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THE ADMISSION CHARACTERISTICS OF AND
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Ann M. Avery

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Barbara Given
Major professor

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THE ADMISSION CHARACTERISTICS OF AND CARE DELIVERED TO TERMINALLY ILL HOME HEALTH CARE CLIENTS

By

Ann M. Avery

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ABSTRACT

THE ADMISSION CHARACTERISTICS OF AND CARE DELIVERED TO TERMINALLY ILL HOME HEALTH CARE CLIENTS

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This descriptive study, using a researcher developed record audit tool, and utilizing a convenience sample of 33 clients from a non-hospice affiliated visiting nurse caseload, was undertaken to identify the admission characteristics of terminally ill clients at four and six weeks prior to death as well as to identify the care provided for these clients during the four to six weeks preceding death. Findings included an "average client" profile resembling the average hospice client profile found in the literature except for primary diagnosis. Clients were not in need of care requiring highly technical interventions but were frequently in need of assistance with many activities of daily living. The "average care" profile was client focused, frequently addressing physical needs. Because of the limitations imposed by the retrospective data collection process, findings must be considered with caution. Limitations of the study, recommendations for future research, and implications for nursing practice are presented.

To Roy, who, through example, taught me
the value of higher education.
To Bill, who understood my need to return to school
and who never wavered in his support and encouragement.
To Zak, who made me laugh at least once a day.

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Thank you also to all those associated with Visiting Nurse Service of Southern Michigan, Inc. for supporting this project. This agency's desire to examine patterns of practice and willingness to be openly reviewed was the stimulus behind this entire project.

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INTRODUCTION TO THE STUDY

Over the past 10 years, health care providers have increasingly utilized home health care services as an alternative to institutionally delivered health care services. Medicare costs for certified home health services increased from $1.5 billion in 1983 to $2.8 billion in 1989 for approximately 42.6 million home visits (GAO Report, 1989; Williams, Kornblatt, Torner & Irvine, 1990). According to the American Medical Association's Council of Scientific Affairs (1990), almost every treatment modality employed in the institution setting can now be provided in the home setting. Because of this attitudinal change, the home health care industry grew 20 percent per year over the five year period from 1985 to 1990 (Zanca, 1990) and the familiar phrase, "home quicker and sicker" was born.

Included among the clients who utilize home health care services are those experiencing terminal illness. Many of these individuals remain in a home setting throughout most, if not all, of their illness, being cared for by family members with the assistance of either a hospice program or a traditional skilled home health care agency (Hull, 1992; McCorkle, Benoliel, Donaldson, Georgiadou, Moinpour & Goodell, 1989; Mor & Masterson-Allen, 1990; Ramsay, 1992). Hospice program admission criteria are very specific and seem to indirectly characterize the client population most likely to utilize this type of home health care service (McDonnell, 1986; National Hospice Organization, 1990). The typical hospice client has accepted the physician's estimate of six months or less life expectancy and has chosen a comfort oriented rather than a curative treatment plan which addresses not only his physical and emotional needs but also the emotional needs of his family. Client needs and system resources seem to be congruent.

Less is known about the terminally ill client population which selects for care a non-hospice affiliated home health care provider. When clients enter this health care system of care, the care is focused on restoration of function (Department of Health and Human Services, 1989; Kramer, Shaughnessy, Bauman & Crisler, 1990) and is in conflict with dying, often resulting in highly technical care, futilely directed toward the cure or control of an end-stage disease. This type of seemingly incongruent client/system match may place demands on clients and their families which interfere with dignity in dying as well as being stressful for the professionals who witness client deterioration in spite of their interventions.

Given that this incongruity may exist, the purpose of this research is to describe the care and characteristics of the terminally ill visiting nurse service clients. The characteristics of the terminally ill clients who received services during the final four to six weeks of life from a non-hospice affiliated visiting nurse service in Southern Michigan, from July 1, 1990 through June 30, 1992, will be described as will the skilled home health care services provided for these clients. Through the use of a retrospective chart audit tool, sociodemographic information, functional abilities, technical care needs, utilization of multidisciplinary services, and referral to community resources will be examined. Information obtained by this researcher will provide the first step in assessing the goodness of fit between the non-hospice affiliated home health care system and the needs of the terminally ill client.

Definitions of Variables

Skilled Home Health Care Services

Skilled home health care services are home delivered services with eligibility criteria and service requirements outlined by the federal government. This type of service must be medically prescribed, nurse managed, of an intermittent nature and for a specified duration, available only to the homebound client for the purpose of restoring function and attaining maximum client independence through assessment, teaching and procedural interventions (American Nurses' Association Standards of Home Health Nursing Practice, 1986; Department of Health and Human Services, 1989). Nursing care, the cornerstone of skilled home health care, provides direct care, teaches self-care practices, monitors client progress, and is the designated coordinator of additional delegated services such as the intra-agency multidisciplinary services of physical and occupational therapy, speech therapy, medical social services, nutrition counseling, and other personnel, such as home health aides/home companions as well as referrals to other community resources (Caring, 1988; Johansen, Bowles & Haney, 1988).

Client

Client is defined as any individual served by the visiting nurse organization, who is 18 years of age with no upper age limit, male or female, and not limited by diagnosis.

Client Characteristics

Client characteristics are subdivided into predisposing, enabling, and need characteristics.

Predisposing characteristics are defined as the combination of pre-existing sociodemographic and belief characteristics. For the purpose of this study, the sociodemographic characteristics include: age, sex, marital status, race, place of residence (urban or rural), and primary diagnosis.

Enabling characteristics are defined as positive influencing factors which allow the individual to secure home health care services. For the purpose of this study, these include the availability of a primary caregiver and the availability of third-party health insurance coverage. Insurance coverage includes any government sponsored entitlement programs such as Medicare and Medicaid as well as any private payor sources.

Need characteristics are defined by functional ability, pain and symptoms experienced, and technical care requirements. Functional ability is defined by the activities of daily living which include bathing, dressing, toileting, grooming, transferring, feeding, and ambulating. Total independence, need for assistance, or total dependence in these activities are used to determine functional status and need for assistance.

Pain and symptoms experienced include the presence or absence of constipation, incontinence, an alteration in emotional state (such as anxiety, depression, or anger), a limitation in the ability to communicate or an altered state of alertness, limitation in endurance (easily fatigued), dyspnea or shortness of breath, anorexia, nausea, restless or agitation, and the presence of pain, either chronic or acute.

Technical care requirements, also known as the medical treatment plan, include such needs as total parenteral nutrition, intravenous hydration or antibiotic therapy, enteral nutrition which may include either nasogastric or gastric tube feedings, oxygen therapy, and wound or skin care procedures. Technical care requirements also include the need for the following medications: analgesics, anti-anxiety agents, antiemetics, and hypnotics. (Instrumental activities of daily living will not be included in this research since these activities were not consistently recorded in the agency record system prior to March of 1992.)

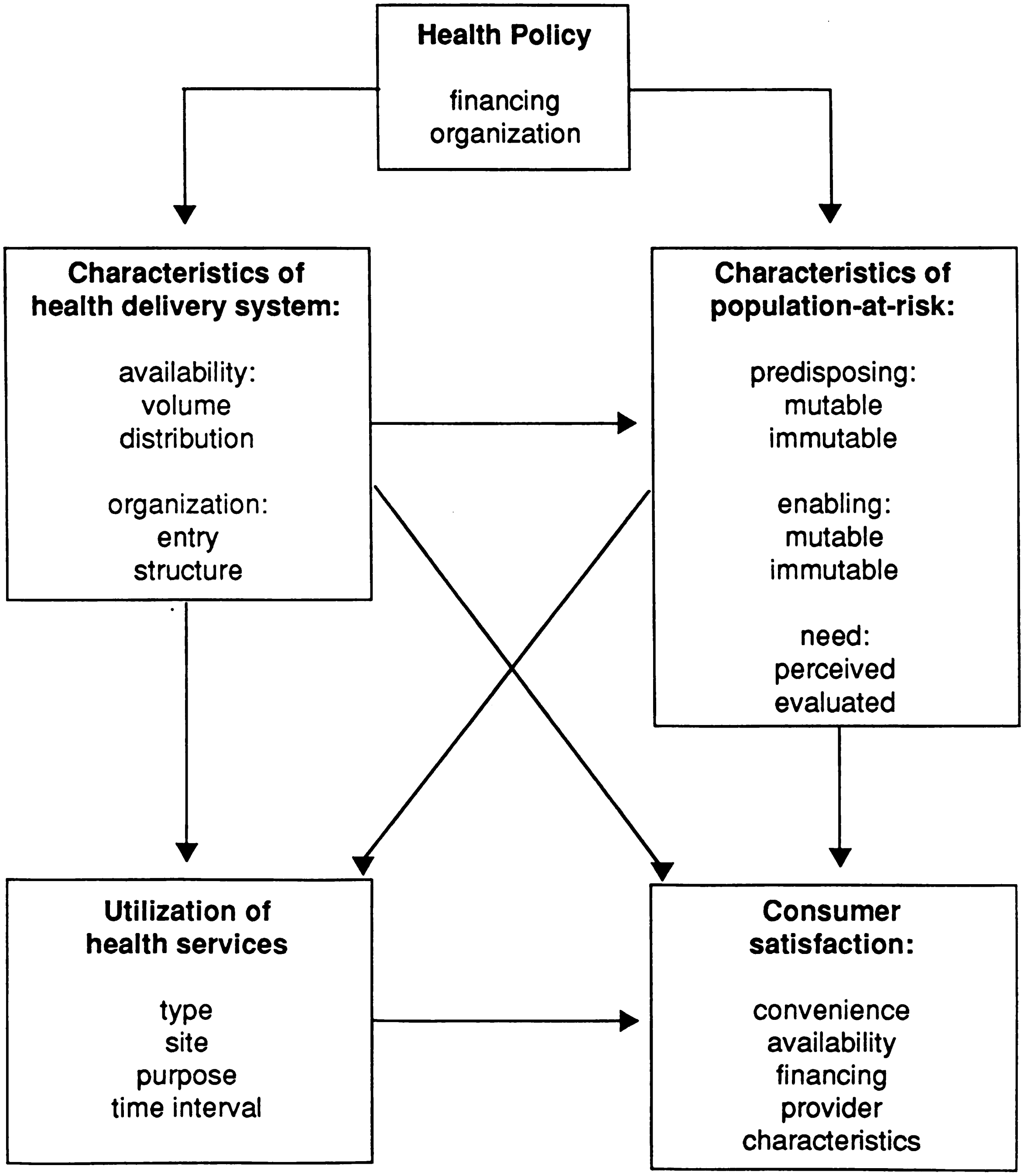
Terminal Illness

Terminal illness is, "A condition in which strategies directed toward cure and control of the disease alone, outside the context of symptom control, are no longer effective" (American Nurses Association Standards and Scope of Hospice Nursing Practice, 1987, p. 26). For the purpose of this research, the expected survival time for clients with terminal illness is defined as four to six weeks. This period of time was determined by counting backwards four to six weeks from the date of death recorded in the client record to the date of admission to the home health care service.

CONCEPTUAL FRAMEWORK

The Access to Medical Care Framework (see Figure 1) is a behavioral model developed to explain health care utilization and access (Aday, Fleming & Andersen, 1984; Aday, Sellers, & Andersen, 1985; Andersen & Aday, 1978). This model begins with health policy "as the starting point for measuring access" (Aday et al., 1985, p. 1), with health policy influencing both the health delivery system as well as the client population. The likelihood of entry into a given system of health care is dependent upon the influences of the structure of the health care system and the wants, needs, and resources of the individuals seeking

Figure 1. Framework for the Study of Access

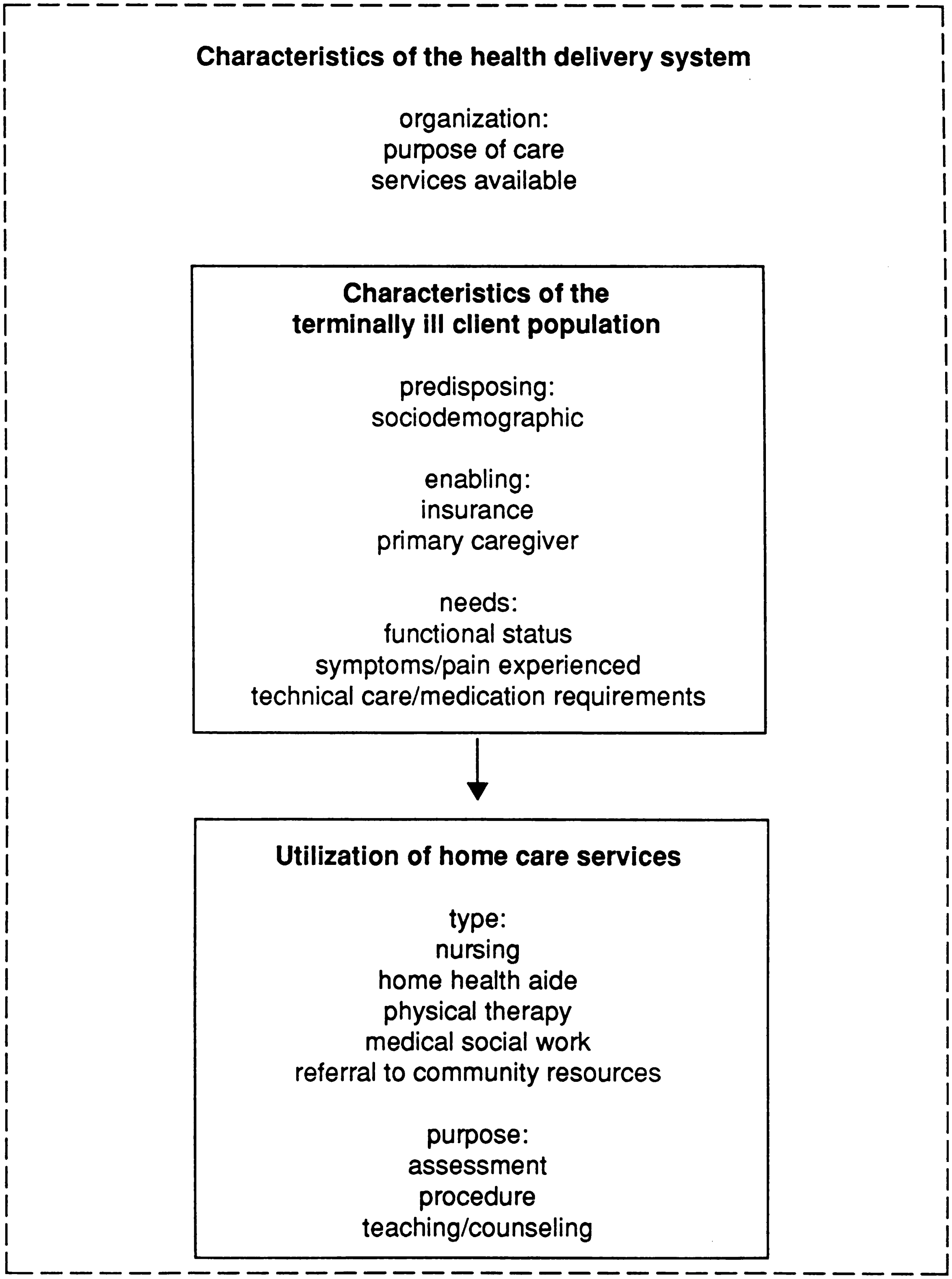


Aday, Fleming & Anderson. (1984). Access to Medical Care in the U.S.: Who has it, who doesn't. Chicago: Pluribus Press health care (Aday & Andersen, 1978; Aday et al., 1985). Actual utilization rates and reported satisfaction with services received provide the objective and subjective evidence that a system of health care has been accessed (Aday et al., 1984). Client satisfaction is also an indicator of the problems experienced in obtaining health care (Aday et al., 1985).

Since this researcher explored, within a given system of care, only the characteristics of a particular client population and the services delivered to that population, an adaptation of the Access to Medical Care Framework (see Figure 2) was used to structure data collection. This adapted model focuses only upon the client characteristics and service utilization variables contained within the original model (see Figure 1).

The Access to Medical Care Framework (see Figure 1) identifies as one of the characteristics of the health delivery system, organization, which refers to..."mechanisms of entry and movement throughout the system" (Aday et al., 1985, p. 2) and includes "what systems are established to handle the patient once entry is gained" (Aday et al., 1985, p. 3). Although the clients in this study had already accessed a system of care and this researcher did not attempt to measure any of the characteristics of the health care delivery system, the adapted model (see Figure 1) places the study variable within the environment of a specific health delivery system and recognizes the influences of that system upon the care provided. The health delivery system organization characteristic in the adapted study model (see Figure 2) recognizes the influences of the purpose of skilled home health care and the type of

Figure 2. Adaptation of Aday et al framework (1984) to the study.



intra-agency multidisplinary services available upon the care delivered to terminally ill clients.

The characteristics of the client population seeking care fall into three sub-groupings known as predisposing, enabling, and need categories which ultimately influence not only the volume of health services consumed but also consumer satisfaction with utilized services (Andersen & Aday, 1978). Predisposing factors include demographic and social characteristics of the population seeking health care as well as the populations' attitudes toward and perceptions of the need for health and medical care. Demographic and social data was examined however, other attitudes toward health and medical care were beyond the scope of this research.

Enabling factors include any factors which positively influence the ability of the individual to secure services and include individual, family, and community resources. The individual's income, the availability of health insurance, and the availability of health care providers are some examples of enabling factors. Again, because this researcher was focusing on clients who had already accessed a system of care, the enabling variable became less significant, however, information regarding the availability of a primary caregiver as well as insurance resources was included in the data collection process.

The third and perhaps most important variable affecting the characteristics of the population seeking health care services was the need variable. Need is based on both self perception as well as perceptions of health care providers (Aday et al., 1985). The individual's perception or evaluation of need is often influenced by the number of symptoms being experienced, by his/her "propensity to respond to symptoms or consider them serious" (Aday et al., 1985, p. 5), or by limitations in function (Aday et al., 1985). Health care providers may evaluate client need through observations and clinical procedures. For the purpose of this research, functional limitations (determined by activities of daily living), symptoms and pain history, and technical care requirements will provide a means for evaluating client need. Utilization of multidisciplinary intra-agency services and referral to community resources were assumed to be the result of client/health care provider agreement since there was no objective system available for assessing how the need for services was determined.

Although the model in Figure 2 outlines client characteristics leading to utilization of health care services, this researcher did not intend to provide a cause and effect relationship between these variables. Likewise, there was no attempt to measure either appropriateness or quality of the service delivered. The purpose of this exploratory research was purely to depict a summary of the data collected, data pertaining to one of the categories of variables that influence care delivered to terminally ill clients. No attempt, however, was made to address all variables influencing that care.

The predisposing, enabling, and need characteristics of the client population are categorized in the Access to Medical Care Framework as being either mutable or immutable, depending upon whether they can be altered to influence the distribution of health services (Andersen & Aday, 1978). The predisposing demographic or social variables such as age, race, place of residence are immutable while the enabling variables of income, insurance coverage, and source of medical care are mutable. Also, the need variable can be considered mutable since perceptions of illness can be altered. Although these are also very important concepts in the Access to Medical Care Framework, they do not have direct applicability to this researcher and therefore were not included in the theoretical framework.

LITERATURE REVIEW

Two themes exist in the literature regarding the needs of terminally ill home care clients. First, needs have been studied almost solely within the context of a hospice system of care, and second, identified needs are almost exclusively the product of research involving cancer and acquired immune deficiency (AIDS) patients (Benoliel, 1988; Etten & Kosberg, 1989; Hull, 1992; Lev, 1991; Moinpour, Polissar, Conrad, 1990; Mor & Masterson-Allen, 1988-90; Ramsay, 1992; Reuben, Mor & Hiris, 1988; Zelewsky & Birchfield, 1992). Eighty-four percent of those cared for by hospice organizations across this country have cancer related diagnoses (National Hospice Organization, 1990). Cancer and AIDS patients, in a hospice system of care, have identified as their most important needs the management of pain and symptoms as well as having available emotional support for the client and family. Terminally ill individuals being cared for in a hospice setting are in agreement with the hospice goal of providing comfort-oriented rather than treatment oriented care.

Absent from the literature are research findings which describe the seemingly incongruent relationship which may exist between the dying client and the restoration focused system of skilled home health care. Could there be confusion in this population of the dying role with the sick role (Mor & Masterson-Allen, 1990)? Are these clients influenced by the perceptions of their medical care providers who are unwilling to attend to the signs of irreversible decline and suggest a palliative

system of care (Mor & Masterson-Allen, 1990; Goetzler & Moskowitz, 1991; Reuben, Mor & Hiris, 1988)? Once in this system of care, are client perceptions further influenced by a professional staff which is skilled in highly technical acute and chronic care, (Hull, 1988) not recognizing the value of a "care-ative" rather than a "curative" treatment plan?

What is documented in the literature is that cardiovascular disease is the most frequent cause of death among medicare and elderly medicaid recipients (Johansen, Bowles & Haney, 1988; Riley, Lubitz, Prihoda & Rabey, 1987; Temkin-Greener, Meiners, Petty & Szydlowski, 1992) and that clients who utilize skilled home health care services do so most frequently because of needs associated with cardiovascular disease or cancer (Johansen et al., 1988; Williams et al., 1990). Also in the literature are reports that the "old old" medicare and medicaid recipients are more likely to receive supportive care during the last weeks of life, either through a nursing home or through home care services, than are the "young old" who more often are cared for in an acute care institution (Temkin-Greener et al., 1992). The degree of chronicity of the illness seems to influence treatment as well as treatment settings. A substantial number of the "old old" die without prolonged periods of acute illness which may be related to their frailty and inability to withstand and benefit from intensive treatment (Riley et al., 1987; Temkin-Greener et al., 1992). Given the above, can it be assumed that the terminally ill who receive service from a skilled home health care system are the very old who are experiencing end-stage cardiovascular or cancer related disease?

Expenditure of medicare benefits is greatest during the last year of life with the last 30 to 60 days of life resulting in the most expensive months of that year (Riley et al., 1987; Temkin-Greener et al., 1992). Much of this cost is related to in-patient hospital care. In an age when cost containment is such an extremely relevant issue, it seems reasonable to try and gain a better understanding of the home care needs of the terminally ill. Once those needs are identified, it may then be possible to develop intervention strategies which may increase the likelihood of a home death thus reducing the high cost of dying.

The recent growth in the skilled home health care industry has resulted in an increasing concern regarding the quality of services delivered by skilled home health care agencies (Kramer et al., 1990). The National League for Nursing (1989), through its Community Health Accreditation Program (CHAP), as well as the Health Care Financing Administration (HCFA) (1989), with its revision of agency survey guidelines, have brought attention to this concern. Without knowledge of the needs of the terminally ill client population which seeks care through this system, how can appropriate intervention strategies be developed or quality outcomes be achieved? Without this knowledge, how can agency staff development activities be planned or appropriate staff members be recruited?

Skilled home health care services are often seen as an extension of hospital delivered health care services, able to continue the provision of high technology services in the home setting once the client's condition has stabilized enough to warrant safe hospital discharge (Halamandaris, 1991). Most clients who require skilled home health care services are referred to that system of care upon discharge from an in-patient setting because of limitations in functional status coupled with the technical skill demand of their medical treatment plan (Department of Health and Human Services, 1989; Johansen et al., 1988.

Clients who are eligible for skilled home health care services are usually temporarily unable to seek care through an ambulatory care setting because of their limitations in function. Entry into this system of home health care provides the client with direct care services, education regarding self-care practices, assessment of changes in status, and a coordinated method of service delivery (Department of Health and Human Services, 1989). Skilled home health care service providers include nurses, physical, occupational, and speech therapists, nutritionists, medical social workers, and home health aides (Johansen et al., 1988). All service is focused on restoring the highest level of client independent function, is available for a limited period of time, and is delivered on an intermittent basis (Department of Health and Human Services, 1989).

Hospice home care services, like skilled home health care services, are coordinated, multidisciplinary services which may also utilize some highly technical methods of care. Hospice nurses, physical, occupational, and speech therapists, medical social workers, nutritionists, and home health aides, however, focus not on restoration of function but rather on enabling clients to maximize their diminishing functional abilities (Gentile & Fello, 1990; Ramsay, 1992). In addition to the service providers listed above, volunteers, chaplains, and bereavement counselors are included on the hospice multidisciplinary team (Gentile & Fello, 1990). Highly technical interventions may be used to care of hospice clients, but only for the purpose of controlling symptoms and relieving pain. The home care provided by a hospice organization is focused as much on the emotional support of the client and his family as it is on the medical treatment plan (National Hospice Organization, 1989) and, "medical intervention takes a back seat to nursing intervention" (Gentile & Fello, 1990, p. 3). Clients who choose this system of home care have completed all active and curative treatment, are aware of their diagnosis and prognosis and accept the goal of hospice care which is to provide comfort-oriented care to the entire family (ANA, 1987; Gentile & Fello, 1990; McDonnell, 1986; Mor & Masterson-Allen, 1990).

In summary, there seems to be information available regarding the needs of the traditional skilled home health care client, the client who, during a recovery period, usually post hospitalization, needs additional health care services delivered in the home. This "typical" client usually has a diagnosis related to cardiovascular disease, a new cancer diagnosis, or a diagnosis of chronic obstructive lung disease. There also seems to be information available regarding the needs of clients who are terminally ill, have chosen a palliative treatment plan, and are being cared for by a hospice home care provider. The majority of these clients usually have a diagnosis of terminal cancer. There is very little information, however, available regarding the needs of terminally ill home care clients who are not in a hospice system of care. The purpose of this research, then, was to answer the questions: during the last four to six weeks of life, a) what were the predisposing (sociodemographic), enabling (availability of a primary caregiver and insurance coverage), and need (limitations in activities of daily living, symptoms/pain experienced, and technical care requirements) characteristics of terminally ill clients who received services from a non-hospice affiliated home health care system, and b) what services were delivered to these clients?

METHODS

Design

The design for this study was a descriptive design since the variables under study had not been studied in this particular population (Brink & Wood, 1988). A non-random selection of records of deceased clients from one non-hospice affiliated home health care agency were reviewed using an audit tool developed by this researcher.

Operational Definitions of Variables

Skilled home health care services were measured in three categories: number of visits, purpose of visits, and referrals to community resources. Descriptive statistics were used in the statistical analysis.

1. The number of documented nursing, physical and occupational therapy, nutrition, medical social service, and home health aide visits were recorded (section 5 audit tool).
2. Services were categorized into assessment, procedure, or teaching/counseling categories and were recorded as such (section 7 audit tool). The frequency of each of these documented interventions was also recorded.
3. Documented record of community resource referrals included the following: meals on wheels, a member of the clergy, transportation service, chore services, respiratory therapist, bereavement/grief counseling, and hospice services (section 6 audit tool). Only the presence or absence of referral to these service providers was noted during the data collection process since no further information

regarding type, frequency, or outcomes of the interventions by these service providers was consistently recorded in the client record.

Client characteristics were measured in three categories: predisposing, enabling, and need characteristics.

1. Predisposing characteristics were measured by the documented sociodemographic data of age, sex, race, marital status, residence (urban or non-urban), and primary diagnosis (section 1 audit tool). Primary diagnosis information was collected to see if the terminally ill clients in this study tended to have the most frequent occurring diagnoses as identified in the literature for other home health care clients.
2. Enabling characteristics were measured by the documented presence of a primary caregiver and the relationship of that caregiver to the client. Documented presence of third-party insurance coverage was also recorded. If present, all types of coverage were included (section 1 audit tool).
3. Need characteristics were measured by documented functional status, symptoms and/or pain present, and technical care needs. Functional status (section 2 audit tool) was determined by activities of daily living (bathing, dressing, grooming, toileting, transferring, feeding, ambulating). The client was classified as being independent, needing assistance, or dependent in each of the seven activities of daily living, upon admission to the home health care service at four to six weeks prior to death. These activities of daily living were used to define client need because deterioration of functional status has been identified as an important clinical factor in estimating survival time (Reuben et al., 1988). Each of the seven activities were scored as

follows: independent = 0, needs assistance = 1, dependent = 2. (Missing data was coded as 9.) The frequencies of the scored values for each of the seven activities of daily living were used to identify which of these activities were most likely to be compromised and to what degree they were compromised (in need of assistance or totally dependent). A mean frequency score and standard deviation score provided information regarding average functional ability when all seven activities of daily living were combined, and a summary functional status score with a standard deviation was calculated by adding together the scores for all of the seven functional status categories (0 = independent, 1 = needs assistance, 2 = dependent). The summary functional status score allowed for relative placement of clients on the 0 to 14 scale of total independence to total dependence in all activities of daily living.

Instrumental activities of daily living such as house cleaning and shopping were not included since the consistent recording of this information did not occur until March of 1992.

The symptom/pain experience is important for two reasons. First, the reduction or relief of pain and other troubling symptoms has been identified as one of the greatest needs of terminally ill individuals and one of the most important goals of hospice care (National Hospice Organization, 1989). Second, symptoms such as shortness of breath, anorexia, and vomiting seem to have predictive value in estimating survival time (Reuben et al., 1988). Symptoms (section 3 audit tool) included alterations related to any of the following: elimination, emotional state, sleep patterns, alertness, or ability to communicate. Symptoms also included complaints of fatigue, dyspnea, anorexia, nausea, restless, agitation, and pain. Pain was included in the process of being scored as either present or absent since no distinction was made in the clinical records of the sample population as to whether the pain was of an acute or chronic nature. All of the above were identified as being either present or absent at four to six weeks prior to death and were scored as either: present = 1 or absent = 0. (Missing data was scored as 9.) Frequencies for each of the 11 symptoms listed above (which included pain) as well as a summary mean frequency score and standard deviation score were calculated by combining all symptoms into a new variable. A summary symptom score and standard deviation score was also calculated by adding the scores (0 = absent, 1 = present) for the 11 symptoms listed above. This provided information regarding the average number of symptoms experienced by this sample population.

The technical care needs (section 4 audit tool) of the client (also known as the medical treatment plan) was subdivided into two types of needs or categories. The first included the need for enteral or parenteral nutrition, oxygen, dressing changes, and intravenous hydration. The second type of need included medications which were classified as analgesics, anti-anxiety medications, antiemetics, hypnotics, and intravenous antibiotics. The presence or absence of any of these technical care needs, upon admission to the home care service, at four to six weeks prior to death, was recorded. Technical care needs were scored as: present = 1 or absent = 0. Frequencies of each need listed above provided information regarding the complexity of need in the average treatment plan. A technical care needs summary score and standard deviation score was calculated by adding the scores (0 = absent, 1 = present) for all five items listed under technical care

needs on the audit tool. This provided a numerical representation of the average number of needs represented in this study population. Likewise, a summary medication score and standard deviation score was calculated by adding the scores for each medication category (0 = absent, 1 = present) listed above. Again, this was used to identify the average number of medications need by the sample population.

Sample

The population for this study consisted of all adult clients, ages 18 years or older, with no upper age limit, male or female, not limited by diagnosis, third party reimbursement source, ability to pay, race, residence, referral source, or cognitive ability, who were admitted to the service four to six weeks prior to death and who received care throughout the final four to six weeks of life from a non-profit visiting nurse service in Southern Michigan, during the time period from July 1, 1990 through June 30, 1992. The final four to six weeks of life was determined by subtracting the date of admission to the visiting nurse caseload from the date of death recorded in the record. A sample of 33 client records represented the total number of records, out of 298 records of clients who died while on the visiting nurse caseload, which met the four to six week prior to death criteria.

The setting for this research was a non-hospice affiliated, private, non-profit, medicare certified, CHAP accredited visiting nurse service in Southern Michigan with a 35 year history of service. A full array of multidisciplinary services were available through employed staff. This moderate sized skilled home health care agency provided services to residents in both rural and urban areas.

Instrument

The chart audit tool (see Appendix A) was developed by this researcher and is a compilation of questions that resulted from a review of the literature, the chart audit tool contained in the Given and Given "Family Homecare for Cancer Patients", grant #PBR-32A (1989), and a visiting nurse agency quality assurance audit tool.

A pilot study was conducted to test for problems with the audit tool and some minor changes were made to delete questions for which there was no available data in the record system. Included in the deletions were instrumental activities of daily living, and questions which asked for whom the interventions were provided, client or family member, since the records reflected only client focused interventions.

Data Collection Procedure and Recording

A retrospective chart audit was conducted to collect all data pertinent to this study. A computerized listing of all the visiting nurse clients who died from July 1, 1990 through June 30, 1992 was obtained. From that list, only those clients who were admitted to the visiting nurse caseload four to six weeks prior to the recorded date of death were retained. This revised list, comprised the total study sample. Because of the narrative nature of the agency's record system, and in order to reduce the possibility of omissions in data collection, auditing was carried out only by the researcher. The entire clinical recorded was audited during the data collection procedure.

Validity and Reliability

Because of the descriptive nature of this research, validity was possible only at a very basic level (Brink & Wood, 1988). The chart audit tool was examined by three nursing researchers in order to establish face validity. The audit tool was developed after a review of the literature regarding the needs of terminally ill individuals and their families which established content validity.

To establish reliability of the chart audit tool, the tool was developed containing only mutually exclusive categories. Also, stability testing was carried out. Stability testing is important because it allows for comparison of results with repeated use of the tool or measurement instrument (Polit & Hungler, 1991). This researcher and a colleague, who is familiar with the record system of the home care agency from which the sample population was taken, audited the same client record. There was a .98 agreement on collection and coding of data.

Data Analysis

The SPSSX computer analysis program was used for the descriptive analysis of this research data. Descriptive statistics appropriate for nominal and ordinal data were used to determine frequency distributions, means, and percentages. Frequency tabulations of variables are depicted in tables. The missing data values of "9" were replaced with "0" in calculating summary scores and mean scores for functional status and symptom/pain experienced. There was no missing data in any of the other categories. Since this was a descriptive study, no attempt was made to correlate services to needs.

Protection of Human Subjects

Several methods were used to ensure the protection of human subjects in this study. A copy of the research proposal was shared with the president of the participating visiting nurse organization, and a letter of support for this research project was obtained. The chart audit tool had been reviewed by the president of the visiting nurse organization. Approval for this research project was obtained from the University Committee of Research Involving Human Subjects at Michigan State University. Client confidentiality was maintained since no names or client identification numbers were recorded during the chart auditing process, and only the researcher had access to the data. Likewise, only this researcher had access to information which identified attending physician names. Physicians were recorded only as being a primary care or specialty provider. The nature of this research was not considered to be embarrassing or intimate, and there were no inherent risks to the deceased sample population or to the visiting nurse staff. Any publication of research findings will include aggregate and not individual findings. Results of the research will be given to the visiting nurse organization from which the sample was taken.

Primary care providers who, by virtue of their position within the health care system, are often responsible for or asked to assist clients with the selection of additional health care resources. Although this research project focused on caring for terminally ill clients, the importance of linking any client with a system of care whose goals are congruent with client needs can not be overstated. It is hoped that information obtained as a result of this research will be of value to primary care providers in making those decisions.

RESULTS/FINDINGS

Description of Study Sample

The nonprobability convenience sample for this study consisted of 33 client records. The 33 record sample reflected the sum total of visiting nurse client records, out of an original list of 298 client cases, which met the study sample eligibility criteria of a documented admission data occurring four to six weeks prior to the date of death, and which contained documentation of care for the four to six weeks prior to death. A majority of the original list of 298 client cases reflected a date of death which occurred in less than four weeks after admission to the visiting nurse caseload.

A descriptive study was undertaken to identify client characteristics on admission to the skilled home health care caseload and to identify services provided to the study population throughout the four to six weeks preceding death. Frequency distributions, means and percentages are used to describe the previously listed variables. The "average" client in this study was an urban dwelling 74 year old Caucasian married female Medicare recipient with a diagnosis of cardiovascular disease and a female primary caregiver.

Research Questions

Question 1

The purpose of this research is to answer two questions, the first of which is: What are the predisposing, enabling, and need characteristics of terminally ill clients who received services from a non-hospice affiliated home health care agency?

Client Predisposing Characteristics. The predisposing, or sociodemographic, characteristics of the terminally ill population examined in this study included age, sex, marital status, race, urban or non-urban residence, and primary diagnosis (see Table 1). Subjects ranged in age from 50 to 93 years with a mean age of 74.4 years. The most frequently appearing age, however, was several years younger, at 66 years. The majority of the sample was female (n=19, 57.6%), Caucasian

Table 1

Client Characteristics

Characteristic (N=33)	N	(%)	Characteristic	N	(%)
Predisposing			**Enabling**		
Age ($\bar{X}$ 74 yrs. SD 9.06)			Primary Caregiver		
50-59	1	3	Wife	11	33
60-69	9	27	Husband	5	15
70-79	14	43	Child (female)	11	33
80-89	7	21	Other+	6	19
> 90	2	6			
			Insurance Coverage		
Sex			Medicare Only	10	30
Male	14	42	Medicare/Medicaid	2	6
Female	19	58	Commercial Only!	1	3
			Medicare/Commercial	20	61
Marital Status			None	0	0
Married	16	49			
Single*	1	3	Other		
Widowed	14	42	Do Not Resuscitate Status		
Divorced	2	6	Yes	12	36
			No	21	64
Race					
Caucasian	29	88	Attending Physician		
African-American	4	12	Family Practice/ Internal Medicine	17	51.5
Residence			Specialist	16	48.5
Urban	20	67			
Rural	13	33	Place of Death		
			Home	21	64
Primary Diagnosis			Hospital	12	36
Cardiovascular Disease	12	37	($\bar{X}$ 4 days SD 2.943)		
Cancer	10	30			
COPD	2	6			
Wound Infection	5	15			
Pneumonia	1	3			
Urinary Obstruction	1	3			
Dehydration	1	3			
Dysphagia	1	3			

+ includes self, significant other, sibling, adult foster care.
! includes all other insurance coverage except medicare and medicaid
* never married

(n=29, 87.9%), married (n=16, 48.5%), and resided in an urban setting (n=20, 66.7%). In the 33 records audited, cardiovascular disease was the most frequently listed primary diagnosis (n=12, 36.4%) followed by cancer (n=10, 30.3%). The third most frequently appearing diagnosis was listed as "infected wound" (n=5, 15.2%) and was related to either a surgical procedure or to a limitation in mobility. Other diagnoses included chronic obstructive lung disease (n=2, 6.1%), pneumonia, urinary obstruction, dehydration, and dysphagia, each occurring in one case and each representing 3 percent of the sample population.

In summary, the average client had the following predisposing characteristics: age of 74 years, married, Caucasian, female, residing in an urban area, and with a cardiovascular disease diagnosis.

<u>Client Enabling Characteristics</u>. The enabling client characteristics included the availability of a primary care provider and the availability of health insurance benefits (see Table 1). Even though the majority of the subjects in this study were married females, the majority of the primary caregivers were not husbands. Female primary caregivers represented 66.6 percent (n=22) of the primary caregivers, half of which were wives and the other half were daughters. The number of female primary caregivers may have been even greater than the above reported number, but the sex of those listed in the other four categories, self, significant other, sibling, and adult foster care provider, was not recorded during the data collection process. The most frequently appearing insurance coverage was a combination of Medicare and a secondary insurance (n=20, 60.6%), the secondary insurance being something other than Medicaid. All 33 records contained documentation of some type of health insurance coverage, and 97 percent (n=32) of the

records contained documentation of Medicare benefits either as the sole insurance benefit or in combination with other types of benefits. In summary, the average client had the following enabling characteristics: a female caregiver and a combination of medicare and some other insurance coverage, insurance other than medicaid.

Incidental Findings. Incidental findings included in the demographic data collection are as follows (see Table 1). A little over half of the 33 records contained documentation of care being provided by a primary care physician (n=17, 51.5%) with the other 48.5 percent (n=16) being cared for by a specialty physician. A "do not resuscitate order" was found in approximately one third (n=12, 36.4%) of the records, and the majority of records contained documentation that the client remained at home throughout the entire course of illness (n=21, 64%). Of those who died in the hospital (n=12, 36%), the mean stay was four days with a range of zero to 10 days.

Client Need Characteristics.

Functional Status in Activities of Daily Living

The need characteristics of the sample population, identified through activities of daily living, symptom/pain experienced, and technical care and medication requirements, are listed in Table 2, Table 3, and Table 4. These need characteristics were assessed only upon admission to the visiting nurse caseload with no subsequent re-evaluation of need being recorded. In the activities of daily living categories (see Table 2) of bathing, dressing, toileting, grooming, transferring, feeding, and ambulating, total independence was recorded in four records (12.1%) as was total dependence (n=4, 12.1%). The remaining 25 records (75.8%) reflected varying levels of independence,

Table 2

Client Functional Status in Activities of Daily Living

Activity	N	Independent n	(%)	Assistance n	(%)	Dependent n	(%)
Bathing	33	6	18	22	67	5	15
Dressing	33	8	24	20	61	5	15
Toileting	33	13	39	15	46	5	15
Grooming	33	8	24	20	61	5	15
Transferring	32	9	28	18	56	5	15
Feeding	32	14	44	13	41	5	15
Ambulating	33	8	24	20	61	5	15

mean = .866
Std. Dev. = .586

Table 3

Client Symptom/Pain Experience

Symptom	N	Present n	(%)
Limited Endurance	33	33	100
Dyspnea/Shortness of Breath	33	23	70
Anorexia	32	19	59
Nausea	32	3	9
Constipation	33	8	24
Incontinence	33	11	33
Alteration in Sleep Pattern (insomnia, "bad dreams")	33	20	100
Alteration in Emotional State (anxiety, anger, depression)	32	9	28
Restlessness/Agitation	33	3	9
Alteration in Alertness/Ability to Communicate	32	6	19
Pain	30	14	47

mean = .419
Std. Dev. = .149

Table 4

Client Technical Care/Medication Needs

Treatment/Medication (N=33)	Present n	(%)
TPN	0	0
IV Hydration	1	3
Enteral Nutrition	1	3
Oxygen	10	30
Wound or Skin Care	13	39
Medications		
Analgesic	19	58
Antianxiety	9	27
Antiemetic	1	3
Hypnotic	6	18
IV Antibiotic	0	0

Table 5

Client Needs

Category	$\bar{X}$	SD	Sum Scores (N=33) Mode &	Mode Frequency	(%)
Functional Status (Range .00 - 14.00)	6.00	4.09	7	11	33
Symptoms Experienced (Range 2.00 - 8.00)	4.52	1.62	3 & 5	10	33
Technical Care (Range .00 - 2.00)	.76	.66	1	17	52
Medications (Range .00 - 3.00)	1.06	.90	1	13	39

need for assistance, and dependence in these seven categories, however, one record had no documentation regarding transferring, and one record had no documentation regarding feeding. The combined activities of daily living functional status mean score was .866, with a standard deviation of 4.09 and a range of .00 to 14.00 (see Table 5). The majority of the sample population was in need of assistance with many activities of daily living.

Symptoms/Pain Experienced

The highest frequency of missing data occurred within this category of data collection. One record had no documentation regarding emotional status, three records had no documentation regarding ability to sleep, one record was missing documentation on alertness and ability to communicate, one record had no documentation regarding presence or absence of nausea, and one record had no documentation regarding the presence or absence of anorexia. The only symptom recorded in all 33 records (100%) was limited endurance. Other frequently occurring symptoms included dyspnea (n=23, 70%), anorexia (n=19, 59%), and pain n=20, 61%). The high frequency rate for altered sleep patterns (n=14, 47%) was an unexpected finding. Record documentation, however, only reflected assessment for this symptom in 30 records unlike the 32 to 33 records for all other symptoms. The mean symptom/pain experience was .419 with a standard deviation of .149 (see Table 3) and a range of .182 to .727, and the mean summary score was 4.52 with a standard deviation of 1.62 and a range of 2.00 to 8.00 (see Table 5).

Technical Care and Medications

The technical care and medication needs of the sample population are listed in Table 4. The most frequently occurring technical care needs were the need for oxygen (n=10, 30%) and the need for some type of wound care (n=13, 39%). The relatively high incidence of wound care was an unexpected finding, and was considerably higher (24% higher) than the recorded primary diagnosis of "infected wound". Enteral nutrition and intravenous fluids were each documented in only one client record (3% each) and total parental nutrition was not documented in any record. Over half of the 33 record documented need for analgesic medications (n=19, 58%), 27 percent of the records documented need for anti-anxiety medications (n=9), hypnotic medications were documented as being necessary in 18 percent (n=6) of the records, antiemetic medications in 3 percent (n=1) of the records, and intravenous antibiotics were never documented in the sample records. The mean technical care needs summary score was .76 with a range of .00 to 2.00, and the mean medication summary score was 1.06 with a range of .00 to 3.00 (see Table 5). The terminally ill clients in this study were in need of very few interventions which were labeled as technical care requirements, nor did they require complex medical regimes.

Question 2

The second research question is: What services were delivered to the terminally ill clients? The skilled care interventions were documented as being provided by three out of five possible disciplines and by home health aides. There was documentation that nursing visits were made to all 33 clients (100%), medical social work visits were made to only a small percentage of the clients (n=5, 15%), and physical therapy visits were rarely made (n=3, 9%). There was no documentation of direct care provided by nutrition or by occupational therapy, however, three records (9%) contained documentation of consultation with the nutritionist regarding the symptom of anorexia. Home health aide services were documented in less than half (n=14, 42%) of the 33 records while 88 percent (n=29) of the client records contained documentation of need for at least assistance with activities of daily living.

A summary of home visits by discipline is listed in Table 6. The large variation in the number of nursing visits, with a mean of 14.27 and a standard deviation of 9.66, as well as the combined discipline visits with a mean of 20.18 and a standard deviation of 15.42. Part of this variability can probably be explained by the fact that one record out of the 33 audited contained documentation of twice a day visits for four weeks. When the twice a day visit case was removed from the data, the mean for nursing visits became 12.84 with a standard deviation of 2.77, and the combined discipline visit mean became 18.44 with a standard deviation of 11.91.

Skilled care interventions were divided into four categories: 1) assessment, 2) procedures, 3) teaching/counseling, and 4) referral to community resources (see Table 7). Documented assessment activities most commonly focused on either the client's general physical status (n=33, 100%) or on the client's physical comfort (n=27, 82%). Documentation of fatigue in the primary care provider was assessed for in only a few instances (n=6, 18%). There was no documentation of assessment for conflict among family members or emotional upset in family members, and the emotional status of the client, when documented, was done so only during the admission visit.

Wound care was the most commonly documented procedure (n=15, 46%), followed by insertion of a feeding tube or foley catheter (n=12, 36%). Central venous access line care was documented in only two (6%) of the

Table 6

Home Visits

			Clients visited	
Visits (N=33)	X	SD	n	(%)
Visits by Discipline Nursing (Range 5.00 - 60.00)	14.27	9.66	33	100
Home Health Aide (Range 1.00 - 34.00)	5.21	8.86	14	42
Physical Therapy (Range 2.00 - 10.00)	.52	1.94	3	9
Medical Social Work (Range 1.00 - 2.00)	.18	.47	5	15
Nutrition (Range .00 - .00)	.00	.00	0	0
Occupational Therapy (Range .00 - .00)	.00	.00	0	0
Combined Discipline Visits (Range 5.00 - 76.00)	20.18	15.42		

Table 7

Skilled Care Interventions

(N=33) Intervention	n	%		n	%
Assessment			Procedures		
Physical Status	33	100	Skin/Wound Care	15	46
Pain	27	82	Central line care	2	6
Fatigue in PCG	6	18	Administer IV Antibiotics	0	0
Emotional Upset Client/Family	0	0	Administer IV Fluids	1	3
Conflict in Family	0	0	Administer TPN	0	0
			Insertion/Care of Feeding Tube/Foley	12	36
			Administer Medication for Symptom/Pain Control	1	3
Teaching/Counseling			Community Referrals		
Emergency Plan	28	85	Home Delivered Meals	3	9
Responses to Illness	0	0	Clergy	0	0
Disease Progression	10	30	Transportation Service	0	0
Signs of Discomfort	4	12	Chore Services	3	9
Medication Management of Symptoms/Pain	12	36	Respiratory Therapist	0	0
Signs of Impending Death	4	12	Bereavement/Grief Counseling Services	2	6
Concerns About Death Event and Arrangements Thereof	3	9	Suggested Hospice	4	12

33 sample records and only one (3%) of the 33 sample records contained documentation of either intravenous fluids or need for the nurse to administer medications for the control of symptoms and pain. There was no documentation of any client requiring the administration of total parenteral nutrition or intravenous antibiotics.

The most frequently documented teaching activity involved the development of an emergency plan (n=28, 85%) which also happens to be an activity required by Medicare regulations. The remainder of the teaching/counseling activities listed on the record audit tool related to the physical comfort and emotional care of the dying individual and his/her family. The documentation of these interventions was found in the 33 sample records much less than 50 percent of the time and occurred in the following descending order: teaching regarding medication management of symptoms/pain was documented in 36 percent of the sample records, teaching regarding the expected progression of the client's disease was documented in 30 percent (n=10) of the sample records, signs of discomfort and signs of impending death was documented in 12 percent (n=4) of the sample records, and concerns about the death event and arrangements thereafter were documented in 9 percent (n=3) of the sample records. None of the records contained documentation of teaching or counseling activities regarding the normal responses of individuals to illness.

Referrals to other community service providers was found to be minimal. Documented referral to a home delivered meal program and to chore service programs was found in 9 percent (n=3) of the 33 sample records, 6 percent (n=2) contained documentation of referral to community bereavement counseling programs, but there was no documentation of referrals to a member of the clergy, to a respiratory therapist, or for transportation services. Documentation of suggested referral to a local hospice organization was found in 12 percent (n=4) of the sample records. Explanations as to why this referral did not occur was not recorded during the record audit procedure.

INTERPRETATION OF FINDINGS WITH RESPECT TO CONCEPTUAL FRAMEWORK, LITERATURE, AND METHODS

The adaptation of the Access to Medical Care Framework (Aday et al., 1984) used in this study was helpful in describing the characteristics of the terminally ill client population cared for by the visiting nurse organization as well as describing the services utilized by the terminally ill client population. This adapted framework also allowed for the recognition of the influences of a given health delivery system on the care provided for a specific client population. In developing the adapted conceptual model used in this study, however, the beliefs of clients regarding their health status and client perceptions of what type of care was most appropriate for them, variables in the Aday et al. Framework for the Study of Access (1984) (Figure 1), had to be deleted due to the retrospective nature of this research.

Organization characteristics

The characteristics of the organization outlined in Figure 2 include the purpose of care and the services available for clients. The purpose of care in the non-hospice affiliated home health care agency, from which the sample population was taken, is to restore function. Although not specifically addressed in questions on the record audit tool, this researcher, in auditing the sample records, noted documentation of this purpose, even when the subjective and objective client data supported a

deteriorating physical condition. The often occurring symptom of anorexia was addressed by three day diet logs and strategies for increasing caloric intake. Those with reported limitations in endurance were often instructed to gradually increase daily activity in order to increase strength.

The visiting nurse agency had available the multidisciplinary professional services of nursing, medical social work, physical, occupational, speech therapy, and nutrition services as well as the paraprofessional services of home health aides. It was, therefore, not because of limitations in service providers that services were not available to the sample population.

Client characteristics

The characteristics of the terminally ill clients who entered this system of care were described in terms of predisposing, enabling, and need characteristics. The predisposing, or sociodemographic, characteristics of the terminally ill clients who were cared for by the visiting nurse organization are contained in Table 1. In looking at primary diagnoses, it is apparent that those documented in this study population are a mixture of traditional medical diagnoses as well as symptoms. The clients in this study, with traditional medical diagnoses, resemble those discussed in other skilled home health care research findings (Kramer et al., 1990; Rile et al., 1987; Temkin-Greener et al., 1992; Williams et al., 1990). As found in the literature, the most commonly appearing diagnosis was cardiovascular disease (n-12, 37%), followed by cancer (n=10, 30%). The third most frequently cited reason for referral, however, differed from the literature findings and was for management of an "infected wound" (n=5, 15%), three of the five cases being secondary to surgical procedures and two being infected decubitus ulcers. Chronic obstructive pulmonary disease (COPD) was listed as the third most frequently appearing diagnosis for skilled home health care services but accounted for only 6 percent (n=2) of the documented diagnoses in this study.

In the predisposing characteristic of age, however, the clients in this study began to look more like hospice clients. The "typical" skilled home care client has been classified as the "old old" client with an age greater than 74 years (Temkin-Greener et al., 1992) while the "typical" home care hospice client is usually in the mid to upper sixties (Carney & Burns, 1992; Moinpour et al., 1990; Mor & Masterson-Allen, 1988; Ramsay, 1992). Over 50 percent (n=18) of the sample population was 74 years or below with the most frequently appearing age of 66 (n=4, 12%).

In the remaining predisposing characteristics, both skilled home health care clients and hospice clients seem to share the same characteristics identified in this study. Just over half (n=19, 58%) of the clients in this study were female, the large majority were Caucasian (n=29, 88%), married (n=16, 49%), and resided in an urban area (n=20, 67%).

The enabling characteristics, according to Aday (1985), that were included in this study were the availability of a primary caregiver and the availability of health insurance. All but two of the sample records audited (n=31, 94%) had someone other than self listed as the primary caregiver. The two who did not have a primary caregiver were clients who were hospitalized at the time of death. It is very difficult to maintain a functionally compromised person in the home environment without some type of caregiver assistance. The availability of a primary caregiver, for clients who are not totally independent, is a requirement for either admission to or continuation of home care through either a skilled home health care or hospice agency. The predominance of female caregivers (n=22, 66%) found in this study is not unlike the research findings in the literature for hospice clients (Carney & Burns, 1991; Mor & Masterson-Allen, 1988; Ramsay, 1992).

All sample records in this study had documentation of insurance benefits with Medicare being the most frequently encountered benefit (n=32, 97%). This is also a common finding in those who received skilled home health care services (Temkin-Greener et al., 1992). Even those with Medicaid coverage (n=2, 6%) had Medicare as a primary insurance. This Medicare benefit would, however, have supplied benefits for either the skilled home health care service utilized by the study sample or for hospice care services.

The need characteristics of the terminally ill study population is based on both self perception and the perceptions of health care providers (Aday et al., 1985). The "typical" client need profile in this study demonstrated a client who was functionally in need of a significant amount of assistance with activities of daily living, who was most often experiencing limitations in endurance, shortness of breath, anorexia, and pain, and who was not receiving highly technical and "curative" focused medical treatment. The "typical" client in this study closely resembled the "typical" hospice client identified in the literature (Carney & Burns, 1991; Mor & Masterson-Allen, 1988; Ramsay, 1992).

Due to the retrospective nature of this research, the client's perception of his/her health status is only open to speculation. Did the sample population choose care from a restorative focused health care system because they did not perceive their condition as being terminal? Did this sample population not know that other needs, those of an emotional or spiritual origin, were legitimate health care needs that could have been addressed? Or were, perhaps, these clients not given a part in deciding who would be the most appropriate service provider for them at this particular stage of their disease process?

Health care providers also influence client perception of need (Aday et al., 1985). Again, because of the retrospective nature of this study, impressions can only be based on documentation contained in the sample records. The health care providers in this study provided relatively high intensity, primarily nursing interventions which focused on the physical needs of the clients, interventions that are appropriate for a non-hospice focused system of home health care (Kramer et al., 1990). With this type of focus, again one could speculate that the client's perception of his/her health status could have been influenced by the actions of the health care system. It may have been because of the actions of the health care professionals that the clients in this study continued to pursue a "curative" treatment plan in spite of a continually deteriorating physical condition.

Utilization of Health Care Services

The care delivered to the sample population, as previously stated, was primarily nursing delivered and focused upon meeting physical needs. The high frequency of nursing care is not surprising since all clients must require the care of either nursing or physical therapy in order to meet skilled care eligibility criteria outlined by Medicare regulations. What is surprising is the infrequent involvement by medical social work (n=5, 15%) especially since very few nursing interventions documented strategies for providing emotional support. Medical social work interventions are a Medicare benefit, and social work interventions are considered appropriate for the terminally ill. Also, emotional support has been identified as a great need for not only the terminally ill client but also for families experiencing terminal illness (Benoliel, 1988; Hull, 1992; Lev, 1991; Mor & Masterson-Allen, 1990).

Referral to emotionally supportive community resources such as bereavement counseling services was documented in only 6 percent (n=2) of the 33 sample records, and referral to members of the clergy was never documented (see Table 7). It is unclear, however, whether these interventions, as well as the suggestion of a social work referral were suggested and refused since that information was not included in the data collection process.

Although physical therapy interventions were minimal (n=3, 9%), it should not automatically be assumed that this was a positive finding. Physical therapy services can be utilized in teaching caregivers how to safely transfer or assist the dependent family member in ambulating thus reducing the risk of injury not only to the client but also to the caregiver.

The use of home health aide services in less than half of the sample population (n=14, 42%) was also surprising. Many of the sample records contained documentation of limitations in activities of daily living with some type of assistance being required in bathing (n=27, 82%), grooming (n=25, 76%), dressing (n=25, 76%), and ambulating (n=25, 76%).

Sixty-one percent of the sample population (n=20) had pain documented at the time of the admission visit, yet only 58 percent (n=19) of these clients received pain medication. Relief of pain is a prime concern of terminally ill individuals and family members (American Nurse, 1992; ANA, 1987; Gentile & Fello, 1990; McCormack, Hunter-Smith, Piotrowski, Grant, Kubik, & Kessel, 1992) and management of pain is one of the primary goals in hospice care (National Hospice Organization, 1989).

The "goodness of fit" between a system of health care and the characteristics of the client, in this research situation, may be questionable. The characteristics of the clients, except for diagnosis categories, although all were experiencing the end-stage of their individual conditions, presented a profile which mirrors those of hospice clients (Carney & Barnes, 1991; Mor & Masterson-Allen, 1988). These clients were not in need of highly technical treatment, yet the skilled care interventions provided for these clients focused generally on meeting some type of physical care need and rarely focused on emotionally supportive interventions. Interventions were focused only upon the terminally ill client and not on the client's family.

The general population seems to recognize the existence of terminal illness with a diagnosis of cancer. Could it be that either the client population or the health care system or perhaps both have more difficulty recognizing terminal status with a diagnosis other than cancer? Did the services meet the needs of the terminally ill clients? That can not be determined from this descriptive study. What was determined, however, was that a system of care, obviously focused on restoration of physical function, provided care to a client population which was rapidly, as a result of end-stage disease, approaching death. The characteristics of the system of care seemed to be incongruent with the characteristic of the client population, and the services utilized by this client population seemed to be incongruent with their need characteristics.

DISCUSSION

Limitations

Several limitations in this study can be linked to the retrospective nature of the study design. The retrospective record audit process allowed only for the collection of previously recorded data, data recorded by multiple persons. This obviously had the potential for not only reducing consistency in documentation but also for limiting the data collection process. An example of the limitations imposed on the data collection process was evident in the fact that there was a lack of consistent ongoing documentation of client need characteristics which restricted data collection to admission assessment documentation only. Care, however, was documented over the entire course of illness. This limitation prohibited any attempt to relate the process of care to client needs. Also, because of the retrospective nature of this study, this researcher had to assume that if something was not written it did not occur.

The non-random and very small sample in this study was also a limitation. Because of this, generalization becomes impossible. Also, missing data posed a more significant problem with interpretation since the small sample size negated the possibility of deleting records with missing data. Familiarity with the agency from which the data was collected provided this researcher with some insight not obvious in the data collected. Often times, only positive or abnormal findings are recorded in client records. the fact that a symptom or the ability to perform an activity of daily living was not documented in the record may have been because that symptom was not present or that a limitation in a particular activity of daily living did not exist.

Another limitation in the study was the fact that relative weights were not assigned to the individual items included in the activities of daily living. Therefore, it became impossible to give meaning to the true nature of functional limitation. Only the number of limitations could be identified.

Absent from the audit tool were prompts that would have included information on whether services, not a part of the plan of care, had been suggested but had been refused. This type of information may have been helpful in describing the limited involvement of home health aides with clients who required assistance with activities of daily living as well as the very limited utilization of medical social work interventions. One could speculate that, perhaps, the limited utilization of home health aides and medical social work services was tied to the lack of consistent, ongoing assessment of functional status. If client functional status is formally assessed only upon admission to the home health care caseload, as required by the documentation system of the home health care agency in this study, then deteriorating status would probably follow a more insidious course occurring gradually over several weeks time. When no formal system of assessment is in place to periodically reassess function, the need for home health aide or medical social work services would be less apparent.

The admission documentation of pain in 20 records (61%) and the documentation of analgesic medication in only 19 records (58%) as well as the ongoing assessment documentation for pain in only 27 (82%) of the 33 sample records was a very disturbing finding to this researcher. Pain, the most feared symptom in those either directly or indirectly experiencing a terminal diagnosis (Ferrell, Cohen, Rhiner & Rozek, 1991), and the symptom for which there are many treatment modalities (Foley, 1991; McCormack et al., 1992; US Department of Health and Human Services, 1992), seemed to be under-addressed in this population. One could speculate that, once again, if pain did not exist, then no documentation of assessment was made, however, that does not explain the one record with documented pain on admission which contained no documented management plan.

What became very evident during the data collection process was that the documentation of assessment, procedure, and teaching interventions most often included only those interventions known to be reimbursable Medicare services. It may be possible that many of the interventions listed in the record audit tool, especially those which addressed emotional needs, were carried out but not documented. If this is true, however, and reimbursement is driving documentation, then there is a serious problem occurring. The majority of the interventions in this study were the result of nursing care. If the interventions that support the social, emotional, and spiritual spheres of man, (all of which are included in the scope of practice for home health nursing practice (ANA, 1992)), were indeed being provided but not valued enough by the nurses providing them to be documented in the client record, nursing will never receive recognition or reimbursement for its very valuable and needed contributions to health care. This lack of documentation will also prevent the health care system from knowing if the interventions provided by nurses truly make a difference in client outcomes. Given the above, one could ask, is professionalism being over run by reimbursement requirements?

Another finding which suggests professionalism being over run by reimbursement requirements was noted in the relative frequency with which altered sleep patterns occurred in the sample population and the relative infrequency with which care related to non-physical needs was provided. Fourteen out of 30 of the terminally ill clients (47%) experienced alterations in sleep patterns described as either insomnia or "bad dreams". Although this is not an uncommon finding in terminally ill clients, the cause is often non-physical in nature and can be addressed through interventions focused on the social, emotional, and spiritual needs of the client. The interventions recorded for these terminally ill clients, however, demonstrated few interventions which may have addressed non-physical needs. Documentation of discussion of disease progression was documented in 30 percent (n=10) of the records, discussion of signs of impending death was documented in 12 percent (n=4) of the records, and discussion regarding concerns about the death event was documented in 9 percent (n=3) records.

Perhaps the most incongruent finding in this study was that non-technically dependent but functionally limited terminally ill clients were cared for by a system organized to provide highly technical interventions focused on restoration of function. In an attempt to understand or explain this obvious incongruity, it may be helpful to again look at the Aday et al (1984) framework in Figure 1. Because of the retrospective nature of this study, several variables from the Aday et al (1984) framework had to be deleted from the conceptual framework adapted for use in this study (see Figure 2). Three of these deleted variables, however, may be especially important in understanding this seemingly incongruent situation. The first variable is health policy, the driving force behind health care. Skilled home health care services are covered benefits for Medicare and Medicaid recipients and are easily accessed with a physician order for service. Respite care or chore services are not covered benefits for Medicare or Medicaid recipients and usually are very scarce community resources.

Other possible influencing variables (see Figure 1) include the beliefs of clients regarding "the salience or severity of certain symptoms or disease states (Aday et al., 1985, p.4) and the perceived and evaluated client need characteristics. According to Aday et al (1984), the need for health care is defined by the individual's perception of his/her health status which is also influenced by the evaluation of that need by health care providers. Again, because of the retrospective nature of this research project, these variables could not be measured.

Although only supposition, if what is known about the influence of health policy is combined with what is suspected about client beliefs and perceived and evaluated client need characteristics, an explanation may be found for the seemingly incongruent client/system match found in this study. If the terminal status of the clients in this study was either not recognized by the clients' physicians or was not discussed with the clients because of physician discomfort, the clients' beliefs and perceptions regarding their health status may not have included the possibility of death in four to six weeks. One could further suppose that this may be why so few clients (36%) had requested a "do not resuscitate" status and why the clients accepted a referral to a non-hospice type of home health care. These clients could have entered the skilled system of home care because access was relatively easy and included little client financial responsibility while other home care assistance, such as respite or chore services, was not readily available and could have been quite costly. Once within the skilled system, the clients received the type of care for which reimbursement is authorized. This may also explain why anorexic clients were asked to keep three day diet logs and encouraged to eat high calorie foods and why those with diminishing endurance were encouraged to gradually increase activity. This could also explain why so many clients received some type of wound care, often times when there was no admission diagnosis relating to any type of wound or skin problem. Wound care, however, is often a reimbursable reason for making skilled home care visits.

Implications of Results for Existing Literature

The research findings in the literature which relate to skilled home health care are very limited and seem to focus on the delivery of technically sophisticated and restorative focused health care services. Research findings relating to the home care of terminally ill individuals seem to be the result of studies involving only those with a terminal cancer diagnosis being cared for by a hospice organization. Most of the information available in the literature does not address the needs of terminally ill clients who are experiencing end-stage disease from causes other than cancer.

SUMMARY

This research project draws attention to the fact that non-hospice focused home health care service providers are caring for terminally ill clients, many of whom do not have cancer diagnoses. A description of a relatively uninvestigated population has been provided and several questions for future research have been posed.

Implications for Advanced Nursing Practice and Primary Care

Since 51.5 percent of the physicians caring for clients in this study were family practitioners, there are many implications for primary care and the primary care Clinical Nurse Specialist. One of the most basic and significant implications for primary care providers is that all client/system matches require "goodness of fit". One of the desired outcomes of primary care is that care needed is care delivered. The goals of care must be congruent with the needs of the client. Prior to referral to any community or health care resource, primary care providers should not only assess client/family needs but also assess the goals of care of the potential referral resource. The Clinical Nurse Specialist in primary care occupies a very unique position within the health care system. Because of a theory based practice which addresses the holistic nature of the client and family, the Clinical Nurse Specialist is well prepared to demonstrate for clients, family members, and other primary care providers, the importance of, as well as how to assess for an appropriate client/system match prior to any request for care. The assessment of client characteristics, as was carried out in this research project, is one way of identifying client needs so that an appropriate service provider can be suggested to meet those needs. After care is instituted, the Clinical Nurse Specialist can demonstrate the importance of continuing the assessment for an ongoing congruent fit between the needs of the client and the goals of care. Again, attention to client characteristics will provide the information needed to assess the goodness of fit between client need and service delivered. If, over time, client needs change and the system providing care can no longer meet those needs, it is the responsibility of the primary care provider to assist the client/family in recognizing and rectifying this problem.

The Clinical Nurse Specialist can indirectly assist families experiencing terminal illness by contributing to the knowledge and comfort levels of other health care providers who care for those experiencing terminal illness. Sharing information, either formally, through educational programs, or informally, through collegial discussion and behavior modeling, the Clinical Nurse Specialist can assist other primary care providers in becoming more knowledgeable and thus, hopefully, more comfortable in recognizing terminal status, using functional limitations rather than diagnostic categories as indicators of longevity, and in communicating this status to clients and their families.

As an educator, the Clinical Nurse Specialist can provide inservice education programs to home care agency staff members focusing on the unique needs of clients and family members experiencing terminal illness. The need for education regarding pain assessment and management techniques were obvious in this study. The very limited supportive nursing care, medical social work interventions, referrals to bereavement programs, and the absence of any referrals to members of the clergy found in this research project may be related to a lack of knowledge, on the part of home care staff members, of the importance of such emotionally supportive interventions for families experiencing terminal illness. Assessment for fatigue in the primary caregivers in this study was documented in very few records, yet without a primary caregiver, home care can rarely be a health care option. Also, less than half of the clients in this study received home health aide services even though client functional abilities were limited at the time of admission to care and deteriorated over the four to six weeks preceding death. Home health aide interventions could have helped relieve some of the burden of caregiving for the primary caregiver.

The Clinical Nurse Specialist can also develop for home are agencies criteria for terminal versus curative home care. Such criteria would provide more concrete guidance for agency staff members and would assist in the process of tailoring the goals of care to meet client/family needs. With the goals of care tailored to meet those needs, not only will appropriate care be delivered, but staff members providing that care will no longer be experiencing the frustration of trying to restore function in cases where that goal can never be achieved.

In the face of deteriorating status, the home health care nurse may be the most appropriate person to discuss with clients/families the possibility of a resulting poor prognosis. Home health care nurses often develop very trusting relationships with clients and their families in relatively short periods of time, relationships in which the client/family often view the nurse as being an expert in planning for their health care needs. Once home health care is instituted, clients often have relatively little direct contact with physicians. It is often the home health care nurse who reports changes in client status to the physician and who suggests changes in treatment plans based on their assessments. The Clinical Nurse Specialist can assist home health care nurses in recognizing not only the importance but also the appropriateness of identifying terminal status and facilitating a change in the treatment plan which reflects interventions best suited to meet the needs of a terminally ill client and his/her family. As a consultant, the Clinical Nurse Specialist might suggest a modification in the documentation system which requires assessment of functional status at each visit. Use of such a prompting system would provide a more consistent method of assessing client status over time and would hopefully prompt re-evaluation of treatment plans as change occurred.

As a consultant to a home health care agency, the Clinical Nurse Specialist can assist the agency in recognizing the need for and developing a supportive network for those who provide care for the terminally ill. Once feelings of loss are legitimized for staff as well as for clients and families, this process can often be achieved by utilizing the services of staff social workers through a system of individual and staff meetings.

As a researcher, the Clinical Nurse Specialist can continue the process of adding to what is now known as the needs and care of those experiencing terminal illness. The value of intervention strategies currently being utilized and further exploration of family needs could be addressed through the use of focus groups or questionnaires sent to surviving family members.

The Clinical Nurse Specialist can play an important role in counseling and supporting families who are presented with a terminal diagnosis. Through a continual process of clarifying client and family perceptions of the client's health status, families may be supported in mobilizing resources and coping with death. The Clinical Nurse Specialist can act as an advocate by familiarizing the client and family with available community resources. As the client's physical condition weakens, referrals to home delivered meal programs, to chore service programs, to services which assist with the personal care needs of the client, or to respite care services for the relief of family caregiver stress may be helpful to the family. The Clinical Nurse Specialist can educate the client/family regarding the pros and cons of a "curative" verses a "carative" approach to care. If the client/family have chosen a palliative treatment plan, then supportive services such as hospice care may be appropriate. Facilitating the utilization of the most appropriate community resource is well within the scope of practice of the Clinical Nurse Specialist.

A client referred to a hospice or other home care agency still requires the services of the primary care Clinical Nurse Specialist. As the client's condition deteriorates, it becomes even more important for the Clinical Nurse Specialist to be involved in coordinating care, particularly since the Clinical Nurse Specialist in primary care has a previously developed relationship with the client and the family and will continue to intervene with surviving family members, even after the death of the client, through bereavement counseling.

Ongoing communication, initiated by the Clinical Nurse Specialist, with home care providers could facilitate the coordination of care which is vitally important to the delivery of primary care. In this study, 61 percent of the clients experienced pain yet only 58 percent had analgesic medication prescribed. Care coordinated by a Clinical Nurse Specialist could have prevented such an occurrence. Home visits made by the Clinical Nurse Specialist would provide an opportunity for the assessment of the physical as well as the psychosocial well-being of both the client and the family. Ongoing teaching in the home regarding the course the disease may follow, methods for managing symptoms, available community resources, and possible responses of family members to loss are just a few of the very important issues that the Clinical Nurse Specialist is well prepared to discuss with the family experiencing the last few weeks of life.

The Clinical Nurse Specialist who cares for those experiencing terminal illness is very privileged. Assisting such clients and families in achieving an optimum level of functioning while coping with one of life's most significant events is one of the very important contributions nurses in advanced practice can make to health care.

Recommendations for Future Research

This research project, because of the retrospective design, provided a very limited description of terminally ill clients and the care they received within this non-hospice focused system of home health care. If, in future research projects, the data of interest has little potential for change over time, if the researcher is sure the data was recorded in a consistent manner, or if the researcher is interested in events which occurred at only one point in time, this type of design may be satisfactory, otherwise caution is advised.

The adequacy of the care provided by the non-hospice skilled home health care agency was not addressed but very much deserves attention in future research. Especially now, with the recent growth in the home health care industry, attention must be paid to not only the way in which care is provided but also to the outcomes experienced by clients and their families. Future studies, using a prospective study design will allow for a more controlled examination of patterns of care and will allow for the measurement of client/family outcomes. A prospective study design would allow for an ongoing assessment of client needs at specified intervals using some type of consistent measurement technique, it would allow the assignment of weights to activities of daily living, it would allow for a consistent type of documentation, and it would allow for correlational analysis to test if interventions met client needs. With a population like the one in this study, a prospective study would provide a means for determining if client symptoms/pain were managed, if clients/families felt their need for support was met, if clients/families felt needed information was provided, and if clients/families felt they were equal partners in decisions made regarding care provided. A prospective study design would also allow for the exploration of client/family perceptions or beliefs and a comparison of care provided in light of those beliefs.

Also tied to the recent expansion of the home health care industry are concerns relating not only the level of clinical expertise but also to the level of comfort of home health care agency staff members involved in providing care to terminally ill clients. An appropriate client/system match can not occur if health care providers are ill prepared or uncomfortable in caring for those with terminal illness. Research comparing the level of knowledge of non-hospice home health care staff members with those who practice within a hospice focused organization regarding the needs of terminally ill clients and family members may provide valuable information for the non-hospice focused home care agency that can be applied to inservice education programs as well as to recruiting efforts.

Although not necessarily a reliable indicator of quality in care, client/family satisfaction studies do provide valuable information. Knowing how satisfied family members were with the care they received during a terminal illness experience as well as knowing what types of interventions resulted in that satisfaction could benefit health care providers in planning care for other terminally ill clients and their families. Research which examines not only client satisfaction with care delivered but also investigates what other interventions families feel would have improved their ability to provide home care for a dying family member would also be an extremely valuable addition to the current body of knowledge regarding this population.

A descriptive study of the characteristics of skilled home health care clients experiencing end-stage disease who were referred to a hospice home care by a skilled home health care agency would provide an opportunity for comparison of those characteristics to the characteristics of clients who remained, until death, in the care of a non-hospice system of home care. If there are differences in needs between these two groups of clients, are the differences apparent at the time of admission to a system of home care, are client needs or family expectations different between these two populations of clients, or are, perhaps, these referrals to hospice care more likely to occur simply as a function of primary nurse assignment?

Although the descriptive results from this non-randomized study sample are not generalizable or directly applicable to nursing practice, they do raise the level of consciousness regarding the needs of terminally ill clients and their families and how important it is to match the service capabilities of a provider to the needs of the client and family. These descriptive findings have also generated many more researchable questions, questions which do have the potential for direct applicability to advanced nursing practice and primary care and to improving the delivery of care to terminally ill client and their families.

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APPENDIX A

Audit Tool

RETROSPECTIVE CHART AUDIT TOOL
TERMINAL CARE STUDY

1. IDENTIFYING DATA

SEX
☐ MALE ☐ FEMALE

DOB
☐☐☐☐☐☐☐☐ AGE: ____________

RACE
☐ B ☐ C ☐ O

MARTIAL STATUS
☐ M ☐ S ☐ W ☐ D ☐ SE

COUNTY OF RESIDENCE
☐ CALHOUN ☐ BRANCH ☐ HILLSDALE
☐ ST. JOSEPH ☐ BARRY ☐ EATON
☐ JACKSON ☐ ZIP CODE: ____________

PRIMARY CAREGIVER
☐ SELF ☐ HUSBAND ☐ WIFE
☐ PARENT ☐ SIG. OTHER ☐ SIBLING
☐ CHILD ☐ OTHER: ____________ (Specify)

PHYSICIAN
☐ PRIMARY CARE PHYSICIAN ☐ SPECIALIST

INSURANCE COVERAGE – (CHECK ALL THAT APPLY)
☐ MEDICARE ☐ MEDICAID
☐ COMMERCIAL ☐ NONE (SELF PAY)

PRIMARY DIAGNOSIS (SPECIFY): ____________

IS THERE A "DNR" ORDER IN RECORD?
☐ YES ☐ NO

2. FUNCTIONAL STATUS ON ADMISSION	INDEP	ASSIST	DEPEND
BATHING			
DRESSING			
TOILETING			
GROOMING			
TRANSFERRING			
FEEDING			
AMBULATION			

3. SYMPTOMS / PAIN ON ADMISSION	Y	N
ALTERATION IN ELIMINATION		
CONSTIPATION		
INCONTINENCE		
ALTERATION IN EMOTIONAL STATE (i.e. anxiety, depression, anger)		
ALTERATION IN SLEEP PATTERNS (i.e. insomnia, "bad dreams")		
LIMITATIONS IN ALERTNESS, ABILITY TO COMMUNICATE		
ENDURANCE – Limited (Fatigue)		
DYSPNEA/SOB		
ANOREXIA		
NAUSEA		
RESTLESSNESS/AGITATION		
PAIN		
ACUTE		
CHRONIC		

4. TECHNICAL CARE NEEDS ON ADMISSION (Medical Treatment Plan)	Y	N
TPN		
IV HYDRATION		
ENTERAL NUTRITION		
OXYGEN		
WOUND/SKIN CARE		
MEDICATIONS		
ANALGESICS		
ANTI-ANXIETY MEDICATIONS		
ANTIEMETICS		
HYPNOTICS		
IV ANTIBIOTICS		

5. MULTIDISCIPLINARY CARE	Y	N	TOTAL # OF VISITS
NURSING			
HOME HEALTH AIDE			
NUTRITION			
PHYSICAL THERAPY			
OCCUPATIONAL THERAPY			

6. VNS REFERRALS TO COMMUNITY RESOURCES	Y	N
MEALS ON WHEELS		
CLERGY		
TRANSPORTATION		
CHORE SERVICES		
RESPIRATORY THERAPIST		
BEREAVEMENT/GRIEF COUNSELING		
HOSPICE REFERRAL SUGGESTED		

7. SERVICES PROVIDED	Y	N
ASSESSMENT		
PATIENT PHYSICAL STATUS		
PATIENT PHYSICAL COMFORT		
EXTREME FATIGUE IN PRIMARY CAREGIVER		
EMOTIONAL UPSET OF PATIENT AND/OR FAMILY		
CONFLICT/DIFFERENCES OF OPINION AMONG FAMILY MEMBERS		
PROCEDURES/TECHNICAL ACTIVITIES		
WOUND/ SKIN CARE		
CENTRAL LINE CARE		
ADMINISTRATION OF ANTIBIOTICS (IV)		
ADMINISTRATION OF FLUIDS (IV)		
ADMINISTRATION OF TPN		
INSERTION AND/OR CARE OF ENTERAL FEEDING TUBE/FOLEY CATH		
ADMINISTRATION OF MEDICATIONS TO MANAGE PAIN/SYMPTOMS		
TEACHING/COUNSELING		
EMERGENCY PLAN – WHAT TO DO – WHO TO CALL – WHAT TO REPORT		
RESPONSES TO ILLNESS AND/OR LOSS (i.e. depression, fear, grief)		
DISEASE PROGRESSION, SYMPTOMS, COMPLICATIONS, AND PROGNOSIS		
SIGNS OF DISCOMFORT/PAIN		
MEDICATION ADMINISTRATION FOR PAIN AND/ OR SYMPTOM MANAGEMENT		
SIGNS OF IMPENDING DEATH		
DISCUSSION OF CONCERNS ABOUT DEATH AND ARRANGEMENTS THEREOF, INCLUDING FUNERAL		

04-30-93/AA

APPENDIX B

VNSSM Letter of Support

VISITING NURSE SERVICES

311 East Michigan Avenue, Suite 200
Battle Creek, Michigan 49017-4939

of Southern Michigan, Inc.

March 5, 1993

Ann Avery, RN
320 North Madison
Marshall, MI 49068

Dear Ann:

This letter will serve as official notification that you have my permission and the support of the VNS Board to participate with Michigan State in research at VNS. Your actions here will be covered under the new VNS Research Policy recently adopted by our Board of Directors. Your completed application form was reviewed and approved by the VNSSM Board Executive Committee. You may audit clinical records as part of your project.

I am pleased that you have chosen to take this retrospective audit on as part of your Master's work. I am confident that VNS will benefit by your work. Please let me know what further information you might need before the work begins.

Sincerely yours,

Sally Whitten, RN, MPH
President

SW:blk

CHAP Accredited
(616) 962-0303 Battle Creek
(517) 279-7550 Coldwater
(517) 629-8100 Albion
1-800-622-9822 Toll-Free
(616) 962-8810 FAX
United Way Ag

APPENDIX C

UCRIHS Approval

MICHIGAN STATE UNIVERSITY

OFFICE OF VICE PRESIDENT FOR RESEARCH
AND DEAN OF THE GRADUATE SCHOOL

EAST LANSING • MICHIGAN • 48824-1046

March 30, 1993

TO: Ann M. Avery
320 N. Madison
Marshall, MI 49068

RE: **IRB #:** 93-135
TITLE: NEEDS AND HOME HEALTH CARE SERVICES OF TERMINALLY ILL CLIENTS
CATEGORY: 1-E
REVISION REQUESTED: N/A
APPROVAL DATE: March 29, 1993

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project including any revision listed above.

UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must seek updated certification. Request for renewed approval must be accompanied by all four of the following mandatory assurances.

1. The human subjects protocol is the same as in previous studies.
2. There have been no ill effects suffered by the subjects due to their participation in the study.
3. There have been no complaints by the subjects or their representatives related to their participation in the study.
4. There has not been a change in the research environment nor new information which would indicate greater risk to human subjects than that assumed when the protocol was initially reviewed and approved.

There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.

UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. Investigators must notify UCRIHS promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

If we can be of any future help, please do not hesitate to contact us at (517) 355-2180 or FAX (517) 336-1171.

Sincerely,

David E. Wright

David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

cc: Dr. Barbara Given