1993

Respite caregivers' attitudes about nursing homes

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San Jose State University, 1993

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RESPITE CAREGIVERS' ATTITUDES
ABOUT NURSING HOMES

A Thesis
Presented to
The Faculty of the Department of Nursing
San Jose State University

In Partial Fulfillment
of the Requirements for the Degree
Master of Science

by
Joanne E. J. Weith
May, 1993

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Abstract

RESPITE CAREGIVERS' ATTITUDES ABOUT NURSING HOMES

by Joanne E. J. Weith

This thesis addresses the justification of inpatient respite programs for the caregivers of the chronically ill. An exploratory design was utilized and data were collected by interviewing caregivers ($N=30$) who had used an inpatient respite program. The purposes of the study were to determine the attitudes of caregivers about nursing homes and where those caregivers were in the institutional decision-making process.

The results of the study showed that caregivers who have used an inpatient respite program have markedly positive attitudes about the nursing home where the program was located, while their attitude about nursing homes in general were mixed. The caregivers were found to be distributed in all phases of the institutional decision-making process as well as a pre-phase. These findings support a justification of inpatient respite care that allows for the individualized support of caregivers throughout the institutional decision-making process.

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the Veterans Administration in the San Francisco Bay Area.

TABLE OF CONTENTS

	Page
LIST OF TABLES	vii
 Chapter	
1. INTRODUCTION	1
Background	1
Problem Statement.	4
Purpose	4
Research Questions	5
Definition of Terms.	5
Summary.	6
2. CONCEPTUAL FRAMEWORK AND REVIEW OF RELATED LITERATURE	8
Conceptual Framework	8
Review of Literature	15
Summary	26
3. THE METHOD	28
Design	28
Subjects of Settings	28
Human Subjects Approval.	28
Data Collection Method	29
Instrument	30
Analysis Procedures.	32
Answers to Research Questions.	33

	Page
4. FINDINGS AND INTERPRETATION.	36
Description of Sample.	36
Outside Assistance with Caregiving	42
Previous Exposure to Nursing Homes	42
Stage of Institutional	
Decision-making.	46
Attitudes About Nursing Homes.	48
Summary of Findings.	52
5. DISCUSSION	55
Summary of Study	55
Conclusions.	56
Scope and Limitations.	58
Recommendations.	59
REFERENCES	62
APPENDIXES	
A. Veterans Administration Approval.	66
B. Stanford University Approval.	68
C. San Jose State University	
Approval.	70
D. Consent Form.	72
E. Instrument.	78
F. Gonyea's Letter of	
Permission.	81

LIST OF TABLES

Table		Page
1.	Percentages and Frequency Distributions of the Age of Caregivers Using Inpatient Respite Program	37
2.	Percentages and Frequency Distributions of the Characteristics of Caregivers Using Inpatient Respite Program	38
3.	Percentages and Frequency Distributions of the Age of Care Receivers Using the Inpatient Respite Program.	41
4.	Percentages and Frequency Distributions of the Primary Diagnosis of Care Receivers Using the Inpatient Respite Program.	43
5.	Percentages and Frequency Distributions of Outside Provider of Assistance to Caregivers Using an Inpatient Respite Program	44

	Page
6. Percentages and Frequency	
Distributions of the Frequency of	
Caregiving Assistance to Caregivers	
Using an Inpatient Respite Program	45
7. Percentages and Frequency	
Distributions of the Stage of	
Institutional Decision-making	
for Caregivers Using an	
Inpatient Respite Program.	47
8. Percentages, Frequency, Mean and	
Standard Deviation of Respite	
Caregivers' Attitudes About	
Nursing Homes.	49
9. Percentage, Frequency, Mean and	
Standard Deviation of Respite	
Caregivers' Attitudes About	
Nursing Homes.	51

Chapter 1

INTRODUCTION

Background

Respite programs were developed to give family members who care for the chronically ill or disabled time at home free from their caregiving responsibilities. In Great Britain "respite care is accepted as an integral part of the geriatric service system" (George, 1985, p. 98). In the United States, these programs were first developed for families of disabled children, then adopted for the chronically ill geriatric population. Respite services can offer relief for a few hours in the home, as a daily program, or overnight in an institution. Respite services are not as widely available in the United States as they are in Great Britain.

In general, the primary rationale behind respite programs was that caregivers would be able to continue caregiving longer, delaying expensive institutional placement for the people for whom they cared. The Veterans Administration has a number of respite programs which were started using such a delay as a rationale. Only one study has attempted to measure this alleged delay, finding only a 22-day delay in a group receiving respite services (Lawton, Brody, & Saperstein, 1989a). Delaying institutional

placement 22 days is not a significant financial justification for continued funding of respite programs.

There may not be a measurable delay in the decision to institutionalize for a fundamental reason; caregivers may not be accessing respite programs until too late in the illness process. Gonyea (1987) proposes that caregivers follow a decision-making process when considering institutionalization. It is unknown where caregivers are in the process, when they begin to use respite services, or how they progress through it once in the program. This lack of information makes it difficult to substantiate claims of delay of institutionalization. Respite program proponents are forced to look in other areas to justify continued funding.

A number of studies have examined family satisfaction and found that caregivers are overwhelmingly satisfied and appreciative of respite programs (Miller & Goldman, 1989; Miller, Gulle, & McCue, 1986; Scharlach & Frenzel, 1986). However, is improving the quality of life of caregivers enough to justify continued support of expensive programs such as inpatient respite? This very question has spurred a vigorous argument in the gerontological community, leaving respite providers searching for other avenues to document the strengths of respite programs (Callahan, 1989).

Regardless of where the caregiver may be in making a decision about placing the dependent family member in a nursing care facility, easing that decision-making process provides a possible alternative justification for inpatient respite programs. While it is unknown whether caregivers who use inpatient respite services institutionalize the elder any later, they may find the process less difficult with respite provider support. By exposing caregivers to a satisfying nursing home experience, an inpatient respite program may improve their attitude toward nursing homes, facilitating a decision to institutionalize. Several investigators have documented a relationship between positive caregiver attitude toward nursing homes and eventual placement of the family member in an institution (Brody, 1969; Deimling & Poulshock, 1985; Greenberg & Ginn, 1979).

Participation in an inpatient respite program may promote a positive attitude about nursing homes. This positive attitude may be a mechanism for facilitating the institutional decision-making process. To evaluate this idea, it is important to discover what attitude caregivers hold about nursing homes and, if they have a positive attitude, why. It is also of value to determine the stage of the institutional decision-making process the caregiver is in while receiving inpatient respite services.

Problem Statement

Respite care needs a strong justification to continue to warrant funding in a tight economy. There is inadequate evidence of the actual effect this service has on family members' decisions whether or not to continue to care for the person in the home. The little research that has been reported on the role of inpatient respite programs has failed to validate the assumption that access to respite care will delay institutionalization more than marginally. Therefore, more information is needed to strengthen the argument for an alternative justification such as assisting the caregivers' decision-making process about nursing home placement.

Purpose

There were dual purposes to this study. The first purpose was to determine the attitudes of caregivers who use an inpatient respite program about institutionalization and nursing homes. The second purpose was to determine where caregivers are in the institutionalization decision-making process by using Gonyea's (1987) model of four stages of decision-making.

Research Questions

The following research questions were developed from the problem statement:

1. What are the demographic characteristics of caregivers and care receivers who use an inpatient respite program?
2. What are the attitudes of caregivers who use inpatient respite programs about nursing homes in general?
3. What are the attitudes of caregivers who use inpatient respite programs about the specific nursing home where the program is located?
4. What are the attitudes of caregivers who use inpatient respite programs about nursing home placement of their family member?
5. Using Gonyea's (1987) four stages of decision-making, where are caregivers who use inpatient respite in the institutional decision-making process?

Definition of Terms

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

1. Inpatient Respite is a 10-bed unit in a nursing home that provides overnight care for 3 to 28 days a year to qualified veterans living in the community.

2. Attitude is "a learned predisposition to respond in a consistently favorable or unfavorable manner with respect to a given object" (Fishbein & Ajzen, 1975, p. 6).

3. Nursing Home is a skilled nursing facility that provides 24-hour residential nursing care.

4. Caregivers are unpaid family members or friends who provide or are responsible for care of an identified patient comparable to care that would be received in a nursing home.

5. Institutionalization is the permanent placement of the disabled or chronically-ill person in a long-term residential care facility (nursing home).

Summary

To provide successful community services, there are two parties that must be satisfied. The consumer, in this case the caregiver, has already been shown to be satisfied with inpatient respite care services. The degree of satisfaction of those providing the financing for respite services is not as clear. If the financial justification for providing these services is based upon a faulty premise or an unproven assumption, it becomes more difficult to fund such programs in an era of cost containment.

Delaying institutional placement by use of a respite program has not been well documented. If this is the only justification of respite care offered by proponents of such care, then respite programs become vulnerable to loss of

funding. Providing documented justification for respite care can only strengthen these programs.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF RELATED LITERATURE

The literature reviewed focused on inpatient respite programs and a controversy surrounding the justification of such programs. Literature pertaining to attitude was also reviewed, particularly the relationship of caregivers' attitudes about nursing homes to subsequent placement. Decision-making and the institutional decision-making process provided the conceptual framework.

Conceptual Framework

The conceptual framework for this study was Gonyea's (1987) "Institutional Decision-making Process" which is derived from Janis and Mann's (1977) analysis of the decision-making process.

Janis and Mann's Decision-making Process

Janis and Mann (1977) proposed a five stage, sequential process of decision-making: (a) appraising the challenge, (b) surveying the alternatives, (c) weighing the alternatives, (d) deliberating about commitment, and (e) adhering despite negative feedback.

Appraising the Challenge

In the first stage of the decision-making process, Janis and Mann noted there must be an impetus or a challenge to peoples' behavior to initiate the decision-making

process. Something must cause individuals to stop and question their behavior. Unless challenged by some form of information, people will continue to follow the same patterns of behavior indefinitely; however, an event or series of events may jar people into acknowledging a conflict, problem, or challenge. Individuals must see their goals in danger and perceive that others may think of them as foolish if they do not change. This must override the possible disapproval by ones' self or others for not persevering on the current course. The example used by Janis and Mann (1977) is a personal balance sheet where the new information or events shift the balance from the side of the status quo toward the side of rejecting current behavior or course of action. This phase is titled "Appraising the Challenge."

Surveying the Alternatives

Once the status quo has been challenged, people enter the second phase of decision-making which involves seeking new ways to deal with the problem. Individuals may search their memory for possible solutions, other people may be consulted, or the mass media looked to for alternatives. By the end of the second stage, choices that have too high a cost or are ineffectual at meeting the challenge at hand have been eliminated.

Weighing the Alternatives

During the next stage, the decision-maker evaluates the remaining alternatives' advantages and disadvantages. The possible consequences of each alternative are analyzed. Using the imagination to follow a new course of action with the accompanying feelings, as well as projecting the current course of action into the future, helps to clarify the value of each possible solution. Janis and Mann (1977) point out that during this stage, the decision-maker is not yet committed to an alternative, but is no longer satisfied with the status quo. A return to stage two may occur if more information is needed to make the best choice.

Deliberating about the Commitment

Once a commitment is made, the decision-maker enters into the fourth stage, planning the implementation of the decision and assessing the means to obtain the most favorable response from others. The more people or groups who are told of the decision, the greater the incentive to stick with the decision.

Adhering Despite Negative Feedback

The final stage is similar to state one except now the decision-maker ignores or counters the challenges and negative feedback to the new course of action. If challenges cannot be successfully countered or ignored, a return to stage one may be necessary. The stability of the

decision depends on the "amount and intensity of negative feedback" and "the decision-maker's capacity to tolerate negative feedback" (Janis & Mann, 1977, p. 178).

The authors indicate the model may not be followed in a linear fashion. If a person is not vigilant, stages two, three, and four may be skipped, resulting in a jump from challenge to new commitment without adequate weighing of the alternatives. The decision-maker may get stuck midway in the process, unable to resolve the conflict for extended periods.

The coping pattern of the decision-maker will determine the amount of time and energy spent within each phase. "This conceptualization of the sequence seems to us to provide a useful framework for analyzing how the decision-maker's coping pattern is related to responsiveness to new information and to changes in his decisional balance sheet as he moves from one step to the next" (Janis & Mann, 1977, p. 178).

The Institutional Decision-making Process

Gonyea (1987) based the institutional decision-making process upon Janis and Mann's (1977) model of decision-making as it describes how a vigilant decision is made. Gonyea (1987) identified factors associated with institutional decision-making and divided the process into four stages. The first stage, recognition, begins when the

caregiver starts to think about nursing home placement as an option, either at the present time or in the future. The second stage, discussion, includes the caregiver talking about the possibility of nursing home placement, either with professionals or friends and family members. Stage three, implementation, involves identifying appropriate institutions, filling out applications, and being placed on a waiting list. Stage four is the placement itself.

Gonyea (1987) used the institutional decision-making process to investigate family planning for institutionalization while the aged relative was still living in the community. Gonyea's (1987) research addressed the question, "What are the most salient structural and dynamic factors associated with each stage of the institutional decision-making process, and do these critical factors vary with each stage of the institutional planning process?" (p. 63).

Gonyea operationalized the stages of institutional decision-making into a questionnaire which was used to study families who were currently using state funded elder chore services in four western Washington counties. Family members who considered themselves to be the primary caregivers of the elders were interviewed. A multivariate analysis was performed to discern which variables, such as kinship and the performance of personal care tasks, were the

strongest predictors of the caregivers' stage in the institutional decision-making process.

While Gonyea's (1987) goal was to identify factors which predict caregivers' stage of institutional decision-making, such predictive factors are not central to the model itself. The model is useful for its description and operationalization of the process of institutional decision-making.

Relationship of Janis and Mann's and Gonyea's

Decision-making Stages

Gonyea's (1987) stage of recognition correlates to Janis and Mann's (1977) stage of appraising the challenge. The caregiver begins to question his/her situation. This may be precipitated by an event such as the person cared for having a significant change in self-care ability. Another example may be entering a respite program and receiving a hiatus from the daily demands of caring for that person. This reassessment of the caregiving relationship may also occur due to new information such as the caregiver being diagnosed with a terminal illness. The caregiver then begins to survey alternatives to providing primary care in the home, such as institutional placement.

There are elements of Janis and Mann's stage of surveying the alternatives in Gonyea's stages of recognition and discussion. Gonyea's first stage, recognition, includes

surveying the alternatives within one's own mind while her second phase, discussion, surveys the alternatives by talking with other persons, professional and otherwise. The weighing of alternatives is seen as an internal process which Gonyea does not discuss or attempt to measure.

Gonyea's second phase, discussion, touches upon Janis and Mann's stage of deliberation about commitment. The caregiver commits to the decision and begins to tell others while gauging their reactions.

Gonyea's third phase, implementation, flows from Janis and Mann's deliberation phase toward their adherence despite negative feedback stage. The caregiver plans and begins to carry out the implementation of institutional placement while in the deliberation phase and completes the process while adhering despite negative feedback. Negative feedback may be in the form of disapproval by family members, a resurgence of guilt feelings, the perception of the physical environment of the nursing homes applied to, or the realization of the cost of institutional placement.

Janis and Mann (1977) and Gonyea (1987) have provided linear models which can be used to describe the process which caregivers go through when deciding about institutional placement for their family member. Such a framework is important when analyzing where families of the chronically ill are within the continuum of care offered

between community and institutional placement. Inpatient respite care may impact the institutional decision-making process of the families who use it. Rather than relying on previous unsubstantiated claims of delayed institutionalization for justification, inpatient respite services can use the decision-making model to show that while institutionalization may not be prevented, the process may be eased by program participation. The institutional decision-making process can provide a framework for defining what happens within an inpatient respite program.

Review of Literature

The topics of respite care and the influence of attitudes about nursing homes on placement decisions were reviewed in the literature. Respite care was defined, including the justification of existing inpatient programs. Attitudes toward nursing home care were reviewed, particularly how they relate to institutional placement decisions.

Inpatient Respite Programs

The purpose and justification of respite care in general will be described in this section. The sparse research evaluating the effect of inpatient respite care on caregivers is included.

In the field of health, respite care is considered to be "temporary care of the frail elderly and disabled to

permit family caregivers to relinquish their duties, stress, and responsibility for time-limited periods to maintain their physical and emotional strength" (Miller, Gulle, & McCue, 1986, p. 467). In the United States, respite care was originally designed to prevent burnout of parents of developmentally disabled children being cared for at home. In Great Britain, respite care is an accepted part of the geriatric services provided by the National Health Services (George, 1985).

There are several ways in which respite care can be delivered, both within and outside of the home. In-home services range from paid providers of nursing care to volunteer sitters. Outside of the home, respite care is available in the form of adult day health programs and overnight respite in hospitals and nursing homes. Since the site for this research project is an overnight respite program, the literature reviewed focused on such programs.

An inpatient respite program was opened at a Veterans Administration (VA) Nursing Home in the San Francisco Bay area in 1979, to give families who care for a chronically ill person time off from their caregiving responsibilities (Berman, Delaney, Gallagher, Atkins, & Graber, 1987). Caregivers on a waiting list for nursing home placement cited the lack of short term relief as the primary reason for requesting placement (Wilson & Ellis, 1983). The

inpatient respite served as the research site for this study. It is described in detail by Berman et al. (1987). The program provides caregivers of veterans up to 28 days of inpatient nursing home care per year, through prescheduled respite visits. Several case studies were used to substantiate the claim that "the program has prevented premature or inappropriate placement by providing training and relief to sustain the in-home caregiver" (Berman et al., 1987, p. 581).

Scharlach and Frenzel (1986) described respite care as part of the continuum of long-term care. They felt that the use of nursing home beds by a community-linked program such as respite might ease the transition to long-term care. They hoped for a unified supportive system for caring for frail older adults, whether they live in the community or in institutions. Scharlach and Frenzel (1986) studied 99 caregivers who utilized inpatient respite care at the VA research site. Eighty-two percent of caregivers were satisfied with the service. Caregivers reported improved health in 72% of the cases. Eighty-four percent of caregivers found it easier to maintain the caregiver role and 56% reported improved relationships with the person for whom they provide care.

Of particular interest in Scharlach and Frenzel's study was the question of whether respite care made it more or

less likely that the care recipient would be placed permanently in a nursing home within the coming year. Thirty-three percent of caregivers responded that respite care made permanent placement less likely, while 30% felt placement was more likely. Of those who felt respite care made permanent placement more likely, some cited the institution as being better than they imagined. Some had the realization of how much they had given up by being a caregiver. Thirty-six percent stated that respite care had no effect on the likelihood of institutionalization which included those caregivers who stated that they would not consider institutional placement under any circumstances. While not directly measuring the decision-making process or attitude about nursing homes, Scharlach and Frenzel (1986) did demonstrate that the respite care program was having an effect on a majority of caregivers' consideration of permanent placement.

Brutz, Eaton, and Bond (1988) studied the effect of a two-week respite stay on a group of dementia and nondementia patients as compared to a group on a respite care waiting list. They found respite had a positive effect, improving cognitive and physical functioning of the care receiver, and decreasing the perceived burden and number of problems of the caregiver. Caregivers found the respite program to be very beneficial in 81% of the cases. Despite this favorable

response, 68% of the caregivers felt that their situation remained unchanged. The study did not examine any relationship of respite use to institutionalization.

In an evaluation of two small respite programs, one institutional and one residential, Miller, Gulle, and McCue (1986) found that only 4 out of 18 family caregivers were dissatisfied. A later evaluation of the same program by 23 respondents by Miller and Goldman (1989) found that 18 wished to use the program again. Miller and Goldman (1989) concluded that families used the respite as a trial for long-term care placement. Six long-term care placements of former respite users in the institutional program setting had occurred since the program had begun. "Family caregivers have reported that they are comfortable with the facility and experience less stress and guilt than family members who place relatives in long-term care institutions with no prior exposure" (Miller & Goldman, 1989, p. 410).

Lawton, Brody, and Saperstein (1989a) published a study of respite service that attempted to measure a delay in institutional placement for those who used the service. In a controlled study, half of 642 caregivers of people with Alzheimer's disease were offered formal respite services, while the control group was given a list of other community resources. The services offered assistance in arranging

in-home respite, day respite, and institutional inpatient respite. There was great variation in the amount of respite that was utilized. Those offered respite services maintained their relatives in the community for only 22 days longer than those in the control group. The experimental group did not demonstrate less risk for institutional placement nor did it show any difference in the well-being of the caregiver. As with previous studies of respite programs (Burdz et al., 1988; Miller & Goldman, 1989; Miller et al., 1986; Scharlach & Frenzel, 1986) the participants were very satisfied with the services.

Callahan (1989) sparked an uproar within the gerontological community by denouncing the rationale Lawton et al. (1989a) proposed for respite program. Callahan felt that since researchers are not able to prove quantitatively that long-term care services, such as respite, have a measurable positive effect on the users, a new and inadequate rationale for such services is being promoted. He dismisses as weak and irrelevant the rationale that since caregivers are satisfied with respite services, such services should be available. He asserts that community-based, long-term care services have a built-in class and race bias and need to be considered as competing for funding with "...food for the hungry and homes for the homeless" (Callahan, 1989, p. 5). He recommends further research by

long-term care providers to provide empirical support for funding.

Lawton, Brody, and Saperstein (1989b) responded to Callahan's criticism of their study by pointing out that community-based, long-term care services should not be seen as an alternative to nursing homes but rather as an adjunct. The authors note another problem in measuring the effect of respite service: Often the care-recipient's health continues to decline, putting more stress on the caregiver even as services are increased. They believe the emphasis of the rationale for respite services needs to shift away from prevention of institutionalization toward a place on the continuum of long-term care.

Attitude

No literature was found that measured the relationship of inpatient respite program participation to attitude about nursing homes and how that attitude may relate to subsequent placement. Scharlach and Frenzel (1986) did find inpatient respite care users to be divided on the question of whether respite care made it more or less likely they would institutionalize the person for whom they care within the next year. While no studies were found that examined the effect of inpatient respite on attitudes about nursing homes and the institutional decision-making process, it might be

useful to explore other ways that attitudes affect decisions to institutionalize care-dependent family members.

For the purpose of this study, it is important to define attitude and how it is related to behavior. The concept of attitude has been used extensively for many years in the field of social psychology. Fishbein and Ajzen (1975) describe an attitude as "a learned predisposition to respond in a consistently favorable or unfavorable manner with respect to a given object" (p. 6), and that the predisposition is "assumed to be the result of past experience" (p. 10). Fishbein and Ajzen (1975) also state:

. . . attitudes lead to a set of intentions that indicate a certain amount of affect toward the object in question. Each of these intentions is related to a specific behavior, thus the overall affect expressed by the pattern of a person's actions with respect to the object also corresponds to his attitude toward the object (p. 15).

While attitude may not predict behavior, it is related to it. Only a few studies looked at attitudes about nursing homes and the influence of those attitudes on institutionalization. A classic study by Brody (1969) compared people who submitted an application to a home for the aged after an initial interview to those who did not. The groups were very similar in many demographic as well as functional

variables. What arose was a difference in attitude. Both applicants and family members had more positive attitudes about institutionalization than the non-applicants. Another significant factor was that 76% of the applicants and their families offered more than one reason for requesting institutionalization, while only 40% of the non-applicants did so.

In a follow-up study, Brody (1969) found both variables, positive attitude about institutionalization and more than one reason for requesting institutional placement, to be significant in the eventual placement of members of either comparison group. Those with positive attitudes were more likely to have actually been placed and the families "were much more likely to be favorably disposed toward admission than non-applicants" (Brody, 1969, p. 188).

As a result of her investigations, Brody (1969) presented an intriguing idea about the concept of attitude. She hypothesized that as a person reaches the end of his/her ability to handle the stresses of disability or caregiving, attitude about institutionalization may change. The study did not show significant differences between groups in other areas so she felt there must be an internal change that occurs within people as they reach the limit of their personal resources.

Greenberg and Ginn (1979) studied clients over 60 years old and their families who had begun to receive long-term care services, either as home care or nursing home care. They found "that if the client's family strongly preferred nursing home care, it was unlikely that the client would be cared for at home" (p. 83). However, when the family had a negative attitude about nursing home placement, it was unlikely that the client would be placed.

In a study of 589 caregiving families of older adults, Deimling and Poulshock (1985) focused on 64 families who had experienced a caregiving crisis. In an initial interview, nearly 50% of families who later institutionalized an elder responded positively to the questions of "how would you feel about putting the elder in a nursing home?" and "what type of care do you think your elder would receive in a nursing home?" (Deimling & Poulshock, 1985, p. 567). Only 3% and 10% respectively responded positively to the above questions in the group of caregivers who subsequently experienced a crisis but did not place the elder in an institution. The researchers found "attitudes toward nursing home care" to be the most powerful variable in a discriminant function analysis (Deimling & Poulshock, 1985, p. 572). Less powerful discriminators were task burden, perception of care in nursing homes, caregiver's health, and stress effects. "Attitudinal factors concerning the suitability and quality

of nursing home care, along with factors relating directly to the caregiving context, operate to determine the nature of the transition from in-home family care to institutional care of the aged" (Deimling & Poulshock, 1985, p. 574).

In a larger context, the general population has been shown to have a low opinion of nursing homes. A 1986 Gallup poll (Stieber, 1986) showed that 53% felt that nursing homes provided moderately or very low quality of care and only 37% felt that the quality of care was high or moderately high. Fifty-one percent of respondents would be unwilling to place a relative in a nursing home.

People who are responsible for a person in a nursing home have a slightly more positive view of nursing homes. In 1984, the California Association of Health Facilities found that 79% of those responsible for a person in a nursing home rated their facility as good or excellent (Pincus, 1986). Only 26% of those same persons felt that other nursing homes would rate as well. They seemed to feel that their chosen nursing home was an exception.

Pincus (1986) expressed the importance in changing attitudes about nursing homes, first by identifying existing attitudes and then by exploring why people hold those views. Respite caregivers' attitudes about nursing homes may give further insight into what ideas people hold about nursing homes, and why.

Many studies looked at risk factors for institutionalization other than attitude, such as age, race, sex, social support, level of functional dependency, and task burden (Barney, 1977; Branch & Jette, 1982; Brody, Poulshock, & Masciocchi, 1978; Chenoweth & Spencer, 1986; Gonyea, 1987; Palmore, 1976; Vicente, Wiley, & Carrington, 1979). Many of these studies were retrospective and none reported findings pertaining to family attitude toward placement. While risk factors other than attitude about nursing homes have been shown to have a relationship to eventual chance of placement, no one factor has been identified as a predictor of institutionalization.

Summary

The literature shows inpatient respite care programs to be a positive experience for the caregivers who use them. Whether or not use of such programs delays institutional placement has not been demonstrated. Failing to find conclusive evidence of a delay in placement, researchers and policy-makers have been calling for a better justification of respite care. Respite care has been termed part of the continuum of long-term care, but what that means has not been adequately defined. The institutional decision-making process may be used to define where respite care users are on the continuum of care. This study used the institutional

decision-making process to locate respite care users within that framework and on the continuum of long-term care.

The question remains as to what effect inpatient respite care has on the institutional decision-making process. Positive family attitudes about institutional placement have been shown to be related to subsequent placement of the family member. By measuring inpatient respite caregivers' attitudes about nursing homes and the nursing home where the program is located, it is hoped that some insight may be gained into caregivers' attitudes about nursing homes. By using that insight together with evaluating where caregivers are in the institutional decision-making process, a clearer picture of the effect and purpose of inpatient respite care should emerge.

Chapter 3

THE METHOD

Design

The study was exploratory and descriptive in nature. Since the areas of attitude about nursing homes and the institutional decision-making process among the users of inpatient respite were not found to have been studied previously, the exploratory method offered the appropriate avenue to gather information about those areas. This chapter outlines the methods used to explore the research questions.

Subjects and Setting

A convenience sample of 30 caregivers participating in an inpatient respite program located at a nursing home care unit in northern California comprised the subjects for the study. All caregivers who were scheduled to use the inpatient respite program over a 7-week period and who had used the program previously were contacted until 30 interviews were completed.

Human Subjects Approval

The proposal was approved by the Veterans Administration division where the inpatient respite program was located. Those granting permission were the Nursing Research and the Research and Development committees, as well as the Assistant Chief of Nursing and the Chief of

Extended Care (Appendix A). Approval to use human subjects was granted by Stanford University (Appendix B) and San Jose State University (Appendix C). Written consent was obtained from the sample in a format meeting the requirements of all institutions involved (Appendix D).

Data Collection Method

Potential subjects were contacted by telephone on the day before the scheduled discharge or admission of the family member to ask whether they would be willing to be interviewed for a study about nursing homes. They were also told that while they were under no obligation to participate, if they chose to do so, 30 minutes of their time would be needed at the respite center.

Each of the subjects was interviewed by the principal investigator. The interview, which took 30 to 60 minutes, was conducted either at the inpatient respite unit in a private office or room, or in the subject's home if it was not convenient to do at the respite unit. Prior to the interview, the consent form was discussed with the subject and completed, with a copy provided for the subject's records.

Confidentiality was insured by numbering the interview guide rather than using a name. Individual data and additional comments or statements made by subjects were not identified in the presentation of findings.

Instrument

The study was conducted through a structured interview with open, closed, and Likert-type scale questions (Appendix E). Content validity was established through the review and endorsement by a panel of experts during a grant application process. This panel of experts in gerontological research was formed for submission of a grant application to fund an extensive evaluation of inpatient respite care at the Veteran's Administration. During the review of instruments for the proposed grant application, the author's instrument was examined and found to have content validity. The instrument was endorsed by the panel for use with the population of caregivers using the inpatient respite program.

There were three parts to the interview. The first section of the guide focused on demographic information. Subjects were asked general information, as well as items specific to caregivers. Included were a self report of health, a listing of outside assistance with caregiving duties, and previous exposure to a nursing home.

The second section of the interview was adapted from Gonyea's (1987) scale to measure the first three phases of institutional decision-making process. Gonyea (1987) gave written permission to use the "Institutional Decision-making Process Scale" (Appendix F). The phases were

operationalized into conditions the subjects may have thought about, talked about, or taken action on relating to nursing home placement. Responses to the operationalized conditions determined the phase of institutional decision-making for the research question. Information on the reliability or validity of the scale has not been published.

An investigator-developed instrument was used for the third section of the interview. This section explored the attitudes of respite caregivers about nursing homes. The Likert-type scale questions were reviewed and endorsed by the panel of gerontological researchers described previously. Subjects could strongly agree, agree, be neutral, disagree, or strongly disagree with four statements pertaining to the quality of care in nursing homes. Subjects were asked if nursing homes gave good care and, in a separate question, if they felt their family member would be well cared for in a nursing home. Then the same questions were asked specifically about the nursing home where the inpatient respite program was located. This was done to examine whether attitudes were the same about all nursing homes or whether the nursing home where the inpatient respite was located was perceived as different. Subjects were also asked to compare the nursing home where the inpatient respite was located to other nursing homes on a 5-point scale ranging from much better to much worse.

Responses were used to answer the research questions pertaining to attitudes about nursing homes and placement of a family member.

Qualitative responses were also encouraged during all three sections of the interview. Subjects were allowed time to elaborate on their answers, and these comments were noted on the interview form.

Analysis Procedures

Once the interviews were completed, the data were analyzed by grouping demographic information and calculating frequencies and percentages. Since there was a large variation of ages within both the groups of the caregivers and care recipients, median and mean ages were also calculated.

The phase of institutional decision-making was determined by positive or negative responses to the questions in the three sections representing each phase. Any positive response in the section asking about actions taken toward placement would place subjects in stage three. Any subject who responded positively that they had spoken to someone about nursing home placement but had not yet taken any action was considered in stage two. Subjects who responded positively that they had considered placement in any one of the six conditions but had not discussed or acted upon that consideration were considered to be in stage one.

Subjects who responded negatively to all questions in the institutional decision-making section were not considered to be in the institutional decision-making process. They were considered to be in a pre-phase.

Attitude about nursing homes was scored from the Likert-type scale questions with 1 being strongly disagree, and 5 strongly agree. The higher the score, the more positive the attitude. General attitude was determined by the first two attitude questions pertaining to care in nursing homes in general. Specific attitude was determined by the scores on the two questions about care in the nursing home where the inpatient respite program was located. The last attitude question compared nursing homes in general to the nursing homes where the inpatient respite was located. In this question, a "5" indicated that the respondents believed the nursing home where the inpatient respite was located was much better than other nursing homes; a "1" indicated the inpatient respite nursing home was worse.

Answers to Research Questions

The research questions were answered by simple frequencies and percentages of responses to the applicable interview questions. Mean and standard deviation for each group of responses were included when appropriate.

1. What are the demographic characteristics of caregivers and care receivers who use an inpatient respite

program? This question was answered by reporting the percentages and frequencies of caregivers' responses to the demographic portion of the interview.

2. What are the attitudes of caregivers who use an inpatient respite program about nursing homes in general? This question was answered by the first two attitude questions.

3. What are the attitudes of caregivers who use an inpatient respite program about the nursing home where the inpatient respite program is located? This question was answered by attitude items three, four and five.

4. What are the attitudes of caregivers who use an inpatient respite program about nursing home placement for their family member? This question was answered by the second and fourth attitude questions which specifically deal with how caregivers perceive the person they care for would be cared for in a nursing home.

5. Using Gonyea's (1987) four stages of decision-making, where are caregivers who use an inpatient respite program in the institutional decision-making process? This question was answered by reporting the frequencies and percentages of caregivers in the pre-phase or in stages one, two or three.

Qualitative responses from the subjects were included whenever relevant. The additional responses were quantified

whenever several caregivers made similar statements and were included in the analysis.

Chapter 4

FINDING AND INTERPRETATION

This chapter analyzes and interprets data collected from interviews of 30 caregivers who used an inpatient respite care program. Data relating to demographics, phases of institutional decision-making, and attitudes about nursing homes are presented. The relationship of the findings to the research questions are explored.

Description of Sample

Demographic data are displayed in Tables 1 and 2 which present percentages and frequency distributions of the characteristics of caregivers using inpatient respite programs. Table 1 displays the distribution of ages of the caregivers with 73% ($n=22$) being 60 or older. Ages range from 41 to 81 with a mean of 64 and a median of 68. Twenty-eight (93%) of the caregivers were female and 2 (7%) were male. Characteristics described in Table 2 are educational level, kinship to care receiver, self-report of health, years of caregiving, and years in the inpatient respite program.

Demographic data show the sample primarily made up of older women caring for their husbands: 22 (73.3%) were wives, 3 (10%) were mothers, 2 (6.7%) daughters, 1 (3%) was a daughter-in-law, and 2 (6.7%) were husbands. Most caregivers, 87% ($n=26$), had completed a high school

Table 1

Percentages and Frequency Distributions of the Age of
Caregivers Using Inpatient Respite Program (N=30)

Age	Frequency (<u>n</u>)	%
80-89	1	3.3
70-79	8	26.7
60-69	13	43.3
50-59	3	10.0
40-49	<u>5</u>	<u>16.7</u>
Total	30	100.0

Table 2

Percentages and Frequency Distributions of the
Characteristics of Caregivers Using Inpatient Respite
Program (N=30)

Characteristic	Frequency (<u>n</u>)	%
<u>Educational Level</u>		
<High School	4	13.3
High School	6	20.0
Some College	12	40.0
College	5	16.7
Graduate School	<u>3</u>	<u>10.0</u>
Total	30	100.0
<u>Kinship to Care receiver</u>		
Wife	22	73.3
Mother	3	10.0
Daughter	2	6.7
Daughter-in-law	1	3.3
Husband	<u>2</u>	<u>6.7</u>
Total	30	100.0

Table 2 - continued

Percentages and Frequency Distributions of the
 Characteristics of Caregivers Using Inpatient Respite
 Program (N=30)

Characteristic	Frequency (n)	%
<u>Self Report of health</u>		
Excellent	6	20.0
Good	15	50.0
Fair	5	16.7
Poor	<u>4</u>	<u>13.3</u>
Total	30	100.0
<u>Years Caregiving</u>		
<5 years	6	20.0
5 to 10 years	13	43.3
11 to 15 years	7	23.3
>15 years	<u>4</u>	<u>13.3</u>
Total	30	100.0
<u>Years in Inpatient Respite Program</u>		
1 year or less	7	23.3
>1 year to 2 years	8	26.7
3 to 5 years	9	30.0
>5 years	<u>6</u>	<u>20.0</u>
Total	30	100.0

education and 67% ($n=20$) had gone to at least 2 years of college. Eighty percent ($n=24$) of the caregivers had been caregiving for 5 years or more. Half ($n=15$) had used the inpatient respite program for 3 or more years.

Seventy percent ($n=21$) of the caregivers felt they were in good or excellent health, while only 30% ($n=9$) felt they were in fair or poor health. Many caregivers volunteered further information about their health status, some reporting chronic health problems. These included 3 (10%) reports of hypertension, 4 (13%) of arthritis and 3 (10%) of back pain. One caregiver had undergone a double coronary bypass only 3 months previously. Another caregiver had intractable bilateral shoulder pain from damage sustained from over 16 years of lifting her husband. One caregiver was receiving treatment for depression. Two reported feeling tired easily, 2 identified sleep difficulties; and 1 noted feeling restless and nervous. One caregiver volunteered that she had been treated for cancer in the past, while another had a history of rheumatoid arthritis.

The percentages and frequency distributions of the age of the care receivers are presented in Table 3 with 90% ($n=27$) being 60 or over. Twenty-eight (93%) of the care receivers were male and 2 (7%) were female. The primary diagnoses of the care receivers are displayed in Table 4.

Table 3

Percentages and Frequency Distributions of the Age of Care
receivers Using the Inpatient Respite Program (N=30)

Age Range	Frequency (<u>n</u>)	%
90-99	2	6.7
80-89	4	13.3
70-79	8	26.7
60-69	13	43.3
50-59	0	0
40-49	2	6.7
30-39	0	0
20-29	<u>1</u>	<u>3.3</u>
Total	30	100.0

These diagnoses include 30% ($n=9$) postcardiovascular accident, 13.3 ($n=4$) with neurological disorders, 13.3 ($n=4$) with multiple sclerosis, 10% ($n=3$) in each of the three categories of chronic obstructive pulmonary disease, spinal cord injury or head injury and 3% ($n=1$) with dementia. Head injury survivors accounted for all the sons being cared for by mothers.

Outside Assistance with Caregiving

Sixty-seven percent ($n=20$) of the sample received regular assistance with their caregiving duties. The percentages and frequency distributions of those providing outside assistance to caregivers are shown in Table 5. Thirty percent ($n=10$) of the total sample used one of the two Veterans Administration day respite programs. Only 23% ($n=7$) of the total sample reported regular help from other family members while 27% ($n=8$) hire a private attendant. Table 6 displays how often caregivers receive assistance from outside providers using percentage and frequency distributions. While 17% ($n=5$) of the total sample received caregiving assistance 1 day a week or irregularly, 50% ($n=15$) received assistance from 2 to 7 days weekly.

Previous Exposure to Nursing Homes

All the caregivers had seen negative reports about nursing homes either in the newspaper or on television and

Table 4

Percentages and Frequency Distributions of the Primary
Diagnosis of Care receivers Using the Inpatient Respite
Program (N=30)

Primary Diagnosis	Frequency (<u>n</u>)	%
CVA	9	30.0
Neurological	4	13.3
MS	4	13.3
COPD	3	10.0
Spinal Cord Injury	3	10.0
Head Injury	3	10.0
HTN	3	10.0
Dementia	<u>1</u>	<u>3.3</u>
Total	30	100.0

Table 5

Percentages and Frequency Distributions of Outside Provider
of Assistance to Caregivers Using an Inpatient Respite
Program (n=20)

Provider of Assistance	Frequency (<u>n</u>)	%
Adult Day Health Center (VA)	3	9.7
San Jose Day Respite (VA)	7	22.6
Non-VA Senior Program	6	19.4
Family	7	22.6
Paid Attendant	<u>8</u>	<u>25.8</u>
Total	31	100.0

Note. Caregivers may use more than one source of assistance.

Table 6

Percentages and Frequency Distributions of the Frequency of Assistance to Caregivers Using an Inpatient Respite Program (N=20)

Frequency of Assistance	Frequency (<u>n</u>)	%
Irregularly	2	10.0
1 day per week	3	15.0
2-4 days per week	9	45.0
5-7 days per week	<u>6</u>	<u>30.0</u>
Total	20	100.0

some had actual experience using a nursing home. Thirty three percent ($n=10$) of the patients had spent at least a few weeks in a nursing home. Sixty-seven percent ($n=20$) of caregivers had experienced some other relative being in a nursing home. Nine (30%) caregivers had been exposed to a nursing home through the placement of a parent, and 8 (27%) had been involved through the placement of their spouse's parent. Three (10%) were exposed through the placement of a relative they termed as very close. Sixteen (53%) had experienced the nursing home placement of a friend.

Stage of Institutional Decision-making

Caregivers were evenly distributed between the first three stages of Gonyea's (1987) institutional decision-making process with 27% ($n=8$) in each of the stages: recognition (stage 1), discussion (stage 2), and implementation (stage 3). Twenty percent ($n=6$) of the caregivers were not considering institutional placement in any of the conditions listed and were considered to be in a pre-phase. All of the caregivers in stage two fit the criteria for stage one. All of the caregivers in stage three fit the criteria for stages one and two. Table 7 displays this information on the distribution of subjects in the four stages of Gonyea's (1987) institutional decision-making process.

Table 7

Percentages and Frequency Distributions of the Stage of
Institutional Decision-making for Using Inpatient Respite
Program (N=30)

Stage	Frequency (<u>n</u>)	%
Stage 0	6	20.0
Pre-phase		
Stage 1	8	26.7
Recognition		
Stage 2	8	26.7
Discussion		
Stage 3	8	26.7
Action		
Total	30	100.0

Attitudes About Nursing Homes

Five Likert-type scale questions provided information about the attitudes of caregivers toward nursing homes (Tables 8 and 9). The first two attitude questions focused on nursing homes in general. Attitude questions three and four focused on the nursing home where the inpatient respite program is located (Table 8). One question dealt with how people felt about nursing home care in the abstract and the second question asked them to evaluate care as it pertained to their loved one in the real sense. Question one and three are abstract while question two and four pertain to the specific person. Attitude question five asked the caregivers to compare the nursing home where the inpatient respite program is located to other nursing homes (Table 9).

The caregivers gave a mixed response to the question of whether nursing homes in general give good care. None of the caregivers strongly agreed with the statement while 10% ($n=3$) strongly disagreed and 23.3% ($n=7$) disagreed, indicating that nursing homes in general did not give good care. Another 23.3% ($n=7$) of the caregivers felt that nursing homes do provide good care while 43.3% ($n=13$) were neutral. The mean of the responses was 2.80 indicating the group as a whole responded in the neutral range.

The caregivers had a slightly more positive attitude about the care that their family member would obtain in a

Table 8

Percentages, Frequency, Mean, and Standard Deviation of Respite Caregivers' Attitudes

About Nursing Homes (N=30)

Statement	Strongly Agree (5)	Agree (4)	Neutral (3)	Disagree (2)	Strongly Disagree (1)	Mean	SD
	n %	n %	n %	n %	n %		
Nursing homes in general give good care	0 0	7 23.3	13 43.3	7 23.3	3 10.0	2.80	0.92
Care receiver would receive good care in a nursing home	3 10.0	12 40.0	5 16.7	7 23.3	3 10.0	3.17	1.20
Nursing home where inpatient respite is located gives good care	11 36.7	16 53.3	3 10.0	0 0	0 0	4.17	0.87
Care receiver would receive good care in the nursing home where the inpatient respite is located	9 30.0	20 66.7	1 3.3	0 0	0 0	4.27	0.52

nursing home other than the one where the VA respite program was located. Half ($\underline{n}=15$) of the caregivers felt that their family member would receive good care in a nursing home while 33.3% ($\underline{n}=10$) did not agree. Only 16.7% ($\underline{n}=5$) of the responses were neutral. The mean of the responses was 3.17, falling in the neutral range.

In contrast to the above questions about nursing homes in general, 90% or 27 of the caregivers strongly agreed or agreed that the nursing home where the inpatient respite program was located gave good care. Ninety-seven percent or 29 respondents felt that their family member would be well cared for in that nursing home. None of the caregivers felt that the nursing home where the inpatient respite was located would not give good care.

The final attitude question asked caregivers to compare the nursing home where the inpatient respite program was located to other nursing homes (Table 9). Seventy-three percent or 22 of the caregivers felt that the nursing home where the inpatient respite program was located was better or much better than other nursing homes. None of the caregivers identified this nursing home as worse or much worse, although 3 of the respondents were neutral or had no opinion. The 16.7% ($\underline{n}=5$) who responded "the same" indicated that the nursing home where the program was located was the

Table 9

Percentage, Frequency, Mean, and standard Deviation of Respite Caregivers' Attitudes

About Nursing Homes (n=27)

Statement	Much Better (5) n	%	Better (4) n	%	Same (3) n	%	Worse (2) n	%	Much Worse (1) n	%	Mean	SD
Nursing home where the inpatient respite is located compared to other nursing homes	9	33.3	13	48.1	5	18.5	0	0	0	0	4.15	0.72

Note. Three subjects declined to make a comparison, claiming lack of knowledge, resulting in n=27.

same as the nursing homes they had experienced in the community.

Summary of Findings

The research questions with their answers provide a summary of the findings of the study. Attitude about nursing homes in the research questions was subdivided into general attitude about nursing homes, specific attitude about the nursing home where the inpatient respite was located, and attitude about care that the family member would receive. The stage of institutional decision-making question was answered by reporting the frequencies and percentages of caregivers in the pre-phase or stages 1, 2, or 3.

1. What are the demographic characteristics of caregivers and care receivers who use an inpatient respite program? This question was answered by reporting the percentages and frequencies of caregivers' responses to the demographic portion of the interview as described previously in the description of the sample, outside assistance with caregiving, and previous exposure to nursing homes (Tables 1, 2, 5, and 6). The percentages and frequencies of the care receivers' ages and diagnosis are presented in Tables 3 and 4.

2. What are the attitudes of caregivers who use an inpatient respite program about nursing homes in general?

This question was answered by the first two attitude questions. The caregivers had a variety of attitudes ranging from positive to very negative with many caregivers neutral (Table 8). Because of the range of responses both positive and negative, no clear answer was formulated. However, the first question about care in nursing homes in general was slightly negative with a mean of 2.80. The second question, interestingly, showed that when asked about the care of their own relative, the attitudes of 25% of the caregivers improved considerably.

3. What are the attitudes of caregivers who use an inpatient respite program about the nursing home where the inpatient respite program is located? This question was answered by attitude items three, four, and five. There was a markedly positive attitude about the nursing home where the inpatient respite program was located. This positive attitude was represented by the overwhelmingly positive response to all three of the interview questions dealing with the program nursing home (Tables 8 and 9).

4. What are the attitudes of caregivers who use an inpatient respite program about nursing home placement of their family member? This question was answered by the second and fourth attitude questions which specifically deal with how caregivers feel their family member would be cared for in a nursing home. In these questions, the caregiver

responses demonstrated attitudes that were neutral for nursing homes in general but positive for the nursing home where the program was located (Table 8).

5. Using Gonyea's (1987) four stages of decision-making, where are caregivers who use an inpatient respite program in the institutional decision-making process? Caregivers were found equally in all stages of the institutional decision-making process with those in the pre-stage in only a slightly smaller percentage (Table 7).

Chapter 5

DISCUSSION

Summary of Study

Regarding the decision-making process, the results of the study were clear. There were caregivers in all three stages of the institutional decision-making process as described by Gonyea (1987) as well as a portion in a pre-phase. Personal decision-making styles (Janis & Mann, 1977) were a factor with 80% ($n=24$) of caregivers exploring alternative methods of caregiving including institutional placement. Twenty percent ($n=6$) of caregivers had not begun to "appraise the challenge" (Janis & Mann, 1977, p. 172) or consider that they might not always be able to care for their family members.

The caregivers had a variety of previous experiences with nursing homes. While they had mixed reactions to nursing homes in general, caregivers had an overwhelmingly positive impression of the nursing home where the inpatient respite program was located. The inpatient respite care program may have had an effect on the caregivers since their perceptions of the nursing home where the program was located were so different than nursing homes in general. This positive attitude about the respite program nursing home persisted despite differences in personal experiences of individual caretakers. Caregivers had a more positive

attitude about the care their specific family member would receive in a nursing home than their abstract perception about nursing homes in general.

Conclusions

The needs and desires of the chronically ill in the community and their caretakers are exemplified by the range of responses from caregivers identified in this study from those who will never consider institutional placement to those awaiting such placement. This range of responses does not support the claim that respite care recruits its participants too late to prevent institutional placement, nor does it support the claim that respite universally delays institutional placement. The responses show that despite different goals as to the eventual outcome of long-term care, these families have a common appreciation and desire for inpatient respite care.

Any justification for inpatient respite care needs to take into account the variation in caregivers' needs and desires in relation to their phase in the institutional decision-making process. Scharlach and Frenzel's (1986) study found that a third of caregivers using respite care felt that the program had made institutional placement more likely while a third felt that the program had made placement less likely. Those findings support the idea that the caregivers were in different phases in the institutional

decision-making process and had different needs. The possibility that nurses working in respite care offer support to the caregiver throughout the institutional decision-making process should be hailed as a strength of the program.

One possible vehicle for easing the institutional decision-making process is through fostering a positive attitude about nursing homes. In this study, the attitude of caregivers about nursing homes in the community varied widely, but there was a consensus of positive opinion about the nursing home where the inpatient respite care unit is located. A positive attitude about nursing homes and nursing home placement has been related to subsequent placement (Brody, 1969; Deimling & Poulshock, 1985; Greenberg & Ginn, 1979). The caregivers' positive attitudes may reflect the lowering of a barrier to institutional placement. On the continuum of long-term care, there are times when institutional placement is an appropriate alternative for caregiving families. As the variables which influence the decision to institutionalize coalesce, the lack of a negative attitude about nursing homes may make that decision easier for the caregiver and perhaps lighten the burden of guilt.

Caregivers had a variety of previous experiences with nursing homes which may have had an effect on their

perception of the inpatient respite nursing home. It could be assumed that caregivers may perceive the nursing home associated with the inpatient respite program as better because they are familiar with it, as was found in Pinus (1986). Another possibility is that the care and facilities at the inpatient respite program may have been above average. The caregivers may then only be more comfortable with eventual placement in the nursing home where the inpatient respite program is located. This outcome could be a problem if the respite care users cannot be accommodated by the nursing home where the program is located.

Scope and Limitations

The scope of the study was limited by the small sample size and the use of a well defined population, caregivers of veterans, which may not be representative of caregivers in general. Therefore, the results cannot be generalized.

Other limitations include the role of the investigator as a provider of nursing care within the inpatient respite program. Despite guaranteed confidentiality, families may fear disclosure of negative attitudes. The nature of any previous relationship may also influence subjects' responses.

Also, the location of the interviews may have had an effect on the outcome. Since some caregivers were interviewed at home, they may have been more relaxed and

taken greater time to consider and express their feelings than caregivers who were in the process of picking up or dropping off the person they care for.

It would be optimal to study respite caregivers over time to clarify the inpatient respite program's influence on the institutional decision-making process and attitudes about nursing homes. By studying caregivers only once, this research cannot show how long caregivers have been in any stage of institutional decision-making. Additionally, this study did not determine what caregivers' attitudes about nursing homes were previous to their exposure to the inpatient respite program.

Only tentative exploration has been made into the areas of attitude about nursing homes and the institutional decision-making process necessitating the use of a pilot instrument. While restricting what inferences can be made from the study, the instrument did provide a framework which allowed caregivers to express their feelings about institutional placement and nursing homes.

Recommendations

The study has brought forth several subject areas for further research. The institutional decision-making process provides a framework to study families on the continuum of long-term care. It would be useful to apply the institutional decision-making process to a group of

caregivers over time and compare the process as defined by Gonyea (1987) with the relationship to the actual outcomes.

By examining caregivers over time, the effect of inpatient respite care on caregivers' attitudes about nursing homes and how those attitudes influence eventual placement could be measured. This study has shown respite caregivers to have a very positive attitude about the nursing home where the program is located. It would be useful to know what portion of the respite population is placed in the nursing home where the program is located versus community nursing homes. Caregivers, respite, and non-respite users could be compared after institutional placement for their ease of adjustment using such factors as grief, depression, and satisfaction to see if respite use eased the transition to nursing home care.

The inpatient respite care program studied provides a valuable service to the families of the chronically ill. Policy-makers and proponents of respite care need to be persuaded that respite care is not a one-dimensional program with a guaranteed outcome of delaying institutional placement. The reality is that patients and caregivers using the respite program become older, sicker, and fatigued, and will have changing needs and desires as they progress through the institutional decision-making process.

This progression must be factored in to any justification of the respite program.

Nursing is central to the support provided by an inpatient respite program. As primary providers of physical and emotional care to a population of chronically ill persons and their caregivers, nurses can utilize the information gained from this and similar studies to guide their practice. As families progress through the stages of institutional decision-making, nurses need to tailor their interventions to suit the needs of the individual situation. The education and support that nurses provide to family members using a respite program may influence the attitude of those caregivers about the institution where the program is located. Nursing has a pivotal role providing individualized support to families of the chronically ill.

That caregivers have been highly satisfied with inpatient respite programs may reflect individualized support for caregivers in the stages of the institutional decision-making process. Meeting the individual needs for support throughout the caregiving and decision-making process should be the explicit goal and justification for inpatient respite programs.

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APPENDIX A
Veterans Administration Approval

Medical Center

**Veterans
Administration**In Reply Refer To: ^{640/118}**Joanne Weith RNC (11 NH)
Nursing Home Care Unit****February 18, 1992****Dear Joanne,**

This letter confirms that your research proposal, "Inpatient Respite Care Givers' Attitudes about Nursing Homes" has been approved by the necessary groups including Nursing Service, Human Subjects, and DVAMC, Research and Development Group.

You have approval to conduct the proposed research according to the proposal until January 6, 1993. Please keep the Nursing Research Committee apprised of your progress.

Sincerely,**Co - Chair Nursing Research Committee***"America is #1—Thanks to our Veterans"*

APPENDIX B
Stanford University Approval

STANFORD UNIVERSITY
Stanford, California 94305
(415) 723-2885

CERTIFICATION OF HUMAN SUBJECTS APPROVAL

69

DATE: January 7, 1992

TO: J. Weith, R.N.C.
Department of Nursing

FROM: Chairman, Administrative Panel
on Human Subjects in medical Research

PROTOCOL TITLE:
Inpatient Respite Caregivers' Attitudes About Nursing Homes.

The Panel approved human subjects involvement in your research project on January 7, 1992.

The expiration date of this approval is January 6, 1993. If this project is to continue beyond that date, please submit an updated proposal in advance for the Panel's re-approval. If this proposal is used in conjunction with any other human experimentation or if it is modified in any way, it must be re-approved for these special circumstances. In addition, the Panel requests prompt notification of any complications which may occur during any experimental procedure.

All continuing projects and activities must be reviewed and re-approved at least annually by the Panel. Panel approval of any project is for a maximum period of one year. It is the responsibility of the investigator to resubmit the project to the Panel for annual review.

for David Oakes, M.D., Chairman

cc: Sponsored Projects
D. Lockard, Ph.D.
M. Hays, M.D., VA

Funding Agency: (VA Study) (N)
Period of Time: 01/07/92 through 01/06/93
Investigational New Drugs: N,
Investigational New Device: N,
Cooperating Institution: N
Full Board Review
Assurance Number: M1272
IRB #01

APPENDIX C

San Jose State University Approval

A campus of The California State University

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: Joanne Weith, Nursing
1311 Montmorency Drive
San Jose, CA 95118

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

Date: March 10, 1992

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

"Inpatient Respite Caregivers' Attitudes about
Nursing Homes"

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: Marcia Canton, Nursing

APPENDIX D
Consent Form

Date

Inpatient Respite Caregivers' Attitudes
about Nursing Home Placement

EXPERIMENTAL SUBJECT'S BILL OF RIGHTS

Persons who participate in a medical experiment are entitled to certain rights. These rights include but are not limited to the subject's right to:

- be informed of the nature and the purpose of the experiment:
- be given an explanation of the procedures to be followed in the medical experiment, any drug or device to be utilized:
- be given a description of any attendant discomforts and risks reasonably to be expected:
- be given an explanation of any benefits to the subject reasonable to be expected, if applicable:
- be given a disclosure of any appropriate alternatives, drugs or devices that might be advantageous to the subject, their relative risks and benefits:
- be informed of avenues of medical treatment, if any available to the subject after the experiment if complications should arise:
- be given an opportunity to ask questions concerning the experiment or the procedures involved:
- be instructed that consent to participate in the medical experiment may be withdrawn at any time and the subject may discontinue participation without prejudice:
- be given a copy of the signed and dated consent form:
- and be given the opportunity to decide to consent or not to consent to a medical experiment without the intervention of any element of force, fraud, deceit, duress, coercion or undue influence on the subject's decision.

Signature and Date

Signature of Investigator or Witness

Inpatient Respite Caregivers' Attitudes
about Nursing Home Placement

INFORMED CONSENT

You are invited to participate in a study of respite caregivers' attitudes about nursing homes. A respite caregiver is a person such as yourself who care for a chronically ill person at home without payment and uses an overnight respite program. I hope to learn what respite caregivers think of nursing homes and where they are in the process of deciding about possible nursing home placement for the person they care for. you were selected as a possible participant in this study because you are currently caring for a family member who has used the inpatient respite program at least once.

If you decide to participate, I will ask you some questions about your feelings. The interview should take 15-30 minutes.

RISKS AND BENEFITS

The risks associated with this interview are minimal. You may feel uncomfortable discussing nursing home placement in relation to the person you care for. You may benefit by having the opportunity to express your feelings about nursing home placement in a confidential setting. Further benefit may occur by respite care providers having a better understanding of your feelings and therefore being better able to understand the services you require.

WE CANNOT AND DO NOT GUARANTEE OR PROMISE THAT YOU WILL RECEIVE ANY BENEFITS FROM THIS STUDY.

No payment will be provided for this project. There will be no additional cost to you for participation in this study.

your decision whether or not to participate will not prejudice you, the person you care for or their medical care. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without prejudice to you, the person you care for or their medical care. If you have any questions, I expect you to ask me. If you have any questions later, I will be happy to answer them. Joanne Weith, R.N. may be reached at (408) 264-7500 or (415) 493-5000 ext. 7193. Complaints about the procedures may be presented to my advisor, Dr. Bobbye Gorenberg, at (408) 924-3130. For any questions or complaints about research subjects' rights, or in the event of a research related injury, contact Serena Stanford, Ph.D., (Associate Academic Vice President for Graduate Studies at San Jose State University) at (408) 924-2480.

Signature and Date

Signature of Investigator or Witness

Inpatient Respite Caregivers' Attitudes
about Nursing Home Placement

All the information you provide will remain confidential. You will be identified only with a code number on the completed interview guide and the data will be stored in a locked file cabinet at my home. Any data that may be published in scientific journals will not reveal the identity of the subjects. In the interest of public safety, patient information will be provided to Federal and regulatory agencies as required. The Food and Drug Administration, for example, has the right to inspect research records and, therefore, could learn your identity if you are involved in any study performed under FDA supervision.

Signature and Date

Signature of Investigator or Witness

Inpatient Respite Caregivers' Attitudes
about Nursing Home Placement

LIABILITY CLAUSE

All forms of medical treatment--whether routine or experimental--involve some risk of injury. In spite of all precautions, you might develop medical complications from participating in this study. If such complications should arise, the researchers will assist you in obtaining appropriate medical treatment but this study does not provide financial assistance for additional medical or other costs. Additionally, Stanford is not responsible for research or medical care by other institutions or personnel participating in this study. You do not waive any liability rights for personal injury by signing this form. For further information, please call (415) 723-5244 or write the Administrative Panel on Human Subjects in Medical Research at Medical School Office Building, Room C-051, Stanford, California, 94305. In addition, if you are not satisfied with the manner in which the study is being conducted, or if you have any questions concerning your rights as a study participant, please contact the Human Subjects office at the same address and telephone number.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PRINCIPAL INVESTIGATOR AND HIS OR HER STAFF, THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED, AND THAT A COPY OF THIS FORM HAS BEEN GIVEN TO YOU.

Signature and Date

Signature of Investigator or Witness

Inpatient Respite Caregivers' Attitudes
about Nursing Home Placement

VA LIABILITY CLAUSE

In the unlikely event you are injured as a result of participating in this study, the Palo Alto Va Medical Center will furnish humanitarian emergency medical care (for non-veteran participants) and medical care (for veteran participants). Compensation for such injury may be available to you under the provisions of Federal Tort Claims Act (for non-veteran and veteran participants) and/or 38 U.S.C. (for veteran participants). For further information, contact the VA District Council at (415) 556-4656.

YOUR SIGNATURE INDICATES THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION, THAT YOU HAVE DISCUSSED THIS STUDY WITH THE PRINCIPAL INVESTIGATOR AND HIS OR HER STAFF, THAT YOU HAVE DECIDED TO PARTICIPATE BASED ON THE INFORMATION PROVIDED, AND THAT A COPY OF THIS FORM HAS BEEN GIVEN TO YOU.

Signature and Date

Signature of Investigator or Witness

APPENDIX E
Instrument

Institutional Decision-making and Attitude Scale

Date

Subject #

*Caregiver age:

*Care receiver age:

*Caregiver sex:

*Care receiver sex: M F

*Educational level of caregiver:

*Kinship/Relationship to care receiver:

*Diagnosis of care receiver:

Primary:

Secondary:

*Rate your own health: E G F P

Comments:

*Length of time caregiving:

Length of time in in-patient respite care program:

*Do you receive outside assistance with your caregiving duties?

Yes/No

Where?

How often?

*During the past year, have you ever thought about placing
(your relative) in a nursing home, a home for the aged, or some
other type of institution in any of these six circumstances?

1. Given her/his present condition?
No consideration/slight consideration/
moderate consideration/great consideration
2. If s/he required constant care?
NC/SC/MC/GC/Receives constant care
3. If s/he becomes incontinent?
NC/SC/MC/GC/Already incontinent
4. If s/he becomes senile or demented?
NC/SC/MC/GC/Already demented
5. If her/his condition worsens in any other way?
NC/SC/MC/GC
6. If your condition worsens in any way?
NC/SC/MC/GC

*During the past year have you discussed the possibility of placing your
(relative) in a nursing home or other type of institution with any
of the following persons?

Family members	Yes/No
Friends	Yes/No
Doctors	Yes/No
Nurses	Yes/No
Social Workers	Yes/No
Psychologists	Yes/No
Physical Therapists	Yes/No
Nurse's Aides	Yes/No
Clergy	Yes/No

*Have your concerns about your (relative) prompted you to take any of the following actions in the past year?

1. Requested the names of specific nursing homes or institutions from family, friends or professionals? Yes/No
2. Visited any nursing home or institution's facilities with an interest or learning how they might suit your (relative's) needs? Yes/No
3. Obtained the admissions applications for any institution? Yes/No
Where?
4. Placed your (relative's) name on a waiting list for a particular institution? Yes/No
Where?

*Previous exposure to nursing homes/Describe

Placement of care receiver	Yes/NA
Placement of family member	Yes/NA
Placement of friend	Yes/NA
TV/newspaper	Yes/NA

Comments:

*Do you think nursing homes in general give good care?

Strongly Agree/Agree/Neutral/Disagree/Strongly Disagree

Comments:

*Do you think the person you care for would receive good care in a nursing home? SA/A/N/D/SD

Comments:

*Do you think the Nursing Home Care Unit where the inpatient respite is located gives good care? SA/A/N/D/SD

Comments:

*Do you think the person you care for would receive good care at the NHCU? SA/A/N/D/SD

*Do you think the NHCU is:

Much Better/Better/Same/Worse/Much Worse
than other nursing homes?

Comments:

Used by permission of and adapted from:

Gonyea, J. G. (1987). The family and dependency:
Factors associated with institutional decision-making.
Journal of Gerontological Social Work, 10(1), 61-77.

APPENDIX F
Gonyea Permission

Judith Gonyea
Boston University
School of Social Work
264 Bay State Road
Boston, MA
02215

Date: 11/28/91

To whom it may concern.

I give my permission for Joanne Weith and her associates to use the model and questions published in the 1987 Journal of Gerontological Social work titled: "Family and dependency: Factors associated with institutional decision-making."

Judith Gonyea