regardless of being told, has been supported by the literature (West, 1980; Glaser and Straus, 1956; and others). What emerges then is a situation in which the social worker's personal anxiety about discussing death and dying is compounded by her doubts about the patients' actual knowledge. Consequently, patients may suffer from guilt and depression in the need to talk about their feelings about dying. Comments by one social worker reflect this concern and are quoted as follows:

"Sometimes you don't know if the patients were told their prognosis, despite the fact that the doctors say they were told. Some doctors cannot say the word 'cancer' and they
are too fearful of telling the patient the prognosis. Some patients, of course, deny, even though they have been told the truth. How does one talk to patients who are dying? Taking cues from the patient is difficult enough, especially if you are not sure they have been told."

**TABLE 33**

ASSIGNMENT OF CASE IN RELATION TO WHEN TERMINAL PATIENTS ARE INFORMED OF PROGNOSIS, REPORTED BY SOCIAL WORKERS (PERCENTAGE)

<table>
<thead>
<tr>
<th>Time Assigned</th>
<th>Number of Social Workers</th>
<th>Percent Of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Two or more weeks before</td>
<td>8</td>
<td>9.3</td>
</tr>
<tr>
<td>One to two weeks before</td>
<td>5</td>
<td>5.8</td>
</tr>
<tr>
<td>Less than one week before</td>
<td>5</td>
<td>5.8</td>
</tr>
<tr>
<td>Usually the same day</td>
<td>3</td>
<td>3.5</td>
</tr>
<tr>
<td>Two or more weeks after</td>
<td>10</td>
<td>11.6</td>
</tr>
<tr>
<td>One to two weeks after</td>
<td>3</td>
<td>3.5</td>
</tr>
<tr>
<td>Less than one week after</td>
<td>7</td>
<td>8.1</td>
</tr>
<tr>
<td>Do not know generally</td>
<td>45</td>
<td>52.3</td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>100.0</td>
</tr>
</tbody>
</table>
TABLE 34

LENGTH OF TIME PATIENTS KNEW THEY WERE TERMINAL, REPORTED BY SOCIAL WORKERS (PERCENTAGE)

<table>
<thead>
<tr>
<th>Time</th>
<th>Number of Social Workers</th>
<th>Percent Of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than one week</td>
<td>7</td>
<td>8.1</td>
</tr>
<tr>
<td>Less than two weeks</td>
<td>12</td>
<td>14.0</td>
</tr>
<tr>
<td>Less than one month</td>
<td>19</td>
<td>22.1</td>
</tr>
<tr>
<td>Over one month</td>
<td>48</td>
<td>55.8</td>
</tr>
<tr>
<td>Total</td>
<td>86</td>
<td>100.0</td>
</tr>
</tbody>
</table>

Social workers believed that, on the whole, families had more difficulty communicating their fears and needs than the terminal patients. Families were often receptive to social service intervention, but were "tired, emotionally and physically, when it came to interacting with the patient," according to one social worker. Consequently, this worker noted, patients frequently "die alone."

Another social worker cautioned against forcing patients into stages, such as anger or acceptance, in order to help families talk to them about dying. She noted that patients may express denial and acceptance in the same conversation, and must be allowed to cope with these feelings at their own pace. Naturally social workers have great difficulty discussing death and dying with the patients and families in the face of contradictory messages. One worker remarked that in discharge planning, patients who deny their illness are more
resistant to planning for young children. When this happens the worker tries to elicit help from a realistic family member. When denial is the major defense of both the patient and family, discharge planning becomes "problematic," according to one worker, because "they (patients and families) get angry when appropriate responsibilities are not assumed, such as financial matters."

Several social workers claimed that patients and families who were communicating openly in the hospital, experienced great difficulty maintaining this level of mutual closeness at home. One worker explained this phenomena and is quoted as follows:

The hospital offers a protective environment for the patient and his family. The attitude in the hospital is that there is always something more that can be done. When the patient is home, the truth will shock him and his family, that nothing more can be done. When this occurs, there is great withdrawal and despair on both sides.

Social workers felt that families are difficult to predict in terms of how they will cope with the patient at home. Some families, who did not cope well with minor crises in the past, somehow rally together to help the dying member. The assessment of the past medical and psychiatric history is important however. One worker noted that if depression had been a dynamic in the patient or family functioning in the past, chances of it recurring during the terminal period were excellent. Several workers remarked that sometimes patients and families who have been the most productive and educated, seem to become the most depressed and despairing. The workers speculated that, perhaps, they suffered the most losses, of people, places and things. Workers noted that health insurance,
such as Medicare and private group and commercial insurance, does not adequately cover the costs of home care. Middle-class families are more likely to take the terminal patient home, since placement would completely deplete their savings. But the cost to the family in terms of the physical and emotional demands is enormous, according to the respondents.

Another issue of consideration to social workers in their practice is their relationship with the members of the medical team. Social workers expressed the need for more collaboration with physicians, nurses and rehabilitation therapists during discharge planning, for two reasons. They wanted to increase their understanding of the other professional points of view, and allow themselves the opportunity to ventilate their more subjective anxieties and hopes about patients and families. Comments reflecting these sentiments are quoted as follows:

I feel anxious when I have to visit a dying patient for the first time. Once a relationship is established, I will visit often... Many professionals I see, doctors, nurses and therapists, tend to avoid dying patients and only go in when they have to--right before discharge. I would like the chance to talk to them about our fears on a regular basis.

Many times the patient will only listen to the doctor when it comes to discharge planning, because of the trust and confidence he has in him. I would like to be able to talk with doctors about how and why patients perceive them in certain ways.

I find that the doctors say little about the dying in the staff conferences. They (doctors) like their patients to receive rehab, because then they can avoid dealing with any discussion about the illness and prognosis. They can just ask the patients how they are doing in rehab.

Some patients just want to be left alone, rather than undergo aggressive physical and occupational therapy. Why can't
the rehab therapists respect this right to die in their own way?

The researcher intended to interview hospice social workers in order to explore similarities and differences in their practice with terminal patients with hospital workers. Noteworthy examples of the unique features of hospice care were cited by the workers and are quoted as follows:

The hospice orientation sees the patient as "dying," whereas the hospital sees the patient as "diseased."

Hospice staff carry around the open admission that the patients are going to die. The orientation is to let people die the way they want. There are no heroic measures or machines. In the teaching hospitals especially, the doctors "can't let patients die," so they concentrate on the heroic measures at the expense of the patient and his family.

Because hospice orientation is very patient and family centered, an important role for the social worker is in advocacy, that is, dealing with organizations and the "system" of the hospital.

Hospice care provides "continuity of care" for the patient and family. For example, the staff visits the patient in the nursing home.

Hospice philosophy helps the family to depend more on the staff. For example, there is counseling done by team members from various disciplines, with the patient and family, around issues of the transition from hospital to home.

By having staff available 24 hours a day, the family is given the reassuring feeling of a strong support system, which frequently is what they need to help mobilize themselves to arrange for home care.

Hospice pays careful attention to top quality physical care, which is the stage on which other services are managed.

Our hospice program offers "respite care," in which the patient is readmitted from home to the hospital, under hospice authorization, for a short period, like a weekend, in order to give the family some relief.

Hospice workers emphasized the bereavement counseling they
perform weekly, in individual and group sessions in the hospital. One problem they encountered was reimbursement for bereavement counseling. Health insurance does not cover this service, so that several hospices had to rely on private funds and several depended on monies from church groups and private foundations.

Gaps in Service:

Social workers identified four major areas of gaps in services to terminal patients and families in the process of discharge planning. The first was the need to develop more community resources to provide financial, psychological, and social aid to patients and families. There is a lack of high quality nursing homes, social agencies that deal with the problems of the dying and not only those patients with cancer, and other types of facilities, such as intermediate care, day programs, and rehabilitative programs, for the dying who are ambulatory and want to live their remaining time productively and meaningfully. More study is needed of hospice services and how their orientation can be translated into medical social work practice in acute care hospitals. There is a need to help patients and families understand the policies and procedures of the Medicaid and Medicare systems of health insurance, so that, in crisis, they know what services they are entitled to and what benefits they should apply for. Social workers did not feel well versed in the knowledge of legislation and regulations affecting discharge planning, such as Medicare and Medicaid coverage for home care or placement.
The second gap in service was follow-up care. Both hospital and hospice social workers recognized the importance of bereavement counseling. Yet the former group rarely offered it. In connection with this, was the need for more training in "reaching out" and "crisis techniques" to help patients and families. Social workers cited their lack of skill in helping the family of a patient dying in the emergency room, for example. They claimed that this type of situation offered the least medical information and the most critical panic reactions in the family. Hospital social workers expressed the need for time to make follow-up home visits, when there is doubt about the accommodation of the home environment to meet the patients' needs.

The third gap in service was defined as the need to learn more about the coping mechanisms used by the terminal patient and the family. Social workers expressed their desire to know more about the psychodynamics of the process of dying and how it affects the patient and family during the decision-making of discharge planning.

Finally, the last area of service that the social workers felt deserved attention was interdisciplinary relationships. Workers expressed the need for new ways of sharing personal and professional feelings and perspectives with members of the medical team. In terms of counseling the patient and family, social workers felt the professional lines of who could offer what, were quite fuzzy. The need was highlighted for greater input from the medical team in pre-discharge conferences with the patient and family to discuss and teach patient management.
CHAPTER 7

SUMMARY AND SIGNIFICANCE OF FINDINGS

This chapter will summarize the problem and methodology of this study and discuss the significance of the findings with regard to the present social, economic, and political climate in this country relating to health care. Issues of practice for social work with terminal patients and their families will be addressed, and areas for further research will be recommended.

This research was completed at a time when social work was becoming sensitive to the needs and problems of the terminally ill and their families, and the service of discharge planning was coming to the forefront of the health care field. This was due in part to the efforts of state and federal legislators who strove to achieve cost-effectiveness, regulation of the quality of patient care, and efficient bed utilization. Several areas of concern about the nature of services to terminal patients and families have been raised in the study and many questions remain unanswered, such as the cost benefits of hospice care in relation to home, nursing home, or hospital care, the relationship of modern and sophisticated medical technology to the protection of the dignity of the dying patient, and the formulation of standards for terminal care, whether carried out in the hospital, home, hospice, or nursing facility. Discharge planning has become
increasingly recognized as a critical segment of patient care. In the face of current retrenchment, however, its future is uncertain.

One inescapable fact is that health care expenditures are escalating at a tremendous rate. In the year ending September 1980, the Federal government spent over $60 billion for personal health care, financing about 29 percent of all personal health care. Expenditures for personal health care include: hospital care, professional services, drugs and supplies, eyeglasses and appliances, and nursing home care. Prices of personal health care goods and services were 10.7 percent higher than in the previous year. The National Hospital Input Price Index, which is a measure of the prices of goods and services used by hospitals in the provision of care, was 11.6 percent higher than in 1979. The National Nursing Home Input Price Index was 9.9 percent higher than in 1979 ( * ). According to the U.S. Department of Health and Human Services, expenditures for hospital care accounted for the largest portion of the health care dollar, 40.2 percent in 1979. Second was physicians' services, 19.1 percent; third was nursing home care, 8.4 percent; and fourth was drugs and supplies, 8.0 percent (Health-United States, 1980). Thus, any discussion of alternate health care models, including those for the terminally ill, will surely be examined in terms of its potential costs.

One of the most significant influences on discharge planning has been the Professional Standards Review Organization (PSRO) legislation of 1977, which was designed as a regulatory mechanism to regulate and control the rise in hospital costs. It created physician-run
utilization review committees to continually review the appropriateness of admission and length of hospital stays of every Medicare and Medicaid patient. Review of cases took place concurrently with the patient receiving care. These committees had final authority to grant or deny payment for care rendered to federally supported patients under Medicare and Medicaid, PSROs were developed to reduce the length of stays in short-term, acute care hospitals and supervise the overall quality of care given by physicians and other medical and ancillary personnel. In 1977, the Health Care Financing Administration (HCFA) was created to bring Medicare, Medicaid, and PSROs together under a single administrator.

Studies of the Medicare portion of the PSRO program by the Health Care Financing Administration for the years 1977 and 1978 indicate a 1.5 to 2 percent reduction in the days of hospitalization for the country as a whole. Thus far, no evaluation of the impact of PSRO review on Medicaid has been possible, and assessing the effects of PSROs on quality of patient care has been difficult. Tentative conclusions seem to be that the influence of PSROs on Medicare and Medicaid expenditures will have little more than a slight effect on health care costs. The measure of the PSRO benefits over the traditional utilization-review systems is not known, since the cost-benefits of the traditional system are not known. The policy question appears to be whether the PSROs are more or less effective and more or less expensive than the programs they replaced. Since costs of health care are expected to continue to rise, the need for monitoring and accounting for the expenditures will continue. The Reagan
administration has proposed to eliminate 40 to 60 PSROs in 1981, another 60 in 1982, and the remainder by the end of 1983 (Smits, 1981). This slow phasing out of PSROs is bound to have effects on discharge planning services in acute care hospitals.

One of the ways in which social workers are pressured by utilization review in discharge planning is in the need for specific and clear documentation in the patient's medical chart of the reasons for continued stay. Patients may be awaiting a nursing home bed or approval for home health care. In addition, the utilization reviewer and PSRO committee have the responsibility to determine the required level of care for patients. For example, once a terminal patient no longer needs acute medical care as stated by his physician and the PSRO representative, the social worker must assess whether the patient is eligible for the Medicare-covered level of skilled nursing home care or skilled home care services and discuss these alternatives with patient and family. Frequently, families do not understand the role that PSRO plays in determining the level of care for appropriate discharge planning, and they tearfully implore the social worker to keep the patient in the hospital because he is too ill to leave. Both social workers and utilization reviewers may interpret the need for continuity of care to patients and families, and therefore, a cooperative relationship between these two professional disciplines is necessary.

For this study, the investigator undertook to describe the parameters of discharge plans for terminal patients by collecting data about discharge planning from two settings: the acute care
hospital and the hospice unit within an existing hospital. Objectives were to examine, with empirical data, those factors already suggested in the literature which were included in discharge planning, to specify the relative importance that social workers gave to various factors in the formulation of discharge plans for terminal patients, to compare discharge planning as between hospital and hospice settings, and finally to formulate hypotheses about the discharge planning process which may be tested in future research.

The method was an exploratory-descriptive survey whose respondents were social workers in hospitals and hospices, selected because of their experience with terminal patients and their families in the process of discharge planning. The sample for the comparative groups was stratified and purposive and selected in two stages. Hospitals and hospices were chosen in the first stage, and social workers in the second. Hospitals and hospices were chosen which allowed for the variable of home vs. institution in their discharge plans for the terminal patient. Data were collected through the use of a questionnaire that sought to measure clusters of factors relating to the patient, the family, and the environment and a follow-up telephone interview, directed by a guide, that sought to obtain personal data on additional variables not listed in the questionnaire. The telephone interview was used on a sub-sample of hospital and hospice social workers. The questionnaire collected quantitative data, whereas the interview secured responses which were analyzed qualitatively. The findings were reported and discussed according to the following areas: the parameters of discharge plans; comparison of hospital and hospice
social workers; and results of the interviews.

With regard to the impact of PSRO on discharge planning, findings from the research show that, although over one-third of all social workers felt pressured by utilization review for patient discharge before an appropriate discharge plan had been formulated, most social workers, both hospital and hospice, did not consider working with administration to be an integral part of discharge planning. An appropriate discharge plan means that the important needs of the patient and family, and dimensions of the home environment and community resources, are best adapted to the plan. Interviewed social workers offered an example of this type of situation. On occasion a physician will refer a patient for discharge planning at the time he/she is medically ready for discharge. Usually the request is for concrete service, such as transportation arrangements or order for special equipment. These concrete plans may take some time to resolve, while utilization review presses for immediate discharge.

PSRO requires that Medicare and Medicaid patients be screened for potential discharge planning needs usually within the first three days following admission. This requirement appears to have had a positive impact on discharge planning, since the majority of social workers felt that earlier intervention would result in adequate time with which to accomplish the tasks necessary for effective planning. Findings indicate that the overwhelming majority of social workers felt that timing of referral played a part in discharge planning (86 %). Interviews substantiated this finding and elicited the opinion
that earlier referral had a decided effect on shortening the length of hospital stay. Workers felt that early intervention generally prevented patient hospitalization which extended beyond the need for acute medical care, because complex discharge planning needs and problems were identified and resolved sooner. Interviews revealed that the majority of hospital social workers in the study relied on the traditional patient referral from health personnel, as opposed to their own independent case-finding. Hospice workers relied on both methods of referral. In this respect, timing of referral became timing of intervention, since the workers began their assessment as soon as they received the referral.

Findings show that the majority of all social workers reported that patient referral came between 3 and 14 days after admission, regardless of disposition outcome. One-third of all workers reported that referral came within the first two days after admission, regardless of disposition. Terminal patients who went home or to an institution upon discharge generally had the same length of stay, from two weeks to over one month. The implication from this finding is that patients who were discharged to nursing homes had not overstayed their hospitalization, despite the fact that over 83 percent of all social workers recognized a lack in available nursing home beds.

Thus, earlier patient referral may result in adequate time to apply to nursing homes and wait for an appropriate bed, or to plan for home care and help the family resolve their anxieties and ambivalence. Earlier referral appears to be one prerequisite for a "successful" discharge plan.
The review of standards in discharge planning is also one of the purposes of the Joint Commission on the Accreditation of Hospitals (JCAH), which recognizes that social work has the major responsibility within this area. The Joint Commission believes that high standards of quality should be maintained in view of regulatory pressures and mandates for cost containment. Like PSRO, the Joint Commission seeks to mitigate the readmission or the over-utilization of hospital beds because of social factors. The Joint Commission also sets standards for utilization review committees, one of the primary ones being the need for early discharge planning so that continuity of care is assured into the community. Standards for social work include the need for adequate documentation in the patient's medical record of social service interventions, and the development of quality control mechanisms. The Commission requires that social work departments in hospitals make the commitment to quality assurance of its services by developing ways to measure the performance of discharge planning activities, such as ongoing reviews, retrospective reviews, and the determination of specific criteria to be used in reaching goals and objectives. Whatever the fate of the PSROs, the Joint Commission expects to maintain its regulatory role in supervising the quality control of discharge planning.

Effective discharge planning works to reduce the costs of medical care by insuring that patients receive those supportive professional services they need to adequately function in the community. Discharge planning seeks to offer the patient alternatives for health care, which allows them more control over their lives and respects their
right to decide what kind of health care programs are best suited to their particular needs. For terminal patients and their families, discharge planning involves planning for the maintenance of the patient at home with community health and social support systems, or planning for placement of the patient in a skilled nursing facility with the provisions for custodial or skilled nursing, rehabilitative and other services. A third alternative, hospice, can also be considered. There are no simple answers as to which alternative is "best" for terminal patients and families. What must be accepted in discharge planning is that critical consideration of all factors relating to the patient, family, and environment, must be undertaken before a meaningful plan can be formulated. In order to practice in accord with the principle of individualization, social work must avoid the danger of blanket acceptance of one or another type of plan.

Of the sample of social workers in the present study, at least three of their last five terminal patients went home upon discharge (74%). The patient's desire to go home was considered to be one of the three main factors in discharge planning by both hospital and hospice social workers (47%). In interviews, workers expressed positive feelings toward their work when patients strongly desired to go home, and families were able to cope with taking them home. When the disposition was home, workers felt more competent in their interventions. They seemed to identify with their patients in perceiving home as a place that was familiar and supportive, and clearly the preferred place to die. Since the evidence suggests that more patients are going home and social workers may be biased in favor of
this direction, it is important to explore under what circumstances home can best meet the needs of both patient and family.

In home health care, the health care services which are provided for the patient in the home come from several professional disciplines, including medicine, nursing, rehabilitation therapy, social work and psychiatry. Other services can include nutrition and income maintenance, and training in the use of medical equipment and supplies. Usually special equipment can be secured through the hospital, health care agency, or private rental or purchase agencies. Assessment of the kinds of supportive equipment and evaluation of the costs is important in setting up a planned program for home care. Additional areas of concern may include delivery services for drugs and the use of volunteers in helping the patient and family cope with the isolation and restrictions caused by severe illness. Volunteers can provide transportation for patients and families needing rides to clinics, hospitals, or other resources in the community. Homemakers and nurses' aides function as companions for the elderly and persons who live alone, and assist in household chores. Public and private community agencies, such as the American Red Cross, Cancer Care, the American Cancer Society, the Visiting Nurse Association, veterans organizations, and others, may provide help with counseling, transportation, nutrition, income supplements, and equipment.

Findings indicate that the majority of all social workers felt terminal patients upon discharge need nursing services (90%) counseling around death and dying (29%), and assistance with obtaining medical equipment (37%). These findings imply that patients are going home,
since discharge to a nursing home would preclude planning for nursing services and equipment. Social workers whose 5 out of 5 referenced cases went home, reported that their patients had significant need of physicians' services, nursing services (less than 40 hours per week), and rehabilitation services. Moreover, the overwhelming majority of social workers felt that the terminal patient who lived alone was the most vulnerable in discharge planning (86%). Thus planning and coordinating community resources would seem to be of utmost importance for patients living alone. Findings point to the need for attention to patients who live alone in apartments without elevators or in private homes with steps and stairs. Workers gave evidence of sensitivity to home conditions, such as the availability of transportation for the patient and family, the geographic location of the home in relation to medical facilities, the existence of adequate cooking facilities, and temperature control, implying that they realize the patients' needs for independence, competence, and mobility inside and outside the home. Not every home is physically well-suited to accommodate the terminal patient, and this assessment must be made prior to the decision of disposition.

Planning for home care requires that the social worker evaluate the financial resources of both patient and family, and this was emphasized by over one-half of all workers involved in discharge planning (51%). Over 74 percent of all workers reported that the most important financial condition for the patient and family was having Medicare and Medicaid insurance. Private insurance and private funds were not considered important factors in planning by the hospital
workers, although hospice respondents considered them to be very important (66%). In interviews, the workers claimed that they, as well as patients and families, needed more knowledge about Medicaid and Medicare benefits. In discharge planning, they said, families are frequently intimidated by the complexities of the eligibility requirements and confused by the terms used to designate those services for which they are covered. They often feel that the terminal patient is as ill as anyone can be, and therefore entitled to receive all services. Good financial planning requires easy access to a community directory of resources, and an understanding of the services they can and cannot provide.

Current Medicare and Medicaid regulations which affect discharge planning for terminal patients and their families are described in Appendixes I and J, respectively. The cost of Medicare benefits for home care has been growing almost 30 percent a year. The proposed 1983 federal budget would require Medicare beneficiaries to pay 5 percent "coinsurance" for home health services. Now home health care visits by professionals are "free and unlimited" under provisions of the Omnibus Reconciliation Act. The Omnibus Reconciliation Act of 1980 has made significant changes in certain home health benefits under Medicare (Appendix I). (New York Times, February 7, 1982).

In an effort to control costs, the Administration budget proposals for 1983 call for a "cap" or ceiling, placed on Medicaid. Some thirty programs of health and social services would be consolidated into block grants for distribution to the states. Community health centers, maternal and child health programs, programs related to
rehabilitation services and other health care services would all go into block grants, under the headings of preventive health services and health service grants. Prior to the distribution of funds to the states, the level of current expenditures would be reduced 25 percent. Also, the 1983 federal budget would reduce the "matching rate" at which it assists states on spending for optional services and certain beneficiaries. Optional services include prescription drugs, eyeglasses and dental care. The Administration intends to offer legislation requiring that Medicaid recipients pay at least $1 for each visit to a physician and at least $1 for each day in the hospital. (New York Times, February 7, 1982).

There are many policy questions that Congress will have to resolve about the block grants, such as the basis for allocation of funds, accountability requirements of states, definitions of eligibility, and standards for minimum services offered by states, before they are fully understood and accepted. Advantages to the states are the authority and the money to designate priorities for those services they feel are important to health care. However, the states are not pleased with the 25 percent cut in funds, nor the cap on Medicaid. The seeming effect that these proposals will have on the consumers of home health care under Medicaid is that there will be fewer resources available for a variety of health services. Findings from the research show that social workers felt the three principal factors considered in discharge planning were the patient's desire to return home (47%), the family's desire to have patient home (44%), and financial resources (51%). However, any decision-making
for home care must now take into account the potential cutback in funds to community resources, which in the past served to support terminal and chronically ill patients and their families in the community.

An alternative to home in discharge planning for terminal patients is the institutional setting, specifically the skilled nursing home. Interviews with social workers indicated that they felt sadness, guilt and frustration when their patients were transferred to nursing homes. They seemed to identify with their patients in perceiving the institution as a place to die alone and unwanted. Workers also questioned the quality of care the nursing homes provided. Findings show that over one-half of all social workers felt that families needed help with nursing home applications during discharge planning (76%), and almost one-half felt that families needed counseling around death and dying (41%). The implied ambivalence of families toward placement was supported by the finding that over one-half of all workers reported working with families whose attitude toward the patient was reflected in the phrase, "I can't put her away," an expression of guilt and ambivalence. Social workers and families appear to view nursing homes in a negative light. This may be understandable in view of the problems associated with nursing home care in recent years that have been brought to public attention. These problems involve characteristics such as depersonalization, poor nursing care, inferior quality nutrition, rehabilitation and other services, and social and psychological isolation. The vast majority of nursing home residents are elderly and many homes refuse to accept younger patients. This policy creates extreme hardships for the younger
terminal patients who need placement in a skilled institutional setting. Nursing homes would seem inappropriate for them for social and emotional reasons. Families are often forced by necessity to take these patients home and endure the financial and psychological drain.

Eighty-three percent of all social workers in the study reported a lack of appropriate extended care beds in community nursing homes. This finding supports previous research (Schrager et al., 1978). Over one-half of all workers found that their patients' medical condition changed over the course of admission (52%). With terminal patients, this change usually means deterioration, as interviews confirmed, so that planning for nursing home becomes a necessary option even if the original plan was for home care. Findings also show that workers were sensitive to patients' need for a nursing home that was geographically close to the family.

Of the various problems associated with nursing home care, one that is particularly damaging is the lack of recognition paid to the needs of the severely ill elderly person who may not be technically terminal in a strict medical sense, but who is slowly dying in a depersonalized and routinized setting. (Loeser et al., 1981). At the 1981 White House Conference on Aging, the majority of participants voiced concern over the two alternatives to hospital care, home and institution. They spoke of the difficult and expensive burden of caring at home for severely and chronically ill spouses and parents, and they cited the economic threat posed by admission to a nursing home (Campion, 1982). Economic threat is a major problem for terminal patients, who frequently require "custodial" care in a skilled nursing
facility, which Medicare does not cover. Thus, they and their families are forced to pay privately until they become eligible for Medicaid. Custodial care has never been specifically defined, as noted by several federal and state court decisions. The cost of care in skilled nursing homes runs from $700 to $1600 per month and is a substantial financial burden on terminal patients and their families (Loeser et al., 1981). Interviews with social workers revealed that most middle-class families preferred to take the terminal patient home because they could not afford the nursing home.

Because of the proposals to cut Medicaid costs, the future for Medicaid reimbursement for nursing home care is uncertain at the present time. In the fiscal year 1978, 46 percent of the nursing home bill or $7.2 billion was paid for by Medicaid. This increasingly massive outlay of public monies, coupled with the discontent over the quality of care found in nursing home facilities, has made this alternative for long or short-term care a critical issue for the Health Care Financing Administration (Comptroller General's Report to the Congress of the United States, November 26, 1979).* In addition to cost-containment controls over Medicaid nursing home expenditures, the 1983 federal budget proposes that states may require the children of elderly persons to contribute to the cost of nursing home care under Medicaid (New York Times, February 7, 1982). If this proposal becomes a reality, families of terminal patients are certain to endure greater financial hardships.

*Entering a Nursing Home—Costly Implications for Medicaid and the Elderly
Thus, the proposed cutbacks in Medicare and Medicaid reimbursement money for home care services and nursing home care will create similar kinds of financial hardships for terminal patients and their families. The existence of fewer community support systems to help defray the costs of homemakers, for example, may require family members to leave their jobs and take on these roles themselves, at the expense of their income and their emotional stability. Patients and families may have to pay privately for special equipment, drugs and supplies, which were formerly covered under Medicare and Medicaid. In terms of formulating discharge plans to nursing homes, patients and families may have to accept and shoulder greater financial responsibility for the costs. This, no doubt, will place a strain on family equilibrium and relationships.

Hospice

Hospice care has been a response to the inadequacies of the hospital system of terminal care. Critics of the hospital orientation pointed out the unnecessary prolongation of life, ineffective control of pain and other symptoms, lack of emotional support for patients and families, and fragmented caregiving responsibilities, as problems that must be corrected in order to make the dying process as comfortable as possible. As a result, hospice care was developed in this country as an innovative approach to offer a comprehensive program of palliative care to dying patients and their families. Rather then rely on heroic measures with machines or treatments, hospice allows for the end of life in a dignified and natural way. Hospice believes
in multidisciplinary services to meet the total needs of the patient and family. The definition of medical team is enlarged to include volunteers, clergy, and community persons.

Hospice attempts to give fulfillment and satisfaction to each remaining day by the individualized relief of physical symptoms, and the focus on the patient and family as the unit of attention. The foremost concern of hospice is the quality, not the quantity of life. Very often medical science cannot predict how much time a patient has remaining, and, at best, those predictions are crude. Hospice brings a dimension of respect for the individuality of the patient and family which adds to the quality of life. Rather than define terminal patients as a homogeneous group, hospice views them in terms of their individual attitudes toward their illness, their needs upon discharge, and their desire to live in the style to which they are accustomed until they die. Hospice also regards the families' needs for emotional support during the pre- and post-death grief periods with utmost importance.

Findings from this research indicate that almost one-half of all social workers reported that their patients felt guilt about their anticipated death during discharge planning (47%). Hospice workers were significantly more likely than hospital workers to consider the following patient attitudes: acceptance; guilt; denial; withdrawal; and isolation. Hospice workers seemed to perceive their patients as more accepting of prognosis, while hospital workers saw their patients as more hopeful. The contrasting philosophical orientation of the two settings may account for these differences. The findings suggest that
patients need to talk about their feelings toward their illness and prognosis, especially feelings of guilt about being a burden on their family, because this has a bearing on discharge planning. Whatever the disposition plan, home or institution, terminal patients will probably feel that they are a financial or emotional burden on their families.

With regard to the needs of the family, hospice social workers were significantly more likely than hospital workers to consider the following needs in discharge planning: counseling around death and dying; medical equipment; physicians' services; nursing (less than 40 hours per week); special diet; assistance with obtaining medication; and help with private insurance. These findings may mean that hospice workers individualize their patients and families more than hospital workers, or that the hospice workers express bias towards home care. Hospice workers were also significantly more likely than hospital workers to take into account the family attitude of leaving the decision of disposition to the patient. In interviews, hospice workers favored discharge plans to home, which may also account for the finding that they were significantly more likely than hospital workers to consider the importance of the patients' home conditions in discharge planning.

Zimmerman (1981) describes how social work duties differ for hospice and non-hospice social workers. He claims that hospice workers demonstrate a special interest in working with dying persons, motivated in part by their personal experiences. Findings from interviews with hospice workers confirm this hypothesis. The workers
stated that their experience with their own families and terminal illnesses motivated them to work in hospice programs.

There are several key areas of concern which pose obstacles to the financial viability and the public and professional acceptance of hospice care. The first is the issue of cost and reimbursement. The determination of costs and reimbursement of services should begin with a plan for standards of care. The National Hospice Organization has produced a guide for such standards, but its relationship with the Joint Commission on Accreditation of Hospitals needs further clarification in order to strengthen the accreditation process as it relates to the quality of care for the terminally ill.

Policy makers in the legislatures and the insurance companies are currently addressing the following questions: Is the care of the terminally ill important, or should financial resources be directed toward curative and rehabilitative medicine? If the services of terminal care are important, which services should be reimbursed and at what level? Given the various models of hospice care—the freestanding facility, the hospital-based unit, and the home care program—what type of organizational format should terminal care take in order to be eligible for reimbursement? How do costs differ for hospice care and traditional medical care for terminal patients? Zimmerman (1981) analyzed costs of the Church Hospital Hospice in 1979 and found that patients' expenses were $174 per day and $1,920 per admission, in contrast to the expenses of patients under general medical-surgical care, $345 per day and $3,431 per admission.

Presently third party payors (primarily the federal government
and Blue Cross) are not making any commitments to reimbursement until
the cost of hospice care and its impact on the cost of health care in
general are evaluated. Thus far hospice has survived through the
generousity of foundations, individual donations and federal grants.
Osterweis and Champagne (1979) believe that if hospices could replace
or substitute for acute care hospital beds, they would then be able
to demonstrate their cost saving benefits. Their rationale is that
hospital reimbursement by third-party payors is based on a formula
which takes account of the number of beds, not the occupancy rate, in
order to determine allowable costs. If occupancy is low, the allow-
able costs are merely shared by fewer people; hence the systems costs
remain approximately the same and each patient, or his third-party
payor pays more. If hospitals were convinced of the value of con-
verting unused or acute care beds or hospital wings into long-term
or hospice units, lower level staffing and cheaper allowable costs
would result, thus achieving a reduction in the total number of acute
care beds and the conversion of excess beds to less expensive uses.
Osterweis and Champagne (1979) believe that if acute care beds were
properly filled with patients requiring acute medical care, and not
with terminal patients who could benefit from hospice care, then
hospice would have an effect on legitimizing necessary hospital costs
by removing patients requiring lower level care.

Under present reimbursement formula, hospitals receive no pay-
ment for some of the important non-medical services that are vital to
hospice care, such as bereavement counseling, overnight family visits,
and the serving of alcoholic drinks to patients without physicians'
orders. Strictly medical services are reimbursable in part. Hospice hospital-based programs are paid for inpatient care in the same fashion as they would be for inpatients receiving non-hospice terminal care. However, for outpatients reimbursement is very limited and many patients do not have any home care provisions in their insurance. Findings from this research show that hospice workers were significantly more likely than hospital workers to take into account the financial conditions of private funds and private insurance for patients and families. This means that hospice workers pay a lot of attention to private funds to cover the costs of their services.

In 1979 and 1980 demonstration projects were initiated by the federal government and Blue Cross to assess the costs of hospice programs. The Health Care Financing Administration sponsored a project to experiment with waivers on some of the restrictions on reimbursement for home care, but the results of such studies are not yet known.* Hospice advocates raise two significant concerns related to these issues. They fear that standards for reimbursement and accreditation may impede the diversity and innovation of the hospice philosophy, and they foresee that once hospice care becomes reimbursable, the potential for exploitation will grow, despite the high level of altruism among its existing personnel. Hospice leaders feel that it is important that the initiative for setting and enforcing standards remain with those in the field of hospice care, rather than in the hands of

*Present cutbacks on expenditures related to health care will no doubt be felt among hospice programs, especially funds for demonstration projects.
government agencies. They do not want to jeopardize the commitment to high quality of care to which hospice is pledged (Zimmerman, 1981).

Another area of consideration of hospice advocates is the relationship between hospice care and traditional medical care of the terminally ill. There are many forms this relationship could take; at one extreme hospice could become a totally separate system of care independent of the rest of the health care field. The danger of this form would be hospice as a cult-like phenomena. At the other extreme hospice could become completely amalgamated into general medical care, as its philosophy and precepts become understood and practiced by the medical and health care professionals. Realistically, the relationship will most likely take a middle form, since care of the terminally ill can fit into the traditional medical system with certain features requiring that it be a specialty. For example, there are many physicians who do not wish to be responsible for their patients once they have reached the terminal stage in their disease. At that point, hospice physicians can take over (Zimmerman, 1981). Also, hospice philosophy has critics who view it as an easy way to euthanasia. The rapid advance in medical technology over the past two decades has raised serious questions about patient autonomy and the right to die with dignity. Both legislatures and the courts have attempted to clarify these issues. Many states have enacted laws providing for "living wills" - legal documents that give patients the right to refuse heroic measures for their care when in a "terminal" condition (Jackson and Youngner, 1979). Responses to these questions have come from the fields of medicine, religion, law, the press, and the public.
Hospice advocates feel that their program does not support euthanasia because it actively treats the dying persons' needs for physical comfort and pain control, and dying with dignity and peace of mind (Cohen, 1979).

Implications for Practice

Findings from the research and interviews with social workers demonstrate several meaningful implications for practice. One of the key areas in discharge planning discussed was the role of the medical team. The rationale for the team, in which interprofessional interaction involves a variety of disciplines, is that the amount of knowledge needed for problem-identification and problem-solving on the individual and family levels is so great, that no one profession can develop the range of expertise required. The social worker works closely with the physicians, nurse, rehabilitation therapists and others in three stages of the discharge planning process.

In the first stage, following patient referral or independent case-screening, the social worker gathers information from members of the team in order to do a comprehensive assessment of the patient's medical condition. She must understand, from the physician, the nature of the illness, the course of treatment, effects of treatment on functioning, the course of the illness, and the prognosis. Furthermore, the social worker will want to know what the physician has told the patient and family. From the nurse, the social worker explores the patient's physical and emotional functioning on a day to day basis, the nature of his contact with his family in the evening, and
his attitudes toward his medical care and treatment. From individual and group contacts with the patient and family, the social worker continues her assessment of the past history, and current attitudes, feelings and coping mechanisms toward the hospitalization. Areas needing problem-solving are identified. Rehabilitation therapists offer the social worker the evaluation of the patient's functional abilities related to post-hospital needs upon discharge. Through the sharing of professional information by those involved in medicine, nursing, rehabilitation, dietary, technical services, volunteers and others, a solid foundation can emerge for the second stage, planning for disposition and identification of services.

At the same time the social worker is counseling the patient and family around their adjustment to the hospitalization and their needs upon discharge, she is helping them clarify where the patient will go upon discharge. The input from the medical team is most necessary, since it is the patient and family who will ultimately decide the plan they wish to follow, based on their knowledge of available options and resources. Once the decision is made on where the patient will go, and a tentative discharge date is set, the third stage of mobilization, coordination, and implementation begins. In this stage, team members can include community resource persons involved with home care or institutional services. The social worker works with the coping strengths of the patient and family to mobilize them toward the objectives. Usually the most comprehensive mechanism for achieving the input of all team members is the pre-discharge conference. At this meeting, all appropriate team members participate to discuss
the working plans, perceived obstacles, and re-evaluation of goals if necessary. The optimal conference includes the patient and family.

Findings show that the majority of all social workers felt that doctors (91%) and physical therapists (54%) were important team members in discharge planning. Hospice workers were significantly more likely than hospital workers to consider religious personnel as important team members. Hospice workers also introduced spiritual needs of patients as important in discharge planning. Limited cooperation of medical staff in necessary paperwork was not found to be notable in discharge planning, refuting previous research (Schrager et al., 1978). Workers recognized the patient and family as essential team members, especially in the pre-discharge conference. Also included in collaboration were community persons and social work supervisors.

Findings indicate that dieticians were largely left out of team interaction in discharge planning. Social workers must recognize that the majority of terminal patients will require a therapeutic diet when they leave the hospital. Cancer patients especially will have problems with nausea, vomiting, taste alterations, and intolerances for specific foods that interfere with their ability to eat. Diet affects the patient's emotional, social and physical responses to his environment, so that nutritional care is significant in discharge planning. Involvement of the family is imperative if the patient is going home, since issues of diet, methods of food preparation, costs of foods, and adequate substitutions, must be realistically discussed prior to discharge.
In the interviews, social workers reported minimal involvement of physicians in communicating openly with patients and families about the illness and prognosis. They voiced concern that their anxieties about discussing issues of death and dying with the patient, were heightened by physicians who did not tell their patients the prognosis. Workers felt the need to communicate more directly and honestly with physicians about talking to terminal patients. They sensed the physicians' avoidance with them, the patient, and the family, which added to their frustration. Although reluctant to discuss serious illness and terminal care, physicians were cooperative in doing the necessary paperwork for applications to nursing homes and home care services.

One area which social workers underscored in working with the medical team was teaching patient management to the family. In view of the economic pressures associated with the decision of home or institution, it would seem crucial for the team to instruct the family on the care of the patient in order for them to decide whether they could manage the patient at home. According to the social workers, the teaching of patient management to families, prior to the pre-discharge conference, was at best sporadic and unstructured.

Ideally the definition of the medical team should be broadened to include all persons as is warranted by the individual case. The scope of discharge planning is so complex that any number of community and hospital persons may be called in to assist in the assessment, planning, mobilization, coordination, and implementation tasks. Larger collaborative groups could exist, composed of professionals,
administrators, service personnel, such as technicians and pharmacy, volunteers, clergy, and community officials, to pool their knowledge and resources. Community persons could even include significant people in the patient and family's home environment, such as employers, friends, and neighbors. No contribution from anyone associated with the patient or family should be underestimated.

Interviews with social workers illustrated that they felt positively about their work with terminal patients and their families when patients and families were open and honest about the illness and prognosis, and patients were realistic about dying. When these conditions existed, the workers felt more competent in their interventions and more helpful and empathic with the patients and families. Workers, on the other hand, expressed feelings of sadness, frustration, and guilt when patients were not alert, families were uncooperative with planning and unrealistic about the prognosis, discharge plans were not in accordance with the patient's wishes, and financial resources were inadequate to support the plan.

In order to work successfully with terminal patients and their families, social workers need certain insights and training. Courses on dying and bereavement should be routinely taught in schools of social work, and be a part of in-service education in health-related work settings. The aim of education is to help social work practitioners develop self-awareness of their personal feelings and attitudes toward death and dying, so that they are able to listen more freely to the needs of the terminal patients and families (Milner, 1980). Social workers must be acquainted with the range of coping behaviors
manifested by patients and families under severe stress. Patterns of family communication must be recognized and understood in terms of their implications for discharge planning. Social workers should learn the techniques of "reaching out" and "crisis treatment" to work with those patients and families who are not immediately amenable to discharge planning or counseling.

Discharge planning means that the patient will probably leave the hospital much different than when he was admitted and may not return to the same place. The family will undergo serious emotional, economic, social, and perhaps, physical changes as well. The adaptation process to these anticipated changes will naturally be slow, and procrastination is expected. Families show reluctance to discharge planning and implementation because an acceptance means acceptance of the irreversible nature of the illness. Guilt and ambivalence, arising from anger toward the patient and his illness, may further deter this acceptance for discharge planning. Anything that represents a drastic change, as terminal illness does, is a crisis, and, as such, arouses strong emotional reactions. For social work practice, this poses an important implication. When intervention occurs early in the admission, there is more time to build supportive and productive relationships with the patient and family. Counseling around death and dying and marital and family counseling should be available as soon as possible after admission, so that communication among patient and family members does not turn into avoidance and rejection.

This research identified a gap in bereavement services to families of hospitalized terminal patients. Although recognized by the hospice
workers, it seemed overlooked by the hospital workers, both as a defined social work responsibility and a hospital responsibility. The need for bereavement counseling raises questions for policy makers and practitioners, such as: Should the community agencies do the counseling? What are the identifiable conditions that indicate the need for intervention by the hospital social worker? Is there a particular point at which intervention is more effective, and receptivity to such help greater? Who will pay for this service, in view of proposed cutbacks in funds to community agencies and health insurance payors?

Bereavement requires that family members go through a complex readjustment in the transference of roles, redistribution of tasks, and steps toward resumption of normal, daily living. Studies on bereavement point to problems in morbidity and mortality, effects of family breakdown on parent-child relationships, and adult maladjustment. This ample evidence stresses the need for social work intervention. This intervention should come early in the admission in the form of anticipatory grief work. Because the need to anticipate death is not generally acceptable, socially and culturally, families have been deprived of this opportunity to mourn for the inevitable and imminent loss. For many families, the actual death increases their vulnerability at a point when their emotional, social, and financial resources are most depleted and their capacity for coping is most strained. Physicians oriented toward "cure" and "hope" may be doing an injustice to the terminal patient and his family. In this regard, hospice transmits a more accepting attitude toward death
and dying, and recognizes the importance of anticipatory grief work. Families in the crisis of terminal illness need impartial and objective guidance to help them cope with the terminal stage and eventual death, and prepare them for the circumstances, whether home or institution, the patient will be living with until his death.

The findings indicate certain attitudes of patients toward their prognosis that require empathy and consideration by social workers. During discharge planning, patients express anxiety about leaving the protective hospital environment where their care is supervised 24 hours a day. They fear receiving inadequate care on the outside. Patients who are discharged to nursing homes, especially, need reassurance. It is probably very difficult for social workers to offer this reassurance if they themselves doubt the quality of care in the institutions. When patients feel that their families know how to manage them, they are less fearful of going home, and feel less guilt about being a burden. Also, during discharge planning patients express the desire to maximize their independent functioning in order to feel they are still "living."

Perhaps one of the most pressing implications for practice, in light of the current public and political concerns over cost-containment, the quality of health care services, and the proposed changes in the delivery of health care services, is the need for social work practitioners who work with terminal patients and their families to systematically review local, state, and federal regulations that will affect discharge planning. Review should include a thorough knowledge of the governmental agencies that design and disseminate these
regulations and legislation, and focus on the impact of this legislation on the patient and family. Workers should address the systems of accountability required by governmental and accreditation organizations. Constraints and sanctions that detract or support effective discharge planning should be recognized and approaches for meeting the regulations without sacrificing comprehensive, quality service, should be developed.

From research findings and interviews with social workers, the following guidelines were developed to conceptualize the features of a successful discharge plan. These features should be part of effective social work practice in discharge planning with terminal patients and their families.

A. Dimensions of the Social Worker Components:

(1) There is early referral, whether by independent case-finding or by referral from medical team.

(2) Plan is not finalized prematurely due to pressure from utilization review, medical staff, patient or family.

(3) Cooperative and close collaboration exists between social worker and members of the medical team. Definition of who is part of the team is broadened to include community persons and others as the case warrants.

(4) Medical staff is cooperative in the necessary paperwork.

(5) The opportunity exists for adequate supervision and training in techniques of "reaching out" and crisis intervention. Social worker feels free to discuss her personal feelings about death and dying with supervisors and colleagues.
(6) Social worker has a thorough knowledge of all governmental legislation and regulations affecting discharge planning.

B. Dimensions of the Patient Components:

(1) Patient's attitude toward dying reflects a desire to cope realistically with discharge planning.

(2) The majority of patient's needs are met by the discharge plan.

(3) Patient's financial resources support the plan, and he understands the benefits and limitations of his health insurance.

(4) Patient feels that his family has learned how to manage him if he is going home.

(5) Patient understands the alternatives of home or institution in decision-making for disposition and feels assisted by the social worker to plan appropriately.

C. Dimensions of the Family Components:

(1) The majority of the family's needs are met by the discharge plan, especially for follow-up services.

(2) Family's financial resources support the plan, and they understand the benefits and limitations of their health insurance.

(3) Family receives adequate teaching from medical team on patient management.

(4) Family understands the alternatives of home or institution in decision-making for disposition and feels assisted by the social worker to plan appropriately.
D. Dimensions of the Patient and Family Components:
   (1) Patient and family are in agreement on where the patient will go upon discharge.
   (2) Patient and family communicate with their physician about the illness and prognosis.

E. Dimensions of the Environment Components:
   (1) Patient's home is evaluated to accommodate him at home.
   (2) Patients who live alone receive careful assessment of community resources to assess whether their services can make home care feasible.

Recommendations for Further Research

Because of the limited sample and the fact that all hospital data was restricted to Missouri, the findings are not generalizable to all hospital social workers. More rigorous research is needed with patients and families in different settings in order to move from knowing social work attitudes and self-reports to actual knowledge about what social workers are doing in discharge planning. The methodology and instruments developed here can be readily adapted to other health care settings in which discharge planning takes place. The instruments can be applied to discharge planning for dialysis, cardiac, neurological and other patients with life-threatening illness. They can be used systematically by social agencies, nursing homes, hospitals, and clinics for the purpose of exploring the parameters of discharge planning.

One direction for future research can be the construction of
follow-up studies to explore the extent to which posthospital needs of terminal patients and families are met subsequent to discharge. The most meaningful method for follow-up assessment would seem to be personal interviews with patients and/or families. Time intervals could be utilized ranging from one week, one month, and six months following discharge. Berkman (1980) developed a methodology for assessing the outcome of services given by social workers in hospitals using the Berkman-Rehr Classification of Psychosocial Problems and Outcomes. Berkman's study tested whether the Classification system, when used by hospital social workers who had comparable training in the criteria of contracting with their clients on the problems to be dealt with during social work intervention, would give a valid representation of problems and outcomes of intervention. Both social workers' and clients' judgments of problems dealt with and outcomes of intervention were recorded. The study assumed that clients could be used as a source for making valid assessments when looking at problems and outcomes. Outcomes were looked at in terms of the accessibility and adequacy of resources offered in relation to the problems. The study employed the use of the instrument and follow-up telephone interviews. Outcomes were assessed on two levels: whether resources for which clients were referred were adequate, and whether the problems agreed to by social worker and client were changed in a positive direction. The use of this Classification system with larger samples of terminal patients and their families can lead to the collection of data on profiles of patients' and families' needs in relation to outcomes of discharge planning. More knowledge is needed on the
relationship among problems in discharge planning, intervention methods, and outcomes.

Another area for critical investigation is community resources. Since knowledge of and referral to agencies is an integral part of discharge planning, it would seem important to examine the limitations and gaps in services provided by these resources. Certain community services may be unavailable, or there may be long waiting lists, inadequate funding, or have limited personnel. Are there services and programs for chronically ill patients in the home and in the institution that are unavailable to terminal patients?

Many issues relating to hospice programs need further study. What will be the effects of proposed cutbacks in health care expenditures on the availability and services of hospice programs? Are hospices more cost-effective than traditional methods of terminal care? Do patients with different terminal diseases benefit from different models of hospice care, such as the home care model or the free-standing facility? What are the roles and functions of the medical team members in the different hospice models?

New models of discharge planning must be developed by social workers, if the social work profession wants to take a leadership position in the continuity of care of hospital services. In view of the current economic and political realities in this country regarding health care, social workers must learn skills for formulating an audit, monitoring the accountability, and reviewing the efficiency and quality of services of a discharge planning program.
GLOSSARY

Ancillary Services: Hospital or other inpatient health program, services other than room and board, and professional services. They may include x-ray, drug, laboratory, or other services not separately itemized, but whose specific content can be quite variable.

Attending Physician: The physician legally responsible for the care of the patient in the hospital.

Benefit: In insurance, a sum of money provided for certain types of loss or covered services. Benefits may be paid directly to the insured or to others who render the services.

Death: The cessation of life; defined by physicians as a total stoppage of the circulation of the blood, and a cessation of the animal and vital functions thereon, such as respiration, pulsation, etc. For legal purposes, a human body with irreversible cessation of total brain function shall, according to customary standards of medical practice, be considered dead.

Discharge Plan: A written statement by the social worker that tells where the patient will go upon discharge. The plan consists of an assessment of the patient's and family's psychodynamics and

needs upon discharge, an evaluation of the home conditions and financial resources, and a treatment plan that lists and explains the coordination and implementation of hospital and community resources designed to meet the patient's and family's needs for continuity of care. ²

**Dying:** In the case of progressive terminal illness, the end of life. The last few months of life are generally regarded as the period of dying.

**Extended Care Facility (ECF):** A generic term used to describe a skilled nursing home facility. Medicare coverage is limited to 100 days of posthospital extended care services during any episode of illness. Medicaid benefits are not limited in this way.

**Home Health Agency:** An agency that provides home health care. To be certified under Medicare, an agency must provide skilled nursing services, at least one additional therapeutic service (physical, speech, or occupational therapy), medical social services, or home health aide services.

**Home Health Care:** Health services provided by a home health agency or other community public or private agency to the patient in the home. These services may include: nursing; rehabilitation therapy; homemaker; and social services.

**Homemaker Services:** Nonmedical support services to patients at home. These may include: personal care and hygiene; meal preparation; light housekeeping; etc. These services are not covered

²Definition is by the author.
by Medicare or Medicaid, but may be included in the social service programs developed by the states under Title XX of the Social Security Act. These services are intended to maintain independent living and normal family life.

**Hospice**: A program that provides palliative and supportive care for terminal patients and their families. The patient and the family are the unit of care, and support for the family extends through the bereavement period. Emphasis is placed on symptom control and preparation for the eventual death.

**Hospital**: An institution whose primary function is to provide inpatient services, diagnostic and therapeutic, for a variety of medical conditions, both surgical and nonsurgical. Most community hospitals are acute care, short-term, and nonprofit.

**Inpatient**: A patient who has been admitted at least overnight to a hospital or other health facility for the purpose of receiving diagnostic, treatment, or other health services.

**Medical Team**: Those persons responsible for the care and treatment of the patient during his hospitalization. They include: professionals; paramedical personnel; administration; and community persons.

**Paramedical Personnel**: Those health personnel who are not professionals. They include: medical technicians; aides; record keepers; nutritionists; and others.

**Nursing Homes**: A wide range of institutions that provide various levels of nursing care for people, who for various reasons cannot return home. Nursing homes can include skilled nursing
facilities and intermediate care facilities. In Missouri, the latter does not exist. The level of care relates to the degree of incapacity to care for oneself in ambulation and activities of daily living, and the degree to which skilled nursing services are needed.

**Rehabilitation Therapists**: Those professional persons who are specially trained in the principles and practices of neurophysiology and biomechanics to assist patients in using special exercises, assistive devices and equipment. They include: physical, speech and occupational therapists, specialty nurses; physiatrists, and others, who work to relieve pain, restore maximum function, and prevent disability following disease, injury or loss of a bodily part.

**Utilization Review (Professional Standards Review Organization)**: A review committee mandated by legislation—Amendment to the Social Security Act of 1972—whose purpose is to determine the necessity for each patient admission, the adequacy and relevance of medical services provided, and to insure that patients are discharged with appropriate follow-up plans. The committee reviews medical records to ensure that hospitals are admitting and keeping patients for legitimate and documented reasons.

**Terminal Patient**: A patient who has a terminal illness.

**Terminal Illness**: An incurable condition caused by injury, disease, or illness that, regardless of the application of life-sustaining procedures, will, according to reasonable medical judgment, produce death within a given, though unpredictable, period of time.
BIBLIOGRAPHY


Berkman, B.; Clark, E. and Butler, N.G. "Regional Profile Data Basis for Social Work Audit." *Health and Social Work,* (February, 1980).


Breindel, C.L. "Implementing a Multiphased Hospice Program," Hospital Progress, (March, 1979).


Brink, G. "Experts Probe Issues Around Hospice Care," Hospitals, (June, 1980).


Hospital Peer Review. "Study Pinpoints Consequences of Poor Discharge Planning," Hospital Peer Review, (February, 1981).


Linn, M. "Discharge Patterns of 'Discharge Problem' Patients," *Medical Digest*, (1967).


Phillips, B. "Hospital Discharge, By Plan or By Chance?," Hospital Progress, (February, 1972).


Reichelt, P.A. and Newcomb, J. "Organizational Factors in Discharge Planning." Journal of Nursing Administration, (December, 1980).


Schrager et al. "Impediments to the Course and Effectiveness of Discharge Planning," Social Work in Health Care, (Fall, 1978).


Verwoerd, A. Communication with the Fatally Ill. Springfield; C.C. Thomas, 1966.


Weinbach, R. and Dodge, D. "Educating for Discharge Planning," Hospitals, (December, 1974).


...... "Experience With a Hospice-Care Program for the Terminally Ill," (June, 1979).
**Home Health Service Referral Form**

**Form I**

<table>
<thead>
<tr>
<th>PROVIDER NUMBERS</th>
<th>HOME HEALTH SERVICE REFERRAL FORM</th>
<th>BLUE CROSS NUMBER</th>
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</thead>
<tbody>
<tr>
<td>Medicare: 26-7066</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medicaid: 580563708</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Blue Cross: 808</td>
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<td></td>
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</tbody>
</table>

**DATE:**

<table>
<thead>
<tr>
<th>PATIENT NAME (last) (first)</th>
<th>BIRTH DATE</th>
<th>SEX</th>
<th>MEDICARE NUMBER</th>
</tr>
</thead>
</table>

**PRESENT ADDRESS CITY STATE ZIPCODE TELEPHONE NUMBER**

**RESPONSIBLE PERSON ADDRESS CITY STATE ZIPCODE TELEPHONE NUMBER**

**PHYSICIAN ADDRESS TELEPHONE NUMBER**

**HOSPITAL OR CARE FACILITY DIVISION ADDRESS**

**ADMISSION DATE DISCHARGE DATE REFERRAL SOURCE**

**PROGNOSIS GOOD FAIR POOR SPECIFY**

**ADMITTING DIAGNOSIS PRIMARY:**

**SECONDARY:**

**SURGERY DATE FUNCTIONAL LIMITATIONS**

**Physician's Plan of Home Care**

<table>
<thead>
<tr>
<th>ADMITTING SERVICES</th>
<th>FREQ.</th>
<th>SUPPORTING SERVICE</th>
<th>FREQ.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Skilled Nursing</td>
<td></td>
<td>Home Health Aide</td>
<td></td>
</tr>
<tr>
<td>Physical Therapy</td>
<td></td>
<td>Occupational Therapy</td>
<td></td>
</tr>
<tr>
<td>Speech Therapy</td>
<td></td>
<td>Social Services</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EQUIPMENT</th>
<th>ACTIVITIES</th>
<th>ALONE</th>
<th>ASSISTANCE OR DEVICE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wheelchair</td>
<td>Up Ad Lib</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walker</td>
<td>Stairs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other/Specify</td>
<td>Bathroom</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bed</td>
<td>Tub Bath</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Side Rails</td>
<td>Other/</td>
<td></td>
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<tr>
<td>Commode</td>
<td>Specify</td>
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<td>Other/Specify</td>
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**Treatment:**

**Observe for:**

**Medications:**

**Diet:**

<table>
<thead>
<tr>
<th>Circle</th>
<th>Regular</th>
<th>Bland</th>
<th>Low Calorie</th>
<th>Low Sodium</th>
<th>Diabetic</th>
<th>Other</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Monitor</th>
<th>Fluid Balance - Specify</th>
<th>Allergies</th>
</tr>
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</table>

**Goals**

<table>
<thead>
<tr>
<th>Estimated Length of Service</th>
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</thead>
</table>

I certify that the above patient is homebound and requires the skilled services specified.

**Date Last Seen by Physician**

**Physician's Signature/Date**
Form II

THE PURPOSE OF THIS REVIEW IS TO ESTABLISH THAT THE PHYSICIAN'S POST-HOSPITALIZATION PLAN-OF-CARE MEETS CRITERIA FOR SKILLED LEVEL OF CARE IN A SKILLED NURSING FACILITY.

**ACUTE CARE DIAGNOSES & CONDITIONS** which now require continued management in a Skilled Nursing Facility:

1. Primary
   - Name
   - Dosage
   - Times
   - Route

2. Functional Problems: 0 = None  1 = Mild  2 = Moderate  3 = Severe  4 = Absolute
   - Behavior
   - Eating
   - Hearing
   - Continence
   - Mental
   - Dressing
   - Speech
   - Communication
   - Bathing
   - Vision
   - Toilet
   - Mobility

**MEDICATIONS** which require professional supervision and management

<table>
<thead>
<tr>
<th>Name</th>
<th>Dosage</th>
<th>Times</th>
<th>Route</th>
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</table>

**NURSING SUPERVISION & MANAGEMENT** of a complicated or extensive physician's Plan-of-Care: skilled observation, assessment, & monitoring; a complicated or unstable condition, or of the progress of a rehabilitation program. Goals for patient teaching should be included here.

**INTRAVENOUS FLUIDS/FEEDING:**
- GASTROSTOMY FEEDING:
- LEVINE TUBE ADMINISTRATION:
- NASOPHARYNGEAL ASPIRATION:
- TRACHEOTOMY ASPIRATION TUBE MAINTENANCE:
- TREATMENT OF DECUBITI:
- CATHETER (to treat indwelling disease):
- DRESSING REQUIRING ASEPTIC TECHNIQUE:

**REHABILITATION SERVICES** (must be in conjunction with skilled nursing services): PT/OT/ASP/SW. State Feasible goals for each service:

**ADDITIONAL INFORMATION:**

- CERTIFIED from through

- TITLE XIX "PRIOR QUARTER" REVIEW
Form III

ADMISSION: ____________________________________________

DISCHARGE: ____________________________________________

INS. # _________________________________________________

1. Responsible family member: ____________________________________________

2. Relationship to patient: ____________________________________________

3. Address of family member: ____________________________________________
   Phone: ____________________________________________

4. Diagnosis: ____________________________________________

5. Did patient have surgery? ______ If so, what date: _______________________

6. Type of surgery performed: ____________________________________________

7. If Diabetic: Insulin__________ Diet Controlled_____________________

8. Special Diet: ____________________________________________

9. Feeds Self____ Needs Ass't_____ Must be fed_______ N-G Tube___________
   Feeds self if tray set up (i.e., containers opened)_____________________

10. Skin Breakdown: Yes____ No_____ Location _______________________
    Draining?____ Specify treatment required: _______________________

11. Bladder: Incontinent____ Occasionally Incontinent_______
    Continent_______ Retention___________

12. Catheter Required: Foley____ Texas____ Intermittent___________

13. Bowel: Incontinent____ Occasionally Incontinent_______ Continent_______

14. Bathing: Independent____ Needs Ass't____ Bedbath_______________

15. Alert____ Occasionally Confused____ Confused____ Comatose___________
    Cooperative____ Uncooperative____ Combative____ Unresponsive_________
    Needs encouragement____ Depressed____________________

(see reverse side)
Form III--cont'd.

6. Ambulation: Independent __ Ass't of one ______ two _______

   With walker __________ With crutches __________ With cane _______

   Not ambulatory ______________________________

7. Out of bed with assistance of one ______ two _______ more _______

   OOB/chair only _______ bedfast ______

8. If PT involved, describe: _______________________________________

9. Deficits: Speech ______ Hearing _______ Sight ________

10. Needs restraints: Bed ______ Chair ______ What kind? (i.e., jacket, arm, hand, side gates)

11. Oxygen: Continuous __________________ prn basis _______

12. Patient requires: Suctioning ___________________ Chest PT ______

13. IVs ________ To be d/c before discharge ______

14. Discharge Medications: ________________________________

15. Will the doctor be following patient after placement? Yes _____ No ______

16. Is ambulance needed for transfer? Yes / No Amb.Co. _______ Phone ______

17. Funding: Medicare ______ Medicaid Pending ________ Other ______

18. List nursing home preferences & include any additional information you feel necessary:

DATE _______________ SOCIAL WORKER'S INITIALS _______________ 6-79
Form IV  
Social Work Assessment for Long Term Illness Planning

Pt's. Name: ___________________________ D.O.B. ___________ Med. Rec. #: ____________________

Present location of pt.: ___________________ Marital Status: ___________ Medicare #: ________________

Address: ______________________________ Religion: _______________ Medicaid #: __________________

Telephone #: ____________________________ Occupation: ________________________________ Sex: ____________

Pt's. financial status (Please indicate amount)

OASDI __________________________ R.R. ______________ Savings __________________________

SSI ______________________________ V.A. __________________ Owns Property __________________________

ADC ____________________________ G.R. ______________ Other __________________________

Relative/significant other: __________________________ Relationship: ________________

Address: _____________________________ Phone #: ________________________________

Sources of information: ____________________________
APPENDIX A

List of Acute Care Hospitals Used In Study

<table>
<thead>
<tr>
<th>Hospital</th>
<th>Number of Social Workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Barnes Hospital</td>
<td>7</td>
</tr>
<tr>
<td>2. Jewish Hospital</td>
<td>4</td>
</tr>
<tr>
<td>3. County Hospital</td>
<td>1</td>
</tr>
<tr>
<td>4. City Hospital</td>
<td>3</td>
</tr>
<tr>
<td>5. Missouri Baptist Hospital</td>
<td>2</td>
</tr>
<tr>
<td>6. St. John's Mercy Hospital</td>
<td>4</td>
</tr>
<tr>
<td>7. Firmin de Loge Hospital</td>
<td>5</td>
</tr>
<tr>
<td>8. Lutheran Hospital</td>
<td>1</td>
</tr>
<tr>
<td>9. Deaconness Hospital</td>
<td>3</td>
</tr>
<tr>
<td>10. Compton Hill Medical Center</td>
<td>6</td>
</tr>
<tr>
<td>12. St. Anthony's Medical Center</td>
<td>1</td>
</tr>
<tr>
<td>13. Lindell Hospital</td>
<td>8</td>
</tr>
<tr>
<td>14. St. Luke's Hospital</td>
<td>1</td>
</tr>
<tr>
<td>15. St. Mary's Health Center</td>
<td>8</td>
</tr>
<tr>
<td>16. St. Joseph Hospital of St. Charles</td>
<td>8</td>
</tr>
<tr>
<td>17. University of Missouri Medical Center at Columbia</td>
<td>8</td>
</tr>
</tbody>
</table>
APPENDIX B

List of Hospice Programs Used In Study

<table>
<thead>
<tr>
<th>Hospice</th>
<th>Number of Social Workers</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. El Cajon Hospice</td>
<td>2</td>
</tr>
<tr>
<td>El Cajon Valley Hospital</td>
<td></td>
</tr>
<tr>
<td>El Cajon, California</td>
<td></td>
</tr>
<tr>
<td>2. Lutheran Hospital Hospice</td>
<td>2</td>
</tr>
<tr>
<td>Continuing Care Unit</td>
<td></td>
</tr>
<tr>
<td>St. Louis, Missouri</td>
<td></td>
</tr>
<tr>
<td>St. Luke's Hospital</td>
<td></td>
</tr>
<tr>
<td>St. Louis, Missouri</td>
<td></td>
</tr>
<tr>
<td>4. Albert Einstein College Hospital</td>
<td>2</td>
</tr>
<tr>
<td>Hospice Unit</td>
<td></td>
</tr>
<tr>
<td>Bronx, New York</td>
<td></td>
</tr>
<tr>
<td>5. Parkwood Hospice</td>
<td>2</td>
</tr>
<tr>
<td>Parkwood Community Hospital</td>
<td></td>
</tr>
<tr>
<td>Canoga Park, California</td>
<td></td>
</tr>
<tr>
<td>6. Pinecrest Life Acceptance Unit</td>
<td>2</td>
</tr>
<tr>
<td>Pinecrest Hospital</td>
<td></td>
</tr>
<tr>
<td>Santa Barbara, California</td>
<td></td>
</tr>
<tr>
<td>7. Methodist Hospice Unit</td>
<td>2</td>
</tr>
<tr>
<td>Methodist Hospital</td>
<td></td>
</tr>
<tr>
<td>Indianapolis, Indiana</td>
<td></td>
</tr>
<tr>
<td>8. Forbes Health System–Hospice</td>
<td>1</td>
</tr>
<tr>
<td>Pittsburgh, Pennsylvania</td>
<td>15</td>
</tr>
</tbody>
</table>
APPENDIX C

Letter to the Directors of Social Work Departments In
The Acute Care Hospitals

Mrs. Heidi Mandel
8671 Old Bonhomme Rd.
University City, Mo. 63132

Date

Dear Name of Director

With regard to our telephone conversation on __________, I am writing to enlist your help in a research project that I am engaged in for my doctoral dissertation at the Columbia University School of Social Work.

The purpose of this study is to discover the kinds of factors social workers take into account when they formulate discharge plans for the terminal patient. Also, I wish to derive a better understanding of the discharge planning process. I am aware that social workers on your staff may be called upon to construct discharge plans for terminal patients.

Please be assured that all responses will be held in the strictest of confidence.

I have enclosed ______ copies of the questionnaire. A telephone follow-up interview may be necessary, which I will call to schedule once the completed questionnaire is received. If you have any questions about the questionnaire or the study, please feel free to call me at (314) 993-3873.

I will be glad to send you the results of the study as soon as it is completed.

Thank you for your cooperation with this study.

Sincerely,

Heidi Mandel, CSW, ACSW
APPENDIX D

Letter to the Director of Hospice Programs

Mrs. Heidi Mandel
8671 Old Bonhomme Rd.
University City, Mo. 63132

Date

Name of Hospice Program
Address of program

Attention: Name of Director

Dear Name of Director:

I am writing to enlist your help in a research project, that I am engaged in for my doctoral dissertation at the Columbia University School of Social Work.

The purpose of this study is to discover the kinds of factors social workers take into account when they formulate discharge plans for the terminal patient. Also, I wish to derive a better understanding of the discharge planning process. I am including hospice programs in the study because of the unique nature of their services. Your hospice has been identified as one having no coordinated home care program. I am aware that social workers on your staff may be called upon to construct discharge plans for terminal patients.

Please be assured that all responses will be held in the strictest of confidence.

I have enclosed five copies of the questionnaire. A telephone follow-up interview may be necessary, which I will call to schedule once the completed questionnaire is received. If you have any questions about the questionnaire or the study, please feel free to call me at (314) 993-3873.

I will be glad to send you the results of the study as soon as it is completed.

Thank you for your cooperation with this study.

Sincerely,

Heidi Mandel, CSW, ACSW
APPENDIX E

Telephone Interview Guide

Name: ____________________________________________

Years in social work: ______

Years working with terminal patients (since MSW): ______

Nature of caseload with regard to terminal patients:

Majority______  Minority______  All______

Is working with terminal patients a career choice or assignment on the job:

choice _____  assignment _____

Member of NASW: Yes______  no______

Did you have any trouble filling out questionnaire: yes______  no______

Clarify responses that are missing, incomplete, ambiguous or interesting:

__________________________________________________________________________

Have you had personal experience with close friends and terminal illness:

    yes _____  no ______

If yes, how many: ______

What was your experience:

__________________________________________________________________________

Have you had personal experience with family and terminal illness:

    yes _____  no ______

If yes, how many: ______

Who was it: ___________________
What was your experience:

What do you believe to be the single factor that helps you make a good discharge plan for the terminal patient?

Thinking about your last terminal patient who went home, can you briefly describe the feelings you experienced toward the patient and situation?

Thinking about your last terminal patient who went to an institution, can you briefly describe the feelings you experienced toward the patient and situation?

What is your religious orientation: ________________

Does your religion give you a way of coping with death and dying?

   yes ______   no ______

If yes, how?: ____________________________

What would you like to know more about to provide better services to terminal patients?

What have you found to be the major deciding factor in whether a terminal patient goes home or to an institution upon discharge?
APPENDIX F

Code For Additional Items

Patient Factors:

Patients' Needs Upon Discharge:

1. Nursing home geographically close to family
2. Spiritual needs
3. Counseling on issues other than death and dying
4. Patient-family teaching on patient management
5. Knowledge of medicaid/medicare benefits

Patients' Attitudes Toward Dying:

1. Desire for independence and self-sufficiency
2. Anxiety about discharge

Patients' Financial Conditions:

1. Patients has no funds or insurance
2. Patient has only medicare and fixed income, such as social security or disability

Family Factors:

Family Needs Upon Discharge:

1. Knowledge of medicare benefits
2. Counseling on issues other than death and dying
3. Need for doctor to communicate more openly about illness and prognosis of patient
4. Family-staff teaching about patient management

Family Financial Conditions:

1. Extended family wishes to contribute to costs of hospitalization and home care upon discharge

Environment Factors:

Team Members:

1. Patient
2. Family
3. Community resource persons
4. Social service supervisor
APPENDIX F

Case For Additional Items

Environment Factors:

Home Conditions:

1. Availability of transportation for patient and others to get to and from places relating to medical needs, recreation, economic and family matters
2. Geographic location of home in relation to medical facilities
3. Adequate cooking facilities
4. Temperature control of home, such as air-conditioning and heating
APPENDIX G

Code for Telephone Interview

Personal experience - with close friends: what was your experience?

1 = involved with person dying at home
2 = involved with person dying in an institution
3 = uninvolved with person dying at home
4 = uninvolved with person dying in an institution
5 = will not say

Personal experience - with family: what was your experience?

1 = involved with person dying at home
2 = involved with person dying in an institution
3 = uninvolved with person dying at home
4 = uninvolved with person dying in an institution
5 = will not say

Who was it? 1 = mother 2 = father 3 = aunt 4 = uncle 5 = grandparents 6 = child 7 = cousin 8 = sibling 0 = spouse

What do you believe to be the single factor that helps you make a good discharge plan for the terminal patient?

1 = Financial resources of patient and/or family
2 = Patient's needs upon discharge
3 = Patient's wishes upon discharge
4 = Family's attitude toward and ability to cope with patient
5 = Family's needs upon discharge
6 = Availability of community resources
7 = Cooperation of M.D.

Thinking about your last case of a terminal patient who went home, can you briefly describe the feelings you experienced.

1 = Responses reflecting intellectualization and anxiety
2 = Responses reflecting guilt and frustration
3 = Responses reflecting depression and pain
4 = Responses reflecting feelings of competence with job and affection toward patient
5 = Responses reflecting compassion, self-awareness, job satisfaction and acceptance of death and loss

Thinking about your last case of a terminal patient who went to an institution, can you briefly describe the feelings you experienced

1 = Responses reflecting intellectualization and anxiety

2 = Responses reflecting guilt and frustration
3 = Responses reflecting depression and pain
4 = Responses reflecting feelings of competence with job and affection toward patient
5 = Responses reflecting compassion, self-awareness, job satisfaction and acceptance of death and loss

What is your religious orientation?

1 = None  
2 = Jewish  
3 = Hindu  
4 = Catholic  
5 = Protestant  
6 = Other

If yes, how? Provides:

1 = Comfort  
2 = Understanding  
3 = Hope  
4 = Strength  
5 = Acceptance of death

What would you like to know more about to provide better services to terminal patients?

1 = Those related to the patient  
2 = Those related to the family  
3 = Those related to community resources  
4 = Those related to hospital personnel  
5 = Those related to professional social work values, practice or training

What have you found to be the major deciding factor in whether a terminal patient goes home or to an institution upon discharge?

1 = Financial resources of patient and/or family  
2 = Family's attitude toward and ability to cope with patient  
3 = Family's needs upon discharge  
4 = Patient's needs upon discharge  
5 = Recommendation by M.D.
APPENDIX H

Instructions For Filling Out The Questionnaire

The purpose of this study is to discover the kinds of factors you take into account when you formulate a discharge plan for the terminal patient and derive a better understanding of the discharge planning process.

Please answer all the items as best as you can, by simply circling or checking the responses that most accurately describe your own experiences with discharge planning. You will also find questions that ask you to write in your own responses. If you feel you need more space than provided for, please use the reverse side of the questionnaire.

Please be assured that all responses will be held in the strictest of confidence. Your responses will be anonymously transcribed to coded cards and the actual questionnaire will be destroyed. The nature of the study requires that a follow-up interview may be necessary, which is the reason for your name, address and telephone on the questionnaire.

If there are any questions about the questionnaire, or the study, please feel free to call me at (314) 993-3873.

I would appreciate your returning the questionnaire within one week of your receiving it, so that your experiences may be looked at as soon as possible. The results of this study will be sent to you as soon as it is completed as I am sure you would want to know what findings the study made.

Thank you for your cooperation with this study.

Heidi Mandel
8671 Old Bonhomme Rd.
St. Louis, Mo. 63132

Name:
Address:
Telephone:
**Discharge Planning Questionnaire**

**Section A:**

I. **Instructions:** The following is a list of needs that patients may have upon discharge. For your last five cases, how much did each of these needs figure into your discharge planning? Please circle the number that applies to each need, a through t.

<table>
<thead>
<tr>
<th>Needs</th>
<th>Degree of Consideration</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. physicians services</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>b. nursing services -- (RN, LPN, aide)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. 24 hr. care 7 day/wk.</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>2. 20-40 hrs./wk.</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>3. less than 20 hrs./wk.</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>c. rehabilitation services (PT, speech, OT)</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>d. clinical laboratory and radiology services</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>e. special diet and supervision</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>f. counseling around death and dying</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>g. assistance with finding mental health resources</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>h. assistance with private insurance problem</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>Needs</td>
<td>Degree of Consideration</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>-------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>i. assistance with obtaining medical equipment and supplies</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>j. assistance with obtaining medication</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>k. meal services</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>l. food stamps</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>m. assistance with obtaining housing</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>m. assistance with obtaining transportation</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>o. legal aid</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>p. cash assistance application (welfare)</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>q. budgeting</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>r. scheduling clinic appointments</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>s. application for other benefits (ex. SSI)</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>t. assistance in contacting family or friends</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
</tbody>
</table>

II. Please add to the list in Question I any additional needs you feel fit into your discharge planning, and again circle the number that applies to each need.

<table>
<thead>
<tr>
<th>Needs</th>
<th>Degree of Consideration</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>u. ________________</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>v. ________________</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>w. ________________</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>x. ________________</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
</tbody>
</table>
III. For the list of needs in Question I, including those you may have added, which three needs typically figure into your discharge planning? Please write the letters corresponding to the needs as shown above. For example, (a) for physician services, (b) for nursing services, etc.

_____ , _____ , and _____

2. Of the five patients used in responding to Question I, how many went home?
   a. 5  c. 3  e. 1
   b. 4  d. 2

3. Was the number who went home in accordance with your discharge plan for them?
   a. yes  
   b. no

4. If no (to Question 3), what happened to prevent your plan from being implemented?
Section B:

I. Instructions: The following is a list of conditions that may characterize patients' home environment. How much on the average does each of them figure into your discharge planning? Please circle the number that applies to each condition, a through h.

<table>
<thead>
<tr>
<th>Conditions</th>
<th>Degree of Consideration</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. bathroom and bedroom on different floors</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>b. one or more flights of steps to apartment, (no elevator)</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>c. no room for sleep-in aide</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>d. special equipment already installed</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>e. patient lives alone</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>f. inadequate space for rehab therapy equipment</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>g. overcrowded--too many persons living together</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>h. inadequate space for special equipment, (ex. hospital bed, bars, etc.)</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
</tbody>
</table>

II. Please add to the above list any additional conditions you feel figure into your discharge planning, and again circle the number that applies to each condition.

<table>
<thead>
<tr>
<th>Conditions</th>
<th>Degree of Consideration</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>i. ________________________</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
</tbody>
</table>
III. For the preceding list of conditions, a through l, which three conditions typically figure into your discharge planning? Please write the letters corresponding to the conditions as shown.

_____, _____, and ____

Section C:

I. Instructions: The following is a list of needs that family members may have when the patient is discharged. For your last five cases, how much did each of these needs figure into your discharge planning? Please circle the number that applies to each need, a through q.

Needs                          Degree of Consideration Not Applicable
a. counseling around death and dying 9 8 7 6 5 4 3 2 1 0 X
b. assistance with finding mental health resources 9 8 7 6 5 4 3 2 1 0 X
c. assistance with private insurance problem 9 8 7 6 5 4 3 2 1 0 X
d. assistance with obtaining medical supplies 9 8 7 6 5 4 3 2 1 0 X
e. assistance with obtaining housing 9 8 7 6 5 4 3 2 1 0 X
f. application to nursing homes 9 8 7 6 5 4 3 2 1 0 X
Needs | Degree of Consideration | Not Applicable
--- | --- | ---
g. legal aid | 9 8 7 6 5 4 3 2 1 0 | X
h. meal services | 9 8 7 6 5 4 3 2 1 0 | X
i. food stamps | 9 8 7 6 5 4 3 2 1 0 | X
j. case assistance application (welfare) | 9 8 7 6 5 4 3 2 1 0 | X
k. transportation arrangements | 9 8 7 6 5 4 3 2 1 0 | X
l. bereavement counseling when patient dies | 9 8 7 6 5 4 3 2 1 0 | X
m. budgeting | 9 8 7 6 5 4 3 2 1 0 | X
n. other medical problems | 9 8 7 6 5 4 3 2 1 0 | X
o. scheduling clinic appointments | 9 8 7 6 5 4 3 2 1 0 | X
p. assistance in vocational training | 9 8 7 6 5 4 3 2 1 0 | X
q. application for other benefits, (ex. SSI) | 9 8 7 6 5 4 3 2 1 0 | X

II. Please add to the above list any additional needs you feel figure into your discharge planning, and again circle the number that applies to each need.

r.__________________ | 9 8 7 6 5 4 3 2 1 0 | X
s.__________________ | 9 8 7 6 5 4 3 2 1 0 | X
t.__________________ | 9 8 7 6 5 4 3 2 1 0 | X
u.__________________ | 9 8 7 6 5 4 3 2 1 0 | X

III. For the above list of needs, a through u, which three needs typically figure into your discharge planning? Please write the letters corresponding to the needs as shown above.

_____, _____, and _____
Section D:

I. Instructions: The following is a list of attitudes that family members may have toward the dying patient. How much do these attitudes figure into your discharge planning? Please circle the number that applies to each attitude.

<table>
<thead>
<tr>
<th>Attitudes</th>
<th>Degree of Consideration</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. &quot;I'll only take her home if we can afford to pay for home help.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>b. &quot;She's my mother, I can't put her away.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>c. &quot;We have a loving and honest marriage.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>d. &quot;I can't face the thought of him being home.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>e. &quot;I definitely want him home.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>f. &quot;I think the nursing home will take better care of her.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>g. &quot;As long as she's not alert, she won't know where she is.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>h. &quot;I'll leave the decision to (other family member).&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>i. &quot;We can't afford the nursing home so we'll take her home.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>j. &quot;She'll never forgive me if I don't take her home.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>Attitudes</td>
<td>Degree of Consideration</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>--------------------------------------------------------------------------</td>
<td>-------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>k. &quot;I'll leave the decision to (the patient).&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td>X</td>
</tr>
<tr>
<td>l. &quot;We were never that close.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td>X</td>
</tr>
<tr>
<td>m. &quot;I'd like to help but I live too far away.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td>X</td>
</tr>
</tbody>
</table>

II. Please add to the preceding list any additional attitudes you feel figure into your discharge planning, and again circle the number that applies to each attitude.

| n. ____________                                                     | 9 8 7 6 5 4 3 2 1 0 X   | X             |
| o. ____________                                                     | 9 8 7 6 5 4 3 2 1 0 X   | X             |
| p. ____________                                                     | 9 8 7 6 5 4 3 2 1 0 X   | X             |
| q. ____________                                                     | 9 8 7 6 5 4 3 2 1 0 X   | X             |

III. For the above list of attitudes, including those you may have added, which three attitudes typically figure into your discharge planning? Please write the letters corresponding to the attitudes as shown above.

_______, _______, and _______
Section E

Instructions: Please check the box that applies.

1. In your last case of a terminally ill patient who went home upon discharge, how long was the time between admission and referral to you?
   a. same day  d. 8-14 days
   b. one to two days  e. 15-30 days
   c. 3-7 days  f. over 30 days

2. From the preceding question, how long was this patient's admission?
   a. one week or less  c. two weeks to one month
   b. one to two weeks  d. over one month

3. In your last case of a terminally ill patient who went to an institution upon discharge, how long was the time between admission and referral to you?
   a. same day  d. 8-14 days
   b. one to two days  e. 15-30 days
   c. 3-7 days  f. over 30 days

4. From the preceding question, how long was this patient's admission?
   a. one week or less  c. two weeks to one month
   b. one to two weeks  d. over one month

5. Does the timing of patient referral to you play a part in the discharge planning process?
   a. yes  b. no
   c. If yes, please specify ____________________________
6. For your last five terminally ill patients, how long, on the average, would you say they knew they were terminal?
   a. one week or less ______   c. two weeks to one month ______
   b. one to two weeks ______   d. over one month ______

7. On the average, how soon, before or after patients are informed of the terminal nature of their illness, have you been assigned to them?
   a. assigned two or more weeks before they are informed ______
   b. assigned one to two weeks before they are informed ______
   c. assigned less than one week before they are informed ______
   d. assigned usually the same day they are informed ______
   e. assigned two or more weeks after they are informed ______
   f. assigned one to two weeks after they are informed ______
   g. assigned less than one week after they are informed ______
   h. do not know generally when they are informed ______

Section F

I. Instructions: The following is a list of people you may have as members of the medical team. How much say do you usually have in specifying the discharge plan in relation to each member? Please circle the number that applies for each member, a through j.

<table>
<thead>
<tr>
<th>Members</th>
<th>Degree of Consideration</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. doctors</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>b. nurses</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>c. administrators</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>Members</td>
<td>Degree of Consideration</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>-------------------------</td>
<td>-------------------------</td>
<td>----------------</td>
</tr>
<tr>
<td>d. speech therapists</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>e. occupational</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>therapists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>f. dieticians</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>g. physical therapists</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>h. aides</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>i. religious personnel</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>j. volunteers</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
</tbody>
</table>

II. Please add to the above list any additional persons you feel figure into discharge planning, and again circle the number that applies to each person.

| k. __________________ | 9 8 7 6 5 4 3 2 1 0     | X             |
| l. __________________ | 9 8 7 6 5 4 3 2 1 0     | X             |
| m. __________________ | 9 8 7 6 5 4 3 2 1 0     | X             |
| n. __________________ | 9 8 7 6 5 4 3 2 1 0     | X             |

III. List three persons with whom you usually confer about discharge planning. Please write the letters corresponding to the persons as shown above.

___________, __________, and __________

Section C

I. Instructions: The following is a list of situations that you may encounter in doing your work with terminal patients.

1. Please check all the statements that apply.

2. How much do these situations figure into your
discharge planning? Please circle the number that applies to each situation.

<table>
<thead>
<tr>
<th>Situation</th>
<th>Degree of Consideration</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. lack of appropriate care beds when patient is ready for discharge</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td></td>
</tr>
<tr>
<td>b. hospital utilization review says patient must leave when appropriate plan is not yet formulated</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td></td>
</tr>
<tr>
<td>c. physician decides where patient should go upon discharge</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td></td>
</tr>
<tr>
<td>d. difficulty in establishing eligibility of patient for needed benefits</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td></td>
</tr>
<tr>
<td>e. limited cooperation of medical staff in necessary paperwork</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td></td>
</tr>
<tr>
<td>f. patient's condition changes from time of admission</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td></td>
</tr>
</tbody>
</table>

II. Please add to the above list any additional situations you feel figure into discharge planning, and again circle the number that applies to each situation.

<table>
<thead>
<tr>
<th></th>
<th>Degree of Consideration</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>g.</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td></td>
</tr>
<tr>
<td>h.</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td></td>
</tr>
<tr>
<td>i.</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td></td>
</tr>
<tr>
<td>j.</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td></td>
</tr>
</tbody>
</table>
III. List three situations which typically figure into your discharge planning.

a. 

b. 

c. 

Section H
I. Instructions: The following is a list of attitudes that terminal patients may have toward dying. How much do these attitudes figure into your discharge planning? Please circle the number that applies to each attitude, a through j.

<table>
<thead>
<tr>
<th>Attitudes</th>
<th>Degree of Consideration</th>
<th>Not Applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. anger - &quot;The medical care here is worthless.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>b. depression - &quot;What's the point about caring about anything now?&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>c. denial - &quot;I'll recover very soon.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>d. bargaining - &quot;I want to go to my son's graduation.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>e. hopeful - &quot;The treatment will help my strength.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>f. acceptance - &quot;I'm not afraid of death.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
<tr>
<td>g. guilt - &quot;I'm a burden on my family.&quot;</td>
<td>9 8 7 6 5 4 3 2 1 0</td>
<td>X</td>
</tr>
</tbody>
</table>
Attitudes Not

Attitudes Degree of Consideration Not Applicable

h. withdrawal - "I don't wish to talk." 9 8 7 6 5 4 3 2 1 0 X

i. isolation - "Will someone talk to me honestly?" 9 8 7 6 5 4 3 2 1 0 X

j. unable to ascertain, (patient is confused, stuporous, etc.) 9 8 7 6 5 4 3 2 1 0 X

II. Please add to the above list any additional attitudes you feel figure into your discharge planning, and again circle the number that applies to each attitude.

k. __________________________ 9 8 7 6 5 4 3 2 1 0 X

l. __________________________ 9 8 7 6 5 4 3 2 1 0 X

m. __________________________ 9 8 7 6 5 4 3 2 1 0 X

n. __________________________ 9 8 7 6 5 4 3 2 1 0 X

III. For the above list of attitudes, including those you may have added, which three attitudes typically figure into your discharge planning? Please write the letters corresponding to the attitudes as shown above.

__________, ___________ and _________

2. What was the predominate attitude of your last terminally ill patient? Please select from the above list and write the letter corresponding to the attitudes as shown above.

__________

3. Did this patient go home or to an institution?

a. home ___________ b. institution ___________
Section I

I. Instructions: The following is a list of conditions that may characterize the financial situations of both the patient and family. How much do these conditions figure into your discharge planning? Please circle the number in both "Patient" and "Family" columns that applies to each condition.

<table>
<thead>
<tr>
<th>Conditions</th>
<th>Degree of Consideration</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. has medicaid</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
</tr>
<tr>
<td>b. has medicare and medicaid</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
</tr>
<tr>
<td>c. has medicare and private funds</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
</tr>
<tr>
<td>d. has private insurance and</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
</tr>
<tr>
<td>private funds</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
</tr>
<tr>
<td>e. medicaid eligible</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
</tr>
</tbody>
</table>

II. Please add to the above list any additional conditions you feel figure into your discharge planning, and again circle the number that applies to each condition.

<table>
<thead>
<tr>
<th></th>
<th>Patient</th>
<th>Family</th>
</tr>
</thead>
<tbody>
<tr>
<td>f</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
</tr>
<tr>
<td>g</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
</tr>
<tr>
<td>h</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
</tr>
<tr>
<td>i</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
<td>9 8 7 6 5 4 3 2 1 0 X</td>
</tr>
</tbody>
</table>
III. For the above list of conditions, including those you may have added, which three conditions typically figure into your discharge planning? Please write the letters corresponding to the conditions as shown above.

_____, _____, and _____

Section J. Instructions: The following is a list of factors that may be considered in your discharge planning for the terminal patient. Which three of these factors typically figure into your discharge planning? Please write the letters corresponding to the factors.

1. _____ 2. _____ 3. _____

Factors

a. timing of referral
b. lack of appropriate extended care beds
c. change in condition of the patient
d. limited cooperation of medical staff in necessary paperwork
e. patient's desire to go home
f. family's desire to have patient home
g. patient's attitude toward dying
h. the family's need for continuing psychological, social, economic and other support following patient discharge.
i. patient and family's financial resources
j. adaptability of patient's home environment to meet his needs
k. patient's need for continuing medical, nursing, rehabilitative, clinical, dietary care and transportation upon discharge
1. the social worker vis-a-vis hospital administration and medical staff

Section K Instructions: Please submit, along with this completed questionnaire, a copy of any forms used in formulating discharge plans for the terminal patient. Such forms may help discover the kinds of factors that figure into your discharge planning.

Thank you for your cooperation.
Medicare is a federally funded program, under Title XVIII, a 1965 amendment to the Social Security Act, which provides monies for the hospital and related health care costs of those persons over sixty-five and certain disabled persons under sixty-five. Two parts of Medicare—hospital insurance (Part A) and medical insurance (Part B)—combine to provide funds for inpatient hospital care, inpatient skilled nursing home care, and home health care by a licensed home health care agency (Part A), and doctors' fees, outpatient hospital services, outpatient physical and speech therapy, and other services and supplies (Part B). Medicare is not comprehensive in that the recipients are required to pay of the cost of the hospital and medical care. Persons with low incomes or high health care costs usually apply for Medicaid assistance to supplement Medicare. The service providers who participate in Medicare are in the following categories: hospitals; skilled nursing homes; home health agencies; ambulance companies; physicians; chiropractors; rehabilitation therapists; and podiatrists. Also covered by Medicare are facilities providing dialysis, kidney transplant, independent diagnostic and x-ray laboratories, and agencies providing outpatient physical and speech therapy.

The Omnibus Reconciliation Act of 1980 has significantly changed Medicare provisions relating to home health benefits. This new Act provides for the elimination of the 100 home health visits restriction, providing the patient is eligible for the "skilled" services under Medicare home care and the elimination of the three-day prior hospital stay requirements. Also, the Act eliminates the $60 deductible, under Part B, for home health benefits and recognizes the need for occupational therapy as a qualifying service for benefits. With regard to nursing home placement, the Act states that the Medicare period of covered services within which a beneficiary may be transferred after discharge from a hospital to a skilled nursing facility has been extended from 14 to 30 days.

Medicare coverage is severely limited for discharge plans to home or nursing homes. For a patient to be covered by Medicare at home, for a home health aide, occupational therapy, medical social work services, and medical supplies and equipment, he must be certified by his physician as needing the "skilled" services of
part-time registered nursing care and physical and speech therapy. Often the terminal patient does not need a registered nurse, since a trained nurse's aid or home health aide can attend to his personal hygiene and needs, which then makes him ineligible for all the rest of the services. In certain situations physicians will determine the patient's need for registered nursing on the basis of pain control, which enables the patient to benefit from Medicare coverage of the other services. But more often than not, terminal patients who return home must depend upon the family to pay privately for home health aides and rehabilitation. For those patients who are discharged to nursing homes, Medicare may not cover placement costs unless the need is for "skilled" care as opposed to "custodial" care. A terminal patient may be bedridden, incontinent, and unable to care for his needs in any way, and still be ineligible for Medicare coverage because he does not need the skilled nursing and other services noted above.
APPENDIX J

Current Missouri Medicaid Regulations Affecting Discharge Planning for the Terminal Patient and Family

Medicaid is a federal program, part of the Social Security Act of 1965, Title XIX, which provides grants to states for medical assistance to low income persons. The states are responsible for administering the programs. Eligibility involves low income, high medical costs in relation to income, and conditions of aged, blind or disabled and living on a limited income.

The state agency which administers and monitors the Medicaid program is the Division of Family Services in Jefferson City. Medicaid provides for the following services: inpatient hospitalization—maximum 21 days per hospital admission. When number of days runs out, Medicaid will settle with hospital at end of the year. Patient does not have to pay if they cannot. Also, covered: discharge medications; rehabilitation (PT, OT, Speech) inpatient; radiology; and blood bank, first three pints. Medicaid covers the following out-patient benefits: clinic visits, procedures and lab work, only if it is a Medicaid clinic; skilled nursing facilities; skilled nursing at home—does not cover home health aides; equipment and supplies in the home; medications; only PT is covered at home; only emergency ambulance to/from hospital. Also covered include optometric services, dental services and hearing aids.