Respite care: an integral study of caregiver burden and the level of satisfaction of respite care at the VA medical center, Augusta, Georgia

William L. Newson

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The overall objective of this study was to examine the level of satisfaction among caregiver, patient, and staff of a respite care program. Respite care at the Department of Veterans Affairs Medical Center in Augusta, Georgia was used as the model. The sample population consisted of 18 caregivers, 14 patients and 55 staff members. Random sampling was used to select the caregiver and patient population. Staff members having more than six months experience with respite care were selected. A questionnaire was designed specifically to collect data and measure the level of satisfaction with Respite Care at VA Medical Center, Augusta. The findings revealed that over ninety percent of caregivers surveyed expressed a higher level of satisfaction than patients and staff. Also, sixty-one percent of the caregivers reported improvements in their health status following the respite period. Seventy-one percent of the patients stated that they would use the program again, and eighty-nine percent of the caregivers indicated that they would refer the program to others.

The findings were analyzed utilizing percent comparisons and may aid in streamlining services for more efficient use of respite care.
RESPITE CARE: AN INTEGRAL STUDY OF CAREGIVER BURDEN AND THE LEVEL OF SATISFACTION OF RESPITE CARE AT THE VA MEDICAL CENTER, AUGUSTA, GEORGIA

A THESIS
SUBMITTED TO THE FACULTY OF CLARK ATLANTA UNIVERSITY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SOCIAL WORK

BY
WILLIAM L. NEWSON

SCHOOL OF SOCIAL WORK

ATLANTA, GEORGIA
MARCH 1996
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Anyone who assumes the duties and primary responsibilities of caregiver for an elderly relative or other chronically disabled family member soon learns that the caregiver's role is often overwhelming, adversely affecting even the most compassionate person. In most family situations the caregiver must be in attendance almost constantly, ready to respond to the unrelenting needs of parents, spouses, children or other relatives who are unable to care for themselves. It is hardly surprising that caregivers develop burnout along with physical and psychological problems so that they themselves ultimately require help. This help may be in the form of respite care, in other words, care for the caregiver.

The Respite Care Program offered by the Augusta (GA) Veterans Administration Center is designed to provide support and temporary relief to the person caring for a chronically ill veteran in a home setting. The program operates six beds, two each on Spinal Cord Injury, Unit 2B (formally 1B) Intermediate Medicine, and Unit 3D Psychiatry. Admission to the program requires that the veteran: (a) be eligible for VA treatment, (b) be receiving care for chronic illness, (c) not need acute hospitalization, (d) display non-combative behavior, (e) agree to provide his/her own transportation, and (f) agree on the discharge plan as specified for the Respite period. Admission is normally one to two weeks, however it is limited to thirty days per year. The program has been operative since May of 1992 and has admitted 88 patients in Spinal Cord Injury Service,

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1 VA Medical Center Memorandum No. 122-10-92, dated 28 February 1992, Augusta, Georgia.
171 patients in Intermediate Medicine, and 14 patients in Psychiatry Service, as of the time of this study.

Services provided include nursing, medical, recreation and social work. Consultation for other services are provided if identified, such as psychology, physical therapy and occupational therapy.

The Respite Coordinator determines whether the veteran meets the criteria established for the Respite Program, and if so, refers the packet to the screening committee for approval. The Respite Care Screening Committee consists of the Respite Coordinator, a Medical Administration Service Representative, a Physician and the Clinical Nurse Specialist. Once approval is granted, the Coordinator or Designee will interview the veteran and caregiver at the Medical Center, at home or by telephone to finalize admission requirements.

Respite families are dealing with, in most cases, tremendous stress, and although Respite is geared to provide some relief, it too can be a stressor in the beginning. Some caregivers see Respite as "giving in" and subsequently see themselves as inadequate; others are afraid that needed care will not be provided and other feelings and issues surface. A careful assessment of the whole family system with sensitivity to the family dynamics is essential for intervention to be successful.

This study identifies research and practice-based data on what caregivers consider when assessing the availability, accessibility, quality and utility of respite care service. It also examines the effectiveness and satisfaction level of respite care at the VA Medical Center, Augusta, Georgia.
Statement of the Problem

Most commonly, family caregiving has been conceptualized as occurring when one or more family members give aid or assistance to other family members beyond that required as part of normal everyday life. Generally, family caregiving begins when aging family members require assistance due to debilitating chronic conditions or diseases, such as severe arthritis, significant sensory loss, Parkinson's Disease, Alzheimer's Disease, or when they are otherwise frail.

Many conditions that would have proved immediately fatal only a decade ago can now be treated, if not cured. As a result, millions of individuals are neither fully functional nor totally incapacitated. These individuals continue to perform some of their daily activities while relying on others close to them to assist them with other activities. Elderly people are the largest, but by no means the only, age group affected.

As the elderly population grows, so does the prevalence of chronic conditions in older people. The incidence of medical, social, and emotional problems in the older population is also rapidly rising. This increases the need for services from health care professionals.

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3 Ibid.


5 Ibid.

It is now well-established that caring for disabled older people is burdensome and stressful. Caregivers report higher levels of hostility and depression, poorer health, and lower life satisfaction than noncaregivers. Caregiving is emerging as an important risk factor for psychological and medical health problems, and as the population ages, many individuals can anticipate adding the role of caregiver to their self-image.

Contrary to prevalent myths, 95 percent of elderly people do not live in nursing homes. Even if they are disabled enough to need the kind of care provided in institutions, the majority live outside of them in their communities. In 1985, 1.4 million people over 65 lived in nursing homes. Another 5.2 million people who were disabled enough to need help with day-to-day tasks such as food preparation, dressing, and bathing lived alone or with family. Each of these numbers is expected to double by the year 2000.

Significance of the Study

The final stage of human life is equally delicate because it is the stage when people become worn out, tired, weak and unable for the most part to do things they did

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7 Ibid.
10 Ibid.
11 Ibid.
12 Ibid.
formerly. Oftentimes, they are not capable of taking care of themselves without depending on other people. In pre-industrial America, the practice of putting old people in institutions, like nursing homes, was very uncommon. Today, however, that practice is becoming popular because of the increased number of elderly. The population is also constantly increasing with a rising proportion of senior citizens over the age 85. The availability of more nursing home facilities should make it easier for more elderly people to receive nursing home care.

There are problems that remain eternal: aging and the aged, and limited resources. Old age is the last stage of life that everybody comes to—sooner or later. It is inevitable and the more we know about old age and the problems of old people, the better we will be prepared to give respite care. The importance of this research lies in exposing the problems that are encountered by chronically ill patients generally, and in particular those problems that occur in providing respite care where they receive services by other people.

**Operational Definitions**

**RESPITE CARE:** The placing of the cared into an alternate setting for a short period of time; aimed at giving their regular careers a break from their caring responsibilities.

**CAREGIVER:** Refers to the individual who is responsible for providing or coordinating the resources required by the persons with dementia, such as housekeeping, financial help, personal hygiene, and shopping.

**DEMENTIA:** Refers to a person who is deprived of the use of parts of the brain associated with a range of intellectual skills and activities unique to human beings. The irreversible progressive loss of mental faculties, often beginning with memory, learning, attention, and judgment.

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NEED: Refers to an individual's own judgment about the necessity or benefits of a particular service.

SERVICE SUPPORT: Refers to a formal community program designed to contribute to the emotional, physical and economic welfare of persons who provide care to impaired elderly at home.

UTILIZATION: Refers to the frequency of use of a particular support service.

SOCIAL DEPENDENCY: An individual who relies on the provider to develop areas of interest and activity.

PHYSICAL DEPENDENCY: An individual over 65 whose illness, impairments, and social problems have become disabling, reducing his or her ability to carry out independently the customary activities of daily life.
CHAPTER II
REVIEW OF THE LITERATURE

This chapter contains a review of research which covers two major areas pertinent to this study. They include: (1) Caregivers and (2) Support Services for Caregivers.

Caregivers

The majority of caregivers of elderly persons are women. As with the young, caregiving to the elderly appears to be a women's issue. In addition to being women, they are often age-peers. C. L. Johnson indicated in her study that, in serial order, the spouse functions as the primary caregiver; in the absence of the spouse, a child assumes the role; and in the absence of offspring, another family member is responsible. Shanas helped to dispel the myth of family abandonment. Cantor indicated that the primary caregivers tend to fulfill the role with little assistance from others even though they may suffer themselves from age-related physical, financial, and social limitations.

Respite care is a unique field of health care because it provides services to those


who give care as well as those who receive care. The concept refers to care provided on an intermittent basis, relieving family members and caregivers from the responsibility of caring for a chronically ill or disabled person. According to Hildebrant, respite may be "delivered in the home or a facility and may be medical, social, or combined in nature."
The type of respite care provided is usually based on the physical and psychological needs of the dependent person as well as the convenience, availability, and cost of the service.

The literature describes a number of benefits for many caregivers, such as the chance to maintain interests outside caring. According to Grad J. Sainsbury, the families of older clients have more than twice the number of severe problems than do those families of younger clients. The likelihood for institutionalization increases without some type of support for those families. Respite care can provide needed support and enables home care to be an alternative to institutionalization by improving the mental and social relationship of the caregivers, thereby decreasing the stress that accompanies the caregiving. In general, families have expressed satisfaction with institutional respite programs.

Research on caregiving has consistently identified respite as one of the most

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20 Ibid.


22 Ibid.
important unmet needs. This is particularly true for caregivers of patients with progressive dementias, which frequently are characterized by disruptive or troublesome behaviors that greatly increase the burden of caregiving.\footnote{P.V. Rabins, N.L. Mace, & M.J. Lucas, "The Impact of Dementia on the Family," Journal of the American Medical Association 248, 1982, p. 33-35.} In one randomized trial, offering respite services to caregivers of Alzheimer patients increased the length of time the care recipient spent in the community by an average of 28 days.\footnote{M.P. Lawton, E.M. Brody, & A.R. Saperstein, "A Controlled Study of Respite Service for Caregivers of Alzheimer's Patients," The Gerontologist (1989): 8-16.} In light of the rapid growth of the population age 85 and over, among whom the prevalence of Alzheimer's disease may be as high as 47%, the need for respite services can be expected to grow well into the next century.\footnote{Ibid.} The caregivers of these patients are also likely to be older, frailer, and more likely to choose inpatient respite over other services.

Although not a covered benefit in the United States under Medicare or Medicaid, inpatient respite programs have proliferated through special demonstration projects and fee-for-service arrangements.\footnote{Ibid.}

Fengler and Goodrich indicated in their studies that elderly wives caring for disabled husbands have special needs and problems. Through interviews, they discovered that morale scores of disabled husbands and their wives were associated.\footnote{Alfred Fengler and Nancy Goodrich, "Wives of Elderly Disabled Men," Gerontologists 19 -2 (1979): 175-183.} Even though morale was generally low, it was possible to dichotomize the wives into high and low
morale groups. Wives with low morale scores were particularly in need of support if institutionalization of the husband was to be minimized.\textsuperscript{28} Isolation, loneliness, economic hardship and role overload were the most frequent mentioned problems of the low morale wife.

The home or community care of persons with one of the dementias places a major burden on the primary caregivers as well as other family members. In a study by Zarit and Toseland in 1989, the majority of the caregivers were identified as women. One of the major findings of this study was that the extent of burden reported by primary caregivers of persons with dementia was not related to the behavior problems caused by the illness, but was associated with the lack of available social support systems.\textsuperscript{29}

In a study by Mace and Rabins (1983), the need for getting help outside of the family was discussed. It was noted that in a majority of the cases, the family—for a variety of reasons—did not seek or use outside help.\textsuperscript{30} The researchers suggested that the real reason for not seeking outside help may be the inherent desire for most families to provide care for their disabled members for as long as possible.

The researchers suggest that the caregivers have been left out of the support service mechanisms. In addition, the decision of caregivers not to use outside resources may worsen the situation for both the caregiver and the patient, in spite of their efforts to

\textsuperscript{28} Ibid.


care for the family member by themselves.

In the 1960s, the respite care movement began as a way of encouraging families to care for their developmentally disabled children at home, and in the 1970s these programs were extended to older adults. Respite can enable families to continue giving care to chronically ill patients much longer than might otherwise be possible. It can prevent burnout and enable caregivers to cope more successfully in the home environment. For the elderly, respite care can permit them to remain at home longer, thereby enhancing their health, well-being, and quality of life. Respite care can also relieve any guilt feelings held by the elderly and the caregiver regarding the burden of care.

Support Services for Caregivers

Several researchers indicate that family support is an important part of appropriate intervention programs. They tend to increase informal social supports which may be effective with a caregiver. This service may be provided by social workers, nurses, counselors, and physicians, and often forms a supportive counseling relationship with involved family members.

Pasamanic, Scarpitti, and Dinitz reported that home visits made by public health nurses to families of schizophrenics had a beneficial effect on patient outcome. The


32 Ibid.

33 Ibid.

public health nurse listening to clients and their families and their offering of some counseling aided in the success of home care programs for schizophrenics.

Several studies promote the use of group meetings for the caregivers of older people with senile dementia. These groups give members an opportunity to share concerns, clarify problems and roles, and develop skills for problem solving and coping. In addition, it is a means of providing caregivers with information and education on dementia and community resources that may be useful.

Another type of intervention was described by Garrison and Howe. The entire natural support network of the person with dementia is involved in providing assistance to the primary caregiver. The goal of network therapy is to use effective and instrumental resources present within the natural support network to promote coping with problem behavior. By helping the entire natural support network to share in the supportive care of the older person, the responsibilities of the primary caregiver are reduced, thus, burden may be lessened.

A program developed by Florence Stafford was designed with the premise that the needs of the mentally impaired elderly in present and future times can best be served by the sharing of responsibilities for their care by the family and appropriate formal organizations.\(^{35}\)

Institutional settings providing respite care include congregate care facilities, nursing homes, and acute care hospitals. They may set aside a few of their beds, which are then reserved in advance for short-term respite care.\(^{36}\) Costs can range from $30 to


$90 per day and vary based on the community, the rates of the facility, and the level of care required by the client.\textsuperscript{37} Despite the often high costs for respite care, which is not considered a reimbursable service by Medicare or by most private insurance carriers, there is a demand by private pay clients for this type of service.\textsuperscript{38}

According to Grad and Sainsbury, the families of older clients have more than twice the number of severe problems than do those families of younger clients. The likelihood for institutionalization increases without some type of support for those families.\textsuperscript{39} Respite care can provide needed support and enables home care to be an alternative to institutionalization by improving the mental and social relationship of the caregivers, thereby decreasing the stress that accompanies caregiving.\textsuperscript{40}

An example of one respite care program is one offered by Southern Baptist Hospital in New Orleans, Louisiana. The program began as a weekend program that accepted clients for approximately 48 hours with admittance on Friday afternoon and discharge the following Sunday evening. They now accept clients for up to two weeks every three months. To be eligible for admittance to the program, the client must have a caregiver who is responsible for his or her care, be able to pay for the services rendered while in the program, a physician who is in good standing with the hospital, and be 60 years of age or older (Looney, 1987).

In 1992 at McGuire Veterans Administration Medical Center, a quasi-experimental

\textsuperscript{37} Ibid.

\textsuperscript{38} Ibid.


\textsuperscript{40} Ibid.
design was used to evaluate their Respite Care Program's effectiveness in reducing caregiver burden. Sixteen caregivers who had used respite care comprised the experimental group. Fourteen caregivers who had not received respite care comprised the control group. A multidimensional perspective considering veterans activities of daily living impairment, memory and behavior problems, and the caregivers perception of the situation was used.41

All data was gathered thorough telephone interviews. A T-test revealed a significant difference in ADL impairment between the two groups.42 Pearson's Correlation revealed a significant correlation between memory and behavior problems and burden among the non-respite group, but not among the respite group.43 These findings indicate that respite care reduces caregiver burden related to memory and behavior problems.

A study conducted by Karl Kosloski and Rhonda Montgomery explored the factors that influence the extent to which family caregivers of Alzheimer's patients use publicly subsidized respite programs. A model linking caregiver's attitudes concerning the convenience, quality of care, and perceived usefulness of a particular respite program to levels of respite use was hypothesized and tested.44 One hundred and fourteen caregivers throughout Michigan who were eligible for respite services under the auspices of the Michigan Model Respite Program and caring for a noninstitutionalized elder with


42 Ibid.

43 Ibid.

Alzheimer's disease participated in the study. Controlling for functional limitations of the elder, health for the caregiver, use of other support services, perceptions concerning the usefulness of respite and the convenience of respite use were found to have significant direct effects on the level of actual respite use. The study concluded that perceptions of program convenience affected service use indirectly by influencing caregivers' perceptions of program usefulness.

The aim of respite care services is to alleviate the stress placed of primary caregivers of the frail elderly. An exploratory study conducted by Martha Ozawa and Nancy Morrow-Howell describes an innovative respite care program in Missouri that incorporates a service credit system as an incentive for volunteers to participate. It also presents the findings of an exploratory study on the volunteers who participated in the program. Among other things, the study found that the volunteers' level of satisfaction with the program was extremely high and those who were less healthy, were recipients of Supplemental Security Income, and had never done volunteer work before, took the service credit system more seriously than did others.

Homer and Gilleard conducted a study of 58 carers and their dependents, and found that dependents under the care of a highly stressed carer, usually a relative, show the most improvement during respite care. The carers themselves, however showed

45 Ibid.


47 Ibid.

no reduction in stress, possibly because they worried about the quality of care their
dependents were receiving. Although there was no observable improvement in the carers' emotional well-being, the majority of the patients showed an improvement in functioning, particularly those who were being looked after by highly stressed carers. It was reported that many carers expressed a wish for more respite than they were currently offered, and some would have preferred a more flexible type of service.

Separate research literature pertaining to caregiving within various illness scenarios (e.g., dementia, cancer, heart diseases) have developed in isolation. Therefore, very little is known about the commonalities and differences inherent in various chronic illnesses that may influence the caregiving experience. Obviously, the great variability of chronic illness and dissimilar disease courses present formidable problems to investigators trying to understand what is generalizable about the experience of providing care to an impaired person or veteran.

Since 1988, a small number of studies have compared types of caregivers; unfortunately, results of these studies are mixed. Dura, Haywood-Niler, and Kiecolt-Glaser compared spousal caregivers for patients with two types of dementia, Alzheimer's and Parkinson's disease, finding essentially that both groups of caregivers were significantly distressed and comparably so. Similarly, Liptzin, Grob, and Eisen reported no differences in burden between caregivers of demented patients admitted to a geriatric

49 Ibid.


psychiatric inpatient unit and caregivers of depressed patients on the same unit. They concluded that families of depressed patients may require as much attention as relatives of demented patients. A third study compared caregivers of cognitively impaired, functionally impaired, and non-impaired elderly relatives and found no differences in self-reported health and psychosocial functioning.

By contrast, Cohen and Eisdorfer examined the emotional impact on caregivers of caring for demented family members (e.g., probable Alzheimer's disease, organic brain syndrome) and non-demented terminally ill relatives (e.g., cancer, emphysema). Results of this contrast suggests that caregivers of dementia and non-dementia patients experience the caregiving process differently and that on average, dementing illnesses have a more burdensome emotional impact on the caregiver.

Although some research has suggested that elderly patients' health might be adversely affected by respite admissions, subsequent reports have not observed any increase in patients' mortality, nor any functional deterioration. Clear evidence of substantial benefits to carers of patients has also been lacking. Research on the impact of respite admission on carer well-being has been largely confined to studies of patients with dementia, and the effects of respite care of relatives caring for physically frail elderly


54 Ibid.

people has not been so thoroughly investigated.\textsuperscript{56} This same study suggests that while carers generally do not show any marked improvement in well-being during the course of their dependents' inpatient respite admission stay, the patients themselves more often than not show signs of improved functioning. The study cites that patients were not routinely seen by therapists during their stay, however, nursing care was individualized on the respite care wards, and this style of nursing proved to foster greater physical independence.\textsuperscript{57} The study also revealed that many carers visited regularly, often despite encouragement by the staff to stay away. The reasons for this include the carers' missing their dependent, wanting to check on the type of care provided on the ward, and feeling obliged to show that they had not abandoned their relative. Many carers feel guilty about respite care and this can be made worse if their dependents complain of being abandoned.\textsuperscript{58} These factors combined with the disruption to the carers' lifestyle and the apprehension associated with their dependents' return home all might have offset any psychological benefit derived from the break in caring. Many of the problems of caring for elderly dependents are not addressed by removing the patient from the home for a break, which may not be what the carer wants, and more flexible ways of responding to carers' needs for relief seem to be called for if true respite is to be provided for them. The study concluded that the greatest improvement in functioning was associated with patients looked after by highly stressed relatives, particularly patients who were not suffering from

\textsuperscript{56} Ibid.

\textsuperscript{57} Ibid.

\textsuperscript{58} Ibid.
dementia.

The stress and burden of caregiving have been well established as correlates to changes in the relationship with a person needing care, but there has been less research on the association of caregiving with psychosocial variables, especially relationship patterns. France and Alper addressed these issues using Structural Analysis of Social Behavior, a self-report measure of perceptions of interpersonal relationships and self-concepts, and the Symptom Check List -90-Revised, a self-report measure of distress and symptoms. SASB variables measuring attachment, interdependence, and interpersonal/intrapsychic conflict successfully differentiated community-active caregivers from noncaregivers. SASB measures provided substantially greater discrimination and classification accuracy than SCL-90-R variables.

Theoretical Framework

The literature reviewed strongly suggested that there is a need for the provision of appropriate care for chronically disabled patients, as well as adequate knowledge, understanding, and acceptance of the nature of the condition by the caregiver. The literature reviewed supported the need for appropriate intervention for primary caregivers. In addition, emphasis is placed on the multi-disciplinary approach toward intervention and the use of social services.

The theories that best support the issues raised in this study include (1) The General System Theory and (2) The Societal and Individual Determinants of Medical and

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60 Ibid.

61 Ibid.
Social Care Utilization.

**General System Theory**

The best way to attempt to support the mullet disciplinary approach is that of General Systems Theory. This theory has proven to be stimulating and integrative for the tasks of planning, managing, and evaluating community-wide service delivery systems.\(^{62}\)

General System theory is based on the assumption that there are general principles identical across all levels and types of systems, living and non-living. The writer will restrict the analysis to the levels of individuals and organizations. These systems will consider how efforts of human service organizations might be focused for primary prevention and service integration for individuals.

Berger and Federico discussed the characteristics of systems as the whole is more than the sum of its parts.\(^{63}\) The system has characteristics and activities of the components. The unity of the system derives from the roles and functions of the components.

Anthony Browkowski suggest that every system has a boundary that is more or less open to the environment.\(^{64}\) Every system must import matter and energy across its


boundary to maintain itself as an organized structure and to carry out its productive processes. Organizations responsible for a community should consider the make-up of the community and or geographic areas most affecting factors which promote stress. The information shared between the two systems interconnects and thus becomes a whole.

Societal and Individual Determinants of Medical and Social Care Utilization

Researchers suggest that the average age of the primary caregivers to chronically disabled patients are more often age peers who are often women. Further, the review indicates that the determinants for utilization of services may be best supported by the Medical and Social Service Utilization Theory developed by Anderson and Newman. The framework takes into account both societal and individual determinants. It suggests that the main societal determinants of service utilization are technology and norms. The health care system structures the provision of formal health care goods and services in society. This system consists of two major dimensions: resources and organization. The individual determinants that affect medical and social care utilization includes: (1) the predisposition of the individual to use services, (2) their ability to secure services and (3) the degree of illness.

The theoretical constructs used in this study support the researcher's beliefs that program developers have to concern themselves primarily with the community's responsibility to provide care for individuals within the community regardless of the individual's race, age, financial status or dysfunction.

CHAPTER III
METHODOLOGY

The research design employed in this study is known as the descriptive or explanatory design. This research design is utilized for the development of social technology or information, selection, evaluation, and assembly of relevant basic information for purposes of technological innovation.66

Instrument Design

Survey research provides a means for greater assurance of anonymity, limits interviewer bias, and provides accessibility to larger numbers of persons. The feasibility of survey research is that it is used to increase the knowledge of problems that affect a wide variety of people.

The instrument designed to determine the level of satisfaction of the Respite Care Program was a structured questionnaire. The questionnaire for patients and caregivers consisted of 16 questions. The first group of questions was directed to specifics such as demographic data and referral source. The second group of questions was descriptive and concerned patient and caregiver satisfaction with the Respite Care Program and a section for comments. The staff questionnaire was limited to 10 questions, with eight questions directed to satisfaction level and two questions related to staff identification. Each questionnaire was rated from zero to 8, with 8 being the highest possible score, based on the positive responses received from questionnaire participants. The questionnaire was developed by Willie Newson, a Social Work Service Intern and

approved by Ms. Helen T. Bosshart, Coordinator, Spinal Cord Injury Home Health Care. The Intern was responsible for administering the questionnaire to the staff and conducting telephone interviews of patients and caregivers. The questionnaire was tested by social workers in the Social Work Service Department, VA Medical Center, Augusta, Georgia.

Sample

The initial sample population consisted of 100 participants. 87 personnel responded; which included 14 patients, 18 caregivers and 55 staff personnel. Random sampling was used to select patient and caregiver population. Staff members having more than six months experience with Respite Care Program were selected.

Hypothesis

There will be no significant difference between patients, caregivers and staff level of satisfaction with Respite Care offered at the VA Medical Center, Augusta, Georgia.
CHAPTER IV

PRESENTATION OF RESULTS

This chapter is a summary of the data collected from patients, caregivers and staff of the VA Medical Center, Augusta, Georgia in this study. The results of this study are presented in Figures 1 - 7.

The average number of days that patients spent at the medical center for respite care was 11. The survey respondents consisted of 100 people. Out of the 100, 87 responses were received. The level of participation was 70% from patients, 90% from caregivers, and 92% from staff.

Figure 1 presents the overall level of satisfaction for the Respite Care Program as positive. The program objective was to provide caregivers with temporary relief from daily responsibilities of caring for chronically ill veterans. Caregivers scored the highest: level 6 out of a possible 8. Patients and staff scored at level 5 for overall satisfaction with respite care.

Spinal Cord Injury patients and caregivers expressed the same satisfaction level of 6, whereas the staff score of 4 indicates some reservations about the program (Figure 2). The caregivers in Intermediate Medicine measured the highest, level 7 (Figure 3). Figure 4 depicts Psychiatry staff and caregivers level of satisfaction at 5, while patients measured lowest of all groups at level 3, a 50% decrease compared to patients in Spinal Cord Injury and Intermediate Medicine. Figure 6 shows how patients and caregivers rated the respite care program, and there is general agreement among patients and their caregivers as to their level of satisfaction.

One important element of any respite care program is the staff. Input was collected from 55 staff members. Figure 7 shows the satisfaction level of members of the multi-disciplinary team working with respite care. Social Workers measured highest at
level 6, whereas Nursing measured lowest at level 4. The majority of the concerns from the nursing staff dealt with the workload required for patient care.
Figure 1. Overall Satisfaction Level
*Respite Care Program*

![Bar graph showing overall satisfaction level for patients, caregivers, and staff.]

N=87

Figure 2. Spinal Cord Injury Satisfaction Level
*Respite Care Program*

![Bar graph showing spinal cord injury satisfaction level for patients, caregivers, and staff.]

Patients - 6  Caregivers - 6  Staff - 22
Figure 3. Intermediate Medicine Satisfaction Level
Respite Care Program

Figure 4. Psychiatry Satisfaction Level
Respite Care Program
Figure 5. SCI/IM/PSYCH Satisfaction Level

*Respite Care Program*

![Bar chart showing satisfaction levels for SCI, Intermediate Medicine, and Psychiatry departments, comparing patients, caregivers, and staff.]

Figure 6. Patient vs. Caregivers Satisfaction Level

*Respite Care Program*

![Bar chart showing comparison of patient and caregiver satisfaction levels across SCI, Intermediate Medicine, and Psychiatry departments.]

Figure 7. Staff Satisfaction Level

_Respite Care Program_
CHAPTER V
SUMMARY AND CONCLUSION

The results of this study indicate that the consumers of respite care services are needy people who are in most instances performing superhuman feats in caring for their family members and themselves. Over 90% of family members surveyed were pleased with the VA Medical Center's response time for respite care dates. Sixty-one percent of the caregivers reported improvement in their health status, a combination of their physical and mental state of being following respite stay. An indicator of how effective a program is reflected by the referral rate and 89% of the caregivers indicated that they would refer the program to others. A final indicator is reuse and 71% of the patients stated that they would use the respite program again.

Because of the growing number of chronically ill and frail elderly populations in need of long-term health care services, further research is needed. The long-term care and treatment should be a part of a broad continuum of service, including both home health care and institutional care. In most instances, home health care should be recognized as an option to be considered and ruled out before placement in a long-term residential health care facility is made.

The Respite Care Program at the VA Medical Center, Augusta, Georgia, continues to be a challenge. Faced with downsizing, bed space restriction, and the move to more outpatient services versus inpatient care, the program must be capable of change and adaptation to specific situations. Each service provider within the system is challenged to adapt their services to meet the individual's unique needs. Respite is a program that makes sense today, as the demand for nursing home beds far exceeds the supply. It is a program that is still in the growing stages and is in great demand by those who have been exposed to it.
Limitations of the Study

Limitations in this study include the lack of complete individual attention in the medical setting able to be focused on the patient to determine significant improvements. Also, the unlikely possibility that some unknown concurrent historical variable was responsible for the observed improvements in the caregiver's physical and mental state of being during respite care periods.

Suggested Research Directions

Caregivers are not all alike and the factors that characterize those differences are important considerations in the study of family burden. Research should focus on the interrelationship of ethnicity and kinship roles to detect similarities and differences essential for development of appropriate intervention that help different family members manage their caregiving responsibilities and reduce their burden.
CHAPTER VI
IMPLICATIONS FOR SOCIAL WORK PRACTICE

There is consensus among social workers that one of the difficulties in the service delivery for long-term care has been the medicalization of social needs. This trend has occurred primarily because funds for health care, largely under Medical Assistance funding have been more readily available than support for social services. Nevertheless, it is important to remember that many of the services that help to maintain the elderly in the community are supportive social services. It will become increasingly apparent as society continues to explore ways to provide alternatives to nursing home care that the expertise of social workers is essential in the development of services that address elderly people's social needs. Psychosocial assessment and evaluation of the strengths of existing informal support systems. There are identifiable points in the case-management process in assessment and in care planning in which this expertise is required.

The researcher has suggested that practitioners who make decisions about care planning can change providers' market behavior, stimulate the development of new programs, and alter the distribution of funding. Care planning provides an opportunity for social workers to operate as change agents in their local communities by developing case management for the elderly. Social work professionals bring needed expertise in the form of their assessment skills and bring important knowledge about how to change the system.

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through program development, exercising influence, and creative planning. If the provision of services is to move from a narrowly medical approach of long-term care toward a perspective that more accurately addresses elderly people's needs for social services, social workers will have to play a central role in the future development of community-based long-term care.

Concerns for cost containment need to be balanced by an awareness of the need to protect vulnerable individuals and ensure equity in decisions about care planning. Providing the full continuum of care means offering social service programs that maximize independence for the aged. Now and in the future, social workers in health care need to move into positions in which they influence the development of policy for long-term care, program design, and decision making areas in which they can make valuable contributions
APPENDIX A

PATIENT QUESTIONNAIRE

Your cooperation in completing this questionnaire is greatly appreciated. All information will be kept confidential and destroyed after 3 months. The information you provide will assist in the program evaluation and enable us to enhance the delivery of services to Respite Care Patients.

1. How did you learn about the Respite Care Program?
   (13) a. Health Care professional (physician, nurse, social worker, psychologist)
   b. Media (PVA newsletter, VA pamphlet, newspaper, etc.)
   (1) c. Other

2. Why did you get involved in the Respite Care Program?
   (13) a. Caregiver requested a respite from caring from the patient.
   b. Patient requested a respite from the caregiver.
   (1) c. Caregiver's health problems.
   d. Other

3. What is your relationship to your caregiver?
   (6) a. Spouse
   (8) b. Family member
   c. Other

4. Do you live in the same household with your caregiver?
   (14) a. Yes
   b. No

5. How long have you had a caregiver?
   (5) a. 0 - 5 years
   (3) b. 5 - 10 years
   (6) c. more than 10 years

6. How would you rate your health status?
   a. Excellent
   (13) b. Fair
   (1) c. Poor

7. How has the most recent use of the Respite Program effected your health status?
   (2) a. Improved health
   (11) b. No change
   (1) c. Health got worse
8. How close did the VA come to meeting your requested Respite Care dates?
   (13) a. Very close
   b. Not close at all
   (1) c. dates did not matter

9. How much information did you receive about the program prior to your admission?
   a. Too much
   (1) b. Not enough
   (13) c. The right amount

10. How did you spend your time while in the Respite Care program?
   (1) a. Stayed in bed
   b. Participated in recreational activities provided
   (8) c. Socialized with other patients on the ward
   (5) d. Other

11. How would you judge your length of Respite stay?
   (1) a. Too long
   (12) b. Just right
   (1) c. Too short

12. Were you considering nursing home placement prior to the Respite Care admission?
   a. Yes
   (11) b. No
   (3) c. Undecided

13. Are you considering nursing home placement since the Respite Care admission?
   a. Yes
   (13) b. No
   (1) c. Undecided

14. What is the level of satisfaction with the Respite Care program at the VA Medical Center, Augusta, Georgia?
   (4) a. Excellent
   (7) b. Good
   (2) c. Fair
   (1) d. Poor
   If poor, please explain your dissatisfaction

15. Would you use the program again?
   (10) a. Yes
   (2) b. No
   (2) c. Undecided
   If no, please explain
16. Would you recommend the program to other patients?
   (10)  a. Yes
   (2) b. No
   (2) c. Undecided
       If no, please explain________________________________________

17. Please offer any suggestions, feedback or concerns you may have about the Respite Care Program.
______________________________________________________________
______________________________________________________________
______________________________________________________________

Thank you very much for your participation.
APPENDIX B
CAREGIVER QUESTIONNAIRE

Your cooperation in completing this questionnaire is greatly appreciated. All information will be kept confidential and destroyed after 3 months. The information you provide will assist in the program evaluation and enable us to enhance the delivery of services to Respite Care Patients.

1. How did you learn about the Respite Care Program?
   (17) a. Health Care professional (physician, nurse, social worker, psychologist)
   b. Media (PVA newsletter, VA pamphlet, newspaper, etc.)
   (1) c. Other

2. Why did you get involved in the Respite Care program?
   (14) a. Caregiver requested a respite from caring for the patient.
   b. Patient requested a respite from the caregiver.
   (2) c. Caregiver's health problems.
   (2) d. Other

3. What is your relationship to the patient?
   (9) a. Spouse
   (8) b. Family member
   (1) c. Other

4. Do you live in the same household with the patient?
   (17) a. Yes
   (1) b. No

5. How long have you been the veteran's caregiver?
   (6) a. 0 - 5 years
   (6) b. 5 - 10 years
   (6) c. more than 10 years

6. How would you rate your health status?
   (2) a. Excellent
   (12) b. Fair
   (4) c. Poor

7. How has the most recent use of the Respite Program effected your health status?
   (11) a. Improved health
   (4) b. No change
   (3) c. Health got worse
8. How close did the VA come to meeting your requested Respite Care dates?
   (16) a. Very close
   b. Not close at all
   (2) c. Did not matter

9. Did you receive adequate information about the program prior to the patient's admission?
   a. Too much
   (1) b. Not enough
   (17) c. The right amount

10. How did you spend your time while the patient was in the Respite Care Program?
    (5) a. Vacation
    (2) b. Stayed home
    (3) c. Leisure activities
    (8) d. Other

11. How would you judge the length of your Respite stay?
    (2) a. Too long
    (15) b. Just right
    (1) c. Too short

12. Were you considering nursing home placement for the patient prior to the Respite Care Admission?
    (2) a. Yes
    (15) b. No
    (1) c. Undecided

13. Are you considering nursing home placement since the Respite Care admission?
    (3) a. Yes
    (14) b. No
    (1) c. Undecided

14. What is your level of satisfaction with the Respite Care program at the VA Medical Center Augusta, Georgia?
    (8) a. Excellent
    (8) b. Good
    c. Fair
    (2) d. Poor
    If poor, Please explain your dissatisfaction

15. Would you use the program again?
    (15) a. Yes
    (3) b. No
    c. Undecided
If no, please explain________________________________________

16. Would you recommend the program to other patients?
   (16) a. Yes
   (2)   b. No
   c. Undecided
   If no, please explain________________________________________

17. Please offer any suggestions, feedback or concerns you may have about the Respite Care Program.

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Thank you very much for your participation.
APPENDIX C

STAFF QUESTIONNAIRE

Your cooperation in completing this questionnaire is greatly appreciated. All information will be kept confidential and destroyed after 3 months. The information you provide will assist in the program evaluation and enable us to enhance the delivery of services to Respite Care Patients.

1. What is your position and unit at the VA Medical Center?

2. How long have you worked with patients in the Respite Care Program at the VA Medical Center, Augusta, Georgia?
   (10) a. 6 months to 1 Yr
   (14) b. 1 - 2 Yrs
   (28) c. 3 Yrs
   (3) no response

3. Do you agree with the concept of Respite Care?
   (35) a. Agree
   (9) b. Neutral
   (9) c. Disagree
   (2) no response

4. Respite Care patients benefit from the treatment and services offered at the Medical Center?
   (33) a. Agree
   (15) b. Neutral
   (6) c. Disagree
   (1) no response

5. Respite caregivers benefit from the services offered at the VA Medical Center, Augusta, Georgia.
   (36) a. Agree
   (12) b. Neutral
   (6) c. Disagree
   (1) no response

6. Do you have sufficient information on the Respite Care Program?
   (39) a. I have sufficient knowledge
   (7) b. I do not have sufficient knowledge
   (7) c. I would like additional training
   (2) no response
7. Has the Respite Care Program impacted on morale on the unit?
   (3) a. Improved morale
   (23) b. Decreased morale
   (25) c. Morale not affected
   (4) no response

8. How do you view the workload required for Respite Care?
   (26) a. Worthwhile
   (15) b. Undecided
   (11) c. Not worthwhile
   (3) no response

9. Would you recommend the Respite Care Program to all qualified patients?
   (37) a. Yes
   (10) b. No
   (8) c. Undecided

10. What is your level of satisfaction with the Respite Care Program at the VA Medical Center in Augusta, Georgia?
    (8) a. Excellent
    (23) b. Good
    (14) c. Fair
    (7) d. Poor
    (3) no response

11. Please offer any suggestions, feedback, or concerns you have about the Respite Care Program.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Thank you for your time and cooperation.

8/1/95
APPENDIX D

July 18, 1995

Dear Respondent:

I am a student intern in Spinal Cord Injury Unit and a student at Clark Atlanta University School of Social Work, and I am conducting a study to measure the level of satisfaction of the Respite Care Program at the VA Medical Center, Augusta, Georgia. I will be deeply grateful if you would participate in this study by completing the attached questionnaire.

I fully understand that the information I am seeking is highly personal and will be kept confidential to insure that no one will be able to recognize your individual responses. I am confident that your voluntary participation in this research will make a significant contribution to the enhancement of Respite Care at the VA Medical Center, Augusta, Georgia.

Please answer each item as carefully and accurately as possible. Please complete the questionnaire and return it to me in Social Work Services, Downtown Division, 122, no later than August 8, 1995.

Thank you for your participation in this endeavor.

Sincerely,

Willie L. Newson
Social Work Service, Intern


