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Patients' and nurses' perceptions of most important caring behaviors in a long-term care setting

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DOI: <https://doi.org/10.31979/etd.r8hm-du5c>
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behaviors in a long-term care setting**

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San Jose State University, 1994

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PATIENTS' AND NURSES' PERCEPTIONS
OF MOST IMPORTANT CARING BEHAVIORS
IN A LONG-TERM CARE SETTING

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
Margaret K. Smith
August, 1994

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ABSTRACT

PATIENTS' AND NURSES' PERCEPTIONS OF MOST IMPORTANT CARING BEHAVIORS IN A LONG-TERM CARE SETTING

by Margaret K. Smith

Elderly persons living in nursing homes depend on nursing staff for meeting a wide range of human needs. In order to provide humanistic care, nursing staff must be sensitive to the relative importance of these needs.

The CARE-Q instrument was used by 14 nursing home patients and 15 registered nurses to rank 50 caring behaviors in order of importance in making patients feel cared for. Patients and nurses agreed on 6 of the 10 most important behaviors, choosing 3 expressive and 3 instrumental behaviors. Five caring behaviors and 2 subscales were ranked significantly different by residents and nurses. These differences suggest that nurses may be unaware of the value residents place on behaviors validating individual competence, maintaining an honest dialogue about their condition and treatments, and being cheerful. The nurse-patient relationship may grow if nurses explore and validate a wider range of caring behaviors.

ACKNOWLEDGEMENTS

This thesis is dedicated to the residents and nursing staff of the Nursing Home Care Unit. Their willingness to participate and their interest and positive support provided much of the inspiration for carrying out this study.

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Chapter 1

INTRODUCTION

The nature of the health care delivery system is being transformed because of ever increasing health care costs, the limited effectiveness of medical technologies in improving general health status, and rapid demographic changes. This transformation necessitates a new view of the goals of nursing and medicine, both of which will be increasingly directed towards caring rather than curing (Watson, 1988).

The Problem

The rapid growth of the elderly population in the United States has been accompanied by an increase in the proportion of elderly who live in nursing homes. In 1986, 12.1% of the population was over 65 years of age, 4.5% of whom were nursing home residents, an increase from 3.0% in 1980 (National Center for Health Statistics, 1989a).

As the name implies, the nursing home often becomes the long-term or permanent home of the elderly when they are no longer able to stay in their own homes. They enter nursing homes because of physical, cognitive, or functional impairments. Over half of 1,491,400 nursing home residents in 1985 had some mental impairment; two-thirds were dependent in three or more activities of daily living, and most had one or more chronic diseases (National Center for

Health Statistics, 1989a). In addition, most of these elderly had suffered other losses in terms of roles and relationships. Clearly, this is a vulnerable group with ongoing physical, psychological, psychosocial, and spiritual needs.

Nursing home residents have more contact with nursing staff than with either other health professionals or their families. Because medical cure is seldom possible and does not address the range of needs experienced by these elderly, nursing care becomes crucial. It is necessary for this care to be holistic and humanistic and to give attention to the person as a whole.

There is a call in the literature for improving residents' lives by providing humanistic care which includes patience, tolerance, respect, concern, acceptance, and freedom of choice (Mulligan, 1988). The nurse-patient relationship needs to be reciprocal and directed toward meeting human needs (Gallman, 1988). Elderly persons themselves have spoken to their need to be treated as individual human beings, to have choices, and to be heard. They want their social, physical, and emotional needs to be recognized (Select Committee on Aging, 1986). A study by Stirling and Reid (1992) demonstrated that altering caregiving attitudes through staff sensitivity training and giving more attention to individual residents in a nursing home was beneficial. The nurse-patient relationships became

more reciprocal, which increased the residents' sense of well-being and self-esteem.

Purpose of the Study

If caring is seen as an essential human need and central to nursing, then nursing care involves an interpersonal relationship directed toward the gratification of human needs (Watson, 1979). Therefore, in the case of nursing home residents' well-being, it is essential that they have a feeling of being cared for. For this to occur, nurses must have an understanding of what caring behaviors are important to the residents.

The purpose of this descriptive study was to determine the caring behaviors which professional nurses and nursing home residents perceive to be most important. Furthermore, the study sought to determine how these two groups' perceptions differ with respect to types and rankings of behaviors.

Research Questions

The following research questions were derived from the problems identified above:

1. What caring behaviors do residents perceive to be most important in making them feel cared for?
2. What caring behaviors do professional nurses perceive to be most important in making residents feel cared for?
3. What differences in perceptions of important caring

behaviors, in terms of types of behaviors and ranking, are found between residents and nurses?

Definition of Terms

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

Conceptual

Nurse caring behaviors. Conduct, acts, and mannerisms that when enacted convey a sense of being cared for to the patient (Larson, 1981).

Feeling cared for. The sensation of well-being and security resulting from the enacted behaviors of another person (Larson, 1981).

Ranking of behaviors. Determining order of importance from most important to least important.

Professional nurses. Registered nurses.

Nursing home residents. Male and female patients living as permanent residents in the nursing home.

Operational

Perception of important caring behaviors. Types and rankings of caring behaviors in order of importance, as determined by the CARE-Q instrument.

Summary

Humanistic, holistic nursing care is becoming an increasingly important issue. The elderly population is growing, as is the group of frail elderly requiring nursing home care. Because the elderly have little social support

and wide-ranging needs, it is important that nurse caring behaviors be both specific and comprehensive. The findings from this study will add to the knowledge of the priority given to caring behaviors by patients and nurses in long-term care.

Chapter 2

CONCEPTUAL FRAMEWORK AND REVIEW OF THE LITERATURE

Caring has always been closely associated with nursing, but the meaning of the concept, as well as the personal qualities and behaviors needed to enact it, have remained vague and ambiguous. Caring has not been systematically studied until the last two decades. Before 1970, there were fewer than 30 research articles and no books published on the phenomenon of caring; by 1987, there were more than 500 nursing articles and 28 books addressing caring research (Leininger, 1988).

Before considering the theoretical and conceptual aspects of caring, it is helpful to differentiate caring from curing. Curing is derived from the medical model and addresses specific diagnoses and treatments of disease. As such, its focus is very narrow. Curing does not give much consideration to other determinants of disease and health, such as social, economic, lifestyle, emotional, cultural, or spiritual factors. The practice of caring, on the other hand, combines biophysical knowledge with the knowledge of human nature to minister to the suffering and to promote wellness and personal growth (Watson, 1979). Leininger (1984) states that caring is complementary to curing and can take place without curing, but curing cannot take place without caring.

Because caring is a phenomenon based on human experiences and needs, it is not amenable to the traditional scientific theoretical perspective in which measurable conceptual relationships are developed to explain and predict related phenomena. Instead, a qualitative approach has been used by nursing scholars, such as Watson and Leininger, to identify and describe the meanings of caring. This type of approach is essential in order to obtain knowledge of the meanings, symbols, and experiences of little known phenomena (Leininger, 1984). It is only after the concept of caring has been clarified that empirical studies, such as the ranking of important caring behaviors, can take place.

Conceptual Framework

This study was guided by Watson's theory of nursing, the Philosophy and Science of Caring (Watson, 1979). This theory is founded on a humanistic, holistic approach to nursing and a patient-centered orientation. As such, the theory emphasizes the interpersonal relationship between "nurse-person" and "patient-person." Therefore, it is ideally suited to guide the relationship between nurses and residents with multidimensional needs in the nursing home.

Caring, according to Watson (1979), is founded on a humanistic-altruistic system of values for the purpose of gratifying human needs according to the hierarchy of needs first formulated by Maslow. For Watson, the short-term goal

of caring then becomes the gratification of lower order needs. First, physiologic needs must be taken care of; then safety and security needs can be met. When these needs have been satisfied, long-term goals involving the gratification of higher order needs, such as love and belonging, self-worth, and self-actualization, can be addressed. Caring, therefore, involves the integration of biophysical and behavioral sciences.

There are two aspects to nursing care, which Watson (1979) named nursing "core" and nursing "trim." The core constitutes all dimensions of the caring relationship, while the trim consists of the procedures, techniques, and the clinical setting and, as such, is more task-oriented. These two types of nursing care were classified as expressive and instrumental behaviors and activities (Watson, Burkhardt, Brown, Bloch, & Hester, 1979). Expressive or affective nursing behaviors are concerned with establishing relationships based on trust, faith, acceptance of feelings, and genuineness. Expressive relationships also offer support in the form of surveillance, nurturing, and protection of privacy and personal dignity.

Instrumental, task-oriented activities include physical-action as well as cognitive-oriented interventions. Treatments, procedures, medications, stress relief, teaching, and problem-solving would fall in this category.

The nursing core is organized into 10 carative factors which guide all caring interventions (Watson, 1979):

1. The formation of a humanistic-altruistic system of values.
2. The instillation of faith-hope.
3. The cultivation of sensitivity to self and others.
4. The development of a helping-trusting, human care relationship.
5. The promotion and acceptance of the expression of positive and negative feelings.
6. The systematic use of the scientific problem-solving method for decision making.
7. The promotion of interpersonal teaching-learning.
8. The provision for a supportive, protective, and/or corrective mental, physical, sociocultural, and spiritual environment.
9. Assistance with the gratification of human needs.
10. The allowance for existential-phenomenological-spiritual forces. (pp. 9-10)

Watson bases the carative factors on seven assumptions. The most important ones state that caring can only be practiced interpersonally, that carative factors satisfy

human needs, and that effective caring promotes health and personal growth.

In actualizing the carative factors, the nurse is with the other person in an existential sense and understands the meaning of the other person's experience for him or her (Watson, 1985). The relationship becomes transpersonal when the nurse and the client share a phenomenological field (the caring occasion), and the patient experiences replacement of disharmonious thoughts and feelings by those that are more harmonious. This is the mechanism whereby healing and growth take place. Both the nurse and the patient benefit from the shared experience.

Review of the Literature

Actions, in the form of caring behaviors, can be identified and described. Qualitative studies have investigated caring in terms of importance to both patients and nurses.

Nurses' Perceptions of Caring Behaviors

When nurses were interviewed with open-ended questions (Ford, M. B., 1981; Ford, J. S., 1990) or asked to describe their subjective experiences of caring (Forrest, 1989), responses, in general, fell in the psychosocial domain. Affective behaviors, such as listening, comforting, showing respect, empathy, interacting, touching, and establishing trust, were most frequently mentioned.

Patients' Perceptions of Caring Behaviors

Patients' perceptions of what constituted caring also have been obtained by the use of a similar qualitative approach to that used with nurses. From these interviews and descriptions, a different theme emerged. Brown (1982), in a study of 80 hospitalized patients, identified two categories of caring behaviors. The first, "what the nurse does," involved task-oriented behaviors, such as surveillance, availability, and demonstration of professional knowledge. The second category, "what the nurse is like," included behaviors that demonstrated expressive caring in terms of the personal and professional qualities of the nurse.

In a study of 50 home-care patients, Henry (1975) found that both personal and technical skills were necessary components of caring. For these patients, "doing extra things" was mentioned more often than "showing interest in patients" or "enacting skills." Both of these groups of patients emphasized the importance of instrumental activities and, in fact, a later study (Brown, 1986) of 50 medical-surgical patients showed that they identified technical competence as most indicative of caring.

Larson (1981) explored both oncology nurses' and oncology patients' perceptions of caring behaviors by the use of a Delphi technique with 8 expert nurses, and open-ended interviews with 15 patients. The findings were

integrated into a set of 50 caring behaviors which became the basis for the Caring Assessment Instrument (CARE-Q), in which caring behaviors are ranked from most to least important. These behaviors are ordered into six themes or subscales:

1. Accessible
2. Explains and Facilitates
3. Comforts
4. Trusting Relationship
5. Anticipates
6. Monitors and Follows Through

Nurses' and Patients' Perceptions of Caring Behaviors

Until 10 years ago, there were few studies that examined patients' and nurses' views of the importance of various nurse caring behaviors. White (1972) first developed an instrument, based on the literature, listing 50 nursing actions, which was given to 300 hospitalized patients and 100 professional nurses. Nurse-patient agreement was studied in four areas of nursing care. These areas were physical care activities, implementation of medical care, psychosocial care, and preparation for discharge. Both patients and nurses gave highest priority to implementation of medical care. However, patients then ranked physical care activities as the second highest, while nurses indicated that affective-expressive activities were second in importance. White suggested that the discrepancy

may have been due to the increasing emphasis in nursing education on psychosocial aspects of care.

The CARE-Q instrument has been used in most of the recent studies to compare rankings of important caring behaviors as perceived by patients and nurses. Larson (1981, 1984, 1986, 1987) compared 57 oncology patients' and 57 oncology nurses' perceptions of the importance of caring behaviors. She found that nurses' and patients' perceptions differed, and that, on the whole, patients ranked highest instrumental activities from the subscales "Monitors and Follows Through" and "Is Accessible." These subscales include behaviors, such as "knows how to give shots," "gives good physical care," "knows when to call the doctor," and "responds quickly." Nurses, on the other hand, ranked highest behaviors in the "Comforts" and "Trusting Relationship" subscales. Behaviors such as "listens to the patient," "touches the patient," "allows expression of feelings," and "gets to know the patient as an individual" were considered most important by the nurses. Mayer (1987) replicated Larson's study with 28 nurses and 54 patients and obtained similar results, thus supporting the reliability of the CARE-Q instrument.

Other researchers have conducted studies with hospitalized patients in Sweden (von Essen & Sjoden, 1991a, 1991b) and with coronary care patients (Rosenthal, 1992) in which the same essential differences in perceptions were

found with some exceptions. In both Swedish studies, patients ranked "being honest with the patient" in the top five behaviors which differed from all other studies, and in the study by Rosenthal, nurses included two instrumental activities among the five highest ranked behaviors.

More agreement between nurses and patients was found in a study of 26 patients and 26 nurses in a rehabilitation setting (Keane, Chastain, & Rudisill, 1987). Both groups ranked instrumental behaviors, such as "knows when to call the doctor" and "gives good physical care," among the five most important. Listening, the behavior ranked most important by nurses in all the other studies, ranked fifth. These findings reportedly reflected a primary nursing approach and rehabilitation nursing philosophy.

It may be that characteristics of the sample and setting produce variations in the apparent dichotomy of perceptions of important caring behaviors. In a study of 28 elderly home-care patients and 38 nurses, findings again reflected this dichotomy, including the notable finding that while nurses ranked touching as the second most important behavior, patients ranked it 47th (Smit & Spoelstra, 1991). Apparently, these elderly patients did not highly value being touched by nurses. This difference provides an important clue to adjusting nursing care to the needs of the patient.

The importance of a cognitive dimension in caring was uncovered by von Essen and Sjoden (1993) when the CARE-Q was administered to 61 psychiatric inpatients and 63 nursing staff. This time, both patients and staff ranked "listens to the patient" first, and both included several items from the "Trusting Relationship" subscale among the top 10 items. While staff continued to choose affective behaviors as important, patients chose several behaviors from the "Explains and Facilitates" subscale as being very important. It appears that it is important for psychiatric patients to know what is happening to them.

Studies using other instruments validate the caring behaviors and findings of ranked importance in the CARE-Q. Wolf (1986) developed a Caring Behaviors Inventory used by 97 nurses to rank 75 caring words in order of importance. These nurses ranked listening, comforting, honesty, patience, and responsibility as the five most important. The Caring Behaviors Assessment (Cronin & Harrison, 1988) is a list of behaviors divided into seven subscales that correspond to Watson's carative factors, which are also ranked by importance. It was administered to 22 coronary care patients, who ranked "monitoring of the patient's condition," "handling equipment," and "demonstrates professional competence" as the three highest.

It should be pointed out that, on the whole, these studies showed considerable overall agreement between nurses

and patients on the rankings of the importance of caring behaviors. It is the significant differences that have been described here. In addition, most of the studies also compared the least important behaviors, but these findings have not been discussed as they are outside the scope of this study.

From these studies, it can be seen that most nurses value expressive caring behaviors, and that most patients value instrumental activities in the form of demonstration of competence and surveillance actions. The differences in perceptions that emerged, for patients, appear to be influenced by the setting. No studies have been undertaken that compare nursing home residents' and nursing home nurses' perceptions of important caring behaviors. This study was conducted to explore this issue.

Chapter 3

METHODOLOGY

The purpose of this study was to determine the caring behaviors which nursing home residents and professional nurses perceive to be most important in making residents feel cared for. The study examined how these perceptions differed with respect to types and rankings of behaviors. This chapter will describe the research design, instruments, sample and setting, human subjects approval and confidentiality, data collection, and analysis procedures.

Design

This descriptive study utilized a Q-methodology to gather data from residents and nurses. Q-methodology makes it possible to study subjective experiences in an objective manner. "With Q-methodology, the domain is subjectivity, the emphasis is on the individual, and the methods are unique" (Dennis, 1986, p. 7). This methodology is particularly well suited to nursing research, which frequently addresses attitudes, feelings, beliefs, and perceptions in areas such as life experiences, health practices, and client-provider issues.

Q-methodology utilizes a Q-sort to place statements belonging to a domain, such a nurse caring behaviors, along a continuum of significance. Because the middle of the continuum is a neutral zone, with increasingly positive

statements on one side and increasingly negative statements on the other, both ends of the spectrum become equally important. The Q-sort employs a forced-choice format, in which a predetermined number of cards (statements) are placed into designated pockets (points along the continuum). This results in a quasi-normal distribution, with most of the cards in the center and increasingly fewer cards toward the tails. In this way, the statements at either end gain even more in discrimination (Stephen, 1985).

Q-methodology differs from conventional qualitative and quantitative methods in that the items, rather than the subjects, comprise the sample. These items or statements then become the main source of statistical data. With Q-methodology, it is possible to study phenomena as they are perceived by subjects without losing the power of statistical analysis (Dennis, 1986).

Instruments

The Caring Assessment Instrument (CARE-Q) developed by Larson (1981) was used to determine the subjects' perceptions of most important nurse caring behaviors. Permission to use the CARE-Q was obtained from the author (Appendix A). This instrument utilizes the Q-methodology described previously. The CARE-Q consists of 50 nurse caring behaviors grouped under six thematic subscales (Appendix B). Cards, each with a caring behavior on it, are sorted into seven pockets ranging from "most important" to

"not important." The sorting follows a forced-choice format with a predetermined number of cards put into each of the seven pockets (1,4,10,20,10,4,1). Each tail distribution then becomes equally important; thus, most studies utilizing the CARE-Q have focused on both the most and the least important items. However, this study is limited to comparing only the most important caring behaviors perceived by residents and nurses.

Face and content validity of the CARE-Q was established by Larson (1981) with an expert panel of registered nurses and hospital patients. Construct validity has been supported by other instruments such as the Caring Behaviors Inventory (Wolf, 1986) and the Caring Behaviors Assessment (Cronin & Harrison, 1988). The first instrument was given to nurses, and the second to coronary care patients, to rank caring words or behaviors in terms of importance.

Reliability was first addressed in a small test-retest study with nine nursing students (Larson, 1981). A perfect correlation (+1.0) was found for the one most important and the one least important item. There was little correlation for the 48 other items. Further reliability testing was done by Larson (1984) in a test-retest study with 82 oncology nurses. This time, item-ranking consistency for the five most important items was 79.1%. For the five least important items, the consistency ranking was 63.4%.

Setting and Sample

The study was conducted in a Nursing Home Care Unit at a Veterans Affairs Medical Center (VAMC) in a metropolitan area. The VAMC is affiliated with a university medical school. The nursing home has three wards which house about 127 long-term residents. Most are male, with about 5% being female.

Nursing care is delivered by a team approach. The team leader is usually a registered nurse. Team members may be other registered nurses, licensed vocational nurses, or nursing assistants. The proportion of registered nurses is higher than in nursing homes in the community. A convenience sample of 14 residents and 15 registered nurses was used for the study.

Resident Sample

Any long-term resident, with no planned discharge, was eligible to participate in the study, as long as he or she was mentally and physically able to complete the CARE-Q sorting. Potential competence in these areas was determined by the investigator and the nurse manager on each ward, as well as with the individual resident.

Based on the criteria for participation, 17 residents were invited to participate. Three chose not to do the study, finding the Q-sort too stressful or complicated. Of the remaining 14 subjects, 2 were physically assisted by their wives, and 4 were unable to hold the cards and were

assisted by the investigator.

Nurse Sample

Registered nurses who had worked in the nursing home for at least 6 months were eligible to participate. All 15 nurses invited to take part in the study agreed to participate. Nurses from all three wards, as well as all shifts, completed the CARE-Q sorting.

Human Subjects Approval

Before beginning the study, human subjects approval was obtained from the VAMC and its affiliated university, as well as from the Institutional Review Board of the university under whose auspices this thesis was prepared (Appendices C, D, and E). Anonymity, confidentiality, and protection from risk were assured in the informed consent (Appendix F). It was emphasized that participation was voluntary and that any decisions made with respect to participation in the study would in no way affect the care/work situation of the subjects.

Data Collection

Data were collected over a period of 2 months. Nurses and residents were approached individually and, after the study was explained, invited to participate. The subjects received the CARE-Q packet containing the consent form, directions for doing the sorting, and a demographic data sheet (Appendices G, H, I, and J). The packet was in the form of a folder containing seven pockets labeled from "most

important" to "not important," as well as 50 cards with caring behavior statements printed on them. After the consent form had been signed, a copy was given to the subjects, and they were asked to complete the sorting in 2-4 days. Nurses were permitted to do the sorting at home. Verbal instructions were given as needed. Except as stated previously, subjects were asked to do the sorting alone.

Of the 14 residents who completed the study, 6 had difficulty with the physical handling of the cards because of either multiple sclerosis or hemiplegia. Two were helped by their wives, and 4 by the investigator. These subjects were given a typed list, in enlarged print, of the 50 caring behaviors to read from (see example in Appendix K). They were asked to select about 5-20 items that they perceived to be important from the list. From these, they were asked to choose 5-7 of the most important, and then the one "most important." Then they were asked to pick out the 4 "fairly important" and the 10 "somewhat important" items. After the important items were selected, they were asked to follow the same procedure with the unimportant items. The 20 cards left over were placed in the middle or "neither important nor unimportant" pocket. Residents were then given the opportunity to make changes, but none chose to do so. The process took 1.5-2 hours.

Analysis Procedures

Descriptive statistics were used to analyze the demographic data and the CARE-Q scores for the resident and nurse groups. Each subject's sorting was coded with a score of 7 given to the "most important" item, a score of 6 to the "fairly important" items, a score of 5 to the "somewhat important" items, continuing on to a score of 1 for the "not important" item.

Mean scores and standard deviations were calculated for the residents and nurses, for each behavioral item and for the six subscales. The items were ranked in order of importance for each group of subjects. The 10 most important items for each group were listed in ranked order. Significant differences in mean scores for the 50 items as well as the six subscales were calculated using the independent t test. The statistical level of significance was set at $p < .05$.

The findings were then compared to those of selected previous studies, which had been conducted in different settings. These were acute care (Larson, 1987), home care (Smit & Spoelstra, 1991), and rehabilitation (Keane et al., 1987).

Chapter 4

FINDINGS AND INTERPRETATION

Fourteen nursing home residents and 15 registered nurses completed the CARE-Q. Following a forced-choice format, they placed cards with nurse caring behaviors, in ranked order of importance, into seven pockets. Each subject's sorting was coded, with a score of 7 given to the most important item, a score of 6 for the fairly important items, down to a score of 1 for the least important item.

Descriptive statistics were used to analyze the demographic data and the CARE-Q scores for residents and nurses. The independent t test was used to determine significant differences ($p < .05$) in mean scores, between the resident and nurse samples, for individual behavioral items as well as for the six subscales. The five highest ranking items were then compared with selected studies.

Demographic Variables

The residents ranged in age from 55-90 years; most were male, and half were married. Educational levels varied from grade school through graduate school. Twelve of the veterans had had careers other than the service; the average time spent in the service was 6 years. Most of these residents had only lived in the nursing home for a few years (mean = 3). Functional limitations were severe (mean = 5 of

a total of 6) for 12 of the residents as a result of fairly incapacitating chronic illnesses (Table 1).

Table 1

Characteristics of Patient Sample (N = 14)

Characteristic	<u>n</u>	Characteristic	<u>n</u>
Sex		Level of Education	
Male	12	Grade School	1
Female	2	Junior High	1
		High School	1
Mean Age	71	Technical School	4
Range	55-90	College	6
		Graduate School	1
Marital Status		Years in Service	
Married	7	Mean	6
Widowed	4	Range	1.5-20
Divorced	3		
Primary Diagnosis		Years in Nursing Home	
Multiple Sclerosis	6	Mean	5
CVA	2	Range	0.1-9
SCI	1		
Multiple Myeloma	1	Functional Limitations	
Diabetes	1	Mean	5
Tracheostomy	1	Range	1-6
Anemia	1		
ALS	1		

Nurse subjects were all female (n = 15), and most worked full-time as staff nurses on the day shift. They were mature (mean age = 46 years) and experienced, having worked an average of 11 years in long-term care. A wide range of nursing education was represented (Table 2).

Table 2

Characteristics of Nurse Sample (N = 15)

Characteristic	<u>n</u>	Characteristic	<u>n</u>
Sex		Years in Long-term Care	
Male	0	Mean	11
Female	15	Range	1-22
Mean Age	46	Nursing Position	
Range	33-61	Staff Nurse	13
Ethnic Background		Clinical Nurse	
Filipino	5	Specialist	2
Caucasian	10	Employment Status	
Level of Education		Full-time	11
MSN	3	Part-time	4
BSN	6	Shift Worked	
Diploma	4	Day	12
ADN	2	Evening	2
		Night	1

Ten Most Important CARE-Q Items

Mean scores were calculated for each of the 50 CARE-Q items for the resident and nurse groups. The maximum possible score was 7, and the minimum was 1. Mean scores ranged from 5.29 to 2.79 for patients and 5.60 to 2.40 for nurses. Items were ranked in order of importance, with higher scoring behaviors perceived as being more important than lower scoring behaviors.

Patients ranked the item, "puts the patient first, no matter what else happens," from the "Trusting Relationship" subscale as most important. Next in importance were 3 items

from the "Monitors and Follows Through" subscale. These were "knows how to give shots," "gives good physical care," and "knows when to call physician." "Is honest with the patient" from the "Explains and Facilitates" subscale was ranked fifth.

Of the 10 highest ranked patient items, there were 3 instrumental, 5 expressive, and 2 cognitive items. The cognitive items involved providing honest information about the patient's condition and treatments (Table 3).

As has been true in most CARE-Q studies, nurses perceived the item, "listens to the patient," from the "Comforts" subscale as the most important caring behavior. Another expressive behavior, "gives a quick response to the patient's call," from the "Trusting Relationship" subscale was ranked second. "Knows when to call physician," "knows how to give shots," and "gives good physical care," all from the "Monitors and Follows Through" subscale, were ranked third, fourth, and fifth. These three items were also ranked among the top five by the patients.

Items ranked fifth through tenth were all expressive behaviors from the "Comforts" or "Trusting Relationship" subscales. Therefore, there were a total of 7 expressive and 3 instrumental behaviors in the 10 highest ranked items (Table 4).

Table 3

Patient Rankings of the 10 Most Important Caring Behaviors
(N = 14)

CARE-Q Item ^a	Subscale ^b	Mean	SD	<u>t</u>
1. Puts patient first, no matter what else happens.	TR	5.28	1.54	1.84
2. Knows how to give shots, start IVs, manage equipment.	M&F	4.87	1.10	0.46
3. Gives good physical care to patient.	M&F	4.78	1.05	0.63
3. Knows when to call physician.	M&F	4.78	1.05	0.96
5. Is honest with patient.	E&F	4.64	1.22	1.55
5. Listens to patient.	C	4.64	1.08	2.48*
7. Gives a quick response to patient's call.	TR	4.57	1.28	1.89
7. Tells patient, in understandable language, what is important about treatments and possible side effects.	E&F	4.57	1.34	1.08
7. Realizes that patient knows him/herself best.	TR	4.57	1.16	0.10
10. Is cheerful.	C	4.50	0.94	1.75

^aAbbreviated versions of original items.

^bC = Comforts, E&F = Explains and Facilitates, TR = Trusting Relationship, and M&F = Monitors and Follows Through.

*p<.05.

Table 4

Nurse Rankings of the 10 Most Important Caring Behaviors
(N = 15)

CARE-Q Item ^a	Subscale ^b	Mean	SD	<u>t</u>
1. Listens to patient.	C	5.60	0.99	2.48*
2. Gives a quick response to patient's call.	TR	5.40	1.06	1.89
3. Knows when to call physician.	M&F	5.13	0.92	0.96
4. Knows how to give shots, start IVs, manage equipment.	M&F	5.07	1.33	0.46
5. Gives good physical care to patient.	M&F	5.00	0.76	0.63
6. Talks to patient.	C	4.80	0.86	1.21
6. Gets to know patient as an individual.	TR	4.80	1.08	1.48
8. Allows patient to express feelings.	TR	4.67	0.72	0.86
9. Realizes that patient knows him/herself best.	TR	4.53	0.83	0.10
9. Is pleasant and friendly to patient's family.	TR	4.53	0.64	1.79

^aAbbreviated versions of original items.

^bC = Comforts, Tr = Trusting Relationship, and M&F = Monitors and Follows Through.

*p<.05.

Comparison of Patient and Nurse Groups

Although patients perceived "puts the patient first, no matter what else happens," and nurses identified "listens to the patient," as the most important item, there was agreement on 3 of the 5 most important behaviors. Interestingly, these were all instrumental. With less physician involvement in the nursing home, and a focus on maintaining function, it is encouraging that residents and nurses appear to agree on what the crucial instrumental behaviors are.

Nurses and residents agreed on 6 of the 10 most important items, which indicates a basic harmony between the two groups with respect to priorities of care. While patients did not rank the item, "listens to the patient," as highly as nurses consistently have done, these patients, as have patients in other studies, still ranked it among the 10 highest (Larson, 1987; Keane et al., 1987; von Essen & Sjoden 1991a, 1993). Evidently, patients do want to be heard.

Patients also value honesty and information about their conditions and treatments as evidenced by their high ranking (#5 and #7) of two behaviors from the "Explains and Facilitates" subscale. No item from this subscale was present among the 10 highest for the nurses. Instead, nurses included additional expressive behaviors among their 10 highest ranked items. The patients included "is

cheerful" among their 10 highest ranked items, while nurses ranked it 29th. Several of the patients commented that their sometimes depressing existence was made better by seeing a cheerful face.

Only 5 behavioral items, and 2 of the 6 subscales, were ranked significantly different by the patients and nurses. Patients ranked higher than nurses "suggests questions to ask the doctor" and "checks out the best time to talk with the patient," while nurses ranked higher than patients "listens to the patient," "frequently approaches the patient first," and "touches the patient." These differences may indicate that patients value receiving information and self-determination (Table 5).

The mean scores of two of the subscales differed significantly between patients and nurses. As expected from the item rankings, patients ranked "Explains and Facilitates" higher than nurses, and nurses ranked "Comforts" higher than patients. This finding, again, indicates that patients would like to be treated as competent, informed adults. Some solicitous caring behaviors, such as touching, talking, encouraging, and comforting, may not be as appreciated as nurses believe (Table 6).

Table 5

Significant Differences in CARE-Q Items between Patients and Nurses (p<.05)

CARE-Q Item	Subscale ^a	Patient Rank	Nurse Rank
Listens to the patient.	C	5	1
Frequently approaches the patient first, e.g., brings a cup of coffee, back rub, etc.	ACC	46	22
Touches the patient when he/she needs comforting.	C	47	16
Suggests questions for the patient to ask his/her doctor.	E&	38	50
Checks out with the patient the best time to talk with the patient about changes in his/her condition.	TR	39	48

^aC = Comforts, ACC = Accessible, E&F = Explains and Facilitates, and TR = Trusting Relationship.

Table 6

Comparison of Patient and Nurse Mean Scores and Rankings on the CARE-Q Subscales

Subscale	Patients		Nurses		t
	Mean/Rank	SD	Mean/Rank	SD	
Monitors and Follows Through	4.23(1)	0.27	4.27(2)	0.41	0.26
Explains and Facilitates	4.07(2)	0.61	3.67(5)	0.25	2.30*
Trusting Relationship	3.97(3)	0.30	3.92(4)	0.27	0.53
Accessible	3.97(3)	0.43	4.31(1)	0.60	1.73
Comforts	3.93(5)	0.35	4.24(3)	0.34	2.31*
Anticipates	3.76(6)	0.54	3.44(6)	0.39	1.79

* $p < .05$.

Comparison of the Top Five Items
with Selected Studies

Adequate reliability of the CARE-Q has been established for the 5 highest ranked items (Larson, 1984). It is, therefore, of interest to see what differences have emerged in CARE-Q studies done in diverse settings (Table 7).

Nurses, in various settings of acute care, consistently include expressive behaviors in the 5 highest ranked items, lending support to the findings of Larson (1987). Home care staff have also ranked 5 expressive items highest (Smit & Spoelstra, 1991), while rehabilitation nurses have listed 3

Table 7

Patients' Top Five Items^a - Comparison with Selected Studies

No.	This Study	Subscale ^b	Larson (1987)	Subscale
1.	Puts patient first, no matter what else happens.	TR	Knows how to give shots, start IVs, manage equipment.	M&F
2.	Knows how to give shots, start IVs, manage equipment.	M&F	Knows when to call physician.	M&F
3.	Gives good physical care to patient.	M&F	Gives good physical care to patient.	M&F
4.	Knows when to call physician.	M&F	Gives treatments and medications on time.	ACC
5.	Is honest with patient about his medical condition.	E&F	Checks on patient frequently.	ACC
<hr/>				
	Keane, Chastain & Rudisill (1987)	Subscale	Smit & Spoelstra (1991)	Subscale
1.	Knows when to call physician.	M&F	Knows when to call physician.	M&F
2.	Puts patient first, no matter what else happens.	TR	Listens to patient.	C
3.	Knows how to give shots, start IVs, manage equipment.	M&F	Talks to patient.	C
4.	Gives treatments and medications on time.	ACC	Gives treatments and medications on time.	ACC
5.	Gives good physical care to patient.	M&F	Puts patient first, no matter what else happens.	TR

^aAbbreviated versions of original items.^bTR = Trusting Relationship, M&F = Monitors and Follows Through, E&F = Explains and Facilitates, ACC = Accessible, C = Comforts.

instrumental and 2 expressive items as most important (Keane et al., 1987). Staff rankings of the 5 five most important behaviors in this study most closely agree with those found in the rehabilitation setting. Nursing home nurses also chose 3 instrumental and 2 expressive items as most important. Such a selection may reflect a belief in improving or maintaining the physical health status of the residents.

When patient perceptions of the 5 most important caring behaviors were compared, a different picture appeared. Patients in acute care ranked 5 instrumental behaviors highest (Larson, 1987), followed by rehabilitation patients who included 1 expressive behavior (Keane et al., 1987) and home care patients who included 3 expressive behaviors among the 5 most important (Smit & Spoelstra, 1991). The patients in this study included 1 expressive and 1 cognitive item, in addition to the 3 instrumental behaviors, indicating a desire to be considered as valuable, knowledgeable persons.

The selection and ranking of important nurse caring behaviors in this study demonstrated a basic common view between residents and nurses. Nonetheless, the significant differences in rankings between residents and nurses suggest that there is room for adjustment in the character of the delivery of nursing care. Chapter 5 presents a discussion, summary, and conclusions based on these findings and offers recommendations for further research.

Chapter 5

DISCUSSION

This CARE-Q study sought to explore what nurse caring behaviors nursing home residents and registered nurses perceived as most important in making residents feel cared for in a nursing home setting. This chapter will summarize the study, discuss the significance of the findings, and make recommendations for new directions in caring research, as well as in the actualization of caring for the elderly nursing home resident.

Summary

Although rankings differed, residents and nurses agreed on 3 of the 5, and 6 of the 10 most important nurse caring behaviors. Of the 6 behaviors perceived as most important by both groups, the 3 instrumental behaviors were valued somewhat higher than the 3 expressive behaviors. In addition to the 3 instrumental behaviors, nurses chose 7 expressive, while patients chose 5 expressive and 2 cognitive behaviors.

Five caring behaviors and 2 subscales were ranked significantly different by residents and nurses. Residents ranked behaviors from the "Trusting" and "Explains and Facilitates" higher than nurses. Nurses, on the other hand, ranked behaviors from the "Comforts" and "Accessible" subscales higher than residents. This divergence appeared

again when the residents ranked the subscale, "Explains and "Facilitates," higher than nurses, and nurses ranked higher than residents the subscale, "Comforts." "Listens to the patient," although ranked in the top 10 group by the residents, was ranked significantly higher, and the most important behavior, by nurses.

Conclusions

The findings from this study demonstrate a basic agreement in perception of caring priorities between the residents and nurses. Only a few significant differences were found, but they suggest that residents and nurses may differ in the gestalt they have of the nurse-patient relationship in the nursing home. It appears that nurses approach caring as the demonstration of a few instrumental behaviors performed in the context of accessibility and comforting. Residents, however, seem to value the same clinically competent behaviors in a broader context. While they apparently appreciate expressive behaviors having to do with comforting and trust, they also indicate a desire to be valued as individuals, as well as a desire for informed dialogue about their condition and treatments. Residents also value honesty and cheerfulness more than nurses may be aware of.

Discussion

The perceptions of the nurses in this study of most important caring behaviors were most similar to nurses

studied in coronary care (Rosenthal, 1992) and rehabilitation (Keane et al., 1987) settings. In addition to a selection of predominantly expressive behaviors, these nurses also ranked competent clinical judgment and clinical care highly. If nursing education emphasizes a psychosocial approach to nursing care (White, 1972), then the decidedly high ranking of clinical judgment and technical skills by residents and nurses could reflect either the serious medical problems of the patient subjects or limited physician involvement. There is a physician on staff in the nursing home; therefore, nurses working in nursing homes in the community may perceive instrumental behaviors as even more important.

Nursing home nurses would do well to heed the residents' expressed need for a broader nurse caring approach. Possibly too much emphasis on solicitous caring behaviors could encourage dependency rather than independency in the elderly resident. Paying attention to the residents as individuals, providing pertinent information, and discussing the residents' overall status would enable them to be actively involved in their care and to make appropriate choices. The high rankings residents give to certain items, such as "puts the patient first, no matter what," "realizes that the patient knows her/himself best," "tells the patient in understandable language," and "checks out with the patient the best time to talk," clearly

show that residents want to be valued, respected, and informed.

The high ranking given to several instrumental behaviors by nurses in this study, as well as the two discussed previously, cast doubt on Larson's (1981) proposal that nurses may emphasize expressive behaviors because they have internalized the value of technical competence and automatically incorporate it into their roles. Nonetheless, even in these settings, nurses chose more expressive behaviors than patients. In the nursing home, this difference has several possible explanations. Residents had only themselves to consider in ranking behaviors, while the nurses probably considered all the residents. The majority of residents would have been unable to complete the CARE-Q because of severe physical and/or mental impairments. Perhaps these residents would value affective behaviors more than the actual subjects did.

Finally, in this study, all the nurses were female, and most of the residents were elderly males. Obvious differences in socialization between the sexes, as well as a cohort effect, could easily lead to different attitudes towards the value of some affective behaviors. For example, touching, which was ranked 16th by the nurses, was ranked 47th by the residents.

Scope and Limitations

This study is limited in scope because of the small sample size, unique setting, and characteristics of a Q-methodology. A Veterans Affairs nursing home differs from nursing homes in the community in that the residents are predominantly male and do not usually have to pay for their care. Furthermore, the sample is not representative of all the residents, many of whom are not mentally or physically able to complete the CARE-Q sorting.

There are inherent weaknesses in the use of a Q-methodology because of its forced-choice distribution. Only one behavior can be ranked as most important, four as fairly important, and so on. This means that no behavior is necessarily unimportant, only relatively less so. Many of the subjects expressed frustration over this issue. There may also be behaviors that are very important to nursing home residents which are not included in the instrument, which is based on the perceptions of patients and nurses in an acute setting.

Adequate reliability has only been established for the five most and the five least important behaviors. Therefore, the ranking of the 40 behaviors in the middle cannot be evaluated with any confidence. In addition, the subscale categories were developed by a panel of experts (Larson, 1981) and lack the scientific validation of a factor analysis. None of the previous studies have had a

sample large enough to conduct such an analysis.

The CARE-Q, itself, may have caused some problems. Some statements were very short; others were excessively long. Some terms, such as perceptions, goals, and planning of care, were probably more meaningful to nurses than residents.

It is clear that the findings from this study cannot be considered representative of the care needs of all elderly in nursing homes. The findings do, however, shed some light on directions for future research.

Recommendations

The perceptions of most important caring behaviors by nursing home residents and registered nurses need further investigation to ensure a truer understanding of what is needed to develop even more agreement on caring priorities. It is recommended that this study be replicated using a larger sample size in both Veterans Affairs and community nursing homes.

Reliability studies need to be extended, at least to the 10 most and least important behaviors. Factor analysis should, if possible, be undertaken. With 50 different behavioral items, it is conceptually very helpful to have reliable and valid subcategories. Finally, condensing some of the excessively wordy CARE-Q statements would eliminate the real possibility that subjects chose brief statements more often simply because they are more accessible.

It appears that residents and nurses, in this study, agree on the importance of a combined scientific-humanistic caring approach. Nurse caring behaviors representing this approach address Maslow's hierarchy of human needs, which Watson (1979) incorporated into her theoretical framework. Residents and nurses perceived as important nurse behaviors which satisfied physiological, security, and emotional needs, in ascending order. Findings from the study, however, suggest that residents have higher-level needs that may go ungratified. These needs have to do with self-esteem, such as being treated with respect and receiving individualized attention.

Progress could be made towards establishing the transpersonal relationship described by Watson (1985) if nursing home nurses would validate each individual patient's caring needs. On a larger scale, nurses may grow even more in understanding their elderly patients' needs and the importance these patients give to certain caring behaviors.

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APPENDIX A

Permission Letter

School of Nursing
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San Francisco, CA 94143-0610
FAX (415) 476-8899

University of California, San Francisco...A Health Sciences Campus

March 24, 1993

Ms. Peggy Smith
264 N. Whisman Road, Apt. #8
Mountain View, CA 94043

Dear Ms. Smith:

Thank you for your interest in my work on caring. I am enclosing the information on: 1) the description of the derivation of the CARE-Q I items and scales; and 2) the evolved CARE/SAT. As noted the satisfaction paper should be treated as privileged communication.

To use the CARE/SAT all questionnaires must be xeroxed from the enclosed copy. This is to ensure that the visual analog line remains a constant 100mm line (apparently xeroxing from copies causes the line to be enlarged in length). To gain the patients' response use a metric ruler, and measure at the mid-point of the "X". If the patient makes two "X's" toss a coin to select one. If the patient marks an "X" beyond the line consider it 100; if below, it is then ranked as 0. The CARE-Q in its present form does not generate a total score.

You are welcome to use either instrument. If you decide to use one or both please let me know and provide me with an abstract of the study's findings upon completion. I would also appreciate your acknowledgement of my authorship of the instrument.

If I can be of further assistance, please let me know.

Sincerely,

A handwritten signature in cursive script, appearing to read "Patricia J. Larson".

Patricia J. Larson, RN, DNSc
Associate Professor
Director, Oncology Program
American Cancer Society Professor in Oncology Nursing
Director, Center for Symptom Management

PL/ad

Enclosures

APPENDIX B

The CARE-Q Items and Scales

Subscales	Item
<u>ACCESSIBLE</u>	<ol style="list-style-type: none"> 1. Frequently approaches the patient first, e.g., offering such things as pain medication, back rub, etc. 2. Volunteers to do "little" things for the patient, e.g., brings a cup of coffee, paper, etc. 3. Gives the patient's treatments and medications on time. 4. Checks on the patient frequently. 5. Gives a quick response to the patient's call. 6. Encourages the patient to call if he/she has problems.
<u>EXPLAINS AND FACILITATES</u>	<ol style="list-style-type: none"> 7. Tells the patient of support systems available, such as self-help groups or patients with similar disease. 8. Helps the patient not feel dumb by giving him/her adequate information. 9. Tells the patient, in understandable language, what is important to know about his/her disease and treatment. 10. Teaches the patient how to care for himself/herself whenever possible. 11. Suggests questions for the patient to ask her/his doctor. 12. Is honest with the patient about his medical condition.
<u>COMFORTS</u>	<ol style="list-style-type: none"> 13. Provides basic comfort measures, such as appropriate lighting, control of noise, adequate blankets, etc. 14. Provides the patient encouragement by identifying positive elements related to the patient's condition and treatment. 15. Is patient even with "difficult" patients. 16. Is cheerful. 17. Sits down with the patient.

Subscales	Item
	<p>18. Touches the patient when he/she needs comforting.</p> <p>19. Listens to the patient.</p> <p>20. Talks to the patient.</p> <p>21. Involves the patient's family or significant others in their care.</p>
<u>ANTICIPATES</u>	<p>22. Realizes that the nights are frequently the most difficult time for the patient.</p> <p>23. Anticipates the patient's and her/his family's shock over her/his diagnosis and plans opportunities for them, individually or as a group, to talk about it.</p> <p>24. Knows when the patient has 'had enough' and acts accordingly, e.g., rearranges an examination, screens visitors, insures privacy.</p> <p>25. Is perceptive of the patient's needs and plans and acts accordingly, e.g., gives anti-nausea medication when patient is receiving medication which will probably induce nausea.</p> <p>26. Anticipates that the 'first times' are the hardest and pays special attention to the patient during these times.</p>
<u>TRUSTING RELATIONSHIP</u>	<p>27. When with a patient, concentrates only on that one patient.</p> <p>28. Continues to be interested in the patient even though a crisis or critical phase has passed.</p> <p>29. Offers reasonable alternatives to the patient, such as choice of appointment times, bath times, etc.</p> <p>30. Helps the patient establish realistic goals.</p> <p>31. Checks out with the patient the best time to talk with the patient about changes in his/her condition.</p> <p>32. Checks her/his perceptions of the patient with the patient before initiating any action, e.g., if she/he (the nurse) has the feeling that the patient is upset with the treatment plan, discusses this with the patient before talking about it to the doctor.</p>

Subscales	Item
	<p>33. Helps the patient clarify his thinking in regard to his/her disease and treatments.</p> <p>34. Realizes that the patient knows himself the best and whenever possible includes the patient in planning and management of his/her care.</p> <p>35. Encourages the patient to ask her/him any questions he/she might have.</p> <p>36. Puts the patient first, no matter what else happens.</p> <p>37. Is pleasant and friendly to the patient's family and significant others.</p> <p>38. Allows the patient to express his feelings about his/her disease and treatment fully, and treats the information confidentially.</p> <p>39. Asks the patient what name he/she prefers to be called.</p> <p>40. Has a consistent approach with the patient.</p> <p>41. Gets to know the patient as an individual person.</p> <p>42. Introduces himself/herself and tells the patient what she/he does.</p>
<u>MONITORS AND FOLLOWS THROUGH</u>	
	<p>43. Is professional in appearance--wears appropriate identifiable clothing and identification.</p> <p>44. Makes sure that professional appointment scheduling e.g., x-ray, special procedures, etc. are realistic to the patient's condition and situation.</p> <p>45. Is well organized.</p> <p>46. Knows how to give shots, I.V.s, etc. and how to manage the equipment like I.V.'s, suction machines, etc.</p> <p>47. Is calm.</p> <p>48. Gives good physical care to the patient.</p> <p>49. Makes sure others know how to care for the patient.</p> <p>50. Knows when to call the doctor.</p>

APPENDIX C

Human Subjects Committee Approval

STANFORD UNIVERSITY
Stanford, California 94305
(415) 723-2883

CERTIFICATION OF HUMAN SUBJECTS APPROVAL

DATE: July 6, 1993
TO: M.K. Smith, R.N.
Department of Nursing
FROM: Chairman, Medical Committee for the
Protection of Human Subjects in Research

PROTOCOL ENTITLED:
Patients' and Nurses' Perceptions of Most Important Caring Behaviors in a
Long-term Care Setting.

The Panel approved human subject involvement in your research project on
July 6, 1993.

The expiration date of this approval is July 5, 1994. 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.

James Theodore, M.D., Chairman

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

Funding Agency: (Un-sponsored) (N)
Period of Time: 07/06/93 through 07/05/94
Investigational New Drugs: N
Investigational New Device: N
Cooperating Institution: N
Expedited Review
Assurance Number: M1272
IRB #01

APPENDIX D

Research Committee Approval

**Department of
Veterans Affairs**

Memorandum

Date : August 19, 1993
From : AA, Research Administration (151A)
Subj : Approval of Research Proposal
To : Margaret K. Smith, RN (11NH)

1. This is to inform you that your research proposal, "Patients' and Nurses' Perceptions of Most-Important Caring Behaviors in a Long-Term Care Setting" was approved by the Research and Development Committee at this facility on August 19, 1993.
2. The proposal received Human Subjects approval on July 6, 1993.
3. Please don't hesitate to call our office if we can be of any further assistance.

Shilo Herrling
x5571

APPENDIX E

Institutional Review Board 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: Margaret K. Smith
264 North Whisman Rd., #8
Mountain View, CA 94043

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

Date: October 20, 1993

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

"Patients' and Nurses' Perceptions of Most Important Caring Behaviors in a Long-term Care Setting"

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 anytime. 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.

APPENDIX F

Consent Form

A campus of The California State University

School of Applied Arts and Sciences • Department of Nursing • Graduate Program
One Washington Square • San Jose, California 95192-0057 • 408/924-3134

Title of Protocol: Patients' and Nurses' Perceptions of Most
Important Caring Behaviors in a Long-term Care Setting

INFORMED CONSENT

1. You are invited to participate in a research study determining the caring behaviors which nursing staff and nursing home residents perceive to be the most important in having residents feel cared for. You were selected to participate because you are either a resident in the Nursing Home Care Unit or a professional nurse working there. The information gained from this study may help nurses, in the future, provide better care.

2. You will be asked to sort cards containing statements about nurse caring behaviors, rating them from most important to least important. This will require about 45 to 60 minutes of your time. You may stop to rest at any time, and continue on when you choose. You can participate in the study at your convenience, either in the nursing home or in a place of your choice. You will be asked to complete the sorting within one week.

3. All forms of medical diagnosis and treatment -- whether routine or experimental -- involve some risk of injury. In spite of all precautions, you might develop medical complications from this study. If such complications arise, the researchers will assist you in obtaining appropriate medical treatment, but this study does not provide financial assistance for additional medical of other costs. Additionally, Stanford is not responsible for research and 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 this 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.

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

5. No alternative procedures will be initiated in this study.

Date

Subject's Signature

Date

Investigator's Signature
Margaret K. Smith

A campus of The California State University

School of Applied Arts and Sciences • Department of Nursing • Graduate Program
One Washington Square • San Jose, California 95192-0057 • 408/924-3134

Title of Protocol: Patients' and Nurses' Perceptions of Most Important Caring Behaviors in a Long-term Care Setting

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

7. 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, may inspect research records and learn your identity if this study falls within its jurisdiction.

8. Any questions about this research study may be addressed to this investigator at (415) 961-2331. Any complaints about the research may be presented to Coleen Saylor Ph.D., Graduate Coordinator, School of Nursing, San Jose State University at (408) 924-3131. Questions or complaints about the research, subjects' rights, or research-related injury may be presented to Serena Stanford, Ph.D., Associate Academic Vice President for Graduate Studies and Research, at (408) 924-2480.

VA Liability Clause

In the unlikely event you are injured as a result of participation in this study, Palo Alto Veterans Affairs Medical Center will furnish humanitarian emergency medical care (for non-veteran participants) or medical care (for veteran participants) as provided by federal statute. Compensation for such injury may be available to you under the provision of the Federal Tort Claims Act and/or U.S.C. section 1151 (formerly section 351) (for veteran participants only). For further information, contact the V.A. District Counsel at (415) 744-7676.

9. You may be assured that your care/work situation will in no way be affected by your decision to participate or not participate in this study. You may withdraw from this study at any time without jeopardizing your relationship with SJSU or your care/work situation in any way. Your decision to participate in this study is entirely voluntary. The alternative to participation in the study is to decline signing this form.

10. Your signature indicates that you have read and understand the above information, that you have discussed this study with the principal investigator and 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.

Date

Subject's Signature

Date

Investigator's Signature
Margaret K. Smith

A campus of The California State University

School of Applied Arts and Sciences • Department of Nursing • Graduate Program
One Washington Square • San Jose, California 95192-0057 • 408/924-3134

Title of Protocol: Patients' and Nurses' Perceptions of Most Important Caring Behaviors in a Long-term Care Setting.

Date:

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 purpose of the experiment;
 - be given an explanation of the procedures to be followed in the medical experiment, and 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 reasonably 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 the 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.

APPENDIX G

Resident Demographic Information

All information on this sheet will be confidential and
and will not be used in any way where the individual
participant will be identified.

1. Age_____
2. Male_____ Female_____
3. Married_____ Widowed_____ Divorced_____ Single_____
4. Ethnic background_____
5. Primary diagnosis_____
6. Highest Level of Education:
Grade School_____ Technical School_____
Junior High _____ College _____
High School _____ Graduate School _____
7. Military Service
Years of Service_____ Rank_____
8. Former occupation:_____
9. Years living in Nursing Home_____
10. Functional Limitations:
Bathing_____
- Dressing_____
- Transferring _____
- Ambulation_____
- Continence_____
- Feeding_____

APPENDIX H

DIRECTIONS
(Residents)

THE NURSE CARING BEHAVIOR STUDY

The purpose of the Nurse Caring Behavior Study is to identify the nurse caring behaviors that you personally feel are important in making you feel cared for.

1. Please answer the questions on the Demographic Information Sheet.
2. Sort the 50 cards, in the CARE-Q packet from "most important" to "not important". Each card has a different nurse caring behavior typed on it. Place each card into one of the pockets, on a range of most important to least important.

Each pocket is labeled with the number of cards that should be put into it (1,4,10,20,etc.). It is essential that only the designated number of cards be placed in the pockets.

When you have completed the sorting, please count the number of cards in each pocket to make sure that the right number of cards are in each pocket.

Thank you so much for your help.

APPENDIX I

NURSE DEMOGRAPHIC INFORMATION

All information on this sheet will be confidential
and will not be used in any way where the individual
participant will be identified.

1. Age_____
2. Male_____ Female_____
3. Ethnic background_____
4. Highest level of Nursing Education:
A.D.N. _____ B.S.N. _____
Diploma _____ M.S.N. _____
5. Years of Experience:
Long-term Care _____ Nursing _____
6. Present Nursing Position Held:
Staff Nurse _____ C.N.S. _____
Head Nurse _____ Other _____
7. Employment Status:
Full time _____ Part-time _____ Intermittent _____
8. Shift Worked:
Day _____ PM _____ Night _____

APPENDIX J

DIRECTIONS
(Nurses)

THE NURSE CARING BEHAVIOR STUDY

The purpose of the Nurse Caring Behavior Study is to identify the nurse caring behaviors that you personally feel are important in making residents feel cared for.

1. Please answer the questions on the Demographic Information Sheet.
2. Sort the 50 cards, in the CARE-Q packet from "most important" to "not important". Each card has a different nurse caring behavior typed on it. Place each card into one of the pockets, on a range of most important to least important.

Each pocket is labeled with the number of cards that should be put into it (1,4,10,20,etc.). It is essential that only the designated number of cards be placed in the pockets.

When you have completed the sorting, please count the number of cards in each pocket to make sure that the right number of cards are in each pocket.

Thank you so much for your help.

APPENDIX K

Sample of Enlarged CARE-Q

1. Frequently approaches the patient first, e.g., offering such medication, back rub, etc.
2. Volunteers to do "little" things for the patient, e.g., bri paper, etc.
3. Gives the patient's treatments and medications on time.
4. Checks on the patient frequently.
5. Gives a quick response to the patient's call.
6. Encourages the patient to call if he/she has problems.
7. Tells the patient of support systems available, such as sel patients with similar disease.
8. Helps the patient not feel dumb by giving him/her adequate
9. Tells the patient, in understandable language, what is impo his/her disease and treatment.
10. Teaches the patient how to care for himself/herself whenever
11. Suggests questions for the patient to ask her/his doctor.
12. Is honest with the patient about his medical condition.