THE CUSTODIAL PATIENT: A SURVEY OF FORTY-SEVEN PERSONS DENIED HOME NURSING SERVICES BY MEDICARE

by

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ABSTRACT

This descriptive study answered the question, "As described by elderly patients or their families, how are nursing care needs being met three and one-half years after termination of professional home nursing care?" utilizing the framework of social adaptation relative to age, health status, living arrangements, and cognitive ability.

Forty-seven elderly patients comprised the total population designated "custodial" by Medicare and denied reimbursement for professional home nursing services. Of the 47, seven were not found and 21 had died, half within 18 months, two dying the day after discharge. The study population of 18 patients or their families responded to a questionnaire in a private interview three and one-half years later.

Literature findings revealed minimal response from legislative, community, and professional groups to needs of these elderly persons. Interview findings revealed that patient needs were met through personally-formed resources rather than organized community resources. Current perceived home nursing needs indicated acceptance of a lower level of existence than was desired.

Replication is recommended utilizing measurement of social adaptation response, comparing male and female response, and comparing adaptation based on marital status. A parallel research investigating the adaptive response of those persons who died in the interim was also recommended.

CHAPTER 1

INTRODUCTION

The Constitution of the World Health Organization (1974, p. 1) declares:

> Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest-attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.

This absolute state of health is rarely realized, however. This is particularly true in the aging person. Well over 75 percent of the population aged 65 or over suffers from at least one chronic condition, and about 50 percent of them report two or more (Moore 1968). The National Center for Health Statistics (United States Department of Health, Education and Welfare [HEW] 1971, p. 38) reported that of persons of all incomes in the 65-74 age bracket, 20.2 percent had a major health limitation. These limitations apparently increased with age, as 26.1 percent of the population over 75 were reported as having major disabilities.

In 1970, 9.4 percent of the United States population, or about 20 million persons, were aged 65 or over. This number was projected to approximately 26 million by 1980 (Rose and Peterson 1965). The 1970 census of Tucson, Arizona, revealed that 10.3 percent of the population, or 35,752 persons were over 65 and that this was expected to increase to over 38,000 by June of 1972.

When, therefore, complete health is unattainable or cannot be attained in the near future, as is frequently the case with the elderly, the role of the nurse is to promote all aspects of health, normal development, and normal living that are attainable. Home nursing services, in particular, enable older people to leave hospitals sooner as well as allowing them to remain at home longer before institutionalization (Butler and Lewis 1973).

In the spring of 1970, the Visiting Nurse Association of Tucson, Arizona, was obliged to discontinue professional home nursing services to 47 of its Medicare patients in compliance with a Social Security ruling which excluded Medicare payment for patients who could not be rehabilitated and were thus labeled "custodial." The nurses who had been providing home care were no longer able to contribute to the health planning and maintenance for these 47 elderly persons.

Loss of professional home nursing services forced modification of the method of handling the long-term needs of these patients upon their families or caretakers, as well as upon themselves. This paper will attempt to explore (1) factors affecting the social adaptation of these elderly persons and (2) manifestations of their social adaptation to this forced change.

Statement of the Problem

This descriptive study was designed to answer the question, "As described by elderly patients of their families, how are nursing care needs being met three and one-half years after termination of professional home nursing care?"

Significance of the Problem

Social adaptation does not occur in a void. Warren (1966, p. 533) sees man as part of a social community in which the satisfaction of biological necessities, sustenance, and protection are considered internal functions. Additionally, a system for accommodation to change is inherently built into community life (Sanders 1963).

An even smaller community in which man functions is the family unit. This community is dynamic in that its structure incorporates persistence in the arrangement of persons relative to one another, members frequently act together in common concerns of life, and there is provision for orderly change when needs are identified (Warren 1966).

An important consideration when changes are introduced into the health system is that the health needs of the recipients do not change, only the method of delivery varies. Therefore, the removal of a specific control of a function from the community, such as funding for professional home nursing services, disrupted the equilibrium, leading groups or individuals to strive to reach a new and stable balance.

Theoretical Framework

The theoretical framework of this descriptive study is based on the work of Rene Dubos in the field of social adaptability. Social adaptability implies a modification to suit new conditions and embodies the changing of one's self so that one's behavior or attitudes will conform to the new circumstances.

Dubos (1965, pp. 256, 261, 271) stated that adaptability is the one attribute that most clearly distinguishes life from inanimate matter.

Living organisms do not submit passively to the impact of environmental changes, but rather respond with expressive behavior. In the process of social adaptation following an environmental change, individuals or groups modify the environment or their habits to achieve a way of life suited to their needs. The ability to adapt is unique to man and remains an indispensable condition of survival.

A phenomenon of man, however, contended Dubos (1965) is that adaptability is often manifested as a passive acceptance of conditions which are not desirable. For the sake of peace or tranquility, the lowest common denominator of existence frequently becomes the accepted criterion. "The ideal environment tends to become one in which man is physically comfortable, but progressively forgets the values that constitute the unique qualities of human life" (Dubos 1965, p. 279).

Social adaptability cannot be considered without acknowledging some of the forces affecting it. Variables considered here are age, health, living arrangements, and cognitive ability.

Change occurs rapidly in our present world of advanced technology and easy mobility. Wolff (1959, pp. 83-84) reported that while the aging must also face these changes, aging in itself brings new problems of adjustment along with a decreasing ability to adjust.

As reported by Pihlblad and McNamara (1965, pp. 58-73), in a pilot study, social adjustment declined in the elderly when a major health condition was present. When the condition limited mobility, adjustment was scored even lower. Wessen (1965, p. 260) declared that when a person required "long-term" health care, that is when care is

necessitated longer than 30 days, and rehabilitation or recovery is not anticipated, the elderly person often feels hopeless and isolated, thus decreasing his social contacts. Rose (1965, pp. 7-8) claimed that aging persons with physical limitations desire a physically easy and calm existence.

Likewise, Kutner et al. (1956, pp. 46, 47, 158), in reporting on the elderly person's ability to adapt found that indifference, acceptance, resignation, or apathy persisted in what he considered a shield against the frustrations and limitations imposed by illness. He further speculated that adaptation required some form of energy to meet the stress of change. However, personal circumstances, such as chronic illness, may prevent the generation of such needed energy. In support of this, from Selye's experiments with stress, came the hypothesis that a form of energy is necessary for adaptive work and that this energy is exhausted by stress (Shock 1960).

Living arrangements had strong impact on social adaptability for both men and women included in a study by Pihlblad and McNamara (1965, p. 60). Those persons living with someone other than family members scored in the lowest adjustment category.

Shock (1960, p. 312) observed that aging is accompanied by a slowing of perception and response while Gaitz (1972, pp. 5-12) suggested that cognitive competence and memory in the elderly decline and that ill health may be a large factor in this decline. Shock (1960, p. 313), continued, " . . . adaptation implies that the individual be able to attend to many simultaneous aspects of his environment and also

to relate this information to a wide spectrum of past and anticipated future events."

We see, therefore, that while social adaptation may be manifested as passive acceptance of a lesser quality of life, such an acceptance is affected by the age, health, living arrangements, and cognitive ability of the recipient of the environmental change.

The preceding theory of social adaptability offers a basis for examining the response of a population of elderly persons whose health care was affected by a decision in which they had no voice. The researcher looks at the factors of age, health, living arrangements and cognitive ability as they contributed to the change in behavior and attitudes in the social adaptation of a study population three and one-half years following the discontinuation of professional home nursing services.

Definition of Terms

For the purpose of this descriptive study, the following terms are defined.

1. Custodial (maintenance) patient: patients who require care to prevent regression to a former state of ill health or who cannot function in daily living or care for their own personal needs.
2. Elderly or aged: persons aged 65 or over.
3. Medicare: a federally funded health system established in 1965 which utilizes Social Security funds to provide a health care system for those aged 65 or over.

4. Professional home nursing services: services prescribed by a physician and administered to patients in the home setting by a registered nurse on a fee-for-service basis.
5. Social adaptation: the changing of one's self so that one's behavior or attitudes will conform to new or changed circumstances.
6. Health status: health described within the limitations of medical diagnosis, length of time the patient received home nursing care and the type of services received.
7. Cognitive ability: perception for the medical reason and type of services rendered by the visiting nurse.

Limitations of the Study

The initial population of 47 persons was identified from the Tucson Visiting Nurse Association records as being ineligible for further home nursing services following a decision by the administrators of Medicare. This decision terminated payment for visits to patients who by definition could not be rehabilitated. Since the study was undertaken three and one-half years following the discharge of these 47 persons, death and relocation had taken a large toll of the potential interviewees. Twenty-one of the patients were deceased, seven were not located, and one was unable to give an interview, leaving only 18 patients or their families to participate in the study interview.

Assumptions

Two assumptions were made prior to the institution of this descriptive study.

1. The 47 persons or their immediate caretakers were unable or unwilling to pay the $12.00 per home visit fee, the standard charge in 1970 for a visiting nurse contact.
2. The needs of these persons were still existent even though professional home nursing services were no longer available to them except on a private fee basis.

CHAPTER 2

REVIEW OF THE LITERATURE

In reviewing the literature over the past three and one-half years pertaining to social adaptation of the elderly, there was found a paucity of printed material. A search of Applied Science and Technology Index, Reader's Guide to Periodical Literature, and Social Sciences and Humanities Index from 1970 to 1973, the Cumulative Index to Nursing Literature from 1969 to 1973, and the Cumulated Index Medicus from 1970 to 1973 failed to reveal a single study which considered the adaptation of the custodial elderly to loss of professional home nursing services. Articles were looked for under the headings "adaptation," "aged," "home health services," "Medicare," "old age," and "social adjustment."

In view of the lack of material oriented to the patient response, the review of literature was directed toward those responses from the legislative, local, and professional communities as they addressed themselves to the plight of the elderly custodial patient. The first paragraphs of this section make reference to the events leading up to the mandate which produced the necessity of social adaptation in the population studied.

The Medicare Mandate

The largest and most expansive Federally funded health care program for the aged since 1965 has been Medicare. The Medicare system

provides for hospitalization, outpatient services in physician's offices, institutionalization, and some home services for its subscribers. From a July 1969 report, one of the frequently utilized services, that of skilled home nursing care, was provided by 15,152 professional nurses employed in home health agencies (Butler and Lewis 1973). The Tucson Visiting Nurse Association served 101 patients receiving reimbursement by Medicare in January 1970.

The dignity and needs of recipients of monies from Federal funding were often ignored in the struggle for and juggling of revenue receipts on the national level. In 1970 Medicare became a victim of politics and those who fared worst were the chronically ill aged. Section 1861(h) of the Social Security Act provided for extended care to patients rendered by or under the supervision of a registered professional nurse for needs on a continuing basis for which the patient had received hospital services [Section 1814(a)]. However, Section 1862 (a)(9) denied payment for expenses for custodial care (U.S. Government 1970). According to a spokesman for the Social Security Office, the providers of benefits had been quite lenient in interpreting this code until 1970 when it was found that monies were insufficient to meet anticipated expenditures. Section 1862(a)(9) came under scrutiny and health providers were notified that benefits would no longer be forthcoming for home nursing care for custodial patients.

By April of 1970, the Tucson Visiting Nurse Association, in compliance with the Social Security Act ruling,discharged from care those patients who were receiving maintenance or custodial services

unless they were able to pay for these services on a private fee basis. Maintenance patients were described by the Visiting Nurse Association as persons who required care to prevent regression to a former state which initially led to institutionalization. Custodial patients were those aged persons or victims of catastrophic disease who could not function in daily living or care for their personal needs. Included were patients with chronic disease or those requiring long-term care, terms frequently used interchangeably since the disease was not self-limiting and the condition was irreversible (Wessen 1965).

Of the 101 patients receiving services from the Visiting Nurse Association, 58 or 57.3 percent were designated as custodial and were given the option of paying for their own care or being discharged. In April 1970, 47 patients were notified they would no longer be receiving home nursing services.

Legislative Response

"From birth, man is part of society. He remains part of it until his death, and his old age is an integral part of his life" (Graz 1972, p. 23). If man is part of society, then he reaps the benefits of that society . . . unless he is aged and chronically ill. The White House Conference on Aging (U.S. Government 1971, p. 107) attacked this very problem with specific recommendations. Recommendation 5 reads:

> It is recommended that a national policy on long-term care needs must have mechanisms for being implemented and financed; that supplementary sources are needed to be allocated to means of financing alternate care; that this is a reason for low

> standards of care in many long-term care institutions; that we need a change in national priorities to human needs; and that we call upon the government to change our national priorities, shifting some of our resources from defense, foreign assistance, and space priorities to the needs of our elderly citizens to implement a national policy on long-term care.

The Ninety-second Congress of the United States on May 10, June 14, and September 20, 1971, held hearings in California and Rhode Island on the cutbacks in Medicare and Medicaid coverage. Throughout the more than 300 pages of transcript, the topics of home care services, custodial care, and the chronically ill patient were presented infrequently. A member of the Association of Home Health Agencies protested strongly the categorization of patients as "custodial" (U.S. Senate 1971-1972, pp. 269-270). In another response, Dr. P. Joseph Pesare (in U.S. Senate 1971-1972, p. 336), in a written statement, listed nine examples of the rejection of requests for professional home nursing services because the patients were considered custodial.

The Senate hearings were used as a route for presentation of current programs, grievances, and recommendations for improvement of health care for the aged. They did not represent any implementation of a program to alter the existing state of affairs.

Three and one-half years following the Medicare ruling, the acknowledgment of a problem in long-term care for the elderly was obvious, but no legislative action had been taken to alleviate the situation. (Author's note: Arizona was the only state in the Union which as late as April 1974 had not adopted Medicaid, a state medical assistance program under Title XIX of the Social Security Act, thus eliminating an alternate route of funding for those persons denied Medicare coverage.)

Community Response

At the community level, long-term care has largely been unplanned, resulting in a piecemeal filling of needs (Wessen 1965). Values in our society militate against the organization and distribution of health services for the elderly on a community level. Identification of needs are usually determined by the relative power of professional groups competing with established agencies. Most city welfare councils do not include or administer the largest and most important programs, those under federal auspices (Taber 1965). What action, therefore, if any was taken by the city of Tucson?

There are no published articles on activity taken by the community of Tucson, Arizona, in response to the needs of these elderly patients. The researcher therefore directed inquiries towards those formal organizations in the city which, by nature of their function of providing home nursing services, might have made some provisions for these patients or become involved in developing an alternate pathway to meet their needs.

Five organizations which met this criterion were identified from the 1972 Directory of Social Resources compiled by the United Way of Greater Tucson. Pima County Health Department, The Nurses' Professional Registry, the American Red Cross, Pima Council on Aging, and Homemaker Service were the only organizations identified as providing home nursing care services to the aged. Since the information in the Directory was sketchy, information was supplemented through telephone calls and interviews with responsible persons in the above listed organizations.

The Pima County Health Department began a Home Health Service in 1966 for patients in Pima County who had referral from a physician. The current staff included a registered nurse, a public health nurse, two licensed practical nurses, and an aide who deliver services. Current services ranged from bed baths, enemas, and vital signs to injections and physical assessment. No direct attempt was made in 1970 to offer services to those patients no longer receiving care from the Visiting Nurse Association. No patients being served by the Health Department was left without care if they were unable to pay fees no longer covered by Medicare.

Private home nursing care may be purchased through the Nurses' Professional Registry, a service of the Arizona State Nurses' Association, District 2. The same restrictions on Medicare reimbursement apply since the 1970 Social Security Act ruling.

In the Spring of 1969, the Tucson Chapter of the American Red Cross instituted a Convalescent Patient Aide course which has trained approximately 500 men and women in the nutrition, diet, feeding, body mechanics, positioning, bathing, and ambulation of long-term care patients. Parenteral administration of medications is not part of this program. The aides may be hired privately or through agencies for any number of hours.

Pima Council on Aging (formerly Tucson Council on Aging) administers two programs which assist in keeping the elderly in the home and out of the hospital or nursing home. (1) The Area-Wide Model Project, instituted in 1972, assists with transportation, meals, day care, and

socialization for approximately 500 elderly persons. Bathing may be provided, but no skilled nursing service is included. (2) The Home Health-Homemaker Care Service was founded in September 1972 and began providing services through the auspices of the Tucson Visiting Nurse Association in November 1972. Persons aged 50 or over, approximately 400 to 600 of them, were expected to participate in this project which aimed to promote and maintain physical and mental health of the elderly. Services to be developed and supervised by a qualified professional nurse were as follows: (1) To provide rehabilitation care and education in health areas; (2) to provide assistance with personal care and hygiene; (3) to provide health and nutrition instruction; (4) to provide assistance from Home Health Aides in shopping, food preparation, laundry service, and related housekeeping services; (5) to provide certain medically oriented services administered by a physician, registered nurse, licensed practical nurse, or directed by professional nursing staff members and performed by paramedical health aides; (6) to provide physician-ordered medical services; (7) to provide and accept referrals; and (8) for a registered nurse or physician to evaluate the patient's condition bi-monthly if the patient is long-term. These services were limited to residents in the Model Cities area. None of the former patients were reinstated for care.

The last agency, Homemaker Service, a private fee-for-service agency, arranges temporary assistance during emergencies for the elderly or handicapped. A limited Home Nursing Aide program is available, but professional nurses are not part of the staff.

Of the five agencies identified as providing home nursing services, Pima Council on Aging was the only one found to have a professional home nursing care program, administered through the Tucson Visiting Nurse Association and started in the fall of 1972. Many of the proposals were in the planning stages and had not become functional at the time of the interview.

Professional Response

Review of the literature in our admittedly youth-oriented culture revealed the needs for the ill aged placed very low in the hierarchy of social values both by the professional and by the layman. Attitudes were apt to be ones of denial and isolation because there were no easy answers for the problems of chronic illness. "Long-term care has not yet emerged as a type of care which has been fully legitimated by professional values. Stated baldly, long-term care lacks prestige and has not yet attracted its requisite share of the attention of the health professionals" (Wessen 1965, p. 262).

The value of home nursing services has long been appreciated as reported by Butler and Lewis (1973, pp. 193-194). They feel that along with educating the family and the patient, these services were often responsible for enabling older people to leave hospitals sooner and stay out of institutions longer. Some of the common ailments cared for by nurses in the home are strokes, arthritis, cancer, hip fractures, paraplegia, and minimal to moderate chronic brain syndromes. Tasks of nursing personnel may be feeding, skin care, personal hygiene, care of the

teeth and mouth, prevention of bedsores, and problems with incontinence, as well as aiding the patient to cope with activities of daily living.

What was the printed response of the professional community when it was known that Medicare was no longer planning to reimburse the elderly ill for home nursing services designated as custodial?

A review of the 1970 Cumulated Index Medicus and the 1969 and 1970 Cumulative Index to Nursing Literature revealed only a handful of articles appearing in professional journals at the time this change was occurring. The September 1969 American Journal of Public Health reports that as of January 1969, 541 Visiting Nurse Associations were certified home health agencies under Medicare and were providing about 25 percent of home health care nationally. Future hopes looked exciting and promising (Ryder, Stitt and Elkin 1969). A medical officer for the Department of Health, Education, and Welfare felt that Medicare had made great strides in providing quality care and defining standards at the institutional and home care levels (Reibel 1969). A social worker believed that home health care was not being used effectively due to lack of physician knowledge of services available (Kinoy 1969).

A search through the briefs and editorial sections of the American Journal of Nursing from July 1969 to June 1970 elicited only one mention of the discontinuation of financial support for home nursing services for the elderly, and this was in a letter to the editor.

In 1970 publications, only one article was found decrying the loss of funds for custodial patients. The author, Michael B. Miller (1970, p. 939) declares, " . . . there is a substantial reservoir of

chronically ill aged in the community who require first-rate medical and nursing care on a continuous basis but, because of lack of funds, are not receiving it." The August 1970 edition of Geriatrics ("Government and Geriatrics" 1970) did not mention the loss of funds, but rather reported that President Nixon's Task Force on the Aging recommended financing of a full range of geriatric health services, especially in the home. However, it noted, current restrictions on funding curtailed immediate implementation.

This chapter on review of the literature looked at the response of the legislature, community, and professional community to the elderly custodial patient when he was faced with the process of adapting to the loss of professional home nursing services. The researcher found that problems were identified, but that no solutions were suggested or implemented.

CHAPTER 3

METHOD OF THE STUDY

This chapter describes the design of the study, the tools for data collection, the setting, the population sample, method of data collection and method of analyzing the data.

Design of the Study

This descriptive study was designed to answer the question, "As described by elderly patients or their families, how are nursing care needs being met three and one-half years after termination of professional home nursing care?" Utilizing Rene Dubos' (1965) theory of social adaptation, the current method of meeting these needs was explored within the context of age, health status, living arrangements, and cognitive ability.

Basic information was collected on an initial population of 47 persons who met the following criteria: (1) the person had been receiving home nursing care from the Tucson Visiting Nurse Association; (2) this care had been reimbursable by Medicare; (3) the person had been declared "custodial"; and (4) the person was no longer receiving services from the Tucson Visiting Nurse Association.

A questionnaire was designed to determine the cognitive ability, living arrangements, current method of meeting home nursing care needs,

and perceived needs for home nursing care. Answers to the questionnaire were obtained by the investigator during a personal interview with either the patient or a member of his family.

The Tools

Two tools were devised and utilized during the study. The first tool was a 4 x 6 card utilized to gather data on the initial total population. The second tool was a specially designed questionnaire to be used during a personal interview.

Prior to making patient contact, Visiting Nurse records on each of the 47 patients considered eligible for the study were reviewed for select data. A 4 x 6 card was made for each person which contained the following data: name, address, special living arrangements (to assist in locating the patient), date of birth, date entered Visiting Nurse Association (abbreviated VNA), date discharged from Visiting Nurse Association, diagnosis, and treatment given by the nurse. The patient's Visiting Nurse record number was recorded in the event records needed to be checked at a future date. A numbering system was used by the researcher for her own benefit in correlating data cards and questionnaire sheets. Space was allocated for the date, cause, and place of death if deceased. A replica of the card devised is shown in Appendix A.

The second tool was a questionnaire to be used during the personal interviews conducted with those persons found to still be alive and residing in Tucson. Identifying data included name, last known address, attempts to locate the patient, and relationship of informant to the patient. The questionnaire explored five specific areas: (1) cognitive

ability as evidenced by recall of the purpose for the services rendered by the Visiting Nurse; (2) current services received and the method of provision; (3) the patient's perception of the effect of discontinuation of Visiting Nurse services on his health; (4) change in the family's way of life to adapt to the patient's needs; and (5) perception of additional needed home nursing services.

A trial questionnaire was prepared and a pilot study was attempted to determine the clarity of the questions. After several unsuccessful attempts to contact elderly persons familiar with Visiting Nurse services, the investigator chose to ask the questions of other elderly persons even though they had never been recipients of such services. The questions were posed to a 73-year-old gentleman, an 86-year-old woman, and a 90-year-old woman. They were not asked to answer the questions, but were requested to state if the question was clear. Based on their recommendations, minor changes were made in two of the questions. The final draft of the questionnaire appears in Appendix B.

Two tools were developed for the researcher's use in this descriptive study. One was a 4 x 6 card used solely for data collection from records. The second was a questionnaire used in personal contact interviews.

The Population Sample

The population sample in this descriptive study was a discreet group. The names of all persons included in the initial population of 47 were garnered from patient files of the Tucson Visiting Nurse Association. The study population was limited to those 18 persons from the

initial 47 who were found to be still living and were located in the city of Tucson.

For a person to be included in the initial population selection, four criteria had to be met.

1. The person had been receiving professional home nursing care from the Tucson Visiting Nurse Association.
2. The patient's cost for this care had been reimbursable by Medicare.
3. The person had been declared "custodial" under the Medicare ruling and was therefore no longer eligible for paid services.
4. The person had elected not to pay for services on a private fee basis and was therefore no longer receiving professional home nursing care from the Tucson Visiting Nurse Association.

In summary, the population sample was not a random one of those elderly persons denied home nursing services under the Medicare ruling, but was a discreet group who were receiving such services from the Tucson Visiting Nurse Association in April of 1970 when the Medicare ruling became effective.

Method of Data Collection

Data were collected from the Tucson Visiting Nurse Association records, the Department of Vital Statistics of the Pima County Health Department, and from patients or their families utilizing the two tools designed for the study.

The data used in selection and identification of the 47 persons in the initial total population came from patient records in the Tucson Visiting Nurse Association office. A 4 x 6 card was filled out for each person included in the study. Data contained under the heading "treatment given by the nurse" came from the physician's orders on the chart as well as from the nursing progress notes.

Since more than three years had elapsed from the date of the patients' discharges to the beginning of the study, the investigator requested, and was granted, permission by the Pima County Health Department Bureau of Vital Statistics to review death certificates from April 1970 to the time of the study to determine how many of these patients had died, where they had died, and from what causes.

The third, and final, source of information came from the patients or their families. A personal visit was made to the last address listed by the Visiting Nurse Association to those patients presumed to be still living. The interviewer wore a white lab coat with her name and position as a registered nurse printed in large letters on a pin. She advised the person answering the door of her name, position, reason for the visit, and requested permission to speak with the patient or a member of his family. If the patient no longer lived at the listed address, aid was asked from the current tenant, landlord, or neighbors in locating the person. Two persons were located through telephone calls and specific appointments were made for the interview. One interview was conducted by telephone.

The questions were broached by the interviewer in the order they appeared on the questionnaire and were recorded by the interviewer on the questionnaire sheet. When someone other than the patient was providing the information, the patient's name was substituted for "you" in the question. The interviewer did not rush the questions, but visited with the patient and his family, taking approximately one hour for each contact. In only one case was she not asked to enter the home and interact with the entire household.

In summary, data for this descriptive study were collected from patient records, death certificates, and through personal interview and were recorded on forms designed specifically for this purpose by the researcher.

Method of Data Analysis

Since this was a non-experimental descriptive study, no numerical value was placed on the data collected. Descriptive information was collected in response to the question, "As described by elderly patients or their families, how are nursing care needs being met three and one-half years after termination of professional home nursing care?" Dubos' (1965) framework of social adaptation was utilized along with factors of age, health status, living arrangements, and cognitive ability as they affected the social adaptation of the study population.

CHAPTER 4

PRESENTATION OF THE DATA

Population Profile

Data were collected from nursing records on a total population of 47 persons. The study population, which numbered 18 of the original 47, supplied oral responses to a questionnaire during a private personal interview.

The purpose of the descriptive study was to answer the question, "As described by elderly patients or their families, how are nursing care needs being met three and one-half years after termination of professional home nursing care?" Data are presented in the four parameters of age, health status, living arrangements, and cognitive ability as they related to the elderly custodial patient's social adaptation to loss of professional home nursing services. Information taken from the Tucson Visiting Nurse Association records provided statistical data in the areas of age and health status. Health status was viewed in terms of length of time service had been received, medical diagnosis, and services performed by the visiting nurse. Living arrangements and cognitive ability were not determinable from nursing records and are, therefore, only included in the data from patients included in the study population of 18.

Of the 47 persons in the total population, 21 were deceased, 7 were not located, and 18 were located and form the study population.

One patient, at the age of 91, was unable to recall data pertinent to the period of her life when the visiting nurse was caring for her.

Of the seven unlocated persons, two were known to have moved to other states, one was presumed by neighbors to be visiting relatives in the East, one's neighborhood now houses the University of Arizona sports center, one moved in with friends after his wife became ill, one person's home was locked up and appeared to be for sale, and one had moved from a trailer park with no forwarding address available.

Eighteen persons were found to be living in the Tucson area and they or their families were contacted for an interview. One of the patients was hospitalized, so his wife was interviewed. Two of the interviewees were husband and wife. Fourteen patients were located at the last address given by the Visiting Nurse Association. The husband-wife pair were located in a low-cost apartment building for the elderly. Two patients who had moved were located through telephone calls to relatives.

The greater portion of the data presented will pertain to the total population (n = 47) and the study population (n = 18). Data on the deceased population (n = 21) will be included in selected tables for comparison.

Age

At the time of discharge from the Tucson Visiting Nurse Association, the mean age of males and females in the total population (n = 47) was essentially equal. In the study population (n = 18) females averaged 4.3 years older than males. A review of the Pima County Health

Department's death certificates showed that 35.7 percent of the males and 48.4 percent of the females from the total population were known to have died. The mean age in years at time of death for males and females was essentially the same--85. In all three populations women were older, ranging from 9 to 13 years older. Those patients who died were in the more advanced age groups for both males and females. Age distribution for the three populations are compared in Table 1.

Table 1. Comparison by age of the total, study, and deceased populations.

Population	Participants		Age Range at Time of Discharge	Mean Age in Years at Time of Discharge
Total (n = 47)	Males	14	66-88	78.8
	Females	33	66-98	78.9
Study (n = 18)	Males	5	69.84	75.4
	Females	13	72-93	79.7
Deceased (n = 21)	Males	5	78-88	83.0
	Females	16	68-101	83.5

The 21 deceased patients had all expired within 30 months following discharge from the Tucson Visiting Nurse Association. Two patients died the day after discharge; five had died at the end of six months; ten were dead after 18 months; 17 were deceased after 24 months. Eight of these persons died while in the hospital; four were dead on

arrival at the hospital; five expired in nursing homes; and four died at home.

A variety of causes of death for these 21 persons were listed on the death certificates. Six patients were listed as dying of arteriosclerotic heart disease, six were victims of coronary thrombosis or myocardial infarction, five expired from cerebrovascular accident, two from bronchopneumonia, one from urinary septicemia, one from ventricular fibrillation, and one from uremia due to liver failure.

Health Status

Health status for the total population (n = 47) is reported in terms of length of time service was received from the Tucson Visiting Nurse Association, diagnosis, and type of service received. For the study population (n = 18), diagnosis and type of service received is included under cognitive ability.

The total population (n = 47) had accumulated a total of 1,254 months of service from the Tucson Visiting Nurse Association with a range of 1 to 100 months and a mean of 26.7 months per person.

The study population (n = 18) accumulated a total of 512 months of service with a range of 2 to 89 months and a mean of 28.4 months per person.

The deceased population (n = 21) accumulated 529 months of service with a range of 1 to 100 months and a mean of 25.2 months per person. Table 2 compares the length of time the total, study, and deceased populations received Visiting Nurse services by 12-month intervals.

Table 2. Comparison of length of time total, study, and deceased populations received Visiting Nurse services (by 12-month intervals).

Number of Months	Population		
	Total n = 47	Study n = 18	Deceased n = 21
1-12	18	8	6
13-24	8	4	4
25-36	11	1	8
37-48	2	0	1
49-60	2	1	1
61-72	1	1	0
73-84	3	2	0
85-96	1	1	0
97-100	1	0	1

In the total population (n = 47), 38.3 percent of the patients received services for 12 or less months; in the study population (n = 18) 44.4 percent received services for 12 or less months; in the deceased population (n = 21) 28.5 percent of the patients fell into this category. When the criteria were extended to 36 months or less of service, 78.5 percent of the total population (n = 47), 72.2 percent of the study population (n = 18), and 85.7 percent of the deceased population (n = 21) fell into this group.

Health status was also viewed in the context of medical diagnosis. Seventy-six separate medical conditions appeared on the records of the total population (n = 47). This averaged 1.6 diagnoses per patient. The study population (n = 18) listed 26 diagnoses, or 1.4 per patient; and the deceased population (n = 21) had 36 diagnoses, or 1.7 per patient. For a more accurate understanding of the custodial patient, the diagnoses and frequency of their appearance on the nursing records for the total population (n = 47) are presented in Table 3.

To further gain a concept of the custodial patient, the types of services performed for these 47 patients were recorded. Physician's orders and nursing progress notes indicated that 143 separate services were being performed by the visiting nurses. These services fell into eight general categories: general care, body dynamics, assessment, elimination, injections, nutritional consultation, supervision and counseling, and miscellaneous. Specific services were identified under seven of the general categories and separate tallies were made for each.

In the category of general care, there were 34 recipients of bathing, 17 of shampoo or shave, and 10 of nail care. Under body dynamics, five patients received range of motion exercise or massage and nine ambulation (prosthesis, corset, and crutches). In the category of assessment, there were 11 recipients of vital signs and 11 of other assessment, including edema, skin condition, and respirations. The types of services and frequency of performance by the nurses are categorized in Table 4.

Table 3. Occurrence of specific diagnoses of the total population discharged from service by the Tucson Visiting Nurse Association (n = 47).

Diagnosis	Frequency of Occurrence
Generalized arteriosclerosis or arteriosclerotic heart disease	13
Arthritis	11
Senility	6
Cerebrovascular accident (stroke)	6
Congestive heart failure	5
Diabetes	4
Parkinson's disease	3
Hypertension	3
Osteoporosis	2
Fracture	2
Anemia	2
Depression	1
Hemiplegia	1
Sinusitis	1
Asthma	1
Gall bladder disease	1
Bell's palsy	1
Phlebitis	1
Hemothorax	1
Hiatus hernia	1

Table 3, continued.

Diagnosis	Frequency of Occurrence
Skin infection	1
Prostatectomy	1
Fibrosis	1
Blindness	1
Gastroenteritis	1
Cancer	1
Neurasthenia	1
Amputation	1
Intracostal neuritis	1
Recurrent impaction	1
Total	76

Table 4. Types of services and frequency of performance by the Tucson Visiting Nurse Association staff for the total population (n = 47).

Service	Number of Recipients
General Care:	
Bath	34
Shampoo or shave	17
Nail care	10
Body Dynamics:	
Range of motion exercise, massage	5
Ambulation (prosthesis, corset, crutches)	9
Assessment:	
Vital signs	11
Other (edema, skin condition, shortness of breath)	11
Elimination:	
Catheter change	1
Enema, bowel training	6
Colostomy irrigation	1
Injections:	
B_{12}	12
Other	3
Nutritional Consult	12
Supervision and Counseling:	
Medications	4
General health	4
Miscellaneous:	
Dressing change	1
Linen change	1
Family training	1
Total	143

The Study Population

Interviews were conducted by the researcher in the homes of the 18 patients who constituted the study population. In 11 cases the patient was the respondent; in three cases it was the spouse; two respondents were children of the patients, one was a sister, and one was a son-in-law.

Living Arrangements

Living arrangements were observed by the researcher at the time of the personal interview although no question on the questionnaire was directed towards this information. The varied living arrangements of the 18 patients in the study population are presented in Table 5.

Table 5. Living arrangements of the study population (n = 18).

Living Arrangement	Number
With spouse	9
Alone	3
With other relative	3
Live-in boarder	1
Live-in housekeeper	1
Nursing home	1
Total	18

Cognitive Ability

The first question on the oral questionnaire was designed to assess cognitive ability through memory. Since 11 interviews were with patients themselves and 7 were with other persons, it was possible to compare the cognitive memory responses of one group with those of the other.

Question number one was in two parts and responses to both parts (a) and (b) are included in each section. This question asked, (a) "What condition was the visiting nurse treating you for?" and (b) "What services did she provide for you?"

With some allowance for discrepancy in terminology, of 15 possible diagnoses in (a), seven, or 47 percent, were recalled correctly. Three patients, or 27 percent, gave totally unrelated diagnoses compared to the ones given on their nursing record, although they did recall appropriate services rendered.

Nursing notes indicated 23 services rendered these 11 persons. Considering "injections" as an appropriate response without differentiating as to type, 14 appropriate responses, or 61 percent, were given by the patients for services rendered in part (b).

Three patients mentioned five additional services not recorded on the nursing notes. It was noted that those services which did not concern touching by the nurse, that is nutritional consult and supervision of medications, while mentioned four times by the nurses, were mentioned only once by the recipients. Responses by 11 patients are recorded in Table 6.

Table 6. Responses of patients compared with record information regarding diagnoses and services rendered (n = 11).

Number	Condition and Service per Visiting Nurse Record	Patient Response
1.	(a) arthritis; fibrositis; hypertension (b) calphoson and vitamin B12 injections	(a) arthritis (b) B12, B complex, and calcium injections
2.	(a) amputated left leg (b) sponge bath; apply prosthesis; ambulate three times weekly	(a) amputated leg (b) bath and shower; apply prosthesis; ambulation; vital signs
3.	(a) cerebrovascular accident (stroke); hemiplegia (b) bath, massage, exercise	(a) stroke (b) bath only
4.	(a) neurasthenia (b) vitamin B1 and B12 injections	(a) nervous problem (b) injections
5.	(a) Parkinson's disease (b) vitamin B12 injection	(a) low blood count (b) vitamin B12 injection
6.	(a) Bell's palsy (b) B12 injections; nutritional consult	(a) Bell's palsy (b) patient insists nurse never gave him care; just care to his wife
7.	(a) anemia (b) B12 injections, vital signs, enema, nutritional consult	(a) anemia (b) injections
8.	(a) anemia (b) B12 injection; check blood pressure and pulse; assist with bath; supervise medications	(a) anemia; elevated blood pressure (b) take blood pressure and pulse; assist with bath
9.	(a) depression (b) B12 and durabolin injections	(a) couldn't care for self (b) B12 injections; assistance with bath, enema

Table 6, continued.

Number	Condition and Service per Visiting Nurse Record	Patient Response
10.	(a) intra-costal neuritis (b) bath once weekly; observe	(a) bronchitis (b) bath, injections, trained patient to give self B12 injections; observation
11.	(a) sinusitis, asthma (b) vitamin B12 injections twice weekly	(a) debilitation following hip fracture (b) vitamin B12 injections twice weekly

When the question was responded to by other members of the family, 7 of 14 possible diagnoses were given correctly for 50 percent accuracy. No totally unrelated diagnoses were offered.

Services rendered these seven patients numbered 26, of which 9, or 35 percent, were recalled by the family. All responses were oriented towards services which involved touching the patient with the exception of one woman who noted that she had been taught to care for two needs of her husband. Responses given by other members of the family are recorded in Table 7.

During conversations with these 18 patients or their families, three additional pieces of information were collected in response to this first question. In one instance, a husband denied that his wife had ever received a bath from the nurse. One patient denied that the nurse had ever exercised or massaged her. One gentleman denied that the nurse even came to see him although he was having a problem, but insisted that she just came to see his wife.

Social Adaptation

The adaptive response of the 18 interviewees is approached in questions two through five. The questions pursue information on sources of aid for home nursing care needs, opinion of affect of discontinuation of services on the patient's health, and perceived home nursing needs at the present time.

Question number two asked, "Are you still getting (bath, injection, etc., mentioned in 1b)? If yes, who is doing it?"

Table 7. Responses given by other members of the family compared with record information regarding diagnoses and services rendered (n = 7).

Number	Condition and Service per Visiting Nurse Record	Family Response
1.	(a) fractured hip (b) hygiene twice weekly; vital signs; check for edema; diet consult; train the family	(a) fractured hip (b) bath
2.	(a) generalized arteriosclerosis (b) sponge bath and shampoo; trim nails; diet consult	(a) senility; helplessness (b) bath
3.	(a) arteriosclerotic heart disease; blindness (b) shower, shampoo; vital signs; encourage ambulation; observe for edema and dyspnea	(a) blindness (b) bathing; feeding; ambulation; exercise
4.	(a) arthritis (b) bed bath once weekly; dressing change on leg ulcer	(a) arthritis (b) bed bath once weekly; change dressing on leg
5.	(a) arthritis (b) assistance with shower and dressing twice weekly; shampoo; encourage activity; prevent ulcers	(a) arthritis (b) bath
6.	(a) cardiovascular accident (stroke); hemothorax (b) check blood pressure; supervise bowel training; exercises; change foley catheter	(a) stroke (b) taught about catheter; trained wife to give bath; bowel training
7.	(a) cancer; arthritis; senility (b) colostomy irrigation; partial sponge bath twice weekly; health counseling	(a) colostomy from cancer operation; arthritis (b) irrigate colostomy

Seven interviewees responded with "no" to the first part of the question. Five of these pertained to injections, one to vital signs and bathing assistance, and one was the patient who denied he was receiving any aid from the nurse.

Of the 11 patients or families who responded with a "yes," 15 sources of help were mentioned. Four persons relied upon themselves, four had hired help, two depended upon their spouses, two on other relatives, two on friends or neighbors, and one on the office nurse. Table 8 lists sources of aid for home nursing care needs.

Table 8. Sources of aid for home nursing care needs in study group (n = 18).

Source of Aid	Number of Responses
Self	4
Hired help	4
Spouse	2
Other relative	2
Friend or neighbor	2
Physician's office nurse	1
Total	15

Question number three approached attitudinal response with the question, "Do you feel that discontinuation of the Visiting Nurse services has affected your health? If yes, in what way?"

Fifteen persons responded with a negative answer to the first part of the question. One patient stated that while her health was not affected, she would still like for the nurse to come as caring for herself is exceedingly difficult.

Three persons felt that health had been affected. A lady with an amputation said she does not get up and walk on her prosthesis any more; a wife whose husband, the patient, is severely arthritic stated she cannot move and turn her husband as the nurse did; and a woman who was receiving vitamin injection felt she still wanted them.

Of the 18 families interviewed, only one had utilized the services of any of the agencies which provide home nursing services. A Home Health Aide was bathing a patient with arthritis three times weekly. However, since the aide was unable to come to the home early in the day to provide service, the family ceased using the service.

Question number four was related to family involvement and was worded, "Since the visiting nurse stopped coming, has your family (children, husband, roommate) had to change their way of life to take care of your needs? If yes, in what way?"

Responding to the first part of the question, 11 families did not feel that their life style had changed while seven families felt that daily living had been affected considerably in a variety of ways. One woman hired a housekeeper to care for her; a wife had to be

available day and night and could not leave the house; and a sister had to take over the task of bathing a patient disabled with arthritis. A wife, herself disabled with a hernia, has to call a friend or neighbor to lift her husband. A family who had to take over the complete care of a blind patient eventually resorted to placing him in a nursing home. The son of an aged senile woman married so his wife could take care of his mother since he is almost blind. His new wife, age 72, gets exhausted. An elderly wife is responsible each day for putting out her husband's pills and checking that they are taken since he no longer receives injections.

Question number five asked, "What home nursing services do you feel are still needed for a person like yourself?"

Five respondents could not think of a need at this time either for themselves or someone else. Of the 13 who had a suggestion, 19 perceived needs were mentioned. Injections were noted three times; bathing five times; bowel control, catheter care, or enema three times. Three were in need of feeding assistance or food preparation; two required ambulation and exercise. Application of a prosthesis, placement in a wheelchair, and blood pressure check were identified as other needs once each. Table 9 contains the perceived home nursing needs provided by the study group.

These 13 persons freely made mention of other needs as they perceived them which were vitally important to their existence but would not necessarily fall into the classification of nursing needs. They are included here as serendipitous findings. Two patients indicated they

Table 9. Perceived home nursing needs of study group (n = 18).

Needed Nursing Service	Number of Responses
Injections	3
Bathing	5
Bowel control, catheter care, enema	3
Feeding assistance, food preparation	3
Ambulation, exercise	2
Application of prostheses	1
Placement in wheelchair	1
Blood pressure check	1
Total	19

were severely in need of some help with routine household chores. Two desired someone they felt they could call for help in an emergency. Three mentioned the financial strain of renting equipment or having to pay hired help or neighbors for assistance. One needed a sitting service and one needed services that could be depended upon to happen early in the day. One woman suggested that bathing assistance was desired more frequently during the hot summer months. One wife very candidly requested that services be resumed for her husband because the visit by the nurse added a lot of cheer and gave her husband something to get up for. She claims that loss of the visit has "affected his disposition."

The 18 patients or their families who were interviewed had been caught up in a network of decisions made at a national level but whose full impact was felt at the individual level. Those affected were the elderly debilitated, persons whose age and health required that they receive some type of home nursing care services. Since many had been receiving care in the home for several years, a loss of this service caused a major disruption.

In 1970 the community of Tucson was not prepared to respond to the needs of this group in the community. These 18 persons were not assimilated into another system which provided professional nursing care in the home nor were they accommodated by the development of another comparable system.

Any changes made were made internally, that is within the family constellation. Families relied upon their own resources or sought help from friends or neighbors, often having to pay for the assistance. As of March 1974, professional home nursing care services were not available to the elderly debilitated except on a private fee basis. Responses indicated that adaptation occurred at a level lower than was desired by the respondents in the study group.

CHAPTER 5

DISCUSSION OF FINDINGS, CONCLUSIONS, AND RECOMMENDATIONS

This chapter investigated the relationship of the theoretical framework to the study, the findings as they related to the review of the literature, independent findings, conclusions, and recommendations.

This descriptive study posed the question, "As described by elderly patients or their families, how are nursing care needs being met three and one-half years after termination of professional home nursing care?"

The theoretical framework of this study embodied Dubos' (1965) perception of social adaptability which implies a modification of behavior to suit new conditions. The self changes so that one's behavior or attitudes will conform to the new circumstances. While the ability to adapt is unique to man and is an indispensable condition of his survival, his adaptability is often manifested as a passive acceptance of conditions which are not desirable.

As reported by Wolff (1959), social adaptability decreases with age. Pihlblad and McNamara (1965) and Kutner et al. (1956) report chronic illness causes stress which further decreases the aged person's ability of adapt to change. Pihlblad and McNamara (1965) further feel that persons living with someone other than a family member adjust less easily. Shock (1960) and Gaitz (1972) feel that aging and ill health lead to decline of cognitive competence and memory.

Based on this theory, the researcher sought information on the social adaptation of a group of elderly persons who had been unexpectedly denied the continuance of professional home nursing services. The study was conducted three and one-half years following the loss of these services. The factors of age, health status, living arrangements, and cognitive ability were viewed in relationship to the patient's current method of meeting his home nursing care needs, the adjustment the family had to make, and the perception of additional home nursing care needs by the patient and his family.

Findings in Relation to the Review of the Literature

Butler and Lewis (1973) report that professional home nursing services were being utilized frequently by the elderly, thus preventing institutionalization. Provision for home health care for the elderly under Medicare was described as exciting and promising by Ryder (1969) and of good quality by Reibel (1969). The persons in the study were all over 65, thus qualifying them for Medicare, and were receiving services from the Tucson Visiting Nurse Association. The initial population of 47 persons ranged in age from 66 to 98 with a mean age of 78.8 for males and 78.9 for females. These 47 persons had received a total of 1,254 months of professional home service for the Tucson Visiting Nurse Association with a range of 1 to 100 months of service and a mean of 26.7 months per person.

The study population of 18 persons living and residing in Tucson revealed an age range of 69 to 93 with a mean age of 75.4 for males and

79.9 for females. A total of 512 months of professional home nursing services had been received, ranging from 2 to 89 months with a mean of 28.4 months per person.

Prior to 1970, by virtue of meeting the criterion of being over age 65, these persons were able to receive Medicare reimbursement for home nursing services. In view of the 1970 Medicare ruling, to be considered custodial patients, these persons required care to prevent regression to a former state of ill health and were not able to function in daily living or care for their own personal needs.

Findings on the initial population of 47 showed a total of 76 medical conditions listed on nursing care records. The conditions were chronic or irreversible. The categories of services received further verified the custodial status of these elderly persons. The number of services received were 143 and fell into the eight following categories: general care (bath, shampoo, nail care); body dynamics, assessment, elimination, injections, nutritional consult, supervision and counseling, and miscellaneous. Of the types of services received, 61 were general care, 14 body dynamics, 22 assessment, 8 elimination, 15 injections, 12 nutritional consult, 8 supervision and counseling, and 3 were miscellaneous services.

Social adaptation takes place in a milieu of family and community. The change affecting these elderly persons occurred at the legislative level and involved the health delivery system. Legislative, community and professional response were investigated by the researcher.

Review of the literature for legislative response revealed that no action had taken place to change the status quo for delivery of health care to these patients. Three and one-half years later, professional home nursing services had not been reinstated.

An overview of community response revealed that only one out of five possibly responsive agencies had provided expanded services for the elderly custodial patient. The researcher found that only one patient had made use of this service and had discontinued it after a brief trial because of incompatability of time between need for the service and its delivery.

Review of the literature as to the response of the professional community indicated the needs of the elderly ill as having low priority. The researcher found that 11 of the patients in the study population of 18 were still receiving services similar to those provided previously by the visiting nurse. The care came from 15 sources, only one of which was a nurse in a physician's office. In four instances the persons provided their own care; in four families help was hired; the spouse provided services for two individuals; other relatives provided care in two other instances; and friends or neighbors provided for patient needs for two people.

Independent Findings

The initial total population selected by the investigator for the study numbered 47. Death had claimed 21 of these elderly persons, 7 could not be located, 1 was unable to give an interview, and 18 patients or their families were interviewed.

The 21 deceased persons represented 44.7 percent of the initial population and were among the older patients. The five deceased males ranged in age from 78 to 88 with a mean age at death of 83.0 years; the 16 deceased females ranged in age from 68 to 101 with a mean age at death of 83.5 years. The 21 persons had died within 30 months of discharge from the Tucson Visiting Nurse Association; two died the day following discharge; five were dead after six months; the total at 12 months was still five; the total at 18 months was ten, at 24 months 17, and at 30 months 21.

Eighteen persons or their families were interviewed. Of the 18 persons in the study population, nine (50 percent) lived with their spouse, three lived alone, three with other relatives, one had a boarder, one hired a live-in housekeeper, and one resided in a nursing home.

Cognitive ability of the patient was elicited from memory response of the patient as to reason for previous professional home nursing care and type of services received. Of the 18 interviews, 11 patients responded to the researcher's questions themselves. Three spouses, two children, a sister, and a son-in-law composed the remaining seven respondents. Memory response was compared for the two groups.

In the patient response group, 7 of a possible 15 diagnoses, or 47 percent, were recalled correctly. Three patients, or 27 percent, gave totally unrelated diagnoses. Of a possible 23 services rendered, 14, or 61 percent, were recalled correctly. When questions were responded to by other members of the family, 7 out of 14, or 50 percent of the diagnoses, were given correctly. No unrelated diagnoses were

offered. For services received, 9 out of 26, or 35 percent, were recalled by the family.

Following collection of data on age, health status, living arrangements, and cognitive ability of the 18 persons in the study group, the adaptive response, attitudes, and perceptions of the patients were investigated.

The adaptive response was pursued through a question which inquired if prior home nursing care was still being received, and if so, who was providing the care. Seven of the 18 interviewees, or 39 percent, were no longer receiving the services they had received three and one-half years prior. Of the 11 patients receiving care for their home nursing needs, 15 sources of aid were identified. Four persons, or 27 percent, were providing care for themselves. Hired help, spouses and other relatives, friends or neighbors, and an office nurse accounted for the 11 other sources of aid.

Family involvement in the adaptive process was also pursued in the questionnaire. Eleven of the 18 families, or 61 percent, felt that the family had not had to change their way of life to adapt to the patient's needs. Each of the other seven families adapted in their own unique manner to meet the needs of the patient: a full-time housekeeper was hired, a wife had to be available day and night and could not leave the house, a sister had to take over care, a neighbor had to be called to lift a patient, a blind patient was placed in a nursing home, an aged man married so his wife could share the load of caring for his senile mother, and a wife must be sure her husband takes his medications.

When queried if discontinuation of professional home nursing services affected the health of the patient, 15 respondents, or 83 percent, felt it had not. Of the three remaining, one woman is not able to ambulate without her prosthesis, a patient with severe arthritis is not turned appropriately, and one patient felt she still just wanted the injections she had been receiving.

When asked about the need for further home nursing services, five respondents were unable to think of any needs. The remaining 13 respondents made 19 suggestions covering the need for injections, bathing, elimination assistance, feeding, ambulation, locomotion, and vital signs.

Conclusions

From the preceding data, the following conclusions are derived:

1. This study contributes to nursing in that it adds to nursing knowledge of the elderly person and how he adapts to social change.
2. The data suggest that age, health status, living arrangements, and cognitive ability affect the elderly person's ability to adapt satisfactorily.
3. The data imply that legislative, community, and professional response to the needs of the elderly custodial patient were minimal.
4. The data indicate that social adaptation in this study group occurred passively as evidenced by the current method of meeting home nursing care needs, family adjustment to meet patient needs, and perception of the effect of loss of home nursing

needs, and perception of the effect of loss of home nursing care on health status.

5. The data support that perceived need for further home nursing care services indicates an acceptance of a lower level of existence than is desired by the patient or his family.
6. The data confirm that nursing has the connotation of comfort and touching.

Recommendations

The researcher recommends replication of the study incorporating the following suggestions:

1. Develop a tool to measure level of social adaptation.
2. Compare social adaptation of elderly males to that of elderly females.
3. Compare social adaptation of those persons living with spouse to those who were widowed or single.
4. Conduct a study to determine the adaptation or lack of adaptation in those 21 patients who died.

CHAPTER 6

SUMMARY

Man in unique in his ability to adapt socially. However, many factors contribute to his adaptive response. Nurses look at the patient as a whole person and as such need to be knowledgeable in the areas of sociology and human behavior.

The purpose of this study was to obtain data on a specific group of elderly persons who were faced with a problem in social adaptation. The information gathered would be useful to nurses in their understanding of the elderly person as he copes with social change.

The study asked the question, "As described by elderly patients or their families, how are nursing care needs being met three and one-half years after termination of professional home nursing care?" The theoretical framework for this descriptive study utilizes Dubos' (1965) theory of social adaptation. The adaptive process was viewed within the perspectives of age, health status, living arrangements, and cognitive ability.

No similar study had been presented in the literature. The review of the literature, therefore, focused on legislative, community, and professional response to the needs of these elderly persons.

The sample population were located from records of the Tucson Visiting Nurse Association which identified persons who were denied

reimbursement for professional home nursing services following a 1970 Medicare ruling. Persons selected were those who were no longer receiving professional home nursing care due to inability to pay for these services on a private fee basis.

The initial population contained 47 persons. Eighteen patients who were alive and residing in Tucson formed the study population. There were 5 males and 13 females ranging in age from 69 to 93 who had accrued a total of 512 months of service from the Tucson Visiting Nurse Association ranging from 2 to 89 months of service per person.

The data is presented as descriptive material.

The data were collected from Tucson Visiting Nurse Association records, death certificates, and through personal interview. Tools developed for use by the researcher were an initial data collection card and a structured interview form.

The conclusions were that the data suggest that age, health status, living arrangements, and cognitive ability contribute to a decreasing ability to adapt. The data imply that legislative, community, and professional response to the needs of the elderly custodial patient were minimal. The data indicate that social adaptation in this group occurred passively and that perceived need for further home nursing care indicates an acceptance of a lower level of existence than is desired by the patient or his family.

Pertinent data were reported in table form.

Findings from this study should prove helpful to nurses working with elderly persons in increasing their understanding of the elderly

person as he adapts to changes in the social environment. Findings should also be helpful to persons planning for home health care, community health planners, legislators, Medicare financing people.

The researcher recommends replication of the study using a tool to measure level of social adaptation, comparing adaptation of males to females, and comparing adaptation levels based on marital status.

The author also recommends a study of the adaptive response in those 21 persons who died.

APPENDIX A

INITIAL DATA CARD UTILIZING VISITING NURSE RECORDS

Name:	VNA# ID#
Address:	Phone:
Special living arrangements:	
Date of birth:	Date of death: Certificate #: Place of death: Cause of death:
- - - - - - - - - -	
Date entered VNA:	Date discharged VNA:
Diagnosis:	
VNA treatment:	

APPENDIX B

INTERVIEW QUESTIONNAIRE

Name: ID#

Last known address:

Attempts to locate:

Relation to patient of person giving information:

Questions

1. a. What condition was the Visiting Nurse treating you for?

   b. What services did she provide for you?

2. a. Are you still getting - - - (answer to b. above) - - ?

   b. (If yes), who is doing it?

3. Do you feel that discontinuation of the Visiting Nurses' services has affected your health? (If yes), in what way?

4. Since the Visiting Nurse stopped coming, has your family (husband, children, roommate) had to change their way of life to take care of your needs? (If yes), in what way?

5. What home nursing services do you feel are still needed for a person like yourself?

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