1993

The effects of inpatient respite on the health care utilization of the care receiver

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DOI: <https://doi.org/10.31979/etd.kc4y-z5w3>
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Okrongly, Mary Ann, M.S.

San Jose State University, 1993

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THE EFFECTS OF INPATIENT RESPITE ON THE HEALTH CARE
UTILIZATION OF THE CARE RECEIVER

A Thesis

Presented to

The Faculty of the School of Nursing
San Jose State University

In Partial Fulfillment

of the Requirements for the Degree
Master of Science

By

Mary Ann Okrongly

December, 1993

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Mary Ann Okrongly

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ABSTRACT

THE EFFECTS OF INPATIENT RESPITE ON THE HEALTH CARE UTILIZATION OF THE CARE RECEIVER

by Mary Ann Okrongly

This thesis describes health care services utilized by a group of 10 Inpatient Respite Program patients over a 12 week period immediately post-respite discharge. Using a longitudinal follow-up study design, data were collected every 2 weeks for a 12 week period. Data included the amount, type, and frequency of health care services each participant used and the perceived health of his family caregiver, who often made health care decisions for her care receiver.

The data indicate that the most common type of health care utilized by participants was scheduled and unscheduled outpatient visits. Home health care was the second most common type of health care utilized, followed by the Emergency Room. No care receivers required an inpatient admission to an acute care facility or nursing home during this 12 week period. The decision concerning the type of health care used was at times dependent on the perceived health of caregivers.

ACKNOWLEDGMENTS

To my family and
friends who contributed
their support and friendship
and to the veterans who
contributed by their
participation

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Chapter 1

INTRODUCTION

The purpose of this study was to determine the impact of an Inpatient Respite Program (IRP) on the amount of health care utilization by elderly care receivers. Impact was measured by determining the health care utilization of the care receiver over a 3 month period immediately following an inpatient respite stay. The type, amount, and frequency of health care utilized by care receivers was recorded by them or their family caregivers and analyzed for a 12 week period following respite discharge.

Respite care is defined as a service providing family caregivers intermittent periods of relief from the burdens of caregiving. These periods are usually planned in advance; however, the service is also provided on an emergency referral basis. By providing periods of caregiving assistance and skilled nursing and interdisciplinary evaluations for the care receiver, respite care is recognized as a service which may prolong the time a care receiver can remain in the community, thereby delaying institutionalization.

The Family Survival Project, recently renamed the Family Caregiver Alliance, reported that the state of California had more than 2,000 families of functionally impaired adults on waiting lists for respite care at the state's 11 Caregiver Resource Centers ("Charting the Future," 1992). These centers provide weekend respite to those families most in need of relief from the burden of caregiving. Funding for these much needed services comes from a combination of participant fees, private donations, and fund raising events. Inpatient respite services, although common in several European countries, are uncommon to the United States. Inpatient respite programs provide all the

services of an adult day care center plus skilled nursing and medical care, such as assessment of hydration and nutritional status. Interdisciplinary care, such as physical and occupational therapy, are provided during the stay. When used as a link between in-home care and institutionalization, respite can ease the transition to an institutional residence.

Elderly care receivers and their caregivers were selected from the IRP at a Veterans Affairs (VA) Medical Center's Nursing Home Care Unit, a highly regarded unit in existence for 10 years. Inpatient respite service is not widely available to caregivers and care receivers in the community at large; however, this unit delivers an innovative continuum of care model for care receivers. The decision to refer a person to the VA Nursing Home IRP is usually a joint one between the primary family caregiver and a health care team member such as a nurse or social worker. Initial referral is made to a member of the health care team and an assessment is performed by the team member, who then presents the case to an interdisciplinary screening committee. Based on the presentation, a decision is made to schedule the care receiver and family caregiver for a tour of the Nursing Home Care Unit and a brief inpatient respite trial. If this trial is successful, the care receiver can be admitted to the IRP for up to four weeks each year. Typical stays are between one and two weeks in length. It should be noted that the health care agency used in this study is the sole health provider for these frail care receivers through its many intervention programs, an advantage many respite users do not have. Most caregivers currently using this service state the need for more frequent inpatient respite admissions and express benefit from the continuum of care model.

Consents were obtained from caregivers after discussion of voluntary

participation and reciprocal expectations. Family caregivers were responsible for data collection and communication with the investigator. However, one care receiver was able to record his own data and communicate on a biweekly basis. All care receivers had varying degrees of chronic illness, with multiple medical and psychiatric diagnoses represented. In cases where caregivers were directly responsible for the data collection and, hence, total care of the care receiver, they were very receptive to talking about the health care needs of care receivers and their own perceived health. All caregivers reported a high degree of stress and burden related to their caregiving roles, regardless of the amount of care they actually delivered.

The Problem and Research Questions

There are few studies available describing the benefits of respite for the care receiver; studies available on the effectiveness of respite services in general are inconclusive and contradictory. Current research yields little information on the evaluation of inpatient respite. Specifically, there is a scarcity of documentation on the overall health benefits and cost effectiveness of extended care programs such as inpatient respite. No study has to date researched amount and cost of health care utilized by care receivers after respite. Overall, this limited body of research points to the need for well designed studies that document cost effectiveness of respite services in relation to the health care utilization of care receivers and caregivers, and in savings due to delay of institutionalization of the care receiver. The research question for this study was what requirements do clients who use an inpatient respite service have for scheduled or unscheduled health care appointments after discharge from respite care?

Purpose and Need

Health care usage by the elderly is of critical importance to the present health spending of this nation. The Department of Health and Human Services (DHHS), as cited by Pear (1993), estimates that fiscal 1992 national spending for health care amounted to \$768 billion. Contributing to that cost estimate were many sources: for example, the American Hospital Association which provides data on hospital spending; the Internal Revenue Service which provides data on doctors' incomes; and Commerce Department agencies, such as the Census Bureau, which estimate spending for drugs and nursing homes. Concurrent information from the National Medical Care Utilization and Expenditure Survey, documented in a study by Garfinkel, Riley, and Iannacchione (1988), describes health care usage of elderly, high cost users, who are a relatively small percentage of the population, but who consume an extremely large share of medical care resources. Results of this study showed that persons over 65 years of age were more likely than those under the age of 65 to be included in high cost categories, reflecting the use of acute or intensive care resources among older persons. In addition, the average per capita out-of-pocket expenditure for persons 65 years of age or over, excluding medical premiums, was more than twice that of persons under age 65.

Garfinkel et al. (1988) maintain that the health status of the elderly directly affects the amount of health care services they consume. They suggest that in situations where the elderly are unable to care for themselves but are cared for in their homes by family caregivers, the amount of health care consumed may be related to the health status of both the care receiver and the caregiver.

Studies of caregivers conducted by Brody (1981) and Brody, Poulshock, and Masciocchi (1978) have found family caregivers to be highly responsible agents who provide substantial physical, emotional, social, and economical support to chronically ill care receivers, usually older relatives. However, caregiving often negatively impacts family caregivers who themselves develop health problems in response to the stressors inherent in the caregiving role. Studies by Blazer (1978) and Koopman-Boyden and Wells (1979) show that anxiety, depression, marital and family conflict, and fatigue are frequent consequences of caring for a family member who is suffering from a chronic illness. In addition, caregivers are likely to experience a reduction in social activity and leisure time and feelings of guilt and resentment.

Gallagher-Thompson, Brooks, Bliwise, Leader, and Yesavage (1992) concluded that caregiving can be an arduous and debilitating experience. Respite care programs are an intervention which may reduce one or several of the above mentioned negative correlates to prolonged caregiving in addition to providing the care receiver intermittent skilled assessment and intervention by an interdisciplinary health care team. Striking a balance between providing available resources or support services and meeting the needs of the chronically ill elderly population is a current major health care dilemma.

Robertson, Griffiths, and Cosin (1977) describe the functioning of one British inpatient respite program that became a model program emulated by others. They indicated that the planned intermittent use of an inpatient respite bed allowed caregivers to temporarily place their frail elder when caregivers themselves needed medical procedures, surgery, or a vacation period. Family members rated these services as "essential" or "very useful," although more

detailed evaluation data about the impact of this program on caregiver well-being were not reported.

Collins, Stommel, King, and Given (1991) contend that the attitude of family caregivers toward community services influences the utilization of programs. Attitudes regarding the acceptability of using the formal service system and attitudes about the quality of services are two areas of caregiver concern. Their study showed that many family caregivers, especially wives, feel obligated to provide the care exclusively as part of their spousal duties. They feel society makes them totally responsible for the care of loved ones. Ethnic, cultural, and familial differences may also influence their utilization of services outside the home.

Respite services developed to meet the needs of caregivers have evolved into different types of programs such as home care, daycare centers, and inpatient facilities. Miller and Goldman (1989) discuss how use of all types of respite services benefit caregivers by helping them see other care options, including the realization that good care can be provided without compromising their own physical and emotional well-being. Berry, Zarit, and Rabatin (1991) report positive mental health and improved social relationships for the caregiver as a result of respite care of any kind. But what of the care receiver?

Few evaluative studies of respite exist, especially those examining care receiver benefit. A study by Burdez, Eaton, and Bond (1988) found that problems diminished significantly for care receivers in the treatment group who received respite, as compared to the waiting-list group who did not receive respite care. However, they found that caregiver burden was not significantly affected by respite intervention. No other reports on the impact of an inpatient

respite program for care receivers could be found.

Studies by Gonyea (1987), Miller and Goldman (1989), and Scharlach and Frenzel (1986) propose that the ideal respite care should be preventive, rather than crisis oriented. Regular and planned relief is an effort to intervene before the caregiving situation escalates to a crisis point. The goal would be relief, not guilt, for the caregiver and prevention of abrupt institutionalization for the care receiver, outcomes often seen following a crisis.

Definition of Terms

For the purpose of this study, the following definitions apply:

1. Respite - a service providing caregivers intermittent periods of relief from the burdens of caregiving.
2. Caregiver - a family member providing the majority of the in-home care for a care receiver.
3. Care receiver - a chronically ill person who is enrolled as an inpatient in the Respite Program, but otherwise cared for at home by a family caregiver.
4. Inpatient Respite Program (IRP) - a program, such as the one accessed in this study, where clients are admitted to a health care facility for a brief period of time to give caregivers relief and care receivers the benefits of health care assessments and socialization with other clients.

Research and Design

Using a longitudinal follow-up design, this study researched a convenience sample of 10 male veteran users of a Veterans Affairs Medical Center's Inpatient Respite Program. All subjects were voluntary; no care receiver was denied IRP services if unwilling to participate in the study. Subjects were given a health diary, which they or their caregivers used to

record data on the amount, type, and frequency of health care used for each 2 week interval over a 12 week post-respite period (Appendix A). The investigator contacted the caregiver or care receiver once during each 2 week interval for 12 weeks. During this telephone contact, health usage information was extracted from the diary and copied onto a similar diary used by the investigator. The study objective was to measure the usage of health care by the care receiver. Variables of the study were respite, the independent variable, and usage of health care, the dependent variable. The setting of this study was a 10 bed Inpatient Respite Unit of a government Veterans Affairs Nursing Home Care Unit. The target population consisted of male veterans who were active participants in an Inpatient Respite Program and who were receiving at least 2 weeks of respite during one scheduled visit. Data were gathered on the first day of discharge from the respite visit and continued biweekly for 12 weeks thereafter. Data were gathered by telephone contacts made by the investigator with the caregiver or care receiver. Instruments used were a demographic form (Appendix B) and health diary, which captured health care variables over the 12 week duration. Data were analyzed using descriptive analysis such as grouping of data by frequencies and percentages from the tallies of demographic answers and health diary entries.

Scope and Limitations

This study was designed to capture the amount of health care used by participants of an inpatient respite program during a 12 week period immediately post-respite stay. This study design did not allow for comparison of data on health care usage during a pre-respite period of time. It was conducted at one location and the convenience sample size was small. No controls were

in place for demographic variables such as age or pre-existing medical conditions, limitations which could have affected the study findings. The instruments were investigator-developed and were not subject to psychometric testing.

Chapter 2
CONCEPTUAL FRAMEWORK AND REVIEW
OF RELATED LITERATURE
Conceptual Framework

Andersen's Behavioral Model was first developed by Andersen in 1968 and revised by Aday, Andersen, and Fleming in 1980. It has been used widely by health care utilization researchers such as Branch and Nemeth (1985), Hibbard and Pope (1986), Hibbard and Weeks (1987), Jewett, Hibbard, and Weeks (1992), Wan (1987), and Wolinsky and Coe (1984) as a framework for studying older adults' utilization of health services. The sociocultural component of this model assesses the effects of individuals' predisposing factors, enabling factors, and need factors on the use of health services by non-institutionalized adults.

The Andersen Behavioral Model postulates that some people have a greater propensity, or predisposition, for using health services than do others. These propensities are predicted from individual characteristics present prior to an episode of illness. Demographics, social structure, and health beliefs are elements of the predisposing factor. Demographics, such as age, marital status, sex, and family size are believed by Andersen to be indicators of a person's relative life cycle position, which, in turn, influences health behavior. Social structure, measured by employment history, education, and ethnicity, are indicators of social relationships and life style. Health beliefs are typically measured by attitudes about medical care, physician ability, and disease and by worries about health.

The enabling factor's influence is based on the assumption that although

people may be predisposed to use health services, they must have the means for obtaining these services. Two elements that measure the enabling factor are community influence and personal ability to provide for care. Self care is measured by familial resources or income, presence of health insurance, and a regular source of health care. Economic influence is measured by community resources, physician-hospital and bed-to-population ratios, geographic location, and population density indexes.

According to Andersen (1968), his predisposing and enabling factors make it possible for individuals to consume health services; however, there must be a perceived need, such as an illness or high risk of one, to receive care. He purports that this need factor is the most significant stimulus for health service utilization. He attributes two elements to this need factor, the first of which he identifies as the perceived health status of the individual as measured by self-reporting. The second element is that of professional assessment of health needs and activity limitations as measured by activities of daily living (ADL) abilities. These elements can trigger the person's recognition that a health problem exists or is imminent and can serve as a stimulus for health care consumption.

Studies by Branch and Nemeth (1985); Hibbard and Pope (1986); Jewett, Hibbard, and Weeks (1992); Rosner, Namazi, and Wykle (1988); Wan (1987); and Wolinsky and Coe (1984) used Andersen's Behavioral Model as a predictor of health care usage. All concurred with Andersen's findings that need factors account for most of the variance in health service usage.

The use of this conceptual framework to understand health care utilization of the elderly is helpful, especially pertaining to the perceived need of

care receivers and, in many cases, their family caregivers. Because this framework suggests that need is the strongest determinant for using health care, the health diary included a question about each caregiver's health status.

Review of Related Literature

Respite services came into existence during the 1970s when management issues such as funding, organizing, and selecting models of care; educating staff and the public; and implementing and evaluating services were being discussed. Van Werkhoven (1992) relates that this respite concept was a result of "the 1970 movement to decentralize care of the mentally and chronically disabled from an institution into a home setting." In the 1980s respite was adapted to serve the needs of family caregivers who provide long term care for more than 80% of frail elderly persons in our society. Approximately 70%-100% of family caregivers are females, 45%-90% of whom are spouses of the care receivers and between the ages of 60-75 years. Caregivers are frequently under a great deal of emotional and physical stress and therefore depend on respite care programs to maintain their physical strength and to provide the care receiver with health assessment, nursing care, and peer socialization. As a result, respite care programs may prevent or delay nursing home placement of care receivers.

There are several different models of respite care for the elderly described in the literature. Van Werkhoven (1992) describes the most common programs as (a) adult day-care, which is community-based and available 1 to 5 days per week during specific hours; (b) inpatient respite, which refers to overnight nursing home stays of up to 2 weeks duration; and (c) those programs specially designed for persons with Alzheimer's disease and related

disorders. These last programs may be day care or provided in an inpatient locked or secured setting. The services of all types of respite programs may include rehabilitation therapy, nursing services, and educational classes for the caregiver and care receiver to help patients continue living in the home. Inpatient respite programs have been developed only on a limited scale in this country. Respite is most commonly known in this country as a day care model, in which family caregivers can bring their disabled family member to a center staffed by health care professionals who provide activities and socialization for the care receiver and community referral for both caregivers and care receivers.

Scharlach and Frenzel (1986) report that respite care strengthens the family's existing natural support system by promoting a much needed interface between the formal and informal providers of care. Traditional long term care programs provide medical, nursing, rehabilitative, and social services to chronically disabled or frail care receivers in an institutionalized setting. An added advantage of respite care is that it provides an opportunity for medical, nursing, and social service assessments of high risk patients before a crisis occurs in the home setting, thus potentially averting or delaying institutionalization of the care receiver.

While many studies have reported the benefits of respite, a 1993 study by Hirsh, Davies, Boatwright, and Ochango cites a noteworthy negative impact. They identified that, in patients with severe cognitive impairment, respite may negatively affect their functional dependence and behavior upon their return to the home setting. This negative effect could temporarily increase the burden of care for the caregiver.

Utilization of health services by the elderly population has been explored

by several studies including those by Beland (1988) and Wolinsky and Johnson (1991). Identification of services that impact health utilization of the population, such as respite care, has not been directly addressed. What has been documented is that the elderly are absorbing greater and greater amounts of health care services.

Callahan (1992) has authored a controversial article stating that a disparity in use of health care resources exists in the United States, with most of the nation's health care consumed by the elderly, who are collectively the wealthiest citizens, and the least health care directed toward the young, the nation's poorest citizens. He suggests rationing health care and redirecting priorities by better balancing acute care and long term care services for the chronically ill. He states that rationing will be needed because this nation will see a doubling of the elderly population over the next 30 years and a concurrent use of high cost technology used to further the life span of the elderly. He challenges leaders of this country to develop a health care system that will focus more on providing care, preventing premature death, and improving quality of life, and less on saving the lives of the very old and incurably ill at great cost.

Research conducted by Gonyea (1987) shows that elderly persons under the care of a family member are affected by caregiver variables such as emotional and physical health, age, relationship to care receiver, income, support system, and commitment. Warren and Cohen (1985) discuss the fact that as both the caregiver and care receiver get older, more frail, and in need of more health care, the potential for the caregiver to need skilled assistance in maintaining the daily care of the care receiver is evident. Both studies suggest

that as family caregivers become overloaded with responsibilities, care receivers' needs may be overlooked. Mahoney, Hyland, and Twomey (1990) suggest that family support services such as respite care may prevent caregiver overload and may, in fact, prevent visits to emergency rooms and unplanned admissions to acute care and may delay the need for institutionalization of the care receiver.

In the current study, Andersen's need factor was demonstrated by caregivers' perception of the care receivers' health states. Usage of health care, as measured by services such as visits to outpatient clinics, emergency room trips, and home care visits resulted from not only complaints of the care receivers but also from the perceived inability of caregivers to manage care receivers health problems due to caregivers' own declining physical or mental health. In several cases, health care decisions for care receivers were dependent on the caregivers' own health conditions.

Chapter 3
THE METHOD
Research Design

This study was of a longitudinal follow-up design (Polit & Hungler, 1983) in which the participants were surveyed every 2 weeks over a 12 week period. Human subjects approval was provided by the Human Subjects-Institutional Review Board (Appendix C). The independent variable in this study was respite care and the dependent variable was usage of health care following discharge from respite care. The objective of this study was to measure the usage of health care for the care receiver for 12 weeks after discharge. The question asked during the study was what requirements do clients who use an inpatient respite service have for scheduled or unscheduled health care appointments after discharge from respite care?

The setting of this study was the 10 bed IRP of a Veterans Affairs Nursing Home Care Unit. The target population consisted of male veterans who were currently receiving respite services of approximately 2 weeks duration. The investigator interviewed at least 15 patients until finding 10 patients who, along with their family caregivers, were willing to participate in the study. Care receivers were selected based on time of admission and discharge from the program and willingness to participate in the study. Subjects received an average of 2 weeks IRP stay prior to their discharge to home. Data collection began on the day of discharge and continued for 12 weeks following the respite stay. Each subject and his caregiver were given a packet containing a health diary for each 2 week period, a demographic data instrument, and a copy of their consent forms. The health diary was individualized for each care receiver,

with name and dates of the 2 week data collection period on each form.

Questions asked in the diary were: (a) did the care receiver have any health care visits, (b) did the care receiver go to an Emergency Room and, if yes, was an ambulance called, (c) did the receiver sleep overnight in either a hospital or nursing home during this time, (d) did the care receiver have a home health visit, and (e) what is the perceived health of the person completing the diary? (Appendix A).

The investigator introduced herself to potential subjects on the day before their discharges from the IRP to solicit volunteer subjects and, based on their positive responses, returned with research packets on the morning of discharge to meet their caregivers and complete consents. The questions on the health diary were explained to caregivers and care receivers, all of whom said that they understood the questions and felt confident in using their diaries correctly.

A schedule for telephone contact was determined, based on the convenience of the participants and their caregivers. Phone contact was made at the same time every 2 weeks. In all but one case, health diary communication took place between the investigator and the caregiver. For one subject, the investigator communicated directly with the care receiver, who also maintained his own diary. Each telephone contact took an average of 20 minutes every two weeks.

The dependent variable, usage of health care, was defined as the number of outpatient health care visits, emergency room visits, acute care admissions, nursing home admissions, and/or home health care visits. Caregivers were asked to record whenever their care receiver used any listed

category of health care. The investigator phoned the caregivers every 2 weeks and asked each question on the diary. Answers were transcribed onto the investigator's duplicate form. All responses were validated through medical record review.

Telephone contacts were made at 2 week intervals, a time span caregivers told the investigator they felt was appropriate. The caregivers could recall each episode of health care utilization in that amount of time between contacts. In one case, however, the caregiver requested contacts every month instead of every 2 weeks, due to her feelings of overwhelming responsibility for her care receiver and other family members. Each caregiver verbalized her ability to document health care used by her care receiver. Most caregivers agreed that it was useful to keep this record and they felt it was interesting reviewing exactly how many times they had to provide some type of health care. In addition, most caregivers were grateful for the opportunity to discuss decisions they had made concerning health care for care receivers. As a result of the communication with caregivers and of medical record review, the investigator deemed the health diary information as accurate.

Analysis of the Data

All data collected were analyzed using descriptive statistics to determine the amount, type and frequency of health care each participant used during the 12 week post-respite collection period. Data were coded according to the care receivers' social security numbers and stored in a confidential and secured area. Data were grouped by question and across subjects. Demographic data were compiled as frequencies and percentages. Health care utilization data were analyzed by calculating the frequency of usage of specific health care

options. Averages were determined for both the demographic data and number of health care visits.

Chapter 4

ANALYSIS AND INTERPRETATION OF DATA

Data collected on each care receiver included demographic information and usage of health care over a 12 week period post-respite stay.

Sample Characteristics

Table 1 summarizes the demographic data of the care receivers, seven Caucasians and three African-Americans. The age of the care receivers ranged from 42 to 94 years, with most participants between the ages of 60 to 80 years, with a mean age of 72 years. All care receivers were male veterans of United States military service and eligible for VA medical services. Eight care receivers were married and had wives who were their caregivers. The 2 unmarried care receivers had female caregivers, one, a sister, and the other, a live-in girlfriend. The level of education ranged from sixth grade to college graduation. Although not portrayed in Table 1, each care receiver had a past occupation including (a) military career, (b) painter, (c) engineering technician, (d) respiratory therapist (e) truck driver, (f) rancher, and (g) paper mill worker. All subjects were retired for several years. Nine received Medicare insurance, one received MediCal, and 4 participants had supplemental private insurance.

Health Care Utilization

Each care receiver had an average of 2 health care visits in the 12 week period. Three of the 10 care receivers had visits to an Emergency Room (ER), one involving transport by ambulance; 5 had a total of 6 home health care visits. The total of 10 subjects completed the 12 weeks of the study without being admitted to an acute care hospital or nursing home facility. However, one care receiver was admitted to a Geriatric Evaluation and Management (GEM)

Table 1

Demographic Characteristics of the Sample (N=10)

Characteristics	Number	Percent
<u>Age</u>		
40 - 59 Years	1	10
60 - 79 Years	6	60
80 - 99 Years	3	30
<u>Gender</u>		
Male	10	100
<u>Ethnicity</u>		
African-American	3	30
Caucasian	7	70
<u>Marital Status</u>		
Married	8	80
Divorced	2	20
<u>Educational Background</u>		
0 - 6 years	1	10
7 - 12 years	6	60
13 - 16 years	2	20
17 + years	1	10

unit at the same VA Medical Center for rehabilitation and restorative care. Two other care receivers were scheduled for another week of respite soon after the study ended, largely due to continued physical deterioration of their caregivers.

Outpatient health care visits included scheduled appointments with these VA clinics: Rehabilitation Medicine, Geriatrics, Speech and Audiology, and General Medicine. Unscheduled appointments were made as urgent drop-in visits to Renal, Medicine, Gastrointestinal Services, and Neurology clinics. The 3 subjects who received ER care presented the following symptoms: (a) syncope, (b) respiratory difficulties, and (c) fluid imbalance. Two of the 3 subjects who received ER care were admitted to long term care facilities shortly after the study ended.

For the care receiver and caregiver participants of the current study, respite served as a transition service between home care and nursing home care. Although not measured in this study, improved quality of life was noted as a benefit of respite care by the caregivers and care receivers. All caregivers realized that, at some point, their care receivers would most likely be institutionalized, but they wanted to delay placement as long as possible. Although not measured in this study, care receivers and caregivers noted improved quality of life as a benefit of respite care, even though they experienced declining health. In fact, the type, amount, and frequency of health care that participants received was highly dependent on their caregivers' availability and self perception of their own emotional and physical health.

The 10 care receivers studied returned to the medical center 23 times for outpatient health care visits during the 12 week post-respite discharge period. Eighteen of these visits were previously scheduled; however, in 5 cases, care

receivers made unscheduled visits for a variety of complaints for which their caregivers felt that they needed urgent, but not emergency, assistance. Some of the scheduled health care visits were follow-up appointments made as a result of assessments from their respite stay.

Six home health care visits were made to the subjects during this period. Registered nurses from an allied VA program of case management and home care provide in-home physical assessments and evaluations of patient needs and determine if medical treatment is required. Three subjects received emergency care; however, no study participant was admitted for either acute care or for permanent nursing home care during the 12 week post-respite discharge period.

Each participant had multiple medical diagnoses such as stroke, chronic obstructive pulmonary disease, cardiac arrhythmia, cancer, hypertension, Parkinson's disease, dementia, and hemiparesis. In addition, history of alcohol abuse and depression were common diagnoses. For those patients not receiving home health visits, their care was coordinated and provided solely by family caregivers.

Health of the Caregivers

All perceptions of caregiver health were by self-report. Six caregivers perceived their health to be, on average, fair, and four perceived their health as poor. Caregivers were quick to tell the investigator of their poor health, both physically and emotionally, and of the demands of constant caregiving. In addition, caregivers reported a difficulty in making decisions related to utilization of health care for their care receivers. Most caregivers felt that respite played a significant role in enabling them to keep their care receivers in the

home as long as they had. Caregivers told the investigator that without respite, scheduled outpatient visits, and home care visits, they would not be able to cope with the medical and psychosocial demands of their care receivers. Caregivers perceived the Inpatient Respite Program as a chance to have a much needed break from these caregiver role demands.

All caregivers agreed that their caregiving demands negatively affected their own physical and mental health. Caregivers also admitted that as their own health declined, so did their abilities to care for their family members. For example, one caregiver was not sure whether she should have brought her care receiver for an unscheduled outpatient clinic visit or to the Emergency Room. She told the investigator that she has had to make similar decisions several times and knows that one day she will not have the time or energy needed to bring him to the hospital for an outpatient visit, due to her own failing health and other family demands. She was aware of the possibility of using the Emergency Room services as an option, albeit an inappropriate one. In another case, the care receiver lived with his caregiver sister who stated that often her health care decision making for her brother was influenced by her own emotional and physical state, since she had several dependent children to care for as well as her brother.

The caregivers felt strongly that respite visits enabled their care receivers to remain in the home setting for a longer time. They felt that respite and home care helped greatly because their care receivers were just too sick to be cared for in the home without these specific services. The caregivers told the investigator that an increase in access to respite might help somewhat, but not enough to prevent admission to a nursing home at some time.

Chapter 5

CONCLUSIONS AND RECOMMENDATIONS

This study describes health care services utilized by a group of 10 care receivers enrolled in an Inpatient Respite Program at a government health facility, a Veterans Affairs Nursing Home Care Unit. Using a longitudinal follow-up study design, data were recorded by their family caregivers and collected by the investigator through telephone contact every 2 weeks for a 12 week period. The independent variable in this study was respite care and the dependent variable was the usage of health care post-respite discharge.

Data collected included the amount, type, and frequency of health care services each care receiver used and the perceived health of his caregiver, who often made health care decisions for her care receiver. The age of care receivers ranged from 42 to 94 years, with a mean of 72 years. Care receivers were chronically ill male veterans who were cared for in their homes by their wives, sister, or girlfriend. In only one case, a care receiver was given brief intermittent care by a secondary family caregiver. However, this care was not physically demanding, leaving the major burden of care for the primary caregiver. Each care receiver had received at least a sixth grade education and all were retired from a previous occupation.

Results of the study showed that each care receiver had an average of two health care visits in a 12 week period post-respite discharge. Health care visits were defined as either scheduled or unscheduled outpatient visits, Emergency Room visits, home health visits, or admission to a nursing home or acute care hospital. Three of the 10 subjects received ER services during the 12 weeks post-respite discharge. Two were brought to an ER by their

caregivers and one was transported by ambulance. In each case the care receiver received medical treatment and was returned directly home to the caregiver. No admissions to acute care occurred as a result of visits to the ER. These 10 subjects received 18 scheduled outpatient visits, most of which were preventive in nature. Three subjects received 5 unscheduled outpatient clinic visits for medical symptoms caregivers felt needed prompt, but not emergency treatment.

Over the 12 week post-respite discharge period, five subjects received 6 home health visits by registered nurses from Hospital Based Home Care, a related program within the same government health facility. For those subjects not receiving home health care, their care was coordinated by their family caregivers.

All primary family caregivers involved in this study perceived their own health to be, on average, either fair or poor. All caregivers described the physical and emotional demands of caregiving as overwhelming at times due to the failing health of care receivers, their own health problems, or additional personal demands. Each caregiver perceived respite care as a welcome break from caregiving demands and a chance to either take a vacation, receive medical care themselves, spend time with other family or friends, or to catch up on household activities.

Caregivers expressed the need for more frequent respite admissions for their care receivers. Caregivers also reported that their own health affected the quality of care they were able to provide for their care receivers and that during respite admissions they were better able to concentrate on their own senses of well-being.

Limited in scope, this study yielded findings which support broad recommendations for clinical care, research, and policy regarding caregiving for the frail elderly. While focusing primarily on health care needs of identified care receivers, the investigation revealed reciprocal health needs of family caregivers to be an important determinant for the amount and kind of health care sought for identified patients. Speculation could be made that care receivers and family caregivers should be viewed as a fragile dyad, with both members in need of care and both deserving further research and policy revision.

One clear recommendation from participants in this study is for more inpatient respite care. The investigator concurs and suggests need for a study comparing care receivers enrolled in an IRP with those not receiving respite service, with emphasis on caregiver benefits, care receiver benefits, and possible benefit to the parent health agency, including costs and amount of intermittent acute care services used by both groups.

Only limited research exists to document effects of respite programs, specifically inpatient respite programs, on the health care utilization of care receivers. Replication of this study using another inpatient setting could compare outcomes from this VA inpatient respite program's comprehensive follow-up and case management approach with that of another VA and other health care providers. Comparisons between models of respite care, adjusting for severity and type of chronic illness and comparing scope and intensity of programs' assessment and referral components, could generate data useful for health care planners.

Further research is needed to determine the effects of respite on the

caregiver's physical and mental health. A study by Berry, Zarit, and Rabatin (1991) noted that the main reason for entering a respite program is the decreasing ability of the caregiver to cope with the demands of the receivers' care. They found that a model of brief in-home care and day care respite offered caregivers relief from care demands and an opportunity to improve their own physical and mental health. They suggest that a non-respite user group be compared with a user group to better determine respite's role in reducing the detrimental effects of caregiving.

Gallagher-Thompson et al. (1992) note that current caregiving literature identifies the fact that family members who provide care to a disabled relative often experience multiple physical and/or psychological health problems associated with their caregiving experience. As noted by Burdez, Eaton, and Bond (1988), respite care is needed, is often used by families with limited support networks, and can reduce stress and promote improvement in mental health for the caregiver. These programs generally have satisfied clients, although caregivers often ask for more available respite time and better trained workers.

Respite has a yet unresearched role in this nation's health care evolution, although much attention has been focused on burgeoning numbers of old-old persons. Economic issues are a growing concern in the United States, especially related to health care delivery. Health care reform has become a central focus for all Americans and the current federal administration. Butler et al. (1992) describe benefits and drawbacks in major health care reform proposals such as managed care, single-payer systems, health maintenance organizations, and the consideration of a prospective payment system. They

emphasize the importance of specific cost containment measures every health service organization must implement and maintain that these efforts may not necessarily be concerned with the general improvement in the quality of life for health care receivers. Further research could suggest respite's efficacy and impact on health care spending.

This nation has yet to address long term care reimbursement specifically related to preventive and restorative care for the elderly. Currently, reimbursement is centered on curative services such as intensive care units, dialysis, and surgeries. For example, while the Medicare system presently provides coverage for acute care services, it falls short when meeting the needs of the elderly for respite, hospice, home care, pharmaceuticals, hearing devices, dental care, and other services that effect quality of life. Comparison studies could examine respite's effect on preventive and restorative care costs.

Forthcoming legislation on national health care reform will focus attention on the long term care issues of our nation and provide reconstruction of the health care system in this country. Organizations such as the American Nurses' Association (ANA) have lobbied for legislative changes to include (a) consumer access to services in community-based settings, (b) utilization of cost effective providers and therapeutic options in appropriate settings, (c) emphasis on prevention, primary care, and utilization of care in the least restrictive and least costly setting, and (d) reconfiguration of the present costly acute hospitalization system. National health reform will address the health care of a needy population, such as the elderly, and must be approved and implemented by our lawmakers. By enacting such law, lawmakers will be given the opportunity to improve quality of life for care receivers and caregivers, while decreasing their

utilization of high cost services. Respite care could be viewed as meeting ANA criteria for health care reform. As expert interpreters of clinical need, nurses are in a strong position to conduct further clinical research on programs such as respite and to advocate for legislation to further support respite care models.

The increasing number of elderly and their concurrent growing health care needs could drain available financial resources. The need for respite services and in-home care will be in even greater demand as our elderly population increases and as already scarce resources become less able to meet this growing demand. The ability of caregivers to keep care receivers at home for a longer time has the potential for saving health care dollars. Incorporating beneficial long term care programs like respite into our proposed national health plan would place an emphasis on cost effectiveness, quality of care, and reduced caregiver burden. Because of the increased need for preventive and primary care programs and the focus on in-home care, respite service should be made available to all care receiver and caregiver dyads.

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APPENDIX A
Health Diary

ID# _____

WEEKS: _____

DATES: _____

HEALTH DIARY

1. Did (care receiver name) have any health care visits during these 2 weeks?

For example: visits to doctors, nurses, mental health therapists, social workers, or any other health worker:

☐ NO ☐ YES

If yes, who did he see?

2. Did (care receiver name) go to an emergency room during this time period?

☐ NO ☐ YES

If yes, was an ambulance called?

☐ NO ☐ YES

3. Did (care receiver name) sleep overnight in a hospital during this time period?

☐ NO ☐ YES

If yes, how many days?

4. Did (care receiver name) sleep overnight in a nursing home during this time period?

☐ NO ☐ YES

5. Did you have someone come to your home to help with (care receiver name) care during this time period?

☐ NO ☐ YES

6. Please rate your own health during this time period:

☐ excellent ☐ good ☐ fair ☐ poor

Appendix B
Demographic Form

GENERAL INFORMATION

Date: _____

Name: _____

ID #: _____

Date of Birth:
1 2 3 4 5 6

PLEASE CIRCLE ANSWER:

1. Gender:

- 1 = Male
- 2 = Female

2. Highest Level of Education:

- 1 = 6th grade
- 2 = 7th - 12th grade
- 3 = Some college
- 4 = College graduate
- 5 = Above college grade

3. Marital Status:

- 1 = Single
- 2 = Married
- 3 = Divorced
- 4 = Widowed

4. Ethnicity:

- 1 = Caucasian
- 2 = Hispanic
- 3 = Asian/Pacific Islander
- 4 = African American
- 5 = Native American
- 6 = Other

5. Past Occupation: _____

6. Insurance Information:

- 1 = VA
- 2 = Medicare
- 3 = Medical
- 4 = Private

Appendix C
Human Subjects-Institutional
Review Board Approval

Office of the Academic Vice President • Associate Academic Vice President • Graduate Studies and Research
One Washington Square • San Jose, California 95192-0025 • 408/924-2480

To: Mary Ann Okrongly
20227 Kirkmont Drive
Saratoga, CA 95070

From: Serena W. Stanford *Serena W. Stanford*
AAVP, Graduate Studies and Research

Date: November 16, 1992

The Human Subjects-Institutional Review Board has approved your request to use human subjects in the study entitled:

"What are the effects of inpatient respite on the health care utilization of the care receiver"

This approval is contingent upon the subjects participating in your research project being appropriately protected from risk. This includes the protection of the anonymity of the subjects' identity when they participate in your research project, and with regard to any and all data that may be collected from the subjects. The Board's approval includes continued monitoring of your research by the Board to assure that the subjects are being adequately and properly protected from such risks. If at any time a subject becomes injured or complains of injury, you must notify Dr. Serena Stanford immediately. Injury includes but is not limited to bodily harm, psychological trauma and release of potentially damaging personal information.

Please also be advised that each subject needs to be fully informed and aware that their participation in your research project is voluntary, and that he or she may withdraw from the project at any time. Further, a subject's participation, refusal to participate or withdrawal will not affect any services the subject is receiving or will receive at the institution in which the research is being conducted.

If you have questions, please contact me at 408-924-2480.

CC: Jayne Cohen