Family Participation In Hospital Care For Elders

By

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This dissertation is dedicated to my country,
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ABSTRACT

TITLE: FAMILY CAREGIVING IN HOSPITAL CARE FOR ELDERS

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The extensive care provided by families to their elderly relatives in the home is well documented. Although family caregiving is likely to be continued during hospitalization of elderly relatives, limited research has been conducted to address the specific roles that family members assume in the hospital. The purpose of this qualitative study was to provide conceptual foundation for developing measures of family participation and preferences about family participation as well as family worry. Altogether 25 interviews were done. Of the 16 participants, 6 were family members, 6 were patients, and 4 were nurses; 7 participants were interviewed once and 9 participants were interviewed twice.

Qualitative analysis based on Lofland and Lofland's (1984) approach resulted in the identification of three major content domains and five process themes of family participation in the hospital care for elders. The three content domains were (1) providing care to the patients; (2) working together with the health care term; and (3) taking care of self. The domain of providing care to the patients included the dimensions of being there, performing usual family practices in the hospital, providing passage between home and hospital, and attending to the patient's personal care. The domain of working together with the health care team included dimensions of exchanging information, collaborating with the health care team to provide personal care, participating in therapeutic health care regimens, and making sure the health care team takes care of the patient's needs. The five process themes included carrying on, modifying, starting new, sharing and arranging care for patients.

A conceptual framework of family participation in the hospital care for elders emerged from the results of this study. The three content domains and five process themes were the core elements in this framework. In addition, antecedent factors and consequences were identified. Family worry and patient preferences were identified as mediating variables between the antecedent factors and the core elements in the framework. Further, the possible ways of measuring the three major concepts (family participation actions, family worry and patient preferences) were generated based on results of this study.

Results were discussed and recommendations for nursing practice, research and theory were provided. With hospital stay getting shorter and elderly relatives returning home in more frail health, family participation in the hospital care is important to improve the transition to family caregiving in the home.

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CHAPTER 1

INTRODUCTION

Statement of Purpose

The purpose of the this dissertation was to provide the conceptual foundation for develooing a series of measures of family participation and preferences about participation in hospital care of elderly patients; and a way to measure caregiver role strain from worry. These measures are needed in order for the researcher to proceed with a program of research, which has been designed to enhance family participation in the acute care of hospitalized older people. A measure is needed for caregiver role strain from worry because worry is considered to be a main source of caregiver role strain when family members are hospitalized. In a future phase of the program of research, the researcher will examine whether worry can be reduced by enhancing family participation in the hospital care of elderly patients.

"Family caregiving" refers to the care which is provided by family members for a frail elderly relative, due to the relative's physical or mental health problems. Although there is extensive literature on family caregiving in the home (e.g., Given & Given, 1991; Horowitz, 1985; Phillips & Rempusheski, 1986), there is little published research regarding the processes of family caregiving for elderly patients in hospital settings. Based on the investigator's own observations as a nurse in an acute care setting, the supportive network of families generally continues to function during hospitalization of elderly relatives. However, the role that families assume in the care of their elderly members in hospitals, and the specific degree of family participation, are not well documented. As a prelude for this dissertation, a preliminary qualitative study on family participation and strain from worry was done by the investigator as part of her doctoral course work (Li, 1992ac).

Specific aims for this study were to:

1. define and further describe the content domains of (a) patient preferences and (b) family preferences about family participation in the care of elderly patients, (c) actual participation of family members in the hospital care of elderly patients, and (d) caregiver role strain from worry during hospitalization;
2. describe relationships among the four concepts and other relevant variables; and
3. Generate ideas for possible ways to measure the four concepts.

Background And Significance

Demographics of Aging and the Hospital Care of Older People

In 1970 there were 20 million people over age 65 in the United States, representing 9.9% of the population. In 1990, the ratio of individuals over 65 had increased to 12.4%. According to Census Bureau projections for the year 2000, the number of people over 65 is projected to be more than 35 million, 13.1% of the total population. These projections indicate that by 2050 older people may number 67 million, or 22% of the population (U.S. Bureau of the Census, 1982, 1989).

In 1987, over 40% of all U.S. hospital beds were occupied by adults over 65, and each year the acuity level of elderly patients continues to rise (U.S. National Institutes of Health, 1987). Higher hospital utilization rates for older people are due largely to age-related differences in surgical procedures. For instance, there were 3,436 eye operations for every 10,000 people aged 65 and older, which is five times the rate for the total population. Operations on respiratory, cardiovascular, lymphatic, digestive, and urinary systems were three times more common among those 65 and older, than among the rest of the population. In 1987, people over age 65 represented 12 percent of the population, accounted for 31 percent of all hospital discharges, and 42 percent of all short-stay hospital days of care (The U.S. Senate Special Committee on Aging, 1991). The average hospital stay for people over 65 years was 8.6 days in 1987, compared with 6.4 days for the general population (National Center for Health Statistics, 1989).

Dysfunctional Syndromes and Family Participation in Hospital Care

Current available evidence suggests that 20% to 40% of patients age 65 or older, suffer functional deterioration during hospitalization. This decline in functioning and quality of life that occurs during therapy for an acute illness or episode of chronic illness consists of one or more dysfunctional syndromes. These include, but are not limited to, (1) acute confusion; (2) incontinence; (3) nutrition problems; (4) immobility; (5) falls; and (6) sensory deficit. For many elderly patients, a dysfunctional syndrome prolongs hospital their stay, decreases the quality of life, and often leads to institutionalization after their discharge from the hospital (Kresevic, Landefeld, Palmer, & Kowal, 1993;

University of Cleveland, 1991).

Dysfunctional syndromes are caused mainly by acute illness and side effects of treatments, such as anesthesia or drugs (Creditor, 1993). Two factors that contribute to the development of dysfunctional syndromes, that are within the domain of nursing practice, are (1) unfamiliar environments and (2) the patient's high stress levels (Foreman, 1989, 1990; Kresevic et al. 1993; Miller, 1991; Roberts & Lincoln, 1988). Although nurses provide the majority of care in hospitals, dysfunctional syndromes for elderly patients may be reduced by having the family play an important role in their care may reduce. Chadwick (1984) states that elderly patients spent 80 to 90% of their time in the hospital doing absolutely nothing. This, in turn, has been likened to sensory deprivation which may be due partly to a lack of interaction between the patient and others in the environment. In this case, family participation in a patient's care may reduce the incidence of confusion, by providing social stimulation with psychological and emotional support.

The importance of family participation and worry are highlighted by results of a preliminary study done by the researcher (Li, 1992a). An elderly patient stated that he felt better when his wife was at his bedside. Family members and nurses also identified the importance of family members staying with the patient and participating in the care. A wife of one patient said, "Even if I don't do a thing and let the nurses do it, he knows I am here, he smiles". Another wife reported, "Although he is confused, I still talk with him and hold his hands. He seems calm when I am around." A staff nurse said, "I have a patient whose wife helps the patient to take medication. The patient only takes medication when his wife gives it to him. If a nurse gives the pills to him, he would spit them out." Two of the nurses believed that it was the job of the nurse to assist family members to learn about their elderly member's care, because they would live with and care for the frail elderly person when he or she returned home.

A significant problem in hospital settings, however, is the lack of communication between nurses and families. This problem is addressed in the literature (Sharp, 1990) and in previous work by this investigator (Li, 1992a). In the latter study, three consequences that occurred because of lack of communication between the nurses and families were: (1) some older patients became depressed as a result of the lack of family participation; or delayed their self-independence as a result of family over-participation in hospital care; (2) some family members became frustrated or dissatisfied with nursing care as a result of nurses' lack of communication with the family about providing care for elderly patients; and (3) nurses complained about families' inappropriate participation in patient's care, such as helping patients to get up, resulting in falls and injuries (Li, 1992a). It is possible that lack of communication between nurses and families may increase the incidence of dysfunctional syndromes. The findings of the qualitative data (Li, 1992a) were basically congruent with the literature of family participation in the hospital care in terms of the importance of having family members participate in the hospital care, and the importance of increasing the communication between nurses and family members.

Family participation in hospital care of elderly patients has positive implications for patients, family, and nursing staff (Collier & Schirm, 1992; Creditor, 1993; Miller, 1991, Sharp, 1990; Stanik, 1987). Moss (1986) has suggested that families who participate in hospital care indirectly affect patients' outcomes including reduced complication rates, fewer patient demands, and shortened length of hospital stay. Benefits to the families may include reducing caregiver role strain from worry during the hospitalization, increasing families' informal caregiving skills and facilitating transition to the home environment (Collier & Schirm, 1992). Benefits to the nurses may include greater job satisfaction and enhanced professional image (Eldridge, 1984; Moss, 1986). However, in order to examine the effects of family participation in hospital care, measures are needed to assess patient and family preferences about participation, and the degree of implementation of the independent variable. In this dissertation, qualitative methods were used to discover more about family participation and worry in order to provide the foundation for measures that will be developed for use in a future intervention study.

Program of Research About Family Participation in Hospital Care

Ultimately, the long term goal of the program of research is in evaluating nursing interventions designed to enhance family participation in the acute care of hospitalized older patients. The rationale for such interventions is twofold. First, increasing family caregiving during hospital, care may facilitate the continuity of care from home to hospital and then back home. For example, Archbold, Stewart, Greenlick, and Harvath (1990) found that preparedness for caregiving was associated with lower levels of family caregiver role strain after patients are discharged from hospitals. It is expected that increasing family participation in hospital care for elderly patients may increase family preparedness for home care when the patients are discharged from hospitals. Second, enhancing the ways in which families participate in the care of their hospitalized relatives, may reduce the dysfunctional syndromes of elderly hospitalized patients and caregiver role strain from worry.

One possible strategy to enhance the collaboration between nurses and family members in providing care for elderly patients in hospital settings, is the use of mutual goal setting by nurses and families (Kodadek, 1992; Li, 1992c). The idea of a Mutual Contract Care Plan is based on the concept of family empowerment and has been used by home care nurses in Archbold et al.'s intervention study of family caregiving in home settings (Archbold et al. 1995). The underlying principle of family empowerment is to treat families as partners with the nurses, on the caregiving team, characteristics of partnerships include the following: (1) knowledge; (2) honesty; (3) openness; (4) self-knowledge; and the most important, (5) respect (Kodadek, 1992).

A preliminary draft of a clinical protocol for enhancing family participation in the care of elderly patients in hospital setting was written as part of doctoral course work by the investigator (see Appendix A). The long term goal of this investigator's program of research, is to test the hypotheses that enhanced family participation in acute care of elderly patients in hospital settings, will decrease dysfunctional syndromes of the patients, reduce the worry of families, and improve families' ability and preparedness for home care when the patients are discharged.

As summarized in Table 1, five phases for the program of study are planned to accomplish this long term goal. First, the qualitative phase refined the definitions and further developed the content domains of the key variables:

> (1) preferences of patients and (2) preferences of family members about family participation in the hospital care of elderly patients; (3) actual participation of family members in the hospital care of older patients; and (4) family member role strain from worry.

Table 1. Phases in the Program of Research

NAME OF PHASE	PURPOSE
	DISSERTATION
Phase 1: Qualitative Phase	1. Refine definitions and describe the content domains of (a) patient preferences and (b) family preferences about family participation in the care of elderly patients (c) actual participation of family members in the hospital care of elderly patients, and (d) caregiver role strain from worry during hospitalization 2. Describe relationships among the four concepts and other relevant variables 3. Generate ideas for possible ways to measure the four concepts
	POST DOC
Phase 2: Scale Development and Evaluation Phase	1. Use the findings of Phase 1 to generate generate items and develop measures of the three concepts 2. Evaluate the content validity of the new measures 3. Evaluate the feasibility of administering the new measures to hospitalized elderly patients and their family members
Phase 3: Psychometric Evaluation Phase	1. Evaluate reliability and construct validity of the new measures 2. Do beginning exploratory work on the feasibility of using the instrument cross culturally, specifically with American-Chinese families of hospitalized older people
	RESEARCH PROGRAM
Phase 4: Intervention Phase	1. Test an intervention to enhance family participation through collaboration between nurses and family members using the clinical protocol
Phase 5: Clinical Trial	1. Evaluate the effectiveness of the intervention

Building on pilot findings of Li (1992ac), the content domains were examined for completeness, and concept definitions were refined. Second, in a post doctoral study, the scale development and evaluation phase will be conducted. Drafts of the new measures will be evaluated for content validity and feasibility by a panel of professional experts, family caregivers, and elderly people who have recently been hospitalized. Third, in the psychometric evaluation phase, reliability and validity of the new measures will be evaluated. Fourth, a pilot study of an intervention to enhance family participation, through collaboration between nurses and family members using the clinical protocol will be conducted. Finally, a clinical trial will be conducted to evaluate the effectiveness of the intervention. The dissertation includes the first phase described above. Post doctoral research studies will involve the development of pretest versions of measures of family and patient preferences about family participation in hospital care, actual levels of family participation, and caregiver role strain from worry during hospitalization. The main purpose of these measures is for research use in describing individual differences in family caregivers about their preferences; actual participation in care of family members during hospitalization (from admission to discharge); and measures of family caregivers' role strain from worry. The intent is to use the measures in descriptive, correlational, and intervention studies. The specific intended uses of the new measures are: (1) to obtain data about patient and family preferences about family participation in elderly patient's care in hospital settings; (2) to determine current baseline family preferences about, and levels of, family participation; (3) to identify areas of worry in which hospital nurses could intervene to reduce family caregiver role strain during hospitalization; and (4) to measure the dosage or degree of implementation of the independent variable (family participation) in the future intervention study, and to improve later family caregiving in the Phase 5. Potential utility of an adapted tool for clinical use will be considered.

Theoretical Perspectives On Caregiving

Role and role behaviors are played out using principles of complementarily and expectations. Each role has expected behaviors. Family members' participation in the hospital care of elderly patients can be viewed as a type of role behavior. The illness-constellation model (Morse & Johnson, 1991) views illness as an experience that affects both the sick person and his or her significant others. Illness and hospitalization represent a potential crisis for the family system. Family members usually respond to the elderly patient's hospitalization by providing support and some help in the hospital care. But the nature and extent of family participation may vary among family members. Conversely, family members may view the patient's hospital stay as respite for them (Haggmark, 1990), perhaps because it is not needed or, alternatively, because there is no clear defined expectations for a family member's role in the hospital setting.

In the hospital, nurses take over the primary caregiver role from family members, who previously have been caregivers in the home. The environment changes from home to hospital; and the patient's condition changes from a chronic to an acute stage. Therefore, family members face a need for role adaptation, as they change from their role at home--either as a primary caregiver or non-caregiver--to their role of co-caregiver in the hospital. Confounding the role adaptation is the family's possible new role of "patient," as the nurse and other health professionals may view both the family and the elderly member as the "patient." Therefore, it seems logical to view family participation in hospital care as a process of role adaptation.

Using Archbold et al.'s Family Caregiving Model (Appendix B) in the home and adapting it for the hospital setting, the family experience in the hospital care of the older adult was viewed as a process of family role adaptation. It moves from primary caregiver, or non-caregiver, at home, toward assuming new roles of family-as-patient, as well as co-caregiver in the hospital. As a preliminary working definition, the concept of "family participation" was viewed as the amount and type of care performed by family members during the elderly patient's hospitalization, from admission to discharge. In a preliminary study (Li, 1992a), the researcher adapted Archbold and Stewart's Family Caregiving Model in the home setting to caregiving in the hospital setting (Figure 1). The detailed information on how the model was adapted is summarized in Appendix C. As a result of the preliminary study, the researcher concluded that out of the 26 indicators of family participation in the hospital care of elderly patients, 8 of them were the same items as in Archbold and Stewart's (1986) measure of amount of direct care, 6 of them were modifications of items from Archbold and Stewart, and 12 were new indicators. Of the 24 indicators of family role strain from worry, 7 of them were the same and 1 was modified from Archbold and Stewart's (1986) measure of caregiver role strain from worry, and 16 were new indicators (Appendix D).

Several differences exist. One important difference between family participation in home and hospital settings, is the voluntary nature of family participation in the care of elderly patients in most, but not all, hospital settings. Currently, in most hospital settings, family members are not required to do any care for the patients according to hospital policy. What nurses can do is provide the opportunity and support to family members who wish to initiate or continue their caregiving role in the hospital. There are always family members who may not be able or want to become involved. Sharp (1990) emphasized that family members should not be forced to participate more than they wish or are able to, or be made to feel guilty should they not participate. Thus, the proposed study will examine not only what families do to assist in hospital care, but also their preferences for amount and type of participation or nonparticipation.

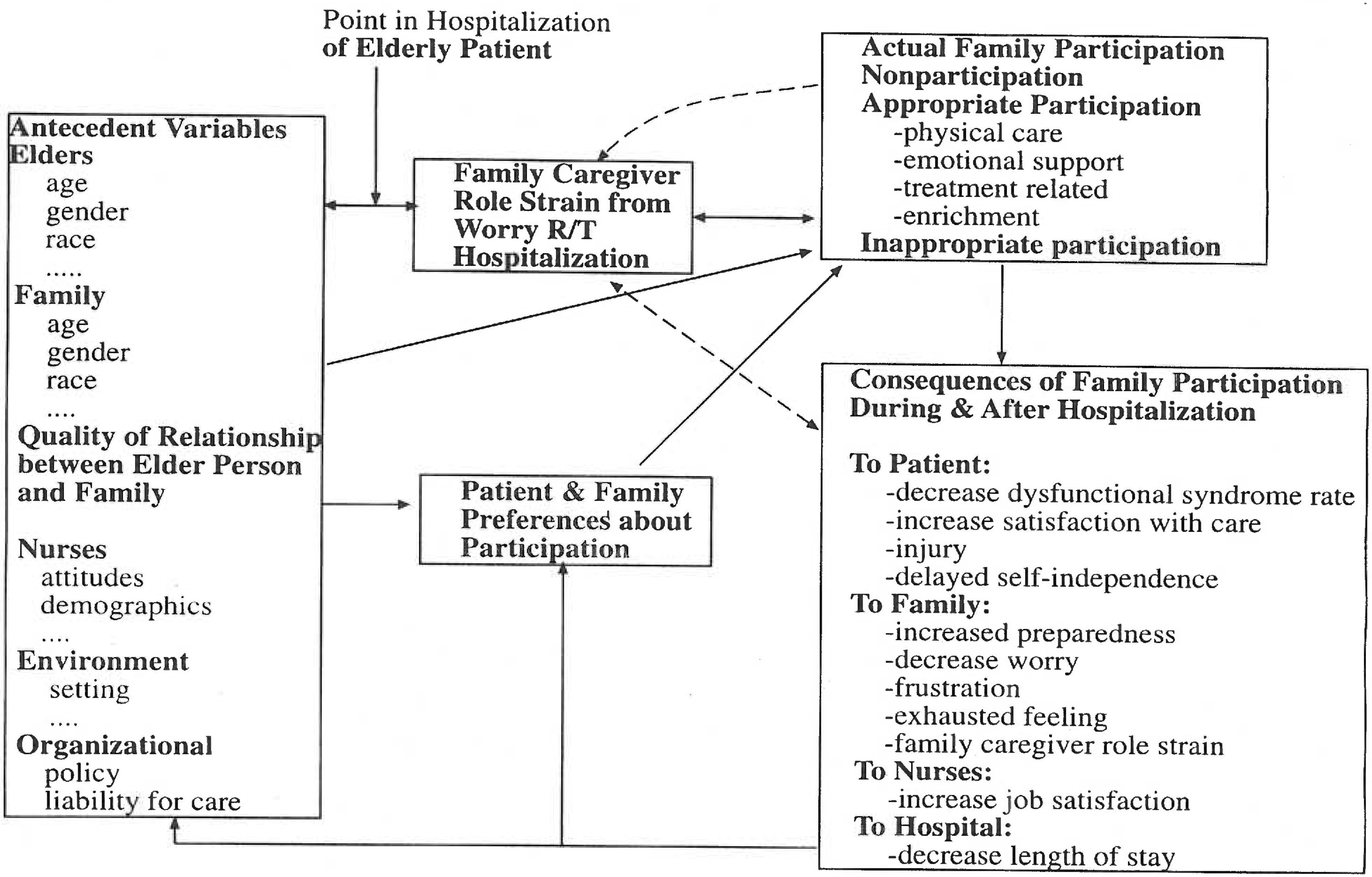

Figure 1: Tentative Model of Family Participation in the Hospital Care of Elders
(Adapted from Archbold & Stewart, 1988)

CHAPTER II

REVIEW OF LITERATURE

Introduction

Faced with a lack of research about family caregiving in the hospital for elderly patients, the literature was reviewed in the following two areas: family caregiving in the home setting and family caregiving in institutional settings. Family caregiving in the home setting was included in this review because of its long history and the richness of the knowledge base that exists in this area. Although there are several differences in family caregiving between home and hospital settings, one may make comparisons and adapt existing knowledge about family caregiving from the home setting, to help examine family caregiving in the hospital. Additionally, the review will focus on the following categories that appear pertinent from the preliminary study: (1) family participation (in the home and hospital settings); (2) patient and family preferences about care (in the home and hospital settings); (3) family member role strain from worry (in the home and hospital settings); (4) antecedent variables related to family participation (in the home and hospital care); and (5) consequence variables related to family participation (in the home and hospital settings).

Preferences of Families and Patients About Participation and Actual Participation In The Care of Elderly Relatives

What family members prefer to do, what kind of tasks they actually perform in the care of elderly relatives, and patient preferences about such care, were the three key variables of interest in this study. To understand the conceptual problems surrounding the study of family participation in the hospital care of elderly patients, a brief review is presented about family caregiving tasks in both home and hospital settings from several different theoretical perspectives. In addition, nurses' preferences, as influences on patients and families, must be examined.

Family Participation in the Home Settings

Researchers have conceptualized family caregiving differently using several theoretical perspectives (Appendix E). Archbold, Stewart and their associates (1988) view caregiving as a role, which is defined as "the amount and type of direct and managed caregiving tasks performed by the caregiver for the care receiver" (Archbold et al., 1986). Their conceptualization was based in part on the work of Burr, Leigh, Day, and Constantine (1979). Using Lazarus and Folkman's (1984) cognitive appraisal model, Oberst et al. (1989) conceptualized the content of caregiving as one of five areas reflecting a potential stress response associated with caregiving. Using social exchange theory for a theoretical framework, Walker et al. (1992) conceptualized the content of caregiving as a situational variable, which affects perceptions of the benefits and costs of the caregiving situation for adult daughters and their dependent mothers.

Although these conceptualizations differ, operational definitions of the content of family caregiving typically focus on family caregiving tasks (see Appendix C), usually including assistance with activities of daily living (ADLs, e.g., eating and bathing), and instrumental activities of daily living (IADLs, e.g., cooking and cleaning). In addition to assisting with ADLs and IADLs, seven other main types of tasks were mentioned: (1) managing behavior problems(Archbold et al. 1986; Oberst et al. 1989); (2) protection (Archbold et al. 1986); (3) little extras (Archbold et al. 1986); (4) emotional support (Oberst et al. 1989); (5) medically- and symptom-related tasks (Archbold et al. 1986; Oberst et al. 1989); (6) communication with health care providers (Archbold, Stewart, 1992); and (7) managing the care given by others (Archbold, 1983). Compared to other measures (e.g. Cicirelli, 1983; Clark & Rakowski, 1983; Oberst et al, 1989), a strength of Archbold and Stewart's measure of caregiving tasks is its comprehensive nature, with their current 1994 version containing 80 caregiving activities. Archbold and Stewart's instrument was developed based on qualitative research with caregivers, as well as input from an expert panel of nursing faculty, nurse clinicians, gerontologists, and measurement faculty during content validation (Archbold et al, 1986). The scales measuring the amounts of the various categories of caregiving tasks exhibited good reliability and validity in the sample of caregivers and care receivers in the home settings (see Appendix C). Therefore, the scale appears to have potential to be adapted and augmented to measure family participation in a hospital setting.

Studies of family caregiving generally have focused on the specific tasks involved in providing care, except for two studies by Bowers (1987, 1988) which distinguished caregiving activities by purpose and meanings rather than by tasks. The strength of Bowers' work lies in its focus on the whole caregiving experience, from the beginning stage of anticipation to the later stage of instrumental care. Bowers' approach was blended with that of Archbold and Stewart to understand family participation in hospital care of older family members, including family participation from admission to discharge.

In addition, two studies (Hasselkus, 1988; Langner, 1995) were found that explored the meaning of family caregiving in caring for elderly relatives. Hasselkus (1988) focused on aspects of caregiver and professional relationships, whereas Langner (1995) emphasized the meanings of motivation and consequences of family caregiving. The commonality of the two studies was the exploration of meaning behind the caregiving tasks. Therefore, perspectives of family members, patients and nurses about participation in hospital care, with a focus not only on the tasks, but also on purposes and meanings of caregiving, were explored in the dissertation study.

Most studies of caregiving have dealt primarily with family caregivers and the inherent strains and burdens they experience. The actual recipients of care themselves, however, are rarely studied. Most studies focus on the provider of care, without reference to the subjective experiences of care recipients and the extent to which the care they receive meets their needs (Barer & Johnson, 1990). Soldo, Wolf, and Agree (1990) identified family preferences as one of the factors influencing care arrangements of frail older women in their secondary data analysis study. However, they did not mention elderly care recipient preferences.

Family Involvement in the Hospital Settings

Thirty-nine research and clinical articles were found through a Medline Database search that focused on family involvement with institutionalized people (Boykoff, 1986; Collier & Schirm, 1992; Daley, 1984; Eldriagge, 1984; Forrester et al. 1990; Foss & Tenhoder, 1993; Fuller, Foster, 1982; Gardner & Stewart, 1978; Halm, 1990; Halm, 1992; Halm, Titler, 1990; Hickey & Lewandowski, 1988; Hosler, 1991; Jacono, Hicks, Antonioni, O'Brien, Rasi, 1990; Jilling, 1981; Johnson, 1986; Krozek, 1991; Laitinen, 1992; Leske, 1986; Leske, 1991; Levy-Shiff et al. 1984; Lynn-chale & Bellinger, 1988; Miller, 1991; Molter, 1979; Moss, 1986; Norris, 1986; O'Malley et al., 1991; Price, 1991; Raleigh, Lepczyk, Rowley, 1990; Rosenthal, Pitach, Greninger, Metress, 1993; Schwartz & Vogel, 1990; Sharp, 1990; Stanik, 1987; Strauss & Corbin, 1988; Titler, Walsh, 1992; Ward, Constancia, Kern, 1990; Watson, 1987; Wolfson, Handfield-Jones, McClaran, Keyserling, 1993). Of these, only five studies (Haggmark, 1990; Halm & Tilter, 1990; Hickey &

Lewandowski, 1988; Laitinen, 1992; and Sharp, 1989) used instruments designed to measure a concept thought to be similar to family participation (Appendix F).

Haggmark (1990) asked 67 relatives to rate family participation by indicating the frequency and duration of their visits for oncology patients. Sharp (1990) measured nurses' and family members' perceptions of family participation in the following ADL categories: feeding, washing, toileting, dressing, and bathing.

Halm and Titler (1990) conducted a descriptive study to examine the attitudes of patients (n=77), family members (n=58), nurses (n=81), and physicians (n=8) redarding visiting in critical care settings. The role of family members during visiting periods was also examined. However, the age of participants was not reported. Eleven role tasks were identified as important by the participants. Of the eleven role tasks, 3 of them were reported by patients, family members, nurses and doctors: (a) providing emotional support, (b) helping patients eat, and (c) giving the patient a backrub or bath; one of the tasks (giving reassurance) was identified by both the patients and family members. Three more roles tasks were suggested by the patients: (a) reading mail, (b) completing tasks desired by the patient and family or suggested by the staff, and (c) providing companionship. Three additional tasks were reported by the family members: (a) calming, (b) touching the patient, and (c) participating in care as desired, with guidance from the nursing staff. Furthermore, some treatment-related care such as suctioning and Hickman line care were perceived as important role for family members by only a few nurses. Encouragement was also reported as an important role of nurses in family participation.

In Laitinen's (1992) study, 18 patients and 7 family members indicated the frequency with which they received or performed each of 18 care activities focused on ADLs and emotional support. The result indicated that family members most often gave emotional support, with 26% giving it every day. The study concluded that family members could be used more in planning, evaluation and even implementation of care; however, their current participation in patient hospital care is minimal. Collier and Schirm (1992) highlighted the absence of documentation in nurses' charts about family participation. These findings point to the need to obtain a more systematic and comprehensive picture of family participation in hospital care of older patients. The proposed study will address this gap.

Based on a computer Medline Database search covering the past 8 years of research on the topic of patient and family preferences about family participation in the hospital care for elderly patients, five studies (Boykoff, 1986; Halm and Titler, 1990; Hickey and Lewandowski, 1988; Reed, 1991; Simpson, 1991) and one review article (Titler & Walsh, 1992) were found.

Hickey and Lewandowski (1988) examined critical care nurses' beliefs or preferences about what family participation in critical care should include. Critical care nurses (n=226) were asked about their agreement or disagreement regarding whether family should participate in 22 activities in critical care units. The top three activities and their respective percentages of nurses in agreement were (1) encouraging the patient to take fluids or eat (100%); (2) helping the patient eat (99%), and (3) reading to the patient (99%). The activities with which nurses had the lowest agreement were (1) assisting with dressing change (48%); (2) assisting with tracheostomy care (68%); and (3) helping clean up an incontinent patient (74%). Even for these activities with the lowest agreement ratings, half to three quarters of the nurses endorsed family participation. In other words, nurses appear open to family participation in a wide range of activities.

Reed (1991) examined terminally ill and non-terminally ill hospitalized patients' preferences, for spiritually related nursing interventions. The study found that family, clergy, and friends were identified more frequently than nurses as spiritual resources. The study was focused on patients' preferences for spiritually related nursing care, but not on family and older patients' preferences about the wide range of potential activities for family participation during hospital care. The study addressed this gap by interviewing both patients and family members about their preferences regarding family participation in hospital care for elderly patients.

Boykoff (1986) examined visitation needs by interviewing patients (n=21) with cardiac disease and their families (n=11) in one hospital's Medical Intensive Care Unit (MICU) setting. Patients' and family members' preferences about visitation and caregiving in the MICU were reported. Both the patients and their family members indicated they would prefer the nurses rather than family members to provide personal care (such as baths and feeding) to the patients. However, it was found that male family visitors not preferred not to help with any patient care, but about half of the women family visitors preferred to assist with the care of the MICU patients. There was no report on the kind of care tasks the women family visitors would prefer to provide to the patients in the MICU setting.

Titler and Walsh (1992) reviewed research of visiting practices in adult Critical Care Units. The findings of two current studies (Halm and Titler, 1990; Simpson, 1991) were included in Titler and Walsh's (1992) review of visiting preferences of critical ill patients. The preferences about numbers of visitors (2 to 3 at a time) and length of visiting (15 to 40 minutes) were reported (Halm and Titler, 1990; Simpson, 1991). Patients' preferences about number of visitors was positively correlated with patients' perception of severity of illness (Simpson, 1991). Patients' preferences on length of visits was correlated with patient's age and negatively correlated with socioeconomic status (Halm and Titler, 1992).

In summary, the majority of family participation literature in hospital settings focused on the needs of families of critically ill patients. Three aspects of the phenomenon that have been emphasized are: (1) the importance of needs of adult family members; (2) descriptions of family needs perceived by family members, patients, and nurses as well as comparisons among the three parties; and (3) examination of the degree of needs satisfaction experienced by patients and family members. The dissertation study took a new angle in studying the phenomenon of family participation in hospital care. Instead of looking at patients who were adults, this dissertation specifically focused on elderly patients. Also, instead of looking at only the critical care period of hospitalization only, this dissertation covered the whole hospital stay from admission to discharge. In addition, instead of addressing only family needs, it focused on the conceptualization of family participation and other relevant concepts, to describe the phenomenon of family participation in hospital care for elders.

Comparing family caregiving tasks in home and hospital settings, it appears that family members may provide more emotional support and decision making than direct personal care, when the older patient is in the hospital, because the patient may be in a critical condition and require more intensive care from professional staff. According to the Illness-Constellation Model (Morse & Johnson, 1991), illness and hospitalization represent a potential crisis for the family system. Therefore, family participation in an elderly patient's care at the point of hospital admission is very important. It is also important for family members to participate during the discharge care in hospital settings, because elderly patients usually suffer from multiple-chronic illnesses and are being discharged earlier, due to hospital funding limitations by Diagnosis Related Groups (DRGs). Thus and family members may need to continue the care at home after hospital discharge (Kirchling, Stewart, Archbold, 1994; Oberst & James, 1985; Oberst & Scott, 1988).

Although the Illness-Constellation Model shows effects of illness on both patient and significant others, the nature of family caregiving in hospital care is not well operationalized. The existing measures of family participation did not capture the care activities during hospital admission and discharge. The dissertation includes family participation during these admission and discharge periods. In addition, a measure of family preferences about participation in the hospital care for elderly patients was not found. As suggested by Watson (1987), "additional research is needed to determine the type and extent of participation desired by patients and families" (p.72). The dissertation addressed this gap.

Family Caregiver Role Strain From Worry

Family caregiver role strain from worry was conceptualized by Archbold, Stewart, and their colleagues (1986, 1990, 1994) as one of the ten aspects of caregiver role strain including strain from (1) direct care; (2) managed care; (3) worry; (4) role conflict; (5) mismatched expectations; (6) lack of resources; (7) increased tension; (8) feelings of being manipulated; (9) problems in communication; and (10) global strain. Compared to the other nine aspects of role strain, family caregiver role strain from worry is important for family caregivers of elderly patients in the hospital settings. Because illness and hospitalization represent a potential crisis for the family system, uncertainty and not knowing may make family members worry more about their loved ones who are in the hospital. The findings of Archbold, Stewart and their colleagues (1990) indicated that mutuality, the positive quality of the relationship between caregiver and care receiver, was associated with lower levels of most aspects of caregiver role strain. However, mutuality was not linked to lower family caregiver role strain from worry. One explanation for the lack of relationship between mutuality and worry is that some caregivers who are very close to the care receiver actually worry more because of their love and affection, than if they were more distant from the care receiver. It is predicted that the higher the family caregiver role strain from worry, the more likely the family members will participate in the patient's care in the hospital setting. Therefore it appears that family caregiver role strain from worry may be related to the level of family participation in the hospital care of elderly patients, though the exact nature of that relationship is not yet described. In the researcher's preliminary study, the initial definition of family caregiver role strain from worry was: family members' felt difficulty in fulfilling the family members' role during hospital care because of worry about the patient, the patient's care, and the future during the hospitalization. As a result of findings from the preliminary study, the conceptual definition of family role strain from worry was added as "family member's affective reaction to the patient's illness, care and future because of uncertainty about the situation during the hospitalization" (Li, 1992b). Because of the changes in elderly patients' illness, care needs and future arrangements due to the hospitalization, the content of family worry during hospitalization was found to be somewhat different than when the elderly person was at home.

Worry in the Home Settings

Family caregiver role strain from worry is well defined in the studies of family caregiving in the home setting. Caregiver role strain from worry is defined as the "caregiver's felt difficulty in fulfilling the caregiver role because of worry about the care receiver, and aspects of caregiving per se" (Archbold, Stewart, 1986). Two instruments (Archbold et al. 1986; Cantor, 1983) were found that measure the concept of family worry in home settings. Four aspects of worry were included in Cantor's worry scale: (1) care receiver's physical condition; (2) their mood; (3) obtaining enough help; and (4) the financial situation. Archbold and Stewart used Cantor's items and added eight additional items in their worry scale (e.g. caregiver's ability to continue the care if the care receiver gets worse, the caregiver's future, and having to make the decision to put the care receiver in a nursing home).

Worry in the Hospital Settings

Family role strain from worry is not well defined in the literature of family involvement in hospital settings. However, family role strain from worry is mentioned in studies of family needs of hospitalized patients (Daley, 1984; Leske, 1986; Lynn-McHale & Bellinger, 1988; Orrester et al. 1990; Molter, 1979; O'Malley et al. 1991; O'Norris & Grove, 1986; Price et al., 1991; Rukholm, 1991). Daley (1984) found that family members in a general medical-surgical ICU reported their highest priority needs during the first 72 hours of hospitalization were for relief from anxiety and honest information. The family stressors identified by Hodovanic and colleagues (1984) were financial concerns, fear of loss of their loved one, and heightened emotional turmoil while the family member is hospitalized. None of these studies examined family worry specifically about an elder.

Comparing family caregiver role strain from worry between home and hospital settings, it appears that the intensity and content of the worry may be different. For example, findings from a preliminary qualitative study (Li,1992b) were basically congruent with the literature of family worry in home settings. However, some indicators related to the patient's illness, care and prognosis were not found in the family role strain from worry scales in the home setting, because the patients were in the hospital and their illness was in an acute stage. In the home setting, the family caregiver is in charge of care for the care receiver.

However, in the hospital, nurses take over the primary caregiver role, and the family member loses some control of the care that the patient receives, the family members worry more about the quality of care, especially when they are not able to be with the patient. Therefore, they may stay with the patient and participate in the care. Also, family role strain from worry may rapidly increase if the patient is acutely ill in the hospital setting. Family members may worry more because of uncertainty and not understanding the new technology, knowledge and skills needed to provide care to hospitalized patients. In order to describe the role strain from worry in the hospital setting, a revised scale of family role strain from worry, based on Archbold and Stewart's worry scale, was developed by the investigator and administrated to a small sample of 10 family members of elderly hospitalized patients (Li, 1992b) in a preliminary study. Because of the small sample, this worry scale will be revised, based on findings from the dissertation.

Antecedents Related to Family Participation In the Care of Elderly Relatives

Antecedents in the Home Settings

Four categories of characteristics which may affect the caregivers' performance of caregiving tasks in the home were identified in the literature: (1) characteristics of the caregiver (such as age, gender, marital status, health, and ethnicity), and preparedness for caregiving (Archbold et al. 1986; Bowers, 1987, Young and Kahana, 1989); (2) characteristics of care receiver (such as age, health, impairment level) (Archbold et al. 1986; Bowers, 1987; Young and Kahana, 1989); (3) characteristics of the dyadic relationship, such as mutuality, and status of the caregiver's relationship with care receiver (i.e., spouse, adult child, or other relative or friend (Archbold et al. 1986); and (4) characteristics of the environment, such as safety issues (Archbold et al. 1986; Young & Kahana, 1989).

Antecedents in the Hospital Settings

Based on previous research by other investigators and preliminary work by Li (1992a), six categories of characteristics which may affect the nature and extent of family participation in hospital care were identified (1) characteristics of patient, such as age, race, illness condition, gender, marriage status, length of stay, and sources of admission (Collier & Schirm, 1992); (2) characteristics of family members, such as age, gender, role relationship with the patient (spouse or nonspouse), health status (Li, 1992a), prior caregiver experience (Li, 1992a), behavior disorder (abusive or alcoholic members) (Collier & Schirm, 1992) and culture; (3) quality of relationship between patient and family members; (4) characteristics of the environment, such as critical care unit (Hickey & Lewandowski, 1988) and distance between hospital and home (Collier & Schirm, 1992); (5) characteristics of nurses, such as gender, prior experience of working with the elderly, communication skills, and attitude of nursing staff toward family participation in elderly patient's care (Li, 1992a; Hickey & Lewandowski, 1988; Laitinen, 1992); and (6) organizational factors, such as hospital visiting policy (Hickey & Lewandowski, 1988; Gardner & Stewart, 1978) and the hospital's administration of treatment and care (Haggmark, 1990; Laitinen, 1992).

In the thirty-nine research and clinical articles being reviewed at hospital settings, there was no hospital written policy on family caregiving, except stating the visiting hours. Patients' length of stay may both influence family participation and be affected by family participation. These factors above were mentioned in the literature, but there were no statistical results to support associations among these factors, or the level of family participation, while the patient was hospitalized.

Consequences Related to Family Participation In the Care of Elderly Relatives

Consequences in the Home Settings

Caregivers often experience emotional, social, financial, and physical health consequences of caregiving (Archbold et al. 1986, 1989; Carr, MaAuley, & Jacobs, 1983; George & Gwyther, 1984; Walker et al. 1992; Zarit, Todd, & Zarit, 1980). Negative consequences of caregiving are referred to as role strain or burden. Recently, researchers (Archbold et al. 1989; Lanhner, 1995; Walker et al. 1992) have also identified positive consequences of caregiving---caregiving rewards (e.g., rewards of meaning and personal growth or learning).

Consequences in the Hospital Settings

The consequences of family participation include benefits to the patient (decreased dysfunctional syndrome rate and increased satisfaction with care), benefits to family caregivers (increased preparedness and decreased worry), benefits to nurses (increased job satisfaction), and benefits to the hospital (decreased length of stay). Adverse outcomes were also reported in the literature, for example, some of the patients who were in Critical Care Units reported family visiting as "tiring" (Simpson, 1991). Also, inappropriate family participation may be a detriment to patients and family members. For example, family members may feel guilty because they are unable or unwilling to participate in the hospital care. In the preliminary study (Li, 1992a), several adverse consequences of inappropriate family participation were identified. For the patient, inappropriate family participation sometimes contributed to a patient's injury, or delayed patient self-independence if the family member did everything for the patient. For the family, inappropriate participation sometimes contributed to family frustration and exhausted feelings, because of over-participation in the care.

Summary

Although various theoretical frameworks have been used as the foundation for existing measures of family caregiving tasks in the home setting, there is an absence of theoretical underpinnings for current measures of family participation in hospital. The preferences of family members and recipients of care, themselves, regarding participation in the care have rarely been studied. Further, existing measures of family participation in hospital, tend to focus on either limited type of caregiving tasks (i.e., visiting and ADLs) or in a specific setting (i.e., Critical Care Units), and have failed to cover the whole hospitalization process from admission to discharge. Therefore, this dissertation was focused on strengthening the conceptual foundation to provide for a measure of family participation in the hospital care of elderly patients, from admission to discharge. The dissertation also emphasized elaborating the conceptual foundation, for measures of preferences of patients and family members, and of family caregiver role strain from worry.

Proposed Conceptual Framework for Family Caregiving in the Hospital

Based on the literature review and the researcher's clinical experience, a preliminary conceptual framework of family participation in the hospital care of elders is presented in Figure 1. The purpose of the framework is to describe the phenomenon of family participation in the hospital care for their elderly relatives. There are five major categories of concepts in this conceptual framework: (1) antecedent variables, including patient characteristics, family member characteristics, dyadic characteristics, nurse characteristics, and environmental and organizational factors; (2) family caregiver role strain from worry during hospitalization; (3) patient and family preferences about family participation; (4) actual family participation in hospital care for their elderly relatives, and (5) consequences during and after hospitalization, including benefits to patients, family members, nurses and the hospital.

In a general sense, the conceptual framework posits that when an elderly patient is hospitalized, family members' worry becomes even more salient. Because the family role in the hospital care of elderly patient is not well defined in this society, the degree to which family members actually participate in the hospital care of their elderly relatives appears to depend on the following three factors: (1) patient and family preferences; (2) family worry; and (3) antecedent variables (pre-existing factors before hospitalization). However, there may be others. Antecedent variables are thought to influence participation both directly and indirectly through patient and family preferences and worry. Actual family participation in the hospital care may reduce their worry as well as having both benefits and adverse effects for patients, family, nurses and the hospital. These consequences may, in turn, influence selected antecedent variables, family preferences about participation in hospital caregiving, and worry.

Preliminary Study

The researcher examined family involvement and strain from worry as a class project of an introductory measurement course. The project was designed to conceptualize family participation in caring for hospitalized elderly patients. In that study, I adapted Archbold and Stewart's model of caregiving in the home setting to caregiving in the hospital setting. Structured, open-ended interviews were conducted with 4 nurses, 3 family members and 1 elderly patient in a Veterans hospital (Li, 1992a). As a result, 26 indicators of family involvement and 24 indicators of family worry were identified and grouped into categories which are listed in Appendix C.

Preferences of family and patients about family participation in the care were not examined in this study. However, due to the researcher's personal clinical experience, elderly patients were found to prefer different family members to do some things for them. Therefore, the dissertation study addressed this issue also.

There were several methodological limitations of the preliminary study. The study included subjects from a Veterans (VA) hospital, and thus was not representative of patients cared for in community hospitals. In addition, more complete qualitative data on family participation and worry are needed to develop comprehensive measures of those concepts.

Finally, two additional things the researcher learned from the preliminary study, contributed to the dissertation study. First, the importance of family participation and worry in the hospital setting for elderly patients became evident, and second, Archbold and Stewart's Family Caregiving Model was able to be adapted from the home to the hospital setting. Some of the 26 indicators of family participation in elderly hospital care and the 24 indicators of worry identified in the preliminary study, were similar to those in the literature. However, many were different, emphasizing the need for concept refinement and measures tailored to the hospital setting.

CHAPTER III

METHODS

Overview of Method

A descriptive, qualitative design was used to study family participation in the care of hospitalized elderly patients, preferences of patients and family members about such participation, and the worry reported by family members. Lofland and Lofland's (1984) qualitative approach for the study of a phenomenon occurring in a social setting was selected for the study. The hospital is one type of social setting. In addition, their method allows for the analysis and refinement of predetermined concepts, as well as the possibility of describing and developing a conceptual model for the phenomenon under investigation. Because the purpose of this study was to explore pre-identified concepts within a hospital setting, the analysis proposed by Lofland and Lofland is appropriate.

Elderly patients, their family caregivers and nurses were asked about their experiences and perceptions of family participation in the hospital care for elders. Intensive interviewing, also called in-depth qualitative interviewing, provided for repeated face-to-face interviews between the researcher and the participant (Lofland & Lofland, 1984; Taylor & Bogdan, 1984), and is "the fullest condition of participating in the mind of another human being" (Lofland & Lofland, 1984). Intensive interviewing is an appropriate strategy to use in concept development and in describing how those concepts are related.

Participant observations were conducted after completion of selected interviews. The method of participant observation was selected because much of family participation in the patient's care is observable, yet may not be at the level of cognitive awareness and thus might not be verbally reported during an interview, especially for those who have been in the role for a long time. Because family members may sometimes be unable to report accurately about certain behaviors, observation was used as an additional means of obtaining information. Also, use of the method of observation can be considered as a strategy of validation (use of multiple methods) to increase the credibility of the data collected by interview and analyzed using qualitative methods (Lincoln & Guba, 1985). In addition, Lofland and Lofland (1984) emphasize "the mutuality of participant observation and intensive interviewing as the central techniques of the naturalistic investigator" (p. 13) because these two methods are interrelated and directed toward understanding the phenomenon by looking and asking.

Data Collection Method

Data were obtained by: 1) semi-structured, open-ended interviews with patients, family members, and nurses, and 2) participant observation. The purpose of interviewing nurses was to gather information regarding family participation from the perspective of nurses.

Settings

The interviews with elderly patients and their family caregivers took place in both hospital and home settings. The interviews with nurses and participant observations took place only in the hospital units.

Hospital units were selected to obtain older patients who had experienced such health events as heart disease, a fractured hip, stroke, or pneumonia. Most hospital admissions of elderly people are for acute episodes of chronic conditions. The most common major categories of diagnosis for the 10.5 million discharges of elderly patients in 1987 were diseases of the circulatory system (including heart disease and cerebrovascular disease) (32%); digestive diseases (12%); and respiratory diseases (e.g. pneumonia) (10%). Although fractures have a lower percentage (3.8%) as a diagnostic category, elderly patients who had fractures remain in the hospital longer than other patients in the above diagnostic categories (National Center for Health Statistics, 1987).

The participants were selected from three units of two hospitals: one an urban university hospital and another a Veteran's (VA) Hospital located in the Northwest. The university hospital had a bed capacity of 365 beds for the 1994-1995 fiscal year, while the VA hospital operated 552 beds during the same time period. Data describing both hospital settings are listed in Table 2 and include the percentage of elderly inpatients, their length of hospital stay, sources of admission, and information about the elderly patients' ethnic minority background. The information related to ethnic minority background was not available for the VA hospital because of the Privacy Act. The VA hospitals do not collect data about any patient's race or ethnic background.

Three units from the two hospitals were used in this study. Data describing the three units are listed in Table 3. Among the three units, Unit #1 was the gerontology unit. The Geriatrics Program includes both an acute medical team and a rehabilitation team. Patients admitted to this area are likely to have chronic medical conditions (such as Cardiovascular

Table 2. Descriptive Data For the Two Hospitals
(July, 1994 - June, 1995)

Hospital #	A	B
Type	University Hospital	VA Hospital
Bed capacity	365	552
Total # of admitted patents	18,026	10,952
% of elderly patients	8	48.4
Elderly patients' Length of stay	6.1	11.3
Ethnic Background (%)		
White	93.8	Not available
Black	4.1	
Asian	0.8	
Other	1.3	
Sources of Admission (%)		
ER	32.8	47%
Clinics	24.5	
Physician ref.	22.9	
Day patient	11.6	
Hospital ref.	6.6	
HMO	0.7	
Unclear	0.7	
Skilled NH ref.	0.1	
Other identified	0.1	
Pre-scheduled admissions & other		53%

Table 3. Descriptive Data for the Three Units
(July, 1994 - June, 1995)

Unit #		1	2	3
Hospital type		VA Hospital	University Hospital	University Hospital
Speciality		Gerontology	Neurology	Cardiovascular
Beds capacity		40	24	24
Patient's room capacity		SingleX8 DoubleX8 Four bedsX4	SingleX6 DoubleX9	SingleX8 DoubleX4 Four bedsX2
Ave. daily census		29	19	16
Ave. length of stay		3-5 Days (Medical) 2-3 wks (Rehab.)	2.8 Days	3.2 Days
Type of nursing staff		RN & LPN	RN & CNA	RN & CNA
Ratio of nurses to patient	Day	1:4	1:4	1:4
	Eve.	1:5	1:5	1:5-6
	Night	1:8	1:6	1:6-8
Visiting hours		8:30am to 8:30pm	11am-8pm	11am-8pm

Disease and Chronic Obstructive Pulmonary Disease), change in mental status, post-stroke, deconditioning or failure to thrive, and functional decline. Unit #2 and #3 were selected from the university hospital's neurological unit and the cardiovascular unit. The patients admitted to these two units were likely to have acute stroke, neurological surgery, cardiovascular diseases in acute stage, or open-heart surgery. Unit #2 and #3 differed from Unit #1 because they served all ages, instead of older patients only.

Sample

The intent of the sampling plan was to interview subjects who were considered expert informants. These included elderly patients, family members, and nurses. Purposeful sampling was used to obtain each of these three types of subjects, at various times during hospitalization from admission to discharge, and in various settings. Not all patients, family members and nurses who were interviewed as subjects, matched. It was assumed that there would be difficulties in finding matched subjects in the hospital. For example, if patients were cognitively impaired and could not participate, the requirement of matching would exclude the experiences of family members and nurses with such patients.

Criteria for Sample Selection

Older persons were included in this study if they (1) were over 65 years of age; (2) were hospitalized on one of the three study units; (3) were not identified as terminally ill nor cognitively impaired; (4) had families who visited in the hospital; and (5) were able to communicate in English.

Family members were defined as adults (18 years or older) who visited the patient and were related to the patient by blood, marriage, adoption, or affinity as a significant other (i.e., life partner, close friend) (Forrester, Murphy, & Monaghan, 1991). Nurses were included in this study if they had experience in taking care of elderly patients in the hospital setting.

The sample was selected to be representative of the gender proportions in the respective populations.

Sample Recruitment

The participants for this study were recruited from the two hospitals described above. A nurse in an administration position in each of the hospitals was approached by the investigator. Letters of support were obtained from each of the hospitals prior to this study (Appendix G). The directors of the three units were also approached by the investigator for the purpose of gaining approved access to their units. Then a letter was posted in the staff bathroom of each of the three selected units, inviting nurses to participate as subjects, and to facilitate the recruitment of family members and patients. A nurse specialist on one of the units approached families and patients to ascertain their willingness to be contacted by the investigator. The investigator then met the family caregivers and/or patients to explain the study and determined their eligibility and willingness to participate. Prior to interview or observation, a consent form was signed by participants (Appendix H). On the other two units, the investigator directly identified and talked to potential participants without mediation by staff. As a reflection of the population served by the hospitals, African Americans and other ethic minorities were not available for inclusion in this sample.

Sample Characteristics

The intensive interviews were conducted with 6 elderly patients, 6 family caregivers of elderly patients and 4 nurses. For participant observation, 3 family-patient-nurse situations were observed on three nursing units. The interviews and participant observations were grouped into 7 cases, according to the different subject matching strategies used among them (Table 4). Case 1 contained one elderly patient,

Table 4. Organization of Data Cases

Case #	Family Caregiver (F)	Patient (P)	RN (N)	Observation (OB)
<u>Matched</u>				
#1	F1	P1		OB1*
#2	F2	P2		
#3	F3	P3		
#6	F6	P6	N6	OB6
#7	F7	P7	N7**	OB7
<u>Unmatched</u>				
#4	F4			
#5		F5		
Nurses			N1	
			N2	
			N3**	

*Observation #1 included F1, P1, and N1, because N1 came into the patient's room during the observation #1. However, N1 who had been interviewed 10 days before Observation #1, was not interviewed specifically regarding F1 and P1. Therefore, N1 was not listed in Case 1.

** N3 and N7 was the same individual. However, the interview with N3 concerned families and pateints in general, whereas the interview with N7 was specifically regarding F7 and P7 as part of OB7.

a matched family caregiver and a participant observation at the unit #1 around the lunch hour. Case 2 and 3 each contained a matched elderly patient and family caregiver. Case 4 contained an elderly patient and case 5 contained a family caregiver. Cases 6 and 7 each contained totally matched subjects including a elderly patient, his or her caregiver, his or her nurse, and a participant observation over the three matched parties. In addition, three nurses were interviewed separately about their experiences working with the elderly population in general, in terms of family participation. One of the three nurses was interviewed twice because she also took care of one of the matched elderly patient and his family caregiver in Case 6.

Description of Sample

Elderly Patients. The mean age of the six white patients was 70.8 years, with a range of 68 to 74 years (SD=2.79). Five of the six patients were male, and admitted from home; only one of them (P1) was admitted through the emergency room. The average length of stay for the six interviewed patients was 18.6 days, with a range from 6 to 57 days (SD=18). Three of the six patients had a history of stroke. For the current hospital admission, three of six patients (P1, P6 and

P7) were admitted for surgery; two of them (P2 and P3) for rehabilitation of post-stroke; and one of them (P5) for "Chest pain and fluid overload." Among the three surgical patients, one of them (P#1) was for unscheduled surgery (gallbladder removal) who was admitted through the emergency room, stayed in the intensive care unit (ICU) after the surgery, and later was transferred to Rehabilitation program. P#6 also had a short stay in ICU after his open-heart surgery. In addition, one more patient's son was interviewed in this study. The father (P4), a 75 years old white man, admitted with a medical diagnosis of rectal cancer. P#4 was admitted from his son's home and had a surgery done during the hospitalization, then was transferred to the Rehabilitation program with a length of stay of 48 days. The average length of stay for the 7 patients (including interviewed and non-interviewed patient) was 25.4 days (SD=19.6).

Family Caregivers. The average age of the 6 white family caregivers was 53 years, with a range of 50 to 69 years (SD=6.92). Four female caregivers (wives) and 2 male caregivers (one husband and one son) participated in this study. All of the caregivers were married. Years of education ranged from 10 to 15, with a mean of 12 years (SD=2.45). Housewives who were retired from work represented the most common occupation and employment status. Four of the six caregivers reported that they were in good health. The other two reported they either had asthma (F3) or history of heart attack (F2). The frequency of visitation and presence reported by the caregivers ranged from 2 to 7 days per week, with a mean of 5.7 days per week (SD=2.16). The length of caregiving experience at home, reported by the caregivers was from none (F4 and F6) to 8 years, with a mean of 2.7 days (SD=4.1). Four of the six caregivers (F1, F2, F3, and F7) reported they had past caregiving experience in the hospital with their elderly relatives. Among the four family caregivers, one of them (F7) had the same hospital care experience with her husband's laminectomy surgery at the same unit two years ago. In addition, one of the family caregivers (F5) was not interviewed in this study. however, her husband (P5) was interviewed. The demographic data for the F5 was not collected.

Nurses. The mean age of the 4 nurses was 34 years, with a range from 25-50 years (SD=11). All were female and had a BSN degree. Three of them were Caucasians and one of them was Asian. Two were charge nurses and the other two were staff nurses. The average length of current employment was 11 years, with a range from 4 to 18 years (SD=6.58). The mean length of experience working with elderly patients was 10.8 years, with a range from 6 to 15 years (SD=4.92).

Participants in Participant Observation. Participant observations involved three of the above elderly patients and their family caregivers as well as their nurses. In Case 1, the family caregiver had 8 years of previous home caregiving experience and past hospital caregiving experience with different types of diagnose and treatment. In the current hospital stay, the patient had been admitted through the emergency room and had a short stay in the ICU after surgery (gallbladder removal), then entered the in-patient rehabilitation program for his post-stroke problems at unit #1. The patient and his wife came from a Midwest state. The nurse who was taking care of the patient was a 32-year-old female charge nurse. The participant observation occurred at the 27th day of the patient's hospitalization (Length of stay: 57 days), and took place in Unit #1.

In Case 6, the family caregiver had no previous caregiving experience, neither at home nor in the hospital. The patient had scheduled open-heart surgery and stayed in the intensive care unit for about 5 days before he was transferred to the unit #3. the patient and his wife came from a distant Western state. The nurse who was taking care of the patient was a 42 year-old Asian staff nurse. The participant observation occurred by the last day of the patient's hospitalization (length of stay: 16 days), and took place in unit #3.

In Case 7, the family caregiver had no previous home caregiving experience, but had previous hospital caregiving experience with her husband for the same kind of surgery and at the same unit. During the current stay, the patient underwent scheduled neurological surgery, without an intensive care unit stay after the surgery. Distance from their home to the hospital was a 1.5 hour drive. The nurse who was taking care of the patient was a 50 year-old female staff nurse. The participant observation occurred at the 5th day (length of stay: 6 days) and took place in unit #2.

Procedures

Intensive Interviews

Consistent with the method, the original plan was to conduct two interviews with each of the family caregivers and elderly patients---one in-person interview during the patient's hospitalization, and one interview by phone after the patient's hospitalization (within 5-10 days). The phone interview was included in order to obtain data regarding patient preferences and family participation in the care during the discharge process. Several advantages of interviewing family members during hospitalization were identified: (1) it was easier to recruit family members during their visit; and (2) it was easier to separate the family member from the patient because the patient was being taken care of by nurses. However, there was an anticipated problem of patients' fatigue related to interviewing early in the hospital stay. Therefore, it was planned that the patients would be interviewed on or after the third day of their hospitalization, when their condition had stablilized after surgery or an acute episode of illness. In this study, the patients and family caregivers (in cases #1 to #5) were interviewed after the 18th (average) day of their hospitalization, with a range from the 10th to 27th days (SD=8.08). The patents and family caregivers (in cases #6 and #7) were interviewed after their discharged from hospital. The participant observation occurred on the average on the 16th day of the patient's hospitalization, with a range from 4 to 27 days (SD=11.5).

All interviews were conducted by using the interview guides. Three semi-structured open-ended interview guides (Appendix I) were designed to elicit information from elderly patients, family caregivers and nurses. The interview with patients was started with an open-ended question that asked what it was like to have family members participate in their care in the hospital setting. They were then asked to list up to five family members or friends who were most likely to visit them in the hospital, and their preference about family participation in particular aspects of their hospital care. The interview with family members was started with an open-ended question, which served as catalyst to elicit information regarding the family member's experiences during their elderly relative's hospitalization. There were several probes used to elicit detailed information (e.g., "What kind of things have you done to help your older relative while he/she has been in the hospital?" " What kind of things have you worried about during your family member's hospitalization?"). The interview with nurses was also started with an open-ended question with several probes, for example, "How do family members participate in the care of older patients?" "Tell me about a situation in which a family member was very helpful in the care of one of your older patients." The interview procedures and interview guidelines were adjusted during the study due to the ongoing issues and problems encountered. Originally, the interviews with the elderly patients and their family caregivers did not have to be matched, and they were interviewed twice, the first time face-to-face in the hospital, and the second time by telephone after the patient was discharged home. The original nurse interview was designed to collect their ideas and observations of the general elderly population in terms of family participation in hospital care.

After interviewing the first five cases, a problem was identified, that the data generated from the elderly patients were quite limited due to the fatigue or stress over the interview, during the acute hospital stay. In addition, there was a lack of data supporting some of the cells of the Lofland and Lofland (1984) analysis matrix. Therefore, at that point, several changes were made regarding the setting, method and frequency for interviewing elderly patients and their family caregivers. Elderly patients and family caregivers were interviewed once instead of twice, at home after the patient had been discharged instead of at the bedside, and in a face-to-face interview at home instead of the telephone interview. Moreover, the elderly patient, family caregiver, nurse and participant observation had to be matched instead of using unmatched individuals. In addition, the interview guidelines for elderly patients, family caregivers and nurses were adjusted accordingly. There were two reasons for making these adjustments. First, it was thought that the patients might provide more information when they were at home in a more controlled and relaxed environment, because they would be more energetic and less fatigued after being discharged to their homes, than they were in the hospital. Second, it was thought that three-way matched subjects (patient-family caregiver-nurse) would generate more enriched data for the purpose of triangulation of sources of data.

The changes in the interview guidelines were considered to be minimal (Appendix I). The general format was kept the same, but some of the questions were reformatted to make them easier for the elderly patient to answer. For example, originally the first question for the patient interview was "what is it like to have the family member being here with you?" The patient either responded with silence or said something short, like "fine." Therefore, the question was changed to "tell me who visited you during your hospital stay", in this way the question was more specific rather than general in order to invite an easy start. The original two interview guides were merged into one guide. In addition, several new questions were added to generate more detailed information based on the five units (role, practice, episode, meaning, and relationship) selected from the Lofland and Lofland analysis method. Data on two more cases (6 and 7) were collected after the changes.

The data collection took place between June of 1994 and October of 1995. Altogether 25 interviews were done; 7 participants were interviewed once and 9 participants were interviewed twice. Of the 16 participants, 6 were family caregivers, 6 were elderly patients, and 4 were nurses. The interviews took approximately 20 to 90 minutes each. Two participants requested that their spouse be present during the interview; therefore, comments made by the spouse were included in the tape recorded interview. The interviews were tape recorded and transcribed. A journal of field notes and impressions from each interview was kept by the investigator.

Participant Observations

Participation observations were conducted with three family-patient-nurse cases. Narrative observational data were recorded in field notes (Lofland & Lofland, 1984; Keith, 1988), which were focused on patient-family-nurse situations, including activities of family members and the verbal and nonverbal interactions between and among family members and the elderly patients. Another emphasis was on what nurses assumed regarding what the family member will do. Three participant observations were conducted for three patient-family-nurse situations; two of them were around the mealtime and the other was during the discharge process. The participant observations took place in the three units and lasted from 1/2 to 1 hour. The participant observations were conducted immediated after the interviews with the elderly patient and his family caregiver for case 1. The other two observations were conducted either just before or after interviewing the nurse who was taking care of the patient participant. Demographic data for patients, family members, and nurses were collected (Appendix J). A journal of field notes and impressions from each observation was kept by the investigator.

Protection of Human Subjects

Approval for this study was obtained from the Human Subjects Review Committee of the Oregon Health

Sciences University, Portland, Oregon (Appendix K). In addition, approval was obtained from Human Subjects Review committee of the VA hospital (Appendix K). Each participant provided informed consent (Appendix H), which was used to inform participants of the goals and methods of the research, the potential risks, and to assure their right to withdraw from the study at any time. Strategies used to protect their anonymity included elimination of personally identifying data from transcripts and destruction of tapes once they were transcribed.

All information obtained from subjects remained strictly confidential. The tapes from the interviews were placed in a locked file. The participants were assigned a code number and only the code number appeared on the typed transcripts. Computer access was limited to the researcher and the transcriber.

The anticipated risk during the interviews was increased fatigue due to the elderly patients' acute illness. The participants were instructed to stop the interview if they felt too tired. In addition, the investigator monitored participants for signs of fatigue and planned to stop the interview if the participants either complained or showed signs of distress. The first 4 patients who were interviewed during their hospitalization showed some signs of fatigue; for example, took a deep breath or changed their gestures. However, they denied undue fatigue and requested to continue the interviews. As a result, the information generated from these interviews was limited. Therefore, the last two patient interviews were rescheduled to be conducted after they were discharged to their homes.

Analytic Method

Lofland and Lofland's (1984) method of analyzing data from transcribed intensive interviews and field notes from participant observation was used. Specifically, the data were analyzed for descriptive comments about the content domains of family participation, worry and preferences and patient's preferences, and for words used by respondents to describe aspects of the dimensions. Analysis and data collection were run concurrently because it is a more productive scheme (Lofland & Lofland, 1984). Each transcript was read soon after the interview to gain a sense of the whole. After the data collection was finished, the final stage of analysis became a period for bringing previously developed ideas to final completion (Lofland & Lofland, 1984).

As the coded statements (or units) from incidents were clustered into categories and dimensions, they were compared with others from the same respondent or other respondents to clarify relationships among categories. These emerging categories were also clarified by comparing them to categories found in the literature. Indicators of these categories and dimensions will then be used in a future study to generate items for the measures.

To achieve aim 2, Lofland and Lofland's (1984) conceptualization of units of social settings was used as the basis for analysis of the qualitative data, in terms of "what is going on" underlying the phenomenon under investigation. The data were coded and analyzed by using social units and answering analytical questions about the social units (Lofland & Lofland, 1984).

Social Units

A social unit is described by Lofland and Lofland (1984) as "a tool to use in scrutinizing your data log" (p.71) in the study of social settings. The following five social units suggested by Lofland and Lofland (1984) were originally selected to be used in this study: meanings, practices, episodes, roles, and relationship. An additional social unit, encounter, was selected later during the analysis process, due to its relevance to this study.

Meanings

Meanings are referred to by social analysis as "culture, norms, understandings, social reality, definitions of the situation, typification, ideology, beliefs, world view, perspective, or stereotypes" (Lofland & Lofland, 1984, p.71). Meanings are also "transbehavioral in the sense that they do more than describe behavior-they define, justify, and otherwise interpret behavior as well." (p.71). Therefore, meanings serve as the most basic unit among all of the social units.

Practices

Lofland and Lofland (1984) described practices as the "smallest behavioral unit of a social setting" (p.75) in participants' everyday life. Practices are referred to as recurrent verbal and/or nonverbal behaviors that are not remarkable to participants, but are observable and are assigned meaning by the researcher.

Episodes

Lofland and Lofland (1984) defined episodes as "remarkable and dramatic to the participants, and therefore to the analyst as well" (p. 76).

Roles

Roles are referred to as categories of social "types of persons" (Lofland & Lofland, 1984, p.79). Roles include both formal and informal types and are used as a label to organize one's own activity and to make sense of the acting of others.

Relationships

Lofland and Lofland (1984) described relationship as "two parties who interact with some regularity over a relatively extended period of time, and who view themselves as 'connected' to one another" (p. 83).

Encounters

Encounters differ from the units discussed above because they tend to be bounded social systems. Lofland and Lofland (1984) defined encounter as "a tiny social system formed when two or more persons are in one another's immediate physical presence and strive to maintain a single focus of mutual involvement" (p.78). The period of time an encounters lasts is only as long as the people remain together.

Reliability and Validity

Criteria for assessing reliability and validity in qualitative research differ from those in quantitative research (Lincoln & Guba, 1985; Strauss & Corbin, 1990). Lincoln and Guba (1985) and Sandelowski (1986) have developed criteria to evaluate the trustworthiness of qualitative research. These criteria are (1) truth value or credibility of the research, (2) its applicability or transferability, (3) consistency or dependability, and (4) neutrality or confirmability.

Credibility can be maximized through prolonged engagement with the informants, triangulation of types and sources of data, peer debriefing, and member checks. In this study, multiple data collection sources (interviews with family, patient, and nurse, and observation notes) and methods (interview and participant observation) were used. Participants were interviewed more than one time if needed to clarify and verify the analysis. Peer debriefing and member checking was achieved through ongoing discussions with advisory faculty and gerontological seminar colleagues. A list of data bits and preliminary categories and definitions was distributed to gerontological seminar colleagues three times during the data analysis process. They were asked to indicate if each data bit fits the category and definition (LeCompte & Goetz, 1982). Imle and Atwood's (1988) approach to retaining qualitative validity was adopted in the format of verification process to ensure clarity and validity.

Transferability is referred to as generalizability of the study to a new situation or population. Detailed information was provided on sample selection and sample characteristics, which included demographic data for patients, family, and nurses. Also, thick descriptions were obtained through detailed field notes and memos of the analysis process so that the reader can make a judgement whether the study can be transferable to another setting.

Dependability or consistency is comparable to reliability in quantitative research. It can be enhanced by conducting a formal inquiry audit. In this study, the dissertation committee performed this function through extensive review of selected transcripts and field notes. The researcher met with the committee regularly throughout the dissertation study. In addition, two of the committee members worked together with the investigator intensively on the process of category confirmation as well as the refinement of definitions from the data bits.

Finally, confirmability is the test of rigor which refers to freedom from bias in the research process and product. The researcher attempted to identify clearly the role of the researcher and the relationship between the researcher and informants, because the researcher serves as an instrument in a qualitative study. The researcher did not recruit subjects for the dissertation from the unit where the researcher worked as a clinician. A research journal (analytical ideas and thinking processes about the study, and notes on discussion of the findings with dissertation committee members and other qualitative researchers) as well as an audit trail (detailed raw data) were maintained from the beginning to the end of the qualitative study (Lofland and Lofland, 1984). Therefore, "an external auditor could examine the process by which the data were collected and analyzed" (Hasselkus, 1988, p.690).

CHAPTER IV

RESULTS AND DISCUSSION

Introduction

The results are organized in three parts: (1) Aim #1: a summary of concept refinement for the four concepts of family participation actions, patient preference about family participation, family preference, family worry, and other emerging concepts; (2) Aim #2: a conceptual framework of family caregiving for elders in the hospital setting; and (3) Aim #3: possible ways to measure the concepts.

Aim #1: Concept Refinement

Although originally four concepts were identified for the study, data from the study did not support one concept--family preferences. Therefore, the report of concept refinement focused on three concepts: Family Participation Actions, Family Worry and Patient Preferences. In addition, a report of three concepts that emerged from the data analysis is included in this section: Patient Worry about Family Members, Role Expectations of the Nurse, and Role Expectations of the Family Caregiver.

Some of the descriptors used by the participants were very similar to the descriptors found in the preliminary study and in the literature. Following is a summary of the findings and a comparison of these findings with those found in the preliminary study and the literature for the three original concepts. The findings will be presented and discussed in four sections: (1) family participation actions, (2) patient preferences, (3) family worry and (4) emerging concepts.

Family Participation Actions

The concept of family participation actions refers to the caregiving actions performed by a family caregiver, including verbal and nonverbal interactions with the patient, health care team (HCT) and other family members in the hospital setting, for the purpose of maintaining continuity of life patterns for the patient and family. As shown in Figure 2, three dimensions of family participation actions, were generated from the qualitative data bits: (1) providing care to patients; (2) working together with the health care team; and (3) taking care of self. The percentage of data bits and percentage of participants as well as the number of data sources (family caregiver, patient, nurse and observation notes) are listed in Table 5.

The percentage of data bits was given for ways to look at the data prevalence per dimension or category. These percentages were used for the purpose of

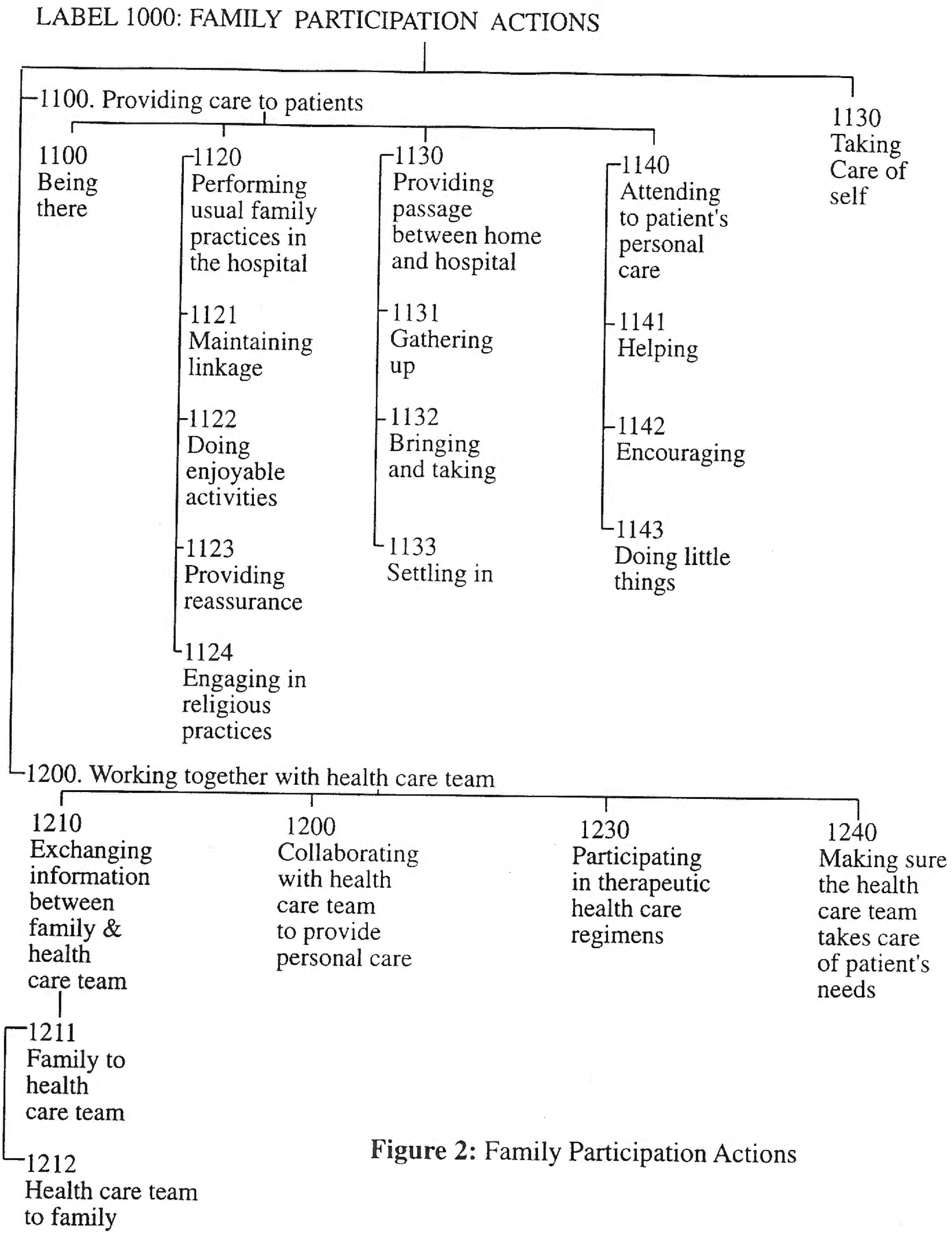

Figure 2: Family Participation Actions

Table 5. Family Participation Actions (Data Distribution)

Name of Category	% of Data Bits (of 311)	% of Partici-patients (of 20)	#F (6)	#P (6)	#N (5)	#OBS (3)
Providing care to patients	**69.8**	**100**	**6**	**6**	**5**	**3**
-Being there	6.4	70	2	2	5	3
-Performing usual family practices in hospital	17.7	85	6	5	4	2
.Maintaining linkage	8.7	75	5	5	3	2
.Doing enjoyable activities	5.5	55	4	3	3	1
.Providing reassurance	2.6	25	2	0	2	1
.Engaging religious practices	1.0	15	2	1	0	0
-Providing passage between home and hospital	15.4	75	6	6	2	1
.Gathering up	5.5	50	5	4	0	1
.Bringing and taking	8.7	65	5	6	2	0
.Settling in	1.3	10	1	1	0	0
-Attending to patient's personal care	30.2	80	4	6	4	2
.Helping	26.4	80	4	6	4	2
.Encouraging	2.3	20	2	0	0	2
.Doing little things	1.6	25	1	3	1	0
Working together with health care team (HCT)	**27.7**	**80**	**5**	**3**	**5**	**3**
-Exchanging information between family and HCT	10.3	60	5	2	3	2
.Family to HCT	4.8	40	4	1	3	0
.HCT to family	5.5	40	4	2	0	2
-Collaborating with HCT to provide personal care	6.1	40	2	1	3	2
-Participating in therapeutic regimens	6.8	45	4	0	3	2
-Making sure the HCT takes care of patient's needs	4.5	30	2	0	2	2
Taking care of self	**2.6**	**25**	**2**	**1**	**2**	**0**

triangulation of data sources, not for deciding the importance of categories. However, the percentage of both data bits and the participants, as well as the number counts from each of the data sources, were used to determine the level of category development. A well developed category has to meet two criteria: (1) representative of content, also called theoretical sampling of phenomenon, refers to having enough content in data bits for the analyst to develop understanding from the data; (2) representativeness of variety data source. A well developed category is defined as a category containing at least one data source; at least 2 participants within that source; and at least 2 or more data bits from each of the participants within that source. A category in its early stage of development is a category that cannot meet the above criteria (M.A. Imle., personal communications, may 10 and May 21, 1996).

The term "action" was selected rather than "task," a commonly used term in the literature, because task was considered to be too narrow for describing family participation actions in this study. There are multiple dimensions and purposes for some of the actions found in the qualitative data. Action is considered to be more descriptive and appropriate in this study, because from a role theory perspective, learned actions and interactions with others are part of the definition of role (Sabin, 1968). Therefore, the label of family participation actions is used to describe the caregiving actions performed for the patient by a family caregiver, and include verbal and nonverbal interactions with the patient, health care team (HCT) and other family members in the hospital setting.

Providing Care to Patients

The first dimension, family providing care to patients, includes four categories: (1) being there; (2) performing usual family practices in the hospital; (3) providing passage between home and hospital; and (4) attending to the patient's personal care. The above four categories were grouped into the same dimension because they are all caregiving actions performed for the patient by a family caregiver. Providing care to patient is a well developed dimension from the four data sources. This dimension contained 69.8% of overall data bits and covered four data sources or 100% of participants.

Being there. This category refers to the family caregiver's presence with the patient for varying lengths of time, sometimes lasting all day or around-the-clock. The caregiver's presence conveys that there is somebody who cares for and supports the patient. It serves as a foundation for family actions and continuity of life patterns during the hospital stay, as well as having inherent value itself. The actions include being present ("I don't know what I could say I did to help him that day. Just hope the presence was soothing." F7), staying there with the patient ("I stayed with him a lot, around the clock," F1), and waiting for the patient during treatment ("I got to go with him until they took him [to surgery] at quarter to twelve. So I was [waiting] in the same room all the time." F7).

Being there is a well developed category from the four data sources. Altogether about 20 data excerpts (6.4% overall data bits) were generated from 60% of participants. The three participant observations were done when the family caregivers were staying with the patients, and the three family members all reported that they had stayed with the patients every day from morning until the evening.

This category has not been reported in the home caregiving literature, perhaps because being there is taken for granted when the patients are at home, instead of hospital. However, being there is somewhat similar to one of Bowers (1987) purposeful categories, anticipatory caregiving. The common denominator shared by the two categories is the sense of anticipation of need for care. The difference between these two categories is that being there refers to actually being present at the patient's bedside, whereas Bowers' anticipatory caregiving by adult children of elderly Alzheimer's patients, refers to moving their homes closer to the parents' homes or continuing to live in the same area as their parents despite opportunities to move. Except for one study (Halm & Tiltler, 1990), most of the literature on family involvement in the hospital, refers to visitation as the basic sign of family participation, without clearly distinguishing being there from visitation. In Halm and Tilter's (1990) study, providing companionship was indicated as one aspect of the family member's role during their visitation periods. The rationale of distinguishing being there from visiting, in this study, was the extensive amount of data indicating that family members were staying with the patient around the clock from morning to evening, which was different from other family members or friends who just came to visit for short period of time. Further, 14 of 20 data excerpts included such terms as "presence," "stay with," "was there" and "being there," reflecting a quality different from just visiting. Being there has a underlying meaning of companionship and anticipation for doing other types of caregiving if needed by the patient. Spending time with patient was identified as an indicator in the preliminary work (Appendix D), and was separated from visiting. However, the two indicators of family participation were grouped under the category of "extra." In this final typology, being there is singled out as a category, whereas visiting is grouped under the category of maintaining linkage.

Performing usual family practices in the hospital. This category refers to actions performed by family caregivers, including verbal and nonverbal interactions for the patient's well-being and maintenance of their family relationships. Action sub-categories are (a) maintaining linkages, (b) doing enjoyable activities, (c) providing reassurance, and (d) engaging in religious practices. Performing usual family practices in the hospital is a well developed category from the four data sources. This category contained 17.7% of overall data bits and was generated from 85% of the participants.

The first sub-category, maintaining linkage, refers to actions performed by caregivers in connecting the patient with everyday life and the outside world.

The actions include talking and chatting with the patient by phone or in person ("Chatter [when I visit her]. That's about it. Told her what was happening at home and the things like that." F3), calling other family members and arranging for other family members to visit, according to the patient's preferences ("In the last two days, he would like to have visitors..We have his brother here." F6), and using reading materials such as newspapers ("Sometimes when he was awake, I would read little articles [from newspapers] that I thought would be of interest to him." F7), magazines ("So I went down and brought him magazines." F6), and books ("I gave him books. He read them in the last two days." F6). Visiting is under the category of maintaining linkage because it serves the purpose of bringing a familiar face and voices, to link the patient with home, family and outside world.

Maintaining linkage is a well developed sub-category from the four data sources. Altogether about 27 data excerpts were generated (8.7% of overall data bits) from 75% of the participants.

Although some actions in this sub-category were found in the literature of both home and hospital family caregiving, as well as in my preliminary work (Appendix D), there was no published concept of maintaining linkage used to group all of the relevant actions under it. For example, the action of "reading to patient" was identified as one of the descriptors of family participation in hospital care of general patients in the CCU (Halm & Titler, 1992; Hickey & Lewandowski, 1988) or elderly patients in regular units (Laitinen, 1992). Although visiting patients in the hospital was often mentioned, it was actually treated as a major indicator of family participation in hospital care, especially in critical care units (Fuller & Foster, 1982; Haggmark, 1990; Halm & Titler, 1990; Hickey & Lewandwandowski, 1988; Lazure & Baun, 1995; Simpson, 1993; Simpson & Shaver, 1990; Titler & Walsh, 1992).

The second sub-category, <u>doing enjoyable activities</u>, refers to pleasant or meaningful actions conducted by either the family caregiver or both caregiver and patient, based on a history of home experience to enrich everyday life during the hospital stay. Enjoyable activities tend to be specific to the individual. For example, P1 said: "The other night we [with his wife] were down on the first floor to a wheelchair party," N2 said: "Actually quite a few people make a big to do over the birthdays. Father's Day was a big day. And they usually have...like a big banner and bring in the whole family." Some of the actions had not been carried out yet, up to the day when the subjects were being interviewed in the hospital, such as: "Maybe watching football games, he kind of likes that. So I would think that maybe he would look forward to doing that with me. Or bowling. He likes sports, and every now and then they bowl on television. I know that he would like me to be able to sit down and watch that with him." F4. Some enjoyable activities, such as getting a weekend pass to leave the hospital (P2) or permission to bring a pet to the hospital (N1), require negotiating with the health care team and need to fit within the regulations of each hospital system.

Doing enjoyable activities is a well developed sub-category from three data sources: family caregivers, patients, and nurses. Two data bits were generated from observation for this sub-category, but only came from one of the observations. Altogether about 17 data excerpts (5.5% of data bits) were generated from 55% of the participants with four of the data sources.

Although some actions in this sub-category were found in the literature of both home and hospital family caregiving, as well as in my preliminary work

(Appendix D), there was no such category of Doing enjoyable activities used to group all of the relevant actions under it. For example, the action of "singing" was identified as the only indicator of family participation in the hospital care for elders, under the label of "other" (Laitinen, 1992). Comparing with the home caregiving literature, the similar caregiving actions were identified in the literature and were labeled differently than enjoyable activities. For example, the task of participation in leisure activities was grouped in the category of "little extra" (Archbold & Stewart, 1988). The concept of enrichment was identified in the literature as both a family caregiving category (Circirelli, 1983) and an intervention strategy (Archbold & Stewart, 1988; Cartwright, 1993). However, the definition of enrichment is different from the one of doing enjoyable activities. Enrichment was defined as "the process of endowing caregiving with meaning or pleasure for both caregiver and care recipient" (Cartwright, Archbold, Stewart, Limandri, 1994, p.32). In the hospital, an action that was under the category of doing enjoyable activities may not necessarily be pleasant or meaningful to both the caregiver and care receiver. For example, F1 brought a cookie jar to the patient's bedside because the patient liked it lot. The cookie jar also had a special meaning to the patient because it was a gift from his wife when he was young. Therefore, the wife brought it in as a symbol to convey the meaning of love and caring, although the patient couldn't eat cookies anymore because of his diabetes illness. It is logical to interpret that the family or patient is carrying on their usual family practices to the hospital (e.g., bringing cookie jar) and using such an action as a way to convey the meaning of caring to each other.

The third sub-category, <u>providing reassurance</u>, refers to actions performed by family caregivers using verbal or non verbal behaviors to help put the patient at ease. The actions include explaining ("Tell him what they [health care team] were trying to do for him. Reassure him that he was going to get help." F1), and physical contact with the patient ("I held his hand one day after he..[when the patient's condition changed unexpectedly after his open-heart surgery]." F6).

The sub-category of <u>providing reassurance</u> is well developed from two data sources: family caregivers and nurses. Eight data excerpts in this sub-category (2.6% of overall data bits) were generated from 25% of participants with three of the data sources. Only one data bit was generated from an observation, and the patients did not report any reassurance support from their family caregivers.

This finding differs somewhat from the current literature. Halm and Titler (1992) reported that both patients and family members identified reassurance as family role task in CCU settings. The possible explanation for the difference could be the sample size and different patient populations between the two studies. However, providing reassurance is an important aspect of family participation in the hospital care for elders, which was confirmed by other data sources in this study and the existing hospital literature. However, it was not found in my preliminary work (Appendix D). The caregiving action of reassurance was not found in the home caregiving literature. Perhaps the action of reassurance is more likely to occur during the acute stage of the patient's illness or condition.

Within the category of performing usual family practices in the hospital, the fourth sub-category is <u>engaging in religious practices</u>, which refers to actions performed by family caregivers by doing religious activities for the patient. Family actions on behalf of the patient are oriented toward seeking or involving religious or spiritual resources. The actions include praying with or for the patient ("She [the patient's daughter] and her husband pray for me." P1), or reading the Bible or other religious writings to the patient ("I've been reading the Bible to him while he eats breakfast" F4).

Engaging in religious practices is in an early stage of development. Altogether only three data excerpts (1% of data bits) were generated from 15% of participants with only two data sources (patient and family caregiver). The rationale for keeping this category was its importance supported by home caregiving literature (Archbold & Stewart, 1988; Cicirelli, 1988), and the small sample employed in this study. This sub-category needs to be developed further in future research.

Providing Passage Between Home and Hospital. This category refers to caregiving actions performed by family caregivers, including gathering up patients and their medications and belongings during both the admission and discharge process, as well as the hospital stay, bringing in and taking back patients and their personal belongings back home, and helping the patient to physically settle in during admission. Providing passage between home and hospital is well developed from three of the data sources: family caregivers, patients and nurses. This category contains 15.4% of data bits and was generated from 75% of participants in the four data sources. It has three sub-categories: (a) gathering up, (b) bringing and taking, and (c)settling in.

The first sub-category, <u>gathering up</u>, refers to caregiving actions performed by family caregivers in managing patients, organizing their personal belongings, and collecting medications during the discharge process. Examples of data excerpts given as following: "She [patient's wife] gathered my stuff up [to go home]" P2 said; "I took the prescription down to the pharmacy and filled it [before they left the hospital]" said by F1.

<u>Gathering up</u> is well developed from both family caregiver' and patients' perspectives because of the multiple data bits generated from the two data sources. Altogether, 17 data excerpts (5.5% of overall data bits) were generated from 50% of participants with the three data sources: family caregiver, patients, and observation. Nurses did not mention any actions under this sub-category. This sub-category was not found in the literature from either home or hospital caregiving.

The second sub-category, <u>bringing and taking</u>, refers to caregiving actions performed by family caregivers in transporting patients and their personal belongings during admission and discharge process as well as the hospital stay. This sub-category includes data excerpts such as "My son brought me here" P3; "My wife come and picked me up [on discharge day]" P5; and "I brought his clean pajamas and I brought him some new night shoes [during his hospital stay]" F2.

Bringing and taking is a well developed sub-category from the three data resources: family caregivers, patients, and nurses. Altogether, about 27 data excerpts (8.7% of data bits) were generated from 65% of the participants in three of the data sources. There were no data bits generated from observation for this sub-category.

The third sub-category, settling in, refers to caregiving actions performed by family caregivers in helping patients to get situated in the new places during admission process. This sub-category included data excerpts such as "She hung all my clothing, put it in a locker [when the patient was admitted]" P2. Settling in is in its early stage of development. Altogether only four data excerpts (1.3% of data bits) were generated from 10% of participants in two data sources. There were no data bits generated from either the nurses or the observations.

The category of providing passage between home and hospital was not found in caregiving literature at either home or hospital setting. Bringing family pictures and stuffed animals were found in my preliminary study, but they were grouped into the category of emotional and spiritual support because these items served as a purpose of enjoyment or meaning rather than clothing or shoes. In this sub-category of bringing and taking, the items being transferred were mainly personal care items (such as underwear). When the patient is at home, family caregivers do not need to bring or taking these personal items to somewhere outside the house, except shopping for them. Therefore, these kind of actions maybe covered in the IADLs at home. Obviously, the category of Providing Passage between Home and Hospital is a unique one when the patient is hospitalized. However, it was not found in the hospital caregiving literature. One explanation would be that the studies conducted in the hospital setting focused on either CCU or regular unit settings, no one included the admission and discharge process when studying family roles in the hospital care for their relatives. Furthermore, the actions under Providing passage between home and hospital were more likely to occur during the admission and discharge process.

<u>Attending to Patient's Personal Care</u>. This category refers to family caregivers providing care in the patient's daily activities, by carrying on and modifying usual care routines from the home to hospital, and/or starting new caregiving actions during the hospital stay. These caregiving actions serve to individualize the patient's care in the content areas of (a) eating, feeding, and drinking; (b) moving and transferring; (c) bathing, showering and hygiene care, including clean up and hair care; (d) toileting; and (e) dressing. <u>Attending to patient's personal care</u> is a well developed category from the four data sources. This category contained 30.2% of data bits and was generated from 80% of the participants in four data sources. The action categories are (1) helping, (2) encouraging, and (3) doing little things.

The first sub-category, <u>helping</u>, refers to verbal and nonverbal actions performed by family caregivers in facilitating the patient in their daily activities. Also, doing things partially or completely to meet the patient's individualized personal care needs, including (a) eating, feeding, and drinking; (b) moving and transferring; (c) bathing, showering and hygiene care, including clean up and hair care; (d) toileting; and (e) dressing. Examples of data excerpts in this sub-category were: "She's been feeding him and getting him things while he was on bed rest," N7; "She helped me feed myself for breakfast." P1; "They [family caregivers] help the patient getting out of bed and into a chair and going into the bathroom." N1; "Sometimes the caregiver will bathe them [patients]." N3; "I helped him brush his teeth and comb his hair." F7; "He needs help taking off these Depends, they're called diapers, that he's wearing. And he has a real hard time on and off. So I would change that for him, and I have been changing, even while he was living with us." F4; "Helped me dress" P7.

Helping is the largest and most well developed sub-category from the four data sources. Altogether, about 82 data excerpts (26.4% of data bits) were generated, from 80% of the participants in four of the data sources.

This finding, of family caregivers providing more instrumental care to care receivers, matched the literature in the home setting (Albert, 1991; Archbold & Stewart, 1988; Bowers, 1987; Cicirelli, 1983, Horowitz, 1985; Stoller, 1990), and hospital setting (Laitinen, 1992; Sharp, 1990), as well as my preliminary study (Appendix D). However, the family role of providing instrumental care was limited in the CCU (Halm & Tilter, 1992; Hickey & Lewandowski, 1988), because the patients' critical illness condition and the environment affected family caregivers' participation in patients' personal care. It is also interesting to note that the ranking of activities that family caregivers were actually involved in was (1) eating, feeding, and drinking; (2) moving and transferring; (3) bathing, showering and hygiene care, including clean up and hair care; (4) toileting; and (5) dressing, which also partially matched the caregiving literature in the hospital setting. The findings of Sharp's (1990) study revealed that the ranking of activities that family members were actually involved in was (1) feeding; (2) toileting; (3) washing; (4) dressing; and (5) bathing. Family caregivers participate more in helping patients to eat in the hospital even in the CCU settings. Actually helping patient to eat or drink was identified in CCU settings as the only task that family caregivers did, to provide patient's ADL care (Halm & Tilter, 1992; Hickey & Lewandowski, 1988). Perhaps the nature of helping the patient to eat is much easier for family to do than performing other ADL tasks in the hospital setting.

This second sub-category of attending to pateint's personal care, encouraging, refers to family caregivers use of verbal and nonverbal actions, to reinforce or motivate the patients in performing their daily living activities for independence, or behaviors leading to more health or independence. The actions include reinforcing patients' eating and moving. This sub-category included data excerpts such as: "The wife sitting in the chair and said [to the patient]:'eat the bread with butter on it'" OB1; and "I had to encourage him to get out of bed" F4.

Encouraging is well developed from two of the data sources: family caregivers and observations. Altogether this sub-category includes 7 data excerpts (2.3% of data bits), which were generated from 20% of the participants in two of the data sources. Patient and nurse participants did not mention actions under this sub-category. Although data in this category is slim, encouraging the patient to drink was identified as one of the family participation tasks in the findings of Hickey and Lewandowski's (1988) study. However, encouraging was not found either in family caregiving in the home setting, or in my preliminary study (appendix D).

The third sub-category of attending to patient's personal care, doing little things, refers to verbal and nonverbal actions performed by family caregivers in being comforting to the patient, and attending to patient's detailed individualized care needs as desired by either the patient or the family caregiver. This sub-category included data excerpts such as: "Often a big help [from family caregivers] is just being comforting to the patient...and doing little things for them" N3; "She got me whatever I need" P5.

Doing little things is in an early stage of development. Altogether this sub-category only had five data excerpts (1.6% of data bits) from 25% of the participants in three of the data sources. There was no action under this sub-category generated from the observation. Although this category is also slim, there were multiple data bits (3) generated from multiple patients (3). The evidence of this sub-category is supported by the family caregiving literature in the hospital. "Completing tasks desired by the patient and family" was suggested by the patients as one of the family roles during their visit in CCU settings (Halm and Titler, 1992, p.32). In addition, the task of running errands was identified by Horowitz (1985) to be one of caregiving assistance, provided by family caregivers to the care receivers in the home setting. This sub-category needs further development in future research.

Working Together with the Health Care Team

The second major dimension of Family Participation Actions refers to verbal and/or nonverbal caregiving actions performed by family caregivers, when interacting with the health care team and serving as a team member. Working together with HCT is a well developed dimension from the four data sources. This dimension contained 27.7% of data bits and was generated from 80% of the participants with four of the data sources. The four action categories in this dimension are (1) exchanging information between family and HCT, (2) collaborating with the health team to provide personal care, (3) participating in therapeutic health care regimens, and (4) making sure that health care team takes care of the patient's needs.

The first category, exchanging information between family and HCT, refers to the verbal and nonverbal actions performed by family caregivers when exchanging information between family caregivers and health care team members. This category contained 10.3% of overall data bits, and was generated from 60% of the participants with the four data sources. However, less data bits were generated from the patients and observations. This category is well developed from the four data sources. It was also divided into two sub-categories: (a) family giving information to HCT; and (b) HCT giving information to family.

The first sub-category, <u>family giving information to HCT</u>, refers to verbal and nonverbal actions performed by family caregivers in presenting information to the HCT members based on their experiences of caring for or living with the patients, so that the HCT can provide patients with individualized care. The actions include: offering information to the team about patients' habits, and ways the patient liked things to be done, and answering questions for the patient. This subcategory include data excerpts such as: "That's the one thing I warned the surgeon about [the patient's medical allergies]" F1; "I just told them [HCT] pretty much his habits and the way he likes things" F7; "They [family caregivers] would come and say: 'my Dad won't ask for this. Can you please ask him if he needs like something for pain. He won't ask'" N1.

<u>Family giving information to HCT</u> is a well developed sub-category from the perspectives of both the family caregivers and the nurses. The sub-category

included 15 data excerpts (4.8% of data bits), generated from 40% of the participants in three of the sources. The observation did not reveal any information on this sub-category. It is possible to observe the actions of the family giving information to HCT during patient admission process, because that is the time this action would most likely occur.

The second sub-category, HCT giving information to family, refers to the actions performed by family caregivers when receiving information, learning new skills, or observing the treatment or therapy for continuity of patient care. The actions include listening and talking to HCT, learning about medications, skills, treatment, and keeping current with the medication list. HCT to family included data excerpts such as: "I learned a lot of things about treatment and stuff that you know, that I wouldn't know, that doctors and nurses know. And then about how he should get up and move around and all" F7; "She [RN] explained all the medications to her [patient's wife] and everything" P5.

Health care team giving information to family is a well developed sub-category from the three data sources: family caregivers, patients, and observations. The sub-category included 17 data excerpts (5.5% of family to nurses (Li, 1992, Appendix D). Two types of information being given by the family caregivers to the HCT were found in this study. One is the information regarding patient's health and illness history. The other kind of information regarding the patient's habits and home care routine, was not found for existing literature in the hospital setting. However, learning from the family was not a new concept in home settings. Harvath's et al. (1994) identification of the family caregiver's local knowledge, lends support to the findings of this study; that during collaboration on care there is a two way exchanging of information between the family caregivers and HCT members.

Collaborating with the health care team to provide personal care. This category refers to verbal and nonverbal actions performed by family caregivers, to supplement the nurses care and to smooth things out for the patients' personal care. The actions include (a) environmental modification, for example,

> She [patient's wife] pushed the call light on and then removed her chair to outside the door because the chair was placed in the path to the bathroom, she then was standing at patient's bedside and waiting for the nurse to come to help the patient to go to the bathroom (OB7).

data bits), generated from 40% of the participants in three of the data sources. Fewer data bits were generated from the patients and observations. The nurses did not report any information in this sub-category. Perhaps the fact that the nurses were interviewed before the patients' discharge, in the matched cases contributed to this finding. Actually, both N6 and N7 mentioned specific information they would give to the patient and family, but they had not yet done that by the time they were interviewed. Therefore, the information was not recorded in this sub-category. The three unmatched nurses mentioned the role expectation of educating the family in understanding the patient's illness process. However, they did not identify what they did in terms of teaching or coaching the family in family participation.

Sharing care between family caregivers and nurses is not a new concept in the literature for caregiving at home (Harvath, Archbold, Stewart, Gadow, Kirschling, Miller, Hagan, Brody and Schook, 1994; Hasselkus, 1988). However, collaborating between family and nurses is new in a hospital setting. In the hospital setting, exchanging information is usually seen in two ways, from nurses to family (Collier & Shirm, 1992) and from

(b) reporting patient's input to nurses, for example,

> The RN came in and asked the family caregiver 'How did he do [with his lunch tray]?' 'He ate everything, no jello' the wife answered. The RN wrote it down on the bedside chart (OB1)

(c) completing patient's personal care when the nurses are called out, or supplementing nurses with the patients' personal care when needed ("We'd start his bath and we got called away; she [patient's wife] would finish the bath" N6); (d) delegating personal care to HCT, or seeking assistance from the health care team for the patient's care, and/or providing personal care per guidelines based on trajectory of the patient's recovery process ("The first day he got up [after his surgery] I believe they [RNs] took him to the shower. I stayed outside and they helped him." F7).

<u>Collaborating with the HCT to provide personal care</u> is a well developed category from three data sources: family caregiver, nurses, and observations. However, multiple data bits came from only one patient participant. Altogether about 19 data excerpts (6.1% of data bits) were generated from 40% of the participants in the four data sources.

Separating helping with patient's personal care, to collaborating with HCT to provide patient personal care, was a new finding in this study and has not been found in either the preliminary study or existing literature, except Halm and Titler (1992). In their study, family members reported their role involved "participating in care as desired, with guidance from the nursing staff" (Halm and Tilter, 1992, p.32). As a result of surgery, or because of the patient's illness, it is understandable that the patient's personal care needs may be changed. Their self-care abilitites may be limited. Gradually, however, the patient will regain their ability to do self-care. Therefore, during the special period of recovery time, family caregivers might need to share the care with nurses. Both family and nurses may need to "give up claims to authority and share the ownership of the interaction with the client" (Hasselkus, 1988). This is a unique area of family participation in the hospital setting for elders, which calls for the further research.

<u>Participating in therapeutic health care regimens</u>. This category refers to verbal and nonverbal actions performed by family caregivers in helping the patient in his or her recovery process according to the health team's recommendations, and facilitating the patient to follow the medical regime. The actions are (a) assessing patient's symptoms by asking questions of the

patient (F7 sat in the patient's bed and asked P7: "Do your fingers feel numb now?" "little bit" F7 said. OB7); (b) providing interventions by bringing in appropriate medications from home or changing dressing for patient's incision ("I was dressing his incision." F1); (c) calling for treatment or technique assistance when needed ("That was probably the only time I've ever put on his call button, was when he threw up the feeding tube." F1); (d) reminding, encouraging and doing for the patient, to follow the treatment plan ("She encouraged him to breath by using the incentive spirometer several times per hour to begin with. So she would hand it to him and make sure he did it." N6). Participating in therapeutic health care regimens is well developed from three data sources: family caregivers, nurses and observations. Altogether about 21 data excerpts (6.8% of data bits) were generated from 45% of the participants in three of the four data sources. No data bits were generated from the patients.

Family caregivers providing treatment related care was identified in the home caregiving literature. "Do you handle or manage medical equipment or machines, such as oxygen, a feeding tube, IV equipment, or catheters?" is one of the questions on the Family Caregiving Inventory (Stewart and Archbold, 1994, p.4).

In addition, some treatment-related categories were identified in the literature; for example, treatments (Oberst, Thomas, Gass, and Ward, 1989), health care (Horowitz, 1985), and assisting with medicines (Albert, 1991; Stewart & Archbold, 1994). The treatment-related tasks were found in my preliminary work (Appendix D), and also in the hospital family participation literature; for example, "assisting with dressing changes" and "tracheostomy care" (Hickey and Lewandowski, 1988).

Making sure that the health cares team takes care of patient's needs. This category refers to verbal and nonverbal actions performed by family caregivers in interacting with health care team members or patients, to make sure patient's personal care needs are being met and to keep the patient from getting lost in the shuffle of a large institution. The actions include making sure the patient receives adequate care, by watching, observing, or asking questions to either the patient or HCT members regarding the patient's personal care needs. The category included data excerpts such as: "I made sure he had something to drink" F6; "The nurse said the patient's sugar was a little up. 'Do you know if the jello [in his tray] is sugar free' the patient's wife asked" OB1.

Making sure the HCT takes care of patient's needs is a well developed category from three data sources: family caregivers, nurses, and observations. Altogether about 14 data excerpts (4.5% of data bits) were generated from 30% of the participants in three of the data sources. No data bits were generated from the patients.

Although "making sure" was not found as a sub-category in the caregiving at home literature, the tasks of making sure care receivers' needs be met were found in the literature (Hasselkus, 1988; Stewart & Archbold, 1994). For example, making sure the care receiver get "enough to eat", "enough rest" and "the right amount of liquids" are listed as indicators in Stewart and Archbold's (1994) Caregiving Activities List. However, these types of making sure caregiving tasks were not found in the literature regarding to family caregiving in the hospital. Although the family caregivers might delegate the care to the HCT members, they continue to assume their responsibility to make sure the patient's personal needs are being met, because the family caregiver's "sense of ownership is as strong as that of the professional" (Hasselkus, 1988. P.689). The findings in this sub-category of making sure the HCT takes care of the patient's needs, lends support to home caregiving literature of managed care.

Taking Care of Self

The third major dimension of Family Participation Actions refers to caregiving actions performed by the family caregiver in interacting with other family members, or taking a break for themselves to meet either or both family caregiver and the patient's needs. The actions include family caregiver's rest and respite, arrangement for breaks during the day of being with the patient, and arrangement for back up care. This major dimension included data excerpts such as: "When I left, some of other relatives came to stay with him while I went home and showered" F1; "I don't like the traffic so each day, one of the kids or grandkids, somebody, picks me up in the morning and somebody else came and got me in the evening" F7.

Taking care of self is a well developed dimension from two data sources: family caregivers and nurses. Altogether, about 14 data excerpts (2.6% of data bits) were generated from 25% of the participants with three of the data sources. Again, no data bits were generated from patient participants, which matched patient's preferences in family participation, because patients did not mention anything in terms of their preferences in this category. However, patient worry about the family caregiver's safety on the road to the hospital, may suggest that the patient was concerned that family caregivers take care of themselves.

Taking care of self as a dimension of Family Participation Actions was not found in the caregiving literature either in the home or hospital settings. However, two issues were mentioned in the literature: family caregivers' respite care in home settings and nurses care of families' physical needs in CCU settings (Daley, 1984; Pfeiffer, Middleton, Alexander Kleine, Elbare, 1989). Family caregivers at home "needed to attend to their own needs" (Langner, 1995, p.81) was identified as an indicator of "rediscovering and redefining self" (p.80). Langner's finding lends support to this dimension of taking care of self. The findings of this study indicated that the family caregivers found ways to take care of themselves while they were participating in the hospital care for their elderly relatives, which had implications for clinical practice.

In summary, two of the three dimensions of Family Participation Actions were well developed from the four data sources: family caregivers, patients, nurses and participant observations. The third dimension of taking care of self was less developed. At the category level, most were well developed from at least two data sources. In addition, all of the categories were well developed from the family caregivers' perspective. However, three sub-categories were in early stages of development: engaging in religious practices, settling in, and doing little things. Although some of the actions of family participation were found in existing hospital family caregiving literature, some of the actions and most of the category labels were new additions to the hospital family caregiving picture. In addition, no previous study has examined the phenomenon of family participation in the hospital care for elders in such a systematic manner. Although the typology of Family participation Actions is new, and some of the sub-categories still in their early stage of development, it adds to the body of knowledge in the area of family caregiving in hospital care for the elderly patients.

Patient Preferences

Family participation actions discussed above were partially based on patient preferences. Patient preference refers to the elderly patients' personal choices, based on their privileged role in family participation actions. In this study, patient preferences were perceived by multiple parties: family caregivers, elderly patients themselves, and nurses. The language that reflected elderly patients' personal choices included such phrases as preferring or not preferring, wanting or not wanting, asking or not asking, and happy to have a specified individual do a given type of caregiving action. The reasons given for patients' personal choices, as perceived by family caregivers, patients, and nurses included: getting care done on time according to patient's habits or beliefs, meeting individual care needs, and making the patient comfortable.

The typology of Family Participation Actions that emerged from this study was applied to <u>patient preferences</u> about family participation in hospital care for elders. <u>Patient preferences</u> occurred only in one of the three dimensions of <u>Family Participation Actions</u>, <u>providing care to patients</u>. The dimensions of <u>working together with the HCT</u> and <u>taking care of self</u> were not mentioned in <u>patient preferences</u>.

<u>Patient Preferences: Providing Care to Patients</u>

Most of the patient preferences about family participation in their hospital care were clustered into the dimension of <u>providing care to patients</u>. There were four categories under this dimension: (1) <u>being</u>

there; (2) performing usual family practices in the hospital; (3) providing passage between home and hospital; and (4) attending to patient's personal care.

Patient preferences: Being there. There were only two data excerpts generated from a patient and a family caregiver. For example, the wife of P1 said: "Once I leave, he [her husband] accepts it. Now, a couple of nights ago, he didn't want me to leave. he wanted me to stay. And so I stayed until about 9:00 PM, and the kids had come."

Patient preferences: Performing usual family practices in hospital. As presented in Figure 2, the four sub-categories under this category are (a) maintaining linkage, (b) doing enjoyable activities, (c) providing reassurance, and (d) engaging in religious practices. Altogether, 8 data excerpts were generated for this dimension. Of the 8 data excerpts, 6 of them were generated for maintaining linkage; 2 of them were for doing enjoyable activities, and none of them were for the sub-categories of providing reassurance or engaging in religious practices.

The sub-category, maintaining linkage, included 6 data excerpts. Of the 6 data excerpts, 4 of them came from three patients; and 2 of them came from two nurses. For example, P3 was a 73 year-old woman who was admitted for post-stroke rehabilitation. When she was asked if she preferred her family members to visit her, she answered:

> Sometimes, yes, sometimes no---Well they [her husband, son and his family] have their other business. If it's serious I would want them here every night. The illness is the main part of it, the reason they should come...I told him [my husband], I said not to come until I'd been here a few days. My son's coming this afternoon. My son's family will be coming eventually, but I said not to rush them.

For the sub-category of Doing enjoyable activities, there were only two data excerpts generated, one from a family caregiver and one from a nurse. F1, for example, mentioned why she did one of the enjoyable activities with the patient (her husband]. She said: "I did take him downstairs yesterday to the canteen. Brought him a small bag of popcorn [because] he wanted some popcorn." The wife stated that she also enjoyed the activity because she would like to be able to take her husband out of the unit often when he is getting better. One reason for lack of data excerpts from patients might be that some of the enjoyable activities were not appropriate for patients to express their preference. For example, with respect to their birthday celebration, one of the nurses said: "Hardly anybody would say: it's [my] birthday, bring me a party." A second reason for the lack of patient data may be that the wording of the interview questions may not have elicited preferences on this sub-category, because the question to patients on their preferences focused more in the area of family providing personal care.

The patients did not express any preference about either providing assurance or engaging in religious practices. This is an interesting finding. As mentioned earlier, family caregivers reported what they did to reassure the patients, but the patient neither perceived it as part of the family role nor expressed any preference about it. One explanation might be that the patients were not aware of it because they took for granted for what family caregivers did in terms of reassurance for them, or did not think of this as part of family participation actions. The second explanation may be the patients did not feel comfortable bringing up these area to a stranger, the interviewer.

Religious practices may be an important action for some caregivers, but it was not mentioned by most caregivers. Another explanation might be that the patients' children performed religious practices as a way to show their care about the patients, as the P6 said: "just to do whatever they want" when he was asked what kind of caregiving he preferred his children or brother to do. Religious practices might belong to the categories of "whatever they want" in the patient's mind. Also, the state where the study took place is not considered as "religious" as many other states. Therefore, there may be geographic variations in the importance of religious practices. For the future study, the researcher may ask the patient to rate the value or importance of each family participation action generated from this study.

Patient preferences: Providing Passage between Home and Hospital. As presented in Figure 2, this category includes three sub-categories generated from the family participation data: (a) gathering up; (b) bringing and taking; and (c) settling in. Altogether, only four data excerpts regarding patient preferences on this category were generated from three patients. Of the four data excerpts, three of them were for gathering up; one was for bringing/taking; and none occurred for settling in. When P6 was asked what kinds of things he preferred his family caregivers to do during discharge, he said: "Nothing other than what they [wife and daughter) did". Then he stated that they "have to go get the clothes" for him when he was discharged, which was included in the sub-category of gathering up. when P3 was asked what kinds of things he preferred his family caregivers to do during discharge, P3 said: "Well, he [the patient's husband] just...talk with me and take me home. That's about it [what the patient preferred], and that's what he did;" this data excerpt was included in the sub-category of bringing and taking.

Patient preferences: Attending to patient's personal care. This category contained 13 data excerpts regarding patient preferences and all of them were clustered on the one sub-category, helping. It contained about 52% of the total data excerpts generated for patient preferences on family participation. This finding reflects the dominant orientation toward the hands-on caregiving actions, evidenced by the caregiving literature for both at home and hospital settings. Of the 13 data excerpts, 12 of them were from four patients, and 1 of them was from a family caregiver.

Patient preferences about wanting a specified individual to do a designated activity were made on the basis of intimacy of the activity, technical skills needed, and the ability to perform the action safely. Family were divided as family caregiver (spouse), family members (children/siblings), and friends, and also by gender (applying to only children, not to one's spouse) and family tie relationship to the patient. Spouse and RN (based on job expectation) were preferred to do the most private personal care; next were the children who were the same sex as the patient, then siblings; and last were friends. The order of most private caregiving actions included toileting, bathing, dressing, cleaning up (hygiene), moving and eating. Patient's preference of who should do what action revealed an association between the closeness or intimacy of the relationship with the family members, and the private nature of the tasks in terms of privacy (to do what type of tasks). This association is more obvious for this sub-category of personal care than for the other categories and sub-categories, because of the nature of the tasks. For example, P2 said: "I don't like my daughter to do that [help him in bathroom]. But my wife is alright." When the same patient was asked what about whether he preferred his son to help him in personal care, he said: "He's alright [to help him in the bathroom]." Then when the same patient was asked about whether he preferred his friend to do anything for him, he said: "No. I don't ever ask him to do anything." When the P1 was asked what kind of things he preferred his friends to do in his care, he also said: "No, very independent in that respect".

RNs were viewed by patients as similar to their family caregivers in terms of providing private personal care because of the job expectation. However, patients made clear distinctions between nurses and family members although they could do similar types of personal care. For example, "They [RNs] can put you to bed a lot better [than family]," stated by P7 who was an elderly man admitted for neurological surgery; and "My wife cared for me more than a nurse, RN is only a job." The same patient also preferred older nurses because they "could get to you and go right on and [intimate care did] not seem to bother them a bit. But these younger nurses, they had a little problem with that [personal care]".

It was not surprising to see that there were no patient data bits for <u>encouraging</u>. Because the responses from patient were usually negative when the family caregiver encouraged them to eat or get out of bed, they may not have viewed this "encouragement" as helpful or desirable. For example, "No. I don't want to eat more" (P1). Ultimately, a long term effect of encouraging will occur for the patient's benefit, although the immediate responses were negative. For example, the patients may see eating or moving as a control issue, rather than patient and family working toward a common goal.

In summary, the concept of patient preferences is well developed from the patient's perspective, but is not well developed from the perspectives of both family caregivers and nurses. It is a reasonable finding because of the subjective nature of the preferences. Some of the nurses' comments on <u>patient preferences</u> were not included in this report because the data bits lack of specificity. For example, when N1 was asked the rationale for family being there, she said: "that could be any of the, I think, it could be family [preferred], or the patient has asked." None of data excerpts of patient preferences were generated under the other two dimensions of <u>Family Participation Actions</u>: <u>working together with the HCT</u> and <u>taking care of self</u>. There might be several reasons: the patients might not realize that family taking care of themselves was part of the family role in family participation, the small sample, and the way questions were asked of the patients.

Compared with existing caregiving literature both at home and in the hospital settings, _patient preferences_ has not been studied, except patient preferences about visiting in the CCU settings (Halm & Tilter, 1992. Titler, 1992; Simpson, 1991). The finding of patient preferences on visiting matched the literature. P6 was a open-heart surgery patient and stayed in the CCU immediately after his surgery; he preferred to have family members come when appropriate and to leave when they saw the patient was tired, which matched the findings of Simpson's (1991) study. Also, P3 reported she preferred to have family stay with her should she have surgery or become severely ill. This finding is in agreement with Simpson's (1991) findings.

Family Worry

Patient preferences and _family worry_ appear to be important variables affecting the concept of _Family Participation Actions_. Family worry refers to the cognitive and affective reaction family caregivers experience when the elderly relative has been admitted as a patient in hospital. Family worry is conceptualized as one type of role strain from being a family caregiver of an elderly patient. It is defined as felt difficulty in fulfilling the family member and/or caregiver obligations because of worry. Also, family worry is viewed as a sign of family caring about the elderly relative. Four dimensions of this concept emerged from the data: (1) worry about patient's health status; (2) worry about patient's care from the HCT; (3) worry about future care for patient by family; (4) worry about finances.

Worry About Patient's Health Status

This dimension refers to the family caregiver's felt difficulty in fulfilling the family member and/or caregiver role, because of worry about the elderly patient during his or her hospitalization. The dimension includes data excerpts such as: "The biggest worry is if he was stable. Because like I said the first Sunday, he had first shock and on the second Sunday he lost his blood pressure" F6; "Mr.G's urine output once dropped off, she was very worried about that. She didn't know what medically happened with him. She was at the motor-home (RV) during the night and she couldn't sleep" stated by the N6 who was taking care of the P6.

This dimension is well developed from the family caregivers' perspective. Altogether 10 data excerpts were generated from two data sources: five family caregivers (7 data bits); and 2 nurses (2 data bits). The majority of the data bits were from the family caregivers. The above descriptors were from a matched case among the patient, family caregiver and nurse. In the matched cases, nurses made statement about specific things they thought the family caregiver worried about. In comparing with matched cases, the nurses in unmatched cases (such as N1 and N2) indicated that they were unsure about what family caregivers worried about. Therefore, the two data bits generated from N1 and N2 were excluded from this report. No data bits were generated from the observation because of the subjective nature of worry. In addition, no data bit was generated from patients because the patients were not asked about family worry.

It is logical to understand that the level of family worry about patient's health status is related to the severity of patient's illness. For example, F3 said: "If she [the patient] were in for operation or something, then that would be a concern. As she was in for therapy [rehabilitation], I knew that everything they did was helping her. There were no worries." Therefore, the different reasons for admission may affect the level of family worry about the patient's health status. In addition, the level of family worry about patient's health status may be reduced if family caregivers have the knowledge and are prepared. For example, when N6 was asked what she thought the F6 would worry about regarding P6's hospital stay, she said: "He [P6] had diabetes, so she's probably worried about his diabetes control." This statement was confirmed by the F6. Later when I asked P6 whether she worried about her husband's diabetes control, P6 said:"Yes, ...because, you know, after surgery the sugar always gets, really goes up and stuff." But she felt that the HCT would "keep pretty much on top of that [diabetes control]." F6 had the same hospital caregiving experience with her husband two years ago when her husband underwent the same kind of neurological surgery in the same unit and hospital. Therefore, she anticipated what would happen and became more prepared and less worried. In this case (#6), the data bits from multiple sources confirmed this content dimension of family worry about patient's health status.

Worry About Patient's Care Received from HCT

This dimension refers to the family caregiver's felt difficulty in fulfilling the family caregiver role, because of worry about the elderly patient's care received from the health care team during his or her hospitalization, including whether the patient may get help on time and get his or her individual needs met. This dimension includes data excerpts such as: "I think

I worry the most about [him] during nights. He didn't seem too good and that he would be not able to get the nurses if he needed some help" said by F1. F1 was at her husband's bedside every day from the morning to the evening during his hospital stay, but went home during the nights.

This dimension is well developed from the family caregiver's perspective. Altogether, about 10 data excerpts were generated from 5 family caregivers, and one were generated from one nurse. Although there were two data bits generated from the two nurses in this dimension, one of them was excluded from the report because of the nurse's unsureness. For example, N1 said: "They [family caregivers] probably worry about are they [patients] getting adequate care? will they get better?" the nurse used the word "probably" in her statement and there was no additional matched data sources to confirm it. Therefore, the data bit with the words of "probably" was excluded from this report. Although multiple data bits were generated from the family caregiver's perspective, only one (F1) of the caregivers reported worry about patient's care from HCT. As a matter of fact, the other family caregivers (F2, F3, F4 and F7) in this study, reported they were not worried about the patient's care either, because they trusted the HCT ("I feel that he's in good hands" F2); or accepted the reality of nursing care; for example, F7 said:

> I felt like he was ...able to punch his buzzer, and that he probably would get anything he really needed. He might get impatient or if something was a little longer. But I didn't think there was anything going to be that serious that he wouldn't get attention soon enough.

It is interesting to note that the four cases (#1, #2, #3 and #4) were from the same nursing unit, and three of the four caregivers reported no worry about the patient's care because they thought the patients received good care from the nurses. However, F1 worried a lot about her husband's personal care, especially when she was not with her husband during the nights. Two explanations might be applicable to this case. First, the patient's level of functional impairment might contribute to the high level of family worry. F1 stated that her husband would not push the call light without his glasses, so she worried about if he could get help when he needed, without her being at the bedside during the nights. Conversely, F7 stated that she did not worry much, in part because she thought her husband could punch the call light if he needed help.

Second, the caregiving situation and relationship between the caregiver and the patient might also contribute to the high level of family worry. F1 had been a caregiver to her husband (P1) at home for more than 8 years, and had experienced multiple caregiving experiences with P1's hospitalization prior to the P1's current hospitalization. Actually, P1 stated that he had been needing his wife's assistance in performing his daily activities for so many years and he was used to his wife's help. In addition both F1 and P1 reported that they had a good relationship between them. Therefore, their special caregiving situation and good relationship might contribute to F1's worry about the patient's care, when she was not being with her husband. In contrast, the other family caregivers had either different caregiving situations or different quality of relationships between the caregivers and the patients. The positive quality of the relationship between caregiver and care-receiver was labeled as "mutuality" by Archbold et al. (1990). The findings from their study showed that mutuality was associated with lower levels of some dimensions of caregiver role strain (for example, role strain from direct care), but not the role strain from worry. Additional study is needed in this area to further explore the relationship among family worry and caregiving situations, including mutuality, in the hospital setting.

Worry About Future Care For Patient by Family Caregivers

This dimension refers to the family caregiver's felt difficulty in fulfilling the family caregiver role, because of worry about how they will manage in the future. This dimension includes data excerpts such as: "Sometimes I worry about what am I going to do, you know, if I get sick [that] I can't take care of him" stated by F2; and "A lot of family members are also really worried about treatment, like if there was a dressing change that we were trying to teach them to do so that they could do it at home." N2.

This dimension is well developed from the family caregiver perspective. Altogether, 5 data excerpts were generated from 3 family caregivers and 1 data bit was from a nurse. Although N2 was not in a matched case with the patients and family caregivers, she used an emphatic words (really worry) and mentioned an important aspect of family worry about future home care, which is technical task preparation. This aspect of worry was not mentioned in caregiving literature for either home or hospital setting. However, family worry about technical care may have implications for nursing practice. Therefore, this data bit was included in this report.

Worry about Finances

This dimension refers to the family caregiver' s felt difficulty in fulfilling the family caregiver role because of worry about their financial situation. Only one data excerpt was included in this dimension which was stated by F2. She said: "I worry about our finances because lots of times we just don't have the money...I would like to come here more often but I don't have the money to pay for the gas."

This dimension is in an early stage of development. However, it was retained because it was supported by the literature as one of the aspect of worry for family caregivers (Archbold & Stewart, 1988; Cantor, 1983; Bull, 199). Further research is needed in this area.

In summary, three of the dimensions of family worry were well developed from the family caregiver's perspective: family worry about patient's health status, worry about patient's care from HCT, and worry about future care for patient by family. However, the fourth dimension of worry about finances was in an early stage of development. Limited data bits were generated from nurses, and no data bits were generated from either the patients or the observations. The patients in this study were not asked about their perception of family worry, because of the subjective nature of worry. However, if patients had been asked about their perceptions of family worry, more data bits might have been generated for the purpose of triangulation.

The findings of the four dimensions of family worry from this study, were basically congruent with the literature of family worry in home settings and the investigator's preliminary work (Li, 1992b, Appendix D). The content of family worry during hospitalization was found to be somewhat different than when the elderly person was at home. On the one hand, the items of family worry identified as specifically related to the home setting were not found in this study. For example, family worry about "obtaining enough help for the things you can't do for him [care receiver]," "safety when he or she uses the stove," "his or her safety because of traffic problems," and "safety because guns or other weapons are present in the home." (Stewart and Archbold, 1994). It was not surprising to see this finding, because the patient's safety became the responsibility of the HCT when the patient was admitted to the hospital.

On the other hand, the family worried more about patient's health condition, especially when the patient was placed in the CCU or at certain periods of time, such as before and after surgery. They worried more about the patient's care, especially during the night time when they were not with the patient. In addition, they worried about what would happen when the patient returned home. It was logical to understand these findings because the patients were in their acute illness stage or undergoing their surgeries, except for the patients in the rehabilitation programs. As a matter of fact, the family caregivers of rehabilitation patients worried less, in general, than the family caregivers of acute illness or surgery patients about patient's health status. But they more worried about future care of patient by the family, because the patients in the rehabilitation program were more physically impaired than the other group. The finding of family worry about patient's health in this study is congruent with the existing literature (Oberst & James, 1985; Oberst & Scott, 1988). Both of the studies (Oberst & James, 1985; Oberst & Scott, 1988) used the term "concern" instead of "worry" in measuring one aspect of the family members' role strains pre-hospital discharge and post-hospital discharge.

Introduction of Emerging Concepts

Three additional concepts emerged from the data analysis: patient worry about family members, role expectations of family members, and role expectations about the RN's involvement with the family. The following discussion will address the three concepts.

Patient Worry About Family Members

This concept refers to the patient's felt difficulty in fulfilling the patient role in the hospital, because of worry about family members. The concept is in its early stage of development. Altogether, it contains four data excerpts from two family caregivers and two patients. The content domain suggested two kinds of sources of worry for patients. First, worry about caregiver's safety on the road: ("I don't want her [patient's wife] driving on that damn crazy road too much...too many crazy people out there." P2). Actually, during the interview, P2 stated that his wife was on her way to the hospital while we were doing the interview, he looked toward the hallway several times during the interview and said he had to go to see if his wife arrived safely right after the interview ended. When he saw his wife, he told her that he worried about her. His wife also stated during the interview that her husband worried about her safety "driving back and forth" to hospital. The second source of patient worry was about what was going on at home, especially if there was another frail elderly spouse or siblings. For example, P3 said: "He [P3' husband] tells me the news and what's going on at the house and how's my daughter doing with cooking the meals. And he tells me these things, which I worry about."

Patient worry directly affected family participation actions through patient preferences. For example, P2 did not want his wife to come too often because he worried about her driving safely on the road back and forth to hospital. As a result, his wife only came to visit him once a week and took him home for the weekends. Of course, there were other reasons that made her visits less frequent than she wants to, but the patient preferences as the result of worry was definitely one of them. There was no existing literature found in the concept of patient worry about family member. Therefore, it is important to further explore the concept of patient worry in a future study.

Role Expectations of the family caregiver role in the hospital

This concept refers to the family caregiver's role obligations in the hospital setting as perceived by the family themselves, patients and nurses. Patients expected family members to be supportive, for example, P3 said: "basically I think that person [patient] should have some support from family during his stay [in the hospital]." And patients expected that family participation in the hospital care would happen in every family, for example, P6 said: "I think that's [to have family support] the normal thing. It will always happen, in any family." However, the same patient had an additional expectation of the family role, "Getting there at a convenient time. Leaving when they see they you're [patient] tiring."

Family caregivers expected themselves to be supporters and to provide hands-on caregiving. For example, F1 said: "I just took care of his [her husband] personal care [during hospital stay] "so the nurses don't have to do it [empty the urinal]." this It could be interpreted into two ways. First, the family caregiver thought it was the nurse's role but the family caregiver was doing it to help nurses. Second, she viewed herself as a co-caregiver. The other family caregivers suggested specified expectations. For example, F7 said: "I mean every family's individual, you know, and have their own ideas [about participation]."

Nurses expected family members to do what they wanted because they were volunteers and their participation was voluntary. N7 said: "I don't think I can leave my work just for her to do, but she's there, so I just feel more comfortable with her being there." However, other nurses might feel that the family should be there and do something that is necessary for the family to do. For example, F1 said that the nurses asked her to remove the contact lenses for her husband at bedtime, otherwise the nurses wouldn't do it for him because they were afraid to lose the contact lenses. N7 said: "I think that the family who doesn't want to be involved shouldn't be forced to be involved."

The family member's role in hospital care is not well established in current U.S. society, because nurses are the designated caregivers in hospital settings. However, due to the emerging aging phenomenon, hospital restructuring, shortening of hospital stay, and health care trend for shifting from hospital to home, changes can be expected. Preparing the family caregiver for such change becomes crucial for maintaining long term family caregiving at home.

Role Expectations About RN's Involvement With the Family

This concept refers to nurse role obligations with respect to nurse involvement with family caregivers in the hospital care of patients. Nurses were expected to encourage and teach family caregivers. For example, N7 said:

> It's an important part of rehabilitation to show them [family members] how to turn the patient and how to have the patient sit up and start to walk. So we strongly encourage them to help. Because, this is for somebody who's going to need it done long term.

Another nurse (N2) said:"[A nurse role in family participation is] to encourage them, to teach them, I encourage them and I teach them." The nurses encouraging role in family participation was supported by the findings of Halm and Titler's (1992) study. Nurses are in a unique position to work collaboratively with the family caregivers. This can turn the patient's hospitalization into a training opportunity for both nurses and family caregivers, if they choose to participate in the care, in order to improve quality of care to elderly patients both during the hospitalization and after they return home. N2 also made a comment to support the teaching role in family participation. She said: "It's the nurse's job, to explain to the family what's happening and what's normal for this situation and help them to understand that it's okay and the patient is going to get through this phase," which indicated that communication between family caregivers and nurses was an important role expectation of the nurses. In addition, the Family 7 said: "If there was something I should know or should be doing that I wasn't doing or didn't know, they should tell me." Further, P7 said: "Let them [family members] know what's going on. Communication." Therefore, communication was a shared expectation of nurses' role in family participation as perceived by three parties: patient, family member and nurse. The needs of increasing the communication between nurses and family caregivers was highlighted by results of this study, which also matched the findings of Sharp's study (1990).

When the study was originally designed, the concept of family preference about family participation in hospital care for elders was anticipated. However, the three other concepts emerged from data analysis. The emerging concept of role expectations of family members replaced the concept of family preferences. <u>Patient preference</u> is related to the patient's role privilege. Patients are the care receivers and they are in the special position of having the privilege to choose the desired person to provide different type of their care, at the same time.

Patients also worry about their family caregivers or other family members, which is related to patients' other roles, and family ties. Both family members and nurses are in the caregiver positions or roles and they have expectations of themselves and others, to provide care to the patients who are in the care-receiver position. Therefore, the three emerging concepts are well justified as the results of this study. However, the three concepts were not well developed due to their emerging nature, and need to be explored further in future research. Exploring the three emerging concepts and incorporating them into the whole picture of family participation in the hospital care for elders is a timely issue.

Aim #2: A Conceptual Framework of Family Participation In Hospital Care for Elders

Introduction

Overview

In this section, the relationships among the major concepts mentioned in earlier sections will be described in order to accomplish research aim #2. A conceptual framework of family participation in hospital care for elders emerged as a result of data analysis using Lofland and Lofland's (1984) qualitative approach (Figure 3).

In this framework, family participation in the hospital care for elders is viewed as a short episode in the family member's long-term practice of being together with the patient and, for some family members, being a caregiver at home. The purpose of the new framework is to describe the phenomenon of family participation in the hospital care for their elderly relatives. There are three major components in this framework: antecedent factors, core elements, and consequences. In addition, there are two mediating concepts in this framework: patient preferences and family worry.

Antecedent factors are those variables that

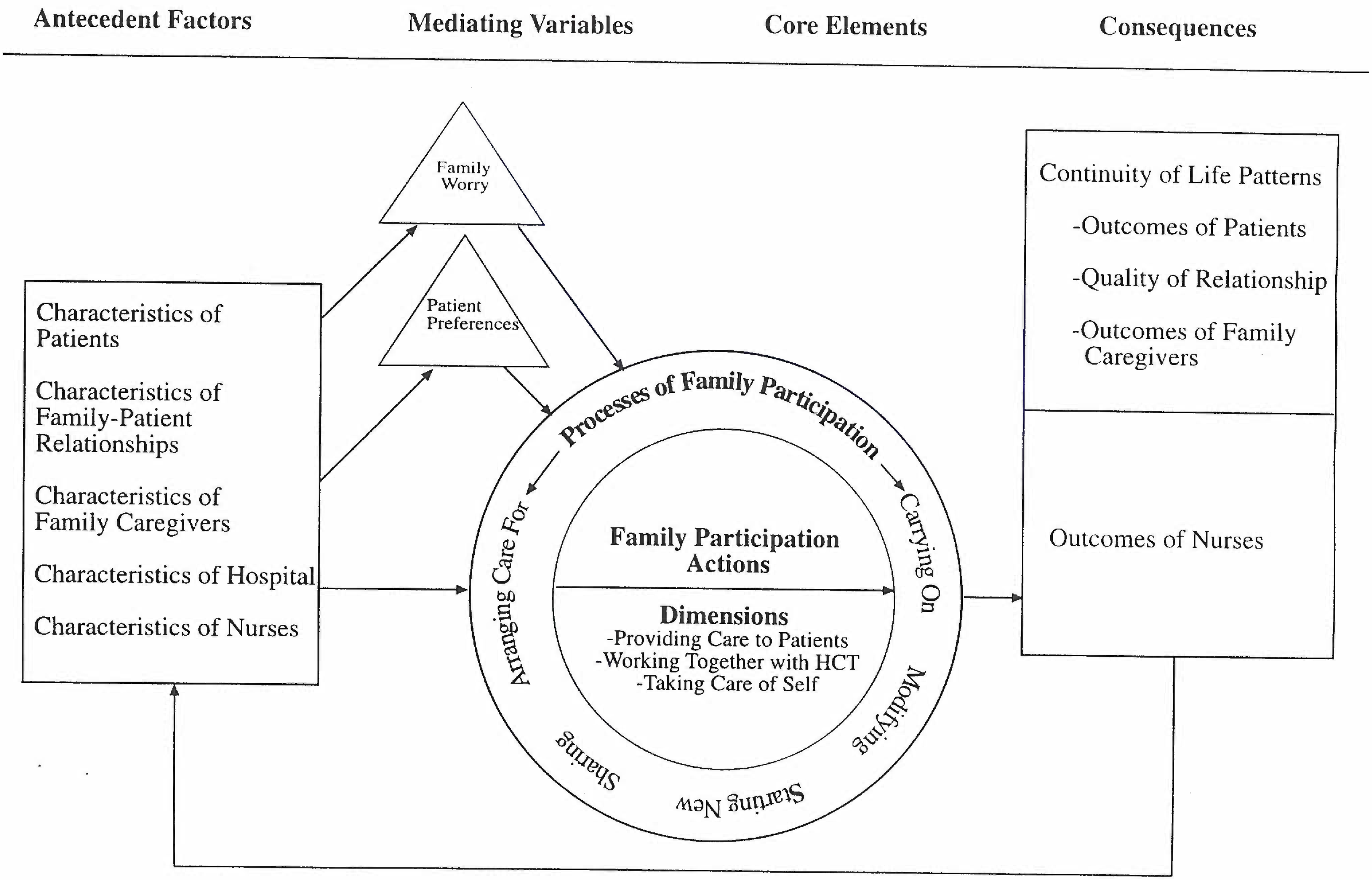

Figure 3: The Conceptual Framework of Family Participation in Hospital Care for Elders

existed prior to the patient's admission. Five sets of antecedent factors are presented in Figure 3. The first set of antecedent factors is characteristics of patients. This set includes age, gender, marital status, illness condition, past medical history, functional level, personal history (including patient's values, beliefs, and role expectations of the family caregiver). Characteristics of family caregivers, the second set of antecedent factors, include the caregiver's age, gender, and marital status, caregiving history, (including previous caregiving experience both at home and hospital), personal history (values, beliefs, and role expectation of themselves in family participation), health status, time availability, finances, worry, and distance between home and hospital. A third set of antecedent factors is the characteristics of family-patient relationship. These factors include quality of the relationship between the family caregiver and patient, and role relationship with the patient such as spouse or child. Characteristics of the hospital (policy, type of hospital such as university or VA hospital, type of unit such as critical care settings or medical-surgical unit, and facilities such as a rest area for family members), and characteristics of nurses (attitude, personality history includes personality traits, education level, and nurses' role expectation of themselves and of family caregivers in family participation, and time availability) are the fourth and fifth sets of antecedent factors.

Core elements, the major findings of this study, consist of three dimensions of <u>Family Participation Actions</u> (providing care to patients, working together with the health care team, and taking care of self) and five process themes (carrying on, modifying, starting new, sharing and arranging care for the patient). As a result of family participation, consequences occur during and after hospitalization. Two types of consequences (continuity of life patterns and outcomes of nurses) are presented in the framework (Figure 3). The first consequence is the continuity of life patterns, including (1) patient outcomes (feeling cared for, feeling calm, relaxed and comfortable, and preventing and providing care for patient's dysfunctional syndromes); (2) Relationship outcomes between the family caregiver and patient (meaningful relationship); and (3) family caregivers outcomes (increased preparedness, decreased worry, and increased role strains from direct care). The second consequence of family participation is nurses outcomes (increased rewards such as feeling good, and increased role strain such as time demands and stress).

In a general sense, the conceptual framework posits that when an elderly patient is hospitalized, family members' worry becomes even more salient because of the health condition of the patients. The family role in the hospital care of elderly patient is not well defined in this society, the degree to which family members participate in the hospital care of their elderly relatives depends on the following three factors: (1) patient preferences; (2) family worry; and (3) antecedent factors. Antecedent factors influence family participation both directly and indirectly through mediated concepts of patient preferences and family worry. Family worry is a complex concept and appears to affect family participation in multiple ways. Family participation in the hospital care can have both benefits and adverse effects for patients, family caregivers, and nurses.

Compared to the preliminary conceptual framework in this study, which was based on the literature search, the relationships among the major concepts have remained the same. Five differences exist between the preliminary and final conceptual frameworks. First, the concepts of family participation, patient preferences and family worry have been refined. Second, the antecedent factors and consequences have also been augmented and refined based on the data generated from the study. Third, the concept of family preferences has been omitted for the final framework. Fourth, the concepts of role expectations of family caregivers, patient worry, values of both patients and family caregivers, and continuity of life patterns have been added. Finally, the consequence of hospital outcomes was omitted in the final framework due to a lack of supporting data.

Analysis Tool

Role was selected as a major social unit for this analysis. The other five relevant social units (practices, episodes, encounters, meanings, and relationships) which were selected from Lofland and Lofland's (1984) matrix (p. 94) served as tools to help describe how family caregivers adapted their roles from home (as family members and caregivers), to a hospital co-caregiver role. In addition, seven analytic questions suggested by Lofland and Lofland (1984) to be asked within the social unit of role, were employed as strategies to describe the relationships among the concepts within the framework. The seven questions are as follows. What is the unit's type? What is the unit's structure? What is unit's frequency? What are the unit's causes? What are the unit's processes? What are the unit's consequences? and What are the unit's strategies? The following discussion provides a framework for understanding family participation in hospital care for elders.

Antecedent Factors

Antecedent factors are defined as contextual variables that existed as characteristics of patients, family caregivers, nurses and hospitals as well as the relationships between patients and their family members prior to the patient's hospitalization. The five sets of antecedent factors are listed in Table 6.

Characteristics of Patients

Patient's age, gender and marital status. In this study, the six patient participants were elderly with an age range from 68 to 74 years old (M=70.8). Five out of the six were men. Considering the relatively young age of the elderly patients, their spouses, if alive, would most likely be their family caregivers. The investigator attempted to recruit some old-old patients into the study, but was not unsuccessful either because of their refusal, the patient's confusion, their disease conditions, or no family members were available.

Table 6. Antecedent Factors of Family Participation

Factors	Content
Characteristics of patients	-Age -Gender -Marital status -Illness condition -Past medical history -Functional level -Personal history .Values (independence, cleanliness, companionship) .Beliefs .Role expectation of family caregivers
Characteristics of family-patient relationships	-Quality of relationships between family caregiver and patient -role relationships between family caregiver and patient
Characteristics of family caregivers	-Age -Gender -Marital status -Caregiving history (home and hospital) -Personal history .Values (independence, individuality) .Beliefs .Role expectations of themselves in family participation -Health status -Time availability -Financial status -Distance from home to hospital
Characteristics of hospital	-Policy -Type of hospital -Type of unit -Facilities
Characteristics of nurses	-Attitudes -Personal history .Personality traits .Education level .Values (family support, pateint rest) .Role expectations of themselves and family caregivers in family participation -Time availability

Patient's illness condition. In this study of the six patient participants, three of them were admitted for surgery; two for post-stroke rehabilitation and one for treatment of the acute stage of a chronic illness (congestive heart failure and fluid overload). All of them were admitted via the admission office except one who was admitted from the emergency room. The illness condition that caused the admission, affects family participation actions directly, as well as being mediated through patient preferences. For example, F3 clearly stated that family participation "depends on the illness." If the illness condition was serious or requested surgery, she would prefer to "have them [family members] come in day and night." Indeed, the family caregivers for the three surgical patients (P1, P6 & P7) were at the patients' bedsides every day from morning until evening throughout their hospitalization, and provided more types of family participation actions than the remaining family caregivers.

Patient's past medical history. This factor includes the patient's illness events over long periods of time. In this study, the medical history of each patient was reported by the family caregivers, when they were asked to tell something about the patient as a person. For example, P1 had history of diabetes since

1958; over the past 35 years, he lost his left eyesight and leg, had falls, a stroke and urology illness and had multiple hospitalization events. The patient had expectations about caregiving in the hospital and said:"In M.M Hospital [past], I usually said, I need such such, the nurse said to me: 'I'll be back.' You see, she wouldn't be right back." Because of his past experiences with hospitalization, the patient preferred his wife to be with him this time.

Patient's functional level. This refers to the patient's ability to take care of him or herself. The patient's functional level was related to his or her past medical history, current illness, and treatment condition. In this study, the three surgical patients needed assistance with their daily activities immediately after surgery, and gradually regained their ability take care of themselves, except for one patient (P1) who had a history of strokes. The three nonsurgical patients needed help to some degree in their daily living activities. Their functional level affected the family participation actions directly and as mediated through the patient's preferences. For example, F1 said: "I just plan to do things for him that he can't do for himself." The more impaired the patient was, the more likely that the family caregiver either participated more during the patient's hospital stay or took a break during the patient's hospitalization and let the nurses take care of the patient.

Patient's personal history. Personal history includes patient's values, religious beliefs, and role expectations, which affect family participation directly and as mediated by patient preferences. Personal history may impact personal meanings.

Meanings, a social unit, according to Lofland and Lofland (1984), are referred to as: "culture, norms, understandings, social reality, definitions of situation, typification, ideology, beliefs, world view, perspectives, or stereotypes" (p. 71). Also, meanings "are transbehavioral in the sense that they do more than describe behavior - they define, justify, and otherwise interpret behavior as well" (p. 72).

According to Lofland and Lofland's (1984) definition of meaning, patients values and beliefs conveyed meaning into family participation in interpreting their preferences or behaviors. Independence, cleanliness and companionship were values identified by participants. For example, F6 said: "He [her husband] didn't want to bother other people. Say, if you want to get up, you just push the call light. He would say oh, 'I can do it'. So with the IV [intravenous] poles to the bathroom, things like that, he doesn't want to bother others, and I [F6] will do it myself." Patient liked being clean and taken care of, therefore, his wife provided his personal care during his hospital stay and worried that the patient could not get his needs or preferences met when she was not there with him. P5 said: "It's important to me that somebody comes around, like to talk to me." The patient valued the <u>family linkage</u> and companionship (<u>being there</u>), therefore, his wife came everyday to visit him and talked with him.

Role expectations of family members by patients is one aspect of the patient's beliefs. For example, P4 expected his son to take care of him and he believed that his son should take care of him now since his wife had died. Therefore, he asked his son to do things for him when his son and daughter-in-law visited him in the hospital.

Religious beliefs is another aspect of the patient's beliefs. For example, one patient's (P1) son prayed for or with him. It had to be meaningful for both of them in order to convey the meaning of caring.

<u>Comparison of the literature on patient characteristics to the findings of this study</u>. Compared

to the preliminary framework, the personal history (values, beliefs and role expectations of family caregivers) was newly added as an antecedent variable. Personal history was not found in the existing hospital family caregiving literature as an antecedent variable. However, length of stay and sources of admission were omitted from the framework due to lack of supporting data from this study. Although the information of patient's length of stay and sources of admission were obtained from the demographic data sheet, no relationships were revealed connecting these variables to family participation in this sample. One possible reason could be the small sample, or the interview guides, which did not capture the relationship between the two factors and family participation. Thus, further study needs to explore the relationships among them.

Compared to the literature on characteristics of family caregivers in the home setting, ethnicity, economic condition and living situation were not included in this study. Among these, living situation was not applicable in the hospital setting. Omission of the other two factors were the shortcomings of this study, and need further research. The concept of patient's values was not found in home caregiving literature as an antecedent factor. Furthermore, it was interesting to note that the patient's functional level may affect family caregiving in the hospital, differently than it does in the home setting. In the home setting, the more impaired patient may need more care from the family caregiver (Archbold et al., 1990). However, in the hospital, there is a choice for the family, of either doing more for the patient or letting the nurses providing the care. The family caregiver was more likely to let nurses provide the care during the patient's stay at critical care (Foss, Tenholder, 1993, Hickey, Lewandowski, 1988).

Characteristics of family caregivers

Age, gender, marital status. In this study, family caregivers were younger than the patients on the average, and the majority of them were female and wives of the patients. The age and gender of family caregivers distributions of this sample are quite similar to national caregiver profiles (Stone, Cafferate, Sangl, 1987). The mean age of family caregivers in the national caregiver profiles is 57.3 year-old, and the mean age of family caregivers in this study was 53 year-old. The majority of the caregivers are female (72%) in the national profiles, and 67% of the family caregivers in this study were female. Gender difference, for example, was identified by nurses in providing patient's personal care. N3 said:

> Most of the time it would be a spouse or sometimes a child helping to bathe their parent. It's most often a woman actually helping. I think women are more comfortable bathing people than men are. Many men haven't had the chance to do it so they're not comfortable. And they're more apt to leave the room. But if the patient is a man, and it's a mother or a wife, they're more apt to bathe the men than if the patient is a woman. If the patient is a child, then the mother is going to be very, very comfortable doing it. So it depends on probably the sex and the relationship.

Nevertheless, the two male family caregivers provided care in certain types of family caregiving actions such as visiting, talking, bringing flowers (F2) and shooting pool with the patient (P4), but their caregiving actions mainly remained in the category of <u>Performing Usual Family Practices</u> in hospital and <u>Providing Passage Between Home and Hospital</u>. <u>Attending to Patient's Care</u> was limited for male family caregivers, which matched the literature on family caregiving in the home setting (Miller & Cafasso, 1992; Stoller, 1990). At the home setting, "female caregivers were more likely to carry out personal care and household tasks" (Stoller, 1990, p.498), whereas "male helpers provide intermittent assistance with occasional tasks but less frequently undertake routine household chores" (Miller & Cafasso, 1992, p.228).

Caregiving history. Caregiving history includes previous caregiving experience both at home and in the hospital. In this study, the six family caregivers had various past caregiving experiences. The caregiving history affected the types of family participation actions. For example, sometimes experienced family caregivers continued care routines they had established at home in the hospital for a physically impaired patient (F1), but they sometimes let the nurses take care of the patient's personal care (F2).

Although role expectations were not the focus of this study, data generated from this study addressed role structure. The family role is voluntary in nature. It is done without pay. The decision about how much care they provide to the elderly patient varies across families. Therefore, a nurse is in a unique position to facilitate the participation for the benefit of long-term care and quality of hospital care. Nurses viewed a helpful family as a plus in terms of providing the patient's hospital care, and patients viewed family members as a source of care that is different from nurses. However, the role activities of nurses can overlap with family caregivers. The family can focus their time on one patient, but nurses have to take care of several patients.

Caregiver's personal history. Personal history includes values, religious beliefs, and role expectations. The values of individuality and independence appeared to provide meaning to the consequence that family members hoped to achieve by their participation in the hospital care of an elderly relative. For example, F1 provided detailed individualized care to her husband during his hospitalization, such as preparing his tray for him including placing a special spoon in his right hand, and salting his food according to his preferences, in order to enhance his independence and enable him to feed himself. She provided a lot of care partially because of the family caregiver's own values. In addition, this family caregiver understood her husband's values as well as his preference.

Caregiver's health status. Family caregivers' current health status also affected their participation directly and indirectly though Patient Preferences. For example, family caregivers (F2 and F3) had poor health (one had asthma and another had a history of heart attack); and came to visit only once over several days of hospital stay.

<u>Caregiver's time availability</u>. This factor refers to whether the family caregiver has the time to spend with the patient in the hospital. This factor may affect <u>Family Participation Actions</u>. For example, F7 said: "On Tuesday, I had regular club activities. If I did not come, he would have not been a happy camper." Although there was a time conflict for the two roles, the family caregiver chose to come spend time with the patient because she knew her husband wanted her to be in the hospital with him. Of the six family caregivers in this study, five of them were retired wives and one was a son, who was a pastor. This explained, in part, why they were able to participate in the elderly patients' care.

<u>Caregiver's financial status</u>. This factor can affect family participation actions either directly or indirectly mediated through patient preferences. For example, F2 said that she would like to come to the hospital more often, but her financial situation prevented her from doing so because she couldn't afford the cost of traveling between home and hospital. Of course, the long distance (1.5 hour drive one way) between their home to hospital was another factor.

Distance between home and hospital. As mentioned above, the distance between home and hospital affected family participation actions. In this study, the majority of the families came from long distances. Two of them were from other states (F1 & F6); three of them (F2, F4, & F7) lived between one and one half hours of driving time from the hospitals; and one of them (F3) lived in town near the hospital. The two family caregivers from other states stayed with the patients in the hospital from the morning to the evening and returned to their trailers near the hospital campus to spend the night. They provided more types of family participation actions for their patients than the family caregivers who lived closer.

Comparison of the literature on family caregiver characteristics to the findings of this study. Compared to the preliminary framework, the caregiver's personal history (values, beliefs and role expectations of family caregivers), time availability, and financial status were newly added as antecedent variables. The above antecedent factors were also not found in the existing hospital family caregiving literature. However, culture and behavior disorders (abusive or alcoholic members) were omitted from the new framework due to lack of supporting data from this study.

Although culture was originally thought to be subsumed as a variable among different cultural groups that could influence family participation, it turned out to be part of values (such as cultural values of individuality and independence). Further study needs to address this issue by examining how differing cultural values affect the nature of family participation in hospital care for elders.

Three factors found in the caregiving literature of family caregivers' characteristics in the home setting, ethnicity, resources (interpersonal and social) and living situation (Archbold and Stewart, 1988) were not included in this study. Among them, living situation was not applicable in hospital setting. However, failure to find evidence for the other two factors may have been a shortcoming of this study, and needs further research. In addition, the concept of the caregiver's values was not found in home caregiving literature as an antecedent factor. Such values may have been taken for granted when they were at home, but became salient when they moved into the hospital. This study did not address the interpersonal and social resources, but the data suggested that family resources (e.g., other family members providing backup care or driving the family caregiver back and forth between the home and hospital) were important to their participation. This suggests social or interpersonal resources as an antecedent factor in the hospital setting, although the data was limited in this study. Further research is needed in exploring the relationship between resources and family participation in hospital for elders.

Characteristics of Family-Patient Relationships

The characteristics of relationships refers to the quality of relationships between the patient and the caregiver, and role relationship between family member and patient, such as spouse, adult child or others. Relationship is identified by Lofland and Lofland (1984) as a social unit. The relationships have to meet three elements: (1) "two parties who interact with some regularity"; (2) "over a relatively extended period of time;" and (3) "who view themselves as 'connected' to one another" (p. 83). There were three parties in this study: patients, family caregivers, and nurses. The periods of time that the three parties spent together were rather limited during the process of admission and discharge. On the unit, the interactions between family caregivers and nurses were also limited, and it would be appropriate to label them as encounters rather than relationships because family caregivers did not view themselves as being "connected" to the nurses. Actually, F4, who came to stay with his father about four times a week, said: "They [nurses] don't talk to me a great deal. I think they talk to Dad more than they do me." N3 said: "Some of our patients will be here for one to four months and when somebody's here for a long time like that, then the family gets comfortable with the nurse, [and] the nurse gets comfortable with the family." Although the data from this study did not support the existence of relationships between family members and nurses, it may be different in a broader sample, similar to this situation described by N3. Further research is needed in exploring the relationship between family caregivers and nurses in the hospital.

The relationship between the family caregiver and the patient fits in the definition of relationship. Both the family caregivers and patients recognized that they had a long history together and usually reported the quality of their relationship, which also affected family participation actions directly and indirectly through the mediating variables. For example, "I prefer my wife [to do personal care], we have a very good relationship." In this study, three out of the six cases reported that they had a long history and a good marital relationship (more than 30 years). These cases also reported more types of family participation actions than with a shorter relationship.

Among the five couples who had spacial relationships, there were varying degrees of dependence, independence, and interdependence. For example, in case #1 and #2, one took care of another in terms of daily activities performed, in another words, one was dependent and another was independent. For example, P1 said:

> I have become very dependent upon her...I need my wife to help me in almost everything I do...I think I am entirely too dependent on her. You know, she cooks for me, she helps me cut the meat off, she helps me butter my bread and everything...I think positively I am too dependent. Now I've done it for 35 years, and I can't get out of it.

Couples #3, #6, and #7, were both in good health or both in bad health. Couple (#3), who were both in bad health (stroke and asthma), had their daughter move into their home to take care of the dad when the mom was in the hospital. The husband, the caregiver of the patient #3 in the hospital, thus became the care receiver of daughter's care at home. F3 said: "If she [his wife] sees I need some help, she gives it to me if she sees it. I take care of her too. We help one other. We've been married 45, 46 years." P3 said: "There is what he can do and what I can do, we both have [physical problems]" while her husband said: "You have to take care of yourself first. And that's her attitude also. So it works out well for the two of us." The couple in this type of relationship, both of whom were in poor health might have different levels of preferences and expectations than the couples in good health before the admission. The type of relationship between the dyad may need to be explored further.

Comparison of the literature on characteristics of relationship to the findings of this study. The findings about characteristics of relationship from this study matched caregiving literature both at home and in the hospital setting. For example, mutuality of caregiver and care receiver is identified as an antecedent factor at home setting (Archbold & Stewart, 1988). Also, the status of the caregiver's relationship to the care receiver, such as spacial or adult-parent relationship is identified as an antecedent factor at both home and hospital settings (Archbold & Stewart, 1986; Collier & Schirm, 1992). However, the types of relationships between the caregiver and patient (independent, dependent, and interdependent) were not found in the caregiving literature for either the home or hospital setting. The type of relationship in caregiving situations is an important antecedent variable and it has implication value for nursing practice.

Although mentioned by several nurse participants in this study that "dysfunctional families" were not helpful in terms of participation, this may be related to conflict in the family relationship. However, it was not clearly stated. Therefore, future study is needed to explore the connection between family relationships and family participation.

Characteristics of Hospital

Characteristics of the hospital include policies such as visiting hours, type of hospital such as university or VA hospital, type of unit such as critical care unit or medical-surgical unit, facilities including type of patient's room (a single or double room) and rest area for family members. These factors affected family participation actions in this study.

Visiting policies were the only type of policies identified by the participants which would affect family participation actions in the two hospitals under investigation. However, the flexibility of carrying out these policies would make a difference in terms of family participation. For example, N1 at hospital A said: "We kind of take [the visiting hours] into judgment, what's the situation, what's going on with the family. Is the person, like, terminally ill. If so, we'd let them stay. So if it's past like 8:30 pm, ...if they [family members] are here and they're causing problems, we all ask them to leave, but other than that, we're not real picky about how late someone's here." The F7 at the hospital B said: "They [nurses] were not fussing about when visiting hours was over and I still was there, they weren't pressing about it or anything." N3 said: "If the visiting hours were restrictive, they would affect her ability to do what she [family caregiver] wanted, to give the care she wanted. In this hospital it's not a problem."

Type of hospital. This variable refers to how different kinds of hospitals would make a difference in terms of family participation in hospital care. For example, N3 said:

> We have a lot of patients that come here because it's the university hospital, that come here from many other states, or from far away in our state. And so they have family members who come with them...And when they come from such a distance,

> then the family is not going to their own home at night...They tend to spend much more time with the patient because they're away from home, they have no friends here, and no business, no other things that are pulling them away...So therefore, they're in the room all the time and they get more involved in the care than patients who live in town whose families go home and just visit them for an hour or two in the evening.

Facilities. The facilities refers to the rest area for family members and the type of patient's room (such as a single room or double room). Hospital facilities made a difference in terms of family participation in hospital care. When F7 from Hospital B was asked what could make a difference in terms of her participation in the hospital care, she said: "I was wishing, for me it would have been much more convenient, you know, if there was a place at the hospital I can have just spent the night there. And then wouldn't have had to go back and forth. It would have been much easier for me." Another example from Hospital A illustrates a similar point. F3 said: "I think they need [to get] extra chairs. You have to scrounge around to get these chairs." Another example would come from the statement of nurse #3 that illustrated how the type of patient room might influence the family participation. She said: "Some family members wanted to stay around the clock, and we don't encourage that, because half of our rooms are double rooms and there's another patient in the same room." The level of family participation was limited by the nature of the hospital facility.

Type of unit. This refers to the settings at unit level. It was noted in this study that different settings in the hospital (such as CCU) might influence the Family Participation Actions. The detailed discussion on this issue is located in the core elements section. Unit type can be considered as an influencing factor to the pattern of family participation.

Comparison of the literature on characteristics of the hospital to the findings of this study. The factor of facility was added in the new framework, when compared to the preliminary one, due to data. Although some studies mentioned the family waiting room in critical care unit settings, there was no relationship identified between the family waiting room and family participation. Hospital type, which was also not found in the family caregiving literature in the hospital setting, was added into the new framework. Because this variable was mentioned only by the nurse participants in this study, further study is needed to verify this finding as applied to family.

Compared to the home caregiving literature, the living situation at home (cleanliness and safety) was identified by Archbold et al. (1988) as an antecedent variable of environment. Although it had a different focus in hospital environment (privacy and convenience to the family and patient), they shared the same domain of environment. It is not surprising to discover a different focus when the patient is transferred from home environment to the hospital environment because the caregiving location changes when the patient is admitted to hospital.

Characteristics of Nurses

Characteristics of nurses include (a) attitude; (b) personal history including personality traits, education level, and nurses' role expectations of themselves and family caregivers; (b) time availability to patient (workload). These factors would effect family participation actions.

Nurses' attitude. Nurses' attitude toward family participation affected family participation actions. For example, N2 said:"I think that family participation is a wonderful thing. And I wish everybody had family who could be present. It makes the hospital stay more comfortable for the patient. Unless there's something dysfunctional about it, then I think it's great. I have no problem with family being involved." "I think it's [family participation] very helpful." (N1). Positive attitude toward family participation may facilitate family participation.

<u>Nurse's personal history</u>. Personal history includes personality trait, education level, and nurses' values, and nurse's role expectation of themselves and family caregivers in family participation. Nurse's personality trait would affect family participation. For example, N2 said:

> I make up assignment at the beginning of the shift. You have to know the nurse's personality. There are some people who don't work well with family members and some people who do...so you need to take that into consideration.

<u>Nurse's education level</u>. This factor would affect <u>Family Participation Actions</u>. For example, N2 said:

> I think the personality of the nurses can influence participation, And I think maybe a CNA or an LPN maybe hasn't had the formal education about the importance of family and so wouldn't maybe involve them as much...I know that I had a nursing [family] course in my RN program and I

> don't think they do [the course] in an LPN program, and I know they don't in a CNA program.

N7 also made a similar statement.

<u>Nurse's values</u>. This factor would affect <u>Family Participation actions</u>. For example, N1 reported that "it always makes me feel very good when I see a family participating in their loved one's care," thus confirmed this nurse's values about family support. Another example would be the N3's answer when she was asked "what is your feeling about family participation?" She said: "I think it's [family participation] very important." Nurses valued the family support which was congruent with their positive attitudes toward family participation in the hospital care for elders. Nurses also value the patient's rest, which may affect their involvement with the family participation. For example, N1 said: "If it's past like 8:30 pm, sometimes we will say, 'it's probably time for you to be going because...there's another patient in this room, and he needs to get his rest...and your loved one probably needs to get some rest.'"

<u>Nurse's role expectations of themselves and family caregivers</u>. This variable was identified as a factor which would affect <u>Family Participation Actions</u>. For example, when N6 was interviewed, she stated that she

would involve F6 in P6's discharge instruction because she thought she had responsibility to teach the family caregiver. Therefore, N6 made her effort to involve F6 during P6's discharge instruction (OB7).

Nurse's time availability. Time availability and nursing behaviors were also identified as factors which would affect family participation actions. For example, N6 said: "The walking, like on the weekends, we don't have time always to walk him as often as we want, so the first several times somebody has to assist him. She [F6] did that." Sometimes nurses' behaviors made family members perceive them as too busy, and then they worried about whether their elderly relatives would receive the care according to their preferences. So, the family caregivers would step in and provide care to the patients. For example, describing nurses' help with P1's meals, F1 said:

> In most of the time, I have found when the nurses do come in, they just opened up all the salt package, the sugar package, and just put it on everything. They don't stop to realize that everybody's taste isn't to the point that you like a lot of sweet on things. They [nurses] just want to get the things set up, so they can move to the next patient. So it was done in a hurry, and

> they should do it so the patient's taste would like it, but they don't have the time to do it.

<u>Comparison of the literature on characteristics of nurses to findings of this study</u>. The characteristics of nurses identified in this study were not found in the home caregiving literature. Nurses' personality traits, education level, nurses' role expectations of themselves and of family caregivers, and time availability to the patient were added in the new framework. Of the four variables, two of them, education level and nurses' role expectations of themselves and family caregivers, were mentioned in the family literature on hospital care as demographic variables that might affect family involvement (Collier & Shirms, 1992; Hickey, Lewandowski, 1988, Sharp, 1990). However, nurse's personality trait and nurse's role expectations were not found in the literature. Findings from this study identified the positive attitude of nurses toward family participation, which matched the research findings of Hickey and Lewndowski (1988) and Sharp (1990). However, the nurse's positive attitude towards the participation of "helpful" families, but not toward "unhelpful" families, was not found in the family caregiving literature in the hospital setting. Thus further study is needed to

explore the relationship between nurse attitude and family participation, the quality of family participation from multiple perspectives, and to define the quality of family participation in hospital care.

It was expected that nurses' gender would be important. In this study the four nurse participants were female care providers with an age ranging from 25 to 50 years old. This sample did not include male nurses because there were no male nurses currently available in the three units where sampling occurred. No specific data suggested that there was a difference between younger or older nurses in terms of affecting Family Participation Actions. However, an interesting finding from P7 suggested that patients might prefer older nurses to younger ones to provide their personal care because the older nurse could "get to you and go right on and [personal care did] not seem to bother them a bit. But these younger nurses had little problem with that [personal care]." This maybe related to the older nurse' s longer experience working with elderly patient, or other unidentified personal reasons, which need further exploration in the next study.

Nursing experience includes working with the elderly population and general patient populations. This factor was anticipated to have an effect on family participation because the more experienced nurses might do something different compared to the ones who had less experience working with the elderly population. However, except for the data excerpt mentioned in the previous paragraph about "older and experienced" nurses, no other significant findings related to this variable were found. The variable of nursing history is probably worth further investigation.

Mediating Variables

Patient preference and family worry were identified as the two mediating variables between the antecedent factors and core elements of Family Participation Actions. The core elements refers to the dimensions and processes of Family Participation Actions.

Patient Preferences

Patient Preferences, a mediating variable between the antecedent factors and Family participation Actions seemed to interact with characteristics of patients, characteristics of family caregivers, quality of relationship, characteristics of hospital, and characteristics of nurses in its effect on Family Participation. Both the family caregivers and patients came to the hospital with their own characteristics. Characteristics of the hospital and nurses also existed before the patient was admitted. Patient preference was based on their personal history and current situation, including all the encountered participants, such as family members, health care team, hospital and environment. Patient preference would serve as a mediator to connect the antecedent factors and family participation actions. However, not all of the antecedent factors have to be mediated by the patient preference. Two other paths were either directly connected to family participation actions or through the other mediating variable of Family Worry.

When compared to the home caregiving literature, family and patient preferences factors are placed among antecedent factors in the home caregiving model (Archbold & Stewart, 1988). But in this framework, Patient preferences was placed as a mediating variable between antecedent factors and the core elements because some of the Patient Preferences had not existed prior to the admission. In the present framework, Patient Preferences is based on multiple antecedent variables, not only on the patient's current situation, but also on the family caregivers' situation, hospital and nurses variables, and distance between home and hospital. In addition, Patient Preferences would be readjusted through the feedback loop of family participation, consequences, and antecedent factors.

Family Worry During Hospitalization

This concept served as a mediating variable between the concepts of antecedent factors and family participation actions. For example, F1 valued individualizing a patient's care, but knew that the reality of nursing could not meet her and her husband's expectations. Therefore, she worried about the care the patient received from the nurses and came to stay with the patient, either doing the care herself or making sure the team provided it. As a result, family worry in certain areas may be decreased, but at the same time the role strain from being a family caregiver in the hospital setting may be raised. Some other family caregivers (F4 and F7) trusted the health care team or accepted the reality of nursing care. As a consequence, they felt less worry during the hospitalization. For example, F4 said: "I've not had much worry since he's [his father] been here. I think he's had very good care here. We've been very impressed, honestly, with the doctors and nurses. Their level of concern for our father has been extremely good." Therefore, F4 stated that he felt good about himself by participating in his father's hospital care.

In the home caregiving literature, family role strain from worry is placed among the consequences of caregiving (Archbold & Stewart, 1988). In the framework for the current study, family worry during hospitalization was placed as a mediating variable between the two concepts: antecedent factors and family participation actions. Although it is logical to anticipate that family role strain from worry could exist prior to the patient's admission for some of the home family caregivers, there was no supporting data generated from this sample to verify it, because the interview questions were designed to focus on worry during the hospitalization. Therefore, further study is needed to clarify the relationships between family worry during hospitalization and other concepts.

Core Elements

Introduction

From a role theory perspective, family participation in hospital care is viewed as a process of role adaptation from the family role in the home, which is sometimes as a family caregiver, to a hospital co-caregiver role with the HCT, to the elderly patient. Therefore, this section refers to the type, frequency and processes of the family member's role in participation in the hospital care for elders (Lofland & Lofland, 1984). The type of role refers to what the family caregiver did in the hospital setting. The frequency of role refers to how often they did it. The process of role refers to how they did it. In addition, four social units (practices, encounters, episodes, and informal role) are employed as tools to illustrate the dimensions and the processes of family participation in the hospital care. The three dimensions of Family Participation Actions are Providing Care to Patients, Working Together with HCT, and Taking Care of Self. The processes are Carrying On, Modifying, Starting New, Sharing, and Arranging for care for patient.

The angle of this research study was widened to capture the whole picture of family caregiving, instead of focusing only on one segment or a specific location such as the ICUs or a specific floor. The whole hospital experience was captured from admission to discharge. Further, instead of focusing only on the segment of hospital caregiving experience, the whole continuum picture of long term home caregiving and hospital-to-home transition issues was considered.

Family caregivers come to the hospital because of their link with elderly relatives who are acutely ill. After what is usually a temporary and relatively short stay in the hospital, life and caregiving will continue to go on for the caregivers and their sick relatives.

Although the hospital stay is short, it may have long term effects on the family's life after the hospitalization. Therefore, in order to go though the process together with the sick relatives, the caregivers adjust their caregiving activities by Carrying On, Modifying, Starting New, Sharing, and Arranging Care for the patient as needed in the hospital setting for providing individualized patient care and continuity of their life patterns in the follow three dimensions: _Providing Care to Patients_, _Working Together with HCT_, and _Taking Care of Self_.

Types and Frequency of the Role

The type of role refers to the earlier discussion (Aim #1) of family participation actions. The role of family caregivers in the hospital setting included three dimensions of role actions: (a) _Providing Care to Patents_, (b) _Working Together with HCT_, and (c) _Taking Care of Self_. The frequency of each dimension action was mentioned in the earlier discussion (Aim #1), in terms of the numerous count of data excerpts within each of the categories of family participation actions.

Among the three dimensions, in summary, the dimension of _Providing Care to Patients_ was the most frequently mentioned by the participants (69.8% of data bits), followed by _Working Together with HCT_ (27.7%)

and <u>Taking Care of Self</u> (2.6%). Within the dimension of <u>Providing Care to Patients</u>, the most frequently mentioned category was <u>Attending to Patient's Personal Care</u> (30.2%), followed by <u>Performing Usual Family Practices in the Hospital</u> (17.7%); <u>Providing Passage Between Home and Hospital</u> (15.4%), and <u>Being There</u> (6.4%). Within the sub-category of <u>Attending to Patient's Personal Care</u>, <u>Helping</u> was the most frequently mentioned one (26.4%), followed by <u>Maintaining Linkage</u> (8.7%), and <u>Bringing and Taking</u> (8.7%). Actually, the sub-category of <u>Helping</u> was the single most frequently mentioned overall (26%) in the data. This finding is congruent with the literature on family caregiving literature in both home and hospital settings (Albert, 1991; Archbold & Stewart, 1988; Bull, 1990; Hickey & Lewandowski, 1988; Horowitz, 1985; Laitinen, 1992; Sharp, 1990).

<u>Processes of the Role</u>

The above discussion addressed the role actions that family caregivers performed in hospital, however, the question of how they carried out these role actions may be raised. The following description will answer this question.

Four units of social analysis (Lofland & Lofland, 1984) are used to describe the dimensions and processes of family participation actions. The four units are practices (daily practices), encounters (short interactions), episodes (dramatic events), and informal roles (supplementing the formal roles). Practices, for example, included Carrying On, Modifying and Starting New Family Caregiving. Starting New Caregiving began as an episode and, through several encounters with the health care team, became a practice. An example of informal role included Arranging Care for patients. An example of an encounter included Sharing Family Caregiving with the health care team. In the following section, the four social units of Lofland and Lofland (1984) will be used to organize and describe how the three dimensions and five processes of Family Participation Actions.

Practices. This social unit is conceptualized by Lofland and Lofland (1984) as "the smallest behavioral unit of social setting" that "participants regard as unremarkable, as a normal and undramatic feature of ongoing life" (p.75), but which the researcher "focuses on as having analytic significance" (p. 75). For example, F1 was a 55 year-old wife who had 8 years of home caregiving experience in taking care of her 69 year-old functionally impaired post-stroke husband. Her husband had a history of multiple episodes of hospitalization and this time was admitted to the hospital for emergency gallbladder surgery. When asking the wife about what she did in helping her husband with personal care in the hospital, she said:

> We have a routine that we do at home. And I'm trying to keep that routine going here, too, as far as his showers go, I know the extent he can do things for himself, you know, and things he can't do for himself. So that helps. One thing I've noticed...I think he's still afraid to wash himself down here [surgical incision], so I have to [wash it for him]. But otherwise, he does pretty good in the shower. I wash his back. And because of the chair that he's on, I'll wash his bottom too. But at home, he washes everything but his back himself.

This quote illustrated the two processes of Carrying On (routines) and Modifying Family Caregiving (what caregiver helped wash). Although to the participant, these actions were treated as ordinary everyday "routines," the investigator singled them out as something that had significant analytical value to the study topic, and therefore classified these actions as practices. Carrying on Family Caregiving refers to the actions that family caregivers have established for the patient's routine care at home or have had past experience with the patient in a previous similar hospital admission. In addition, the actions are being continued during the hospital stay.

The second process theme, Modifying Family Caregiving, also a practice, refers to the actions that family caregivers have established for patient's routine care at home and that have to be adapted in order to fit into the patient's recovery course and the hospital setting. Most actions in the dimension of providing care to patients were considered to be practices for the family caregivers in this study.

Episodes. This social unit is described by Lofland and Lofland (1984) as "remarkable and dramatic to the participants, and therefore to the analyst as well" (p. 76). In this study, some of the family participation actions were presented by the family caregivers as remarkable and thus also had analytic value to the investigator. For example, family caregiver #7 was a 65 year-old wife of a 68 year-old husband who was admitted for scheduled surgery of L2-3 laminectomy. When she was asked about the patient's personal care, she told a story:

> On Tuesday night why he didn't get his dinner for a long time, I don't know. Of course they [nurses]

> always check his blood sugar a little bit before dinner time. And they said: your dinner will be coming in. And it must have been an hour, an hour and a half, and he hadn't gotten his dinner. Everybody's getting their dinner, so I didn't know how his got lost...I had mentioned it to two or three different people [health care team]...I mean that irritated me much more than it did him when he didn't get his dinner on time.

Obviously, this event was dramatic to her, and it was recorded by the investigator as an episode of protecting the patient from getting lost in the shuffle of a large institution. This data excerpt was included in the dimension of Working Together with HCT, specifically in the category of making sure the health care team takes care of the patient's needs. This episode involved the process of Arranging Family Caregiving.

Encounters. This social unit is defined by Lofland and Lofland (1984) as "a tiny social system formed when two or more persons are in one another's immediate physical presence and strive to maintain a single focus of mutual involvement" (p. 78). The encounters between the family caregivers and health care team usually happened when the patient was admitted to the hospital or discharged from the hospital, information was exchanged such as answering questions for patients or participating in discharge teaching. For example, family caregiver #4, who was a son of a 87 year-old patient with a medical diagnosis of rectal cancer, said:

> I helped him answer the questions by the admitting office down there. Some of the questions he didn't understand. We use new terminology today that he's not familiar with a lot of terms at his age. And so some of the questions were hard for him to answer. But he can answer if they're maybe rephrased in the right wording for him.

In this case, the family caregiver helped his father to go through the process of admission, which was an encounter involving three people. The fourth process theme, Sharing Family Caregiving, refers to the actions that involve exchanging of information or skills or collaborating with health care team to provide the patient's care. Most actions in the dimension of working together with health care team involved encounters in this study.

Informal Role. Lofland and Lofland (1984) described informal role as one kind of social unit of role. Formal roles are "linked to such notions as 'position', 'office,' and 'occupation'; they are common sensically understood in societies with an abundance of formal organizations and "organizational charts" (p. 79). However, "there commonly exist informal supplements to the formal role structure" (p. 80). Arranging Care for the Patient was considered as an informal role in supplementing formal role structure in providing hospital care for elders. The fifth process theme of Family Participation Actions, Arranging Care For the Patient, refers to the actions that involve safeguarding the patient's care provided by the health care team and managing self and family resources to keep the patient's care up to the family or patient expectations. Making Sure is one aspect of this informal role, for example, an observation from case #1: "The nurse said the patient's blood sugar was little up. 'Do you know if the jello is sugar free?' the [patient's] wife asked the nurse". In enacting this informal role, family caregivers tend to supplement and assist the health care team to assure the quality of patient's care. Most actions in the categories of making sure the health care team takes care of the patient's needs and taking care of self were involved in this informal role in this study.

Although the five processes used by family caregivers are mutually exclusive, a designated family participation may reflect a different process for different family caregivers. For example, a single action of helping the patient to walk after surgery can include such process themes as Starting New Family Caregiving for a new caregiver, or Carrying on Family Caregiving for the caregiver who has experience with hospital care for her relative for the same kind of surgery, or Modifying Family Caregiving for the caregiver who has home care experience for the relative but now the acute illness or the treatment is new to this caregiver. So this action may or may not involve Sharing or Arranging for care activities by others because the family caregivers in this study range in variety of experiences in home care (long, short time, none) and experiences in hospital care (same, different, none) as well as the different combinations for each of the caregivers.

Episodic actions, encounters, and informal roles work together, and may or may not lead to practices. However, another example illustrates more clearly that some of the family participation actions started as episodes and, through several encounters with the health care team, became practices. For example, F1 said: "I started to dress his incision...because the nurses wanted me to learn." In this case, the family caregiver started and learned new family caregiving through encounters with the nurses and performing the action regularly thereafter. Therefore, the third process theme, Starting New Family Caregiving, refers to the actions that are being newly developed in the hospital. Such actions are either added on for experienced family caregivers or started new for family members new to caregiving.

Patterns of Family Participation Actions

The type and frequency of family participation actions were based on the patient's recovery course. Although the recovery course differed for each of the patients, the pattern of family participation was similar within certain types of patients. For example, the patients who had surgery in this study shared a similar pattern of family participation as compared to the rehabilitation patients.

The family participation for the rehabilitation patients (such as case #2, #3) involved more caregiving practices, which included more Carrying On and Modifying Family Caregiving over the hospital stay. There was less Attending to the Patient's Personal Care and more Performing Usual Family Practices in Hospital.

The family participation for surgical patients (such as case #1, #4, #6, #7), especially the patients who required a stay in the critical care unit immediately after surgery, involved more episodic family caregiving, reflected by Starting New Family Caregiving and Sharing caregiving, and gradually switching to the practices of family caregiving. This was especially true when the patient was admitted for surgery and later switched into a rehabilitation program (such as case #1 and #4). Sharing Caregiving, such as exchanging information, always happened in the beginning and the end of the hospitalization process regardless of the reasons for admission.

It was interesting to note that when the patient was in a critical stage, such as immediately after the surgery, the family participation tended to be limited to categories of Being There, Performing Usual Family Practices in Hospital, and Providing Passage Between Home and Hospital. Attending to Patient's Personal Care started only after the patient was moved out of the critical care unit or several days after the surgery because the nurses took care of the patient during the critical period of time. In other words, when the patient's acuity was high, the nurses took care of the patient, family caregivers gradually picked up more responsibility for providing patient's personal care through encounters with the health care team. Finally, during the discharge teaching, some of the family caregivers participated in an encounter with the nurses about the continuity of care.

The findings of the core elements of family participation in hospital care for elders was not found in the current literature. Although some studies indicated that visiting and some instrumental care were signs of participation of family members (Laitinen, 1992; Sharp, 1990; Titler, Welsh, 1992), there were no comprehensive findings about the phenomenon of family participation in the hospital care for elders. The three dimensions and five processes of family participation were the core findings of this study which added to the new framework as well as the body of knowledge in family caregiving.

Consequences

Consequences refers to variables that are the results of family participation in hospital care for elders. Consequences were of two major types: (a) continuity of life patterns (outcomes of patients, outcomes to the relationship characteristics, outcomes of family caregivers), and (b) outcomes of nurses (Table 7).

Table 7

Table 7. Consequences of Family Participation

Variables	Content
Continuity of life patterns	
Outcomes of patients	-Feeling cared for -Feeling calm, relaxed and comfortable -Preventing and caring for patient's Dysfunctional Syndromes -Increased patient's dependence -Making the patient upset -Interfering with the patient's recovery
Quality of relationship	-Meaningful relationships
Outcomes of family caregivers	-Increased preparedness -Decreased worry -Increased role strain from direct care -Feeling good about themselves (rewards)
Outcomes of nurses	-Increased rewards (feeling good) -increased role strain (time demands and frustration) -Decreased workload

Continuity of Life Patterns

Continuity of Life Patterns served as both a purpose and meaning in terms of what was going on with the phenomenon under investigation. Therefore, maintaining continuity of life pattern was singled out as a major consequence of family participation in hospital care for elders. This concept applied to both type of family caregivers: either caregivers with previous caregiving experience or without. Some family caregivers who had previous home caregiving experience desired to continue their life pattern, including continuing their care routines from home to hospital and then from hospital care back to home. For example, F1 had 8 years caregiving experience at home taking care of her physically impaired husband. Her husband was admitted for an unscheduled gallbladder surgery and later transferred to the rehabilitation program for post-stroke. She said: "I take him down there [physical therapy], and watch what they're doing so if I have to help him I know what to do for him." "He's got several shirts that snap. I try to buy ones with snaps, he can snap them" "We have a routine that we do at home, and I'm trying to keep that routine going here" because "I know the extent [to which] he can do things for himself." Therefore, "I just planned to do things for him that he couldn't do for himself." These data excerpts reflected an underlying meaning of Maintaining Continuity of Life Patterns and were good examples of enhancing independence.

Second, some family caregivers who had not had any experience taking care of their sick elderly relatives at home still liked to maintain their usual family practice and to start their caregiving career in the hospital by providing individualized care, and then carried it back to home in order to maintain the continuity of life patterns. For example, family caregiver #7 whose husband was admitted for neurological surgery said: "I just told them [RNs] pretty much his habits and the way he likes things." Either she would provide care to her husband or by herself or let the nurses know so that they would do it for him based on the patient's preference. "I learned a lot of things about treatment and stuff that...the doctors and nurses know. And then about how he would get up and move around." After he was discharged home, F7 tried to "remember everything they [HCT] told me and try to encourage him to do what they said. I noticed he's much more mobile today than yesterday". Corbin and Strauss's chronic illness trajectory framework (Woog, 1992) described family caregivers as one of the three participants along with the patients and health providers to shape the patient's trajectory over the chronic illness course, including any acute illness stage which required hospitalization. Maintaining the Continuity of Life Patterns was an implied meaning of family participation in shaping the patient's illness trajectory during the hospital stay.

Outcomes of Patients

In this study, three benefits were found to the patients as a result of family participation in their hospital care: (a) feeling cared for, (b) feeling calm, relaxed and comfortable, and (c) preventing and caring for patient dysfunctional syndromes.

Feeling cared for. Feeling cared for, caring, and being there all seem to be meaningful to patient and family caregiver. Family participation conveyed meanings of caring to patients. For example, P6 said: "I felt that someone cares, if you need anything without ringing a bill, something like that she would do it..being there made me feel better." P5: "I feel better [when she was there]...just being around someone who cares for you and cares about you." F4 said: "I think that him seeing us there just made him feel like people care." N2 said: "it's helpful not only for the nursing staff, but for the patient to know that his family is there and they care." The common theme shared by the above data excerpts were the underlying meaning of care and being there. Also, it verified the definition of Being There as a basis for family actions and continuity of life patterns during the hospital stay as well as having inherent value itself.

Feeling calm, relaxed and comfortable. As a result of family participation in their hospital care, patients feel calm, relaxed, and comfortable because of family ties and meaning from the relationship. For example, F7 said: "I think he felt more comfortable with me here...Just made him feel better that I was there...if I had said Wednesday night that I can't come because I've got to go to the club, I don't think [he] would have been a happy camper." When her husband, P7, was asked about what he felt about family participation, he said: "To me it feels fine...It's [to have his wife there with him] comfortable and pleasant all the time." Another good example for addressing the relaxing effect would come from F1's statement. She said:

> He [her husband] told me he was happy to get it done with [morning care]. Otherwise, he had to wait, wait, and wait for it. Because when nurses have a lot of patients to take care of, and some

> of the patients were in very bad shape, it takes longer to get things done. So if I am just being there to get him done, it makes him relax.

F1 also provided another example of helping the patient relax based on her observation of the patient's roommate. F1 talked about hearing the roommate comment one day:

> He was very uptight and that he just couldn't relax. Then when his wife would come in to visit, he said all his tension went away. And he said 'just made me feel so good when she comes in, just helps me to relax.'

F1 went on to say:

> I think they should have somebody there. That means a lot to the patient to have someone come in and if they can't stay, at least a couple of hours or more, not just 10 minutes or 5 minutes. If you could stay an hour with the patients that would relax them.

However, how long that family visiting would relax a patient depends on the stage or the type of illness and treatment. For example, P6 would like visitors "to come [only] when it's convenient and leave when you see they are tired." P6 was an patient who received open-heart surgery, therefore, fatigue was a salient consequence of this type of surgery. As a result, his wife, F6, had to call his relatives and make arrangements for other family members to visit, which might not be the same case, for example, with rehabilitation patients. P5 said:

> I'm in favor of people visiting in the hospital. because...it gets to be a long day in there when no one is coming to see you or nothing. Of course, I've been lucky. My wife comes in every day...A lot of them [patients] aren't that lucky. They get there, they get bored and they get out of sorts. If things don't go just to suit them, they take it out on the nurses.

It appeared that there were three mechanisms through which family participation resulted in patients relaxing: (1) the family made patients feel that somebody cared about them, (2) kept them company, and (3) served as a emotional outlet for the patient. Actually, P7 distinguished care received from the nurses and family members. He said: "I think my wife cared for me more than a nurse, it's a job, she [nurse] just did the best she can." Therefore, family participation means a lot to patients, which to some extent, could not be substituted by the nurses.

Preventing and caring for patient dysfunctional syndromes. This variable was evidenced by the data. Dysfunctional syndromes include, but are not limited to, (1) acute confusion; (2) incontinence, (3) nutrition problems, (4) immobility, (5) falls, and (6) sensory deficit. In this study, family presence eased the care for cognitively impaired patients. N2 said:

> When a family member comes in, things tend to go a lot smoother if the patient is cognitively impaired. They usually are very willing to eat and bathe and get dressed for a family member...A lot of them won't eat when we give them the tray. But if the wife or somebody is there, they'll eat it...If they are so cognitively impaired though that they don't know their family, then it doesn't help usually.

The data excerpts verified that family participation has a special meaning to patients though their relationship. If patients can't recognize their family then there is no difference in outcome between the care to the patient provided by nurses or family members because the meaning could not be sensed by these severely cognitively impaired patients. In terms of preventing acute confusion at the hospital, N3 said:

> I think elderly patients are easily confused. You know, especially if you bring somebody that's over maybe 80 [years old] into hospital. If they have any vision problems or any hearing problems, they get disoriented easily. And if you have a family member, then you have somebody that's there a lot of time that can keep repeating to them where they are and why they're here and what's happening. And, it's a familiar voice and it's a voice that they know and trust.

Family caregivers encouraged eating to prevent malnutrition, or family brought in familiar food for the patient who didn't want to eat. Family caregivers encouraged and made sure patients had something to drink. Family caregivers also helped patients to walk after surgery to decrease complications and prevent deconditioning from immobilization. Family caregivers prevented acute confusion by reassuring patients. They took care of confused patients. They changed diapers for the patient, and washed the patient's bottom after the patient had a bowel movement to protect skin from breakdown. They brought in familiar items from home such as a cookie jar, which helped to orient the patient, and personal underwear, which seemed to comfort the patient. They kept the patients company and made patients comfortable by Doing Little Things and provided needed care when the patient desired. They visited patients and Maintained Linkage and their life patterns, as well as giving the patient hope and "motivation to get better" (N1). They provide the health care team with helpful hints about the patients. Decreasing the elderly patients' dysfunctional syndromes during hospitalization was one of the consequences proposed in the preliminary conceptual framework, and some evidence generated from this study supports this initial hypothesis. Among the six patient participants, only one (P1) had a episode of acute confusion after surgery which was considered to be related to a drug reaction and adverse effect from treatment for increased blood potassium level. Another patient had consistent stool incontinence which was an expected outcome of the rectal cancer surgery.

Three types of negative consequences of family participation to patients were reported only by the three nurses who were not matched with the family caregivers and the patients. They were increased patient's dependence ("They [family caregivers] are doing things for the patient that they shouldn't be, such as feeding him when he can feed himself...he gets dependent when he doesn't need to be." N2); making the patient upset ("you can see the patient getting more and more upset if the family member tells old stories and goes through their long list of problems" N3); and interfering with the patient's recovery ("if the family member that's helping is not mentally balanced or has such problems of their own that this current hospitalization overwhelms them, then they need more care than the patient, and they interfere with the patient's smooth recovery" N3).

Comparison of the literature on outcomes of patients to findings of this study. Decreased dysfunctional syndrome rate and increased satisfaction with care were the two benefits anticipated in the preliminary framework. However, the variables were refined to preventing and caring for dysfunctional syndrome, and positive feelings (feeling cared for, relaxed, calm, and comfortable). The label of continuity of life patterns was not found in the caregiving literature for either the home or the hospital setting. However, Langner (1995) mentioned that caregivers at home setting "made every effort to keep their lives as normal as possible" (P.79), which was grouped under the label of "confronting a new reality". Keeping "normal lives" at home is closer to continuity of life patterns in the hospital.

The negative consequences were purely from the nurses' points of view because neither the patients nor the family caregivers reported them. In fact, the nurses who did discuss negative consequences were not talking about any of the patients and families in the sample. The negative consequences seemed directly related to a label of "unhelpful" participation named by the nurses. This phenomenon needs to be further explored in terms of the quality of family participation and evaluations from multiple parties: family caregivers, patients and nurses.

Quality of Relationship

The meaning of understanding between caregiver and patient was identified by family caregiver #6. In response to the question of what difference her participation in her husband's hospital care made to her husband and to her, she said: "[It] made more understanding of each other." When family caregiver #3 was asked if his visitation and participation made any difference to his wife, he said: "Yes, I think so, certainly, we got married 40 years ago...we just tried to see each other [by visiting]." Then the husband came to visit the patient with flowers at the hospital and reassured her about things at home about which she was worrying.

The category of Doing Enjoyable Activities has to do with sustaining the relationship between the family caregivers and the patients. Not only did the family caregiver initiate the enjoyable activities, but the patient also did the same thing for the family caregiver to maintaining their life patterns. For example, the P1 invited his wife to go out for dinner in celebration of her birthday.

Comparison of the literature on outcomes of relationship characteristics to the findings of this study. The outcomes of family relationship characteristics was added in the new framework. Mutuality is identified as both an antecedent and outcome variable by Archbold and Stewart (1988) in their Family Caregiving Model. The findings of this study on the outcome to characteristics of relationship among the caregiver and the patient supported their findings. Family caregivers who participated in the elders' hospital care conveyed the meaning of caring to each other and sustained their relationship.

Outcomes of Family Caregivers

The positive consequences of family participation to the family caregiver were identified by the participants as feeling more (a) prepared ("I take him down there [physical therapy], and watch what they are doing so if I have to help him I know what to do for him." F1), and (b) assured ("I felt more assured that he was getting the care he needed" F1), (c) knowing what's going on ("I liked to be there and know what's going on." F7), (d) feeling good about themselves ("It's nice to be able to take care of him and help him as best as I can. I guess there's some satisfaction in just knowing that I was there to help." F4; and "I was enjoying doing it, small things [for him]." F6). The family caregivers feel good about themselves because they were being helpful.

The role strain from being a family caregiver to an elderly patient in the hospital was apparent implicitly. However, the role strain from worry about the patient's condition was clearly reported by F6 about her husband's condition after his open-heart surgery, especially when he was in the CCU. For example she said: "The biggest worry was if he was stable." Also, the nurse #6, who was taking care of this patient, said: "His urine output once dropped off, she [F6] was very worried about that...she was at the motor-home during the night and she couldn't sleep." The role strain from direct care was not mentioned by the family participants. However, N1 described family caregivers' fatigue and lack of self-care, such as

"They [family caregivers] are very dedicated most of the time. They're usually here at the crack of dawn. They come in at 6:00 and they don't go home until the day is over. So, they are usually tired." One interpretation of such data is that family caregivers increase their emotional and physical stain as a result of continuing to provide care in the hospital.

The findings of increasing family's caregiving skills and facilitating transition to the home environment by participating in the care matched the existing literature (Collier & Shirm, 1992). However, the other findings were not found in the current literature, such as felt more assured, knowing what was going on and felt good about themselves as a result of participating in the hospital care for elders. Compared to concepts of caregiver strain and burden in the home, which has been extensively studied, caregiver role strain was not explicitly discussed in this study, mainly because of the way that the questions were asked and designed. When family caregivers were asked what differences their participation made to themselves, most of them reported positive consequences instead of negative ones. Perhaps they did not realize that negative consequences were also covered under this question, or they did not feel strain because the participation was voluntary and they might select participation at the level they felt comfortable, or they were using denial as a coping mechanism. Therefore, the negative consequences of participation were not salient to them when compared to the home caregiving literature. Definitely, further research needs to be focused on this area.

<u>Outcomes of Nurses</u>

The positive consequences to nurses of family participation were reported by the participants as decreased nurse work load. The family caregivers reported possible benefits to nurses by their participation. For example, family caregiver #6 said: "Possibly they [RNs] didn't spend that much time with him because I was there to help." Also, family caregiver #4 reported: "I am sure that it probably helped the nurses a great deal. When we were there, we wouldn't have to rely on their helping him quite so much."

The nurses reported benefits in general in terms of helpfulness of family participation ("In the vast majority of patients it's very helpful to have the family participating in the care...and it's often a help to the nurse" N3). They also described specific situations in which family participation was helpful, for example, N6 described a situation in which the matched family caregiver was very helpful. She said: "The walking, like on the weekends, we don't have time always to walk him as often as we want. The first several times [after surgery] somebody has to assist him. She did that." In addition, one of the nurses (N1) reported her feelings: "It always makes me feel very good when I see a family participating in their loved one's care. I am from a family that is very supportive of each other and it always makes me feel that that's a well functioning family." Compared to the literature, nurse's job satisfaction included in the preliminary framework was not reported by the nurse participants in this study, perhaps because of the small sample or the way the questions were worded.

The negative consequences of family participation for nurses included frustration, and time demands. It was interesting to note that only the nurses who were not matched to specific families referred to two types of participation, therefore, two different kinds of consequences. The positive consequences always related to the "helpful" participation. For example, N2 described families as "wanted to learn how to care for their elderly patient, or care for them." In contrast, the most negative consequences were related to "unhelpful" participation (N2), or "dysfunctional" participation (N1). For example, N2 said: "And others are only there to make sure that you're caring for them appropriately. That type of participation can be very stressful." N2 was the only one to describe the family Making Sure as unhelpful and therefore stressful to her. Other nurses didn't mention that. Instead they focused on the patient's outcomes, such as increased dependence or patient recovery. N2 had less care experience and was the youngest of the nurse participants, which may contribute to this opinion. Questions about the consequences of family participation to nurses were not asked of patient participants in this study.

It has been reported in the literature that the family member's anxiety would affect patients in the CCU (Frederickson, 1989; Titler, Walsh, 1992), and also affect nurses as an extra stressor (Hickey, Lewandowski, 1988; Michaels, 1971). However, hospital nurses need to work on reducing the family's anxiety and meet the family's needs as a sign of good nursing care--family centered nursing care (Collier, Schirm, 1992; Hickey, Lewandoski, 1988; Titler and Walsh, 1992). In family centered nursing care, the patients should be viewed as an extension of some family unit rather than family as an extension of the patient (Daley, 1984). However, the reality is that "nurse-family interactions have been described as limited, stressful, and less than satisfactory" (Halm, 1990, p.63). The finding of this study that nurses experienced stressful feelings related to family participation referred only towards the "unhelpful" family, may direct future research exploring nursing interventions for family participation in hospital care for elders.

The consequence to the hospital, as specified in the preliminary framework was not clearly reported by the participants. For example, in response to a question of "what difference do you think your participation made to the hospital?", F4 said: "I guess probably, ultimately it [family help with caregiving] would [help]. If you help the nurses and the doctors, it would help the hospital, too. So I would think that it would help the hospital." Originally, shortening the hospital stay by decreasing dysfunctional syndromes was proposed. In this sample, the length of stay for the six patients was 27.8 days. Among them, the average of length of stay of the four patients who were admitted to unit #1, was 36.3 days (longer than the average length of stay of unit #1, which is 2-3 weeks for rehabilitation). The average of length of stay of the two patients, who were admitted to units #2 and #3, was 11 days (longer than the units' average length of stay of 2.8 to 3.2 days). It was not clear whether family participation in hospital care for elders related to length of stay for these patients, however, due to the complex nature of the influencing variables on length of patient stay, further study is needed in exploring the consequences of family participation in hospital care for elders to the hospital.

In summary, the relationships among the antecedent factors, mediating variables, core elements, and consequences were described in this section. The conceptual framework of family participation in hospital care for elders provided the conceptual foundation for measures of family participation, patient preferences, and family worry.

Aim #3: Develop Possible Ways to Measure the Concepts

Introduction

Possible ways to measure the concepts were identified based on the data generated from this study. The potential items were generated from the data excerpts of the three major concepts: family participation actions, family worry, and patient preferences (see Appendices L, M and N). The scales development and evaluation will be completed in the next phase of this program of research. Based on the findings of this study, various data collection methods and data sources would be considered in planning the next study.

Methods: Self-report vs Observation

Self-report methods will be selected based on the subjective nature of preferences and worry. Self-report methods also will be selected for measuring the concept of Family Participation Actions, although the dimensions of the Family Participation actions were generated from both interviewing and participant observation in this dissertation.

The majority (86%) of the data bits were generated from interviewing methods and only 14% of the data bites were generated from the observation method. In addition, the 14% of data bits generated from the observation method were covered by the 86% of the data bits. In another words, observations did not lead to any additional category of family participation actions beyond categories based on the interview data. The only difference between the data bits generated from the two methods was that the observation data provided more detailed information than the interview data did. For example, in responding to an interview question, F6 said she learned how to take care of her husband from the nurse #6 during the discharge teaching, but she did not provide the detailed information on how N6 did it in terms of Exchanging Data From HCT to Family. However, the information gathered from observation #6 revealed a detailed process of how and what the nurse did during the discharge teaching including both the verbal and nonverbal interactions among the family caregiver #6, patient #6, and nurse #6. In this study, the participant observation served to add more detail that was used in the qualitative data analysis for the purpose of describing the process of family participation in the hospital care for elders. In other words, using the participant observation methods in addition to the interviews was helpful to understand the process of family participation, but was not essential for identifying the broad dimensions of Family Participation Actions. Therefore, the data collection method depends on the purpose of the study.

Data Sources: Multiple vs Single Source

A single data source will be selected based on the subjective nature of preferences and worry. Therefore, the family worry scale will be distributed only to the family caregivers, whereas patient preferences scale will be distributed to the patient participants only.

Family caregivers will be selected as a single source for measuring the concept of Family Participation Actions based on the findings of this study. As a result of this study, 45% of the data bits were generated from the family participants, 21% from the patient participants, 20% from the nurse participants, and 14% from the participant observations. Although only less than half (45%) of overall data bits were generated from the family caregiver participants, they covered all of the dimensions and categories of family participation actions. The remaining 55% of the data bits supplemented the family caregivers' data bits, but did not add any additional category to Family Participation Actions. Based on this study's findings, one might consider using the three-way matched cases (patient-family-nurse) to obtain a broader spectrum of Family Participation Actions. However, limitations of multiple sources needs to be considered. It was more difficult to find three-person matched cases in the clinical settings, compared to recruiting only the patient-family dyads.

This finding was partially supported by the literature. Haim and Tilter (1990) examined visiting practice in CCU settings by gathering information from four data sources: patients, family members, nurses and physicians. They did not report whether the data sources were matched or not. It was appropriate to use such samples because the purpose of their study was to examine the attitude and preferences of the participants on family visiting. In addition, they also examined the participants' beliefs on the importance of family role during their visiting at the CCU. Family caregiving tasks generated from family members were only part of the family role tasks generated from the participants. For example, reading mail was reported by patients and some treatment related care was mentioned by nurses, but were not reported by the family participants. It was not clear whether the family role tasks generated by the participants were actually performed by the family visitors, or they thought that would be important roles for the family to play during their visit. However, results of the Halm and Tilter (1990) study support the findings of this study that the family caregivers were the main data sources in examining the Family Participation Actions.

In the next study, some validation process will be added along with the measure development. For example, ask for family's opinions about their purpose or intent, why they did such, what they hope to get from participation on specific actions. This will strengthen and verify the current findings of the purposeful family participation actions.

In summary, two important decisions on the methodological issues for the next study were discussed in this section. This dissertation not only provided a conceptual foundation for the measures' development, but also provided rationales for selecting research methods for the next study.

CHAPTER V

IMPLICATIONS AND CONCLUSION

Introduction

This chapter includes discussion of the following: (a) summary of important findings; (b) implications for nursing practice; (b) implications for nursing theory and research; (d) strengths and limitations of the study and method; and (e) conclusion.

Summary of Important Findings

Three important findings of this study were (1) core elements-the three dimensions (providing care to patient, working together with the HCT, and taking care of self) and five processes (Carrying On, Modifying, Starting New, Sharing, and Arranging Care for the patient); (2) the conceptual framework of family participation in hospital care for elders; and (3) possible ideas for a future methodological study in the investigator's research program. The findings of this study indicated directions for future study and have implications for theory development, future research, and nursing practice.

Perhaps the most significant finding of the study was that there were few differences in the family caregiving experience in the home and the hospital setting, especially when comparing family participation actions at the pre-discharge stage with family caregiving in the home setting. It was also surprising to discover the "hidden" Family Participation Actions (wide variety and great amounts) in the hospital setting when compared to the limited existing literature regarding family participation for elderly patients in the hospital setting. As suggested by Collier and Schirm (1992), there is an "urgent need to broaden the conception of the family role in the acute care setting and to build a better bridge to the family who manages illness care in the home" (p.56). The findings of this study showed that the meaning of continuity of life patterns was a major consequence of family participation in hospital care for elderly patients. Consistent with Langner's (1995) finding that family caregivers make "every effort to keep their lives as normal as possible" "from the beginning of the elder's illness" (p.79), the result concerning continuity of life pattern in the hospital becomes more salient as the purpose for family participation in the hospital care for elders.

The most practical finding of this study related to the strategies of communication between the family caregivers and nurses in terms of sharing the caregiving. The importance of communication is supported by the literature on quality of nursing care including family-centered care, as well as preparing family caregivers for caregiving in the home after hospital discharge (Collier & Schirm, 1992; Nolan & Grant, 1989). Sharing caregiving was one of the five process themes of family participation and also was one of the three dimensions of Working Together with HCT. Communication between the family and HCT is a basis for exchanging information, collaborating in the patient's personal care and participating in the patient's health care regimens as well as making sure the HCT is taking care of the patient's needs.

Implication For Practices

The findings of this study has implications for nursing interventions related to family participation in hospital care for elders. Nursing interventions that enhance family participation were originally proposed as a result of the preliminary study. However, the findings of this study indicated that enhancing, as a solitary approach, is an inappropriate intervention because of the voluntory nature and complexity of family participation. A more complete package of strategies of nursing interventions was suggested by the findings of this study. The nursing interventions are: (1) Encouraging family members in their participation in the categories of Being There, Performing Usual Family Practices in the Hospital, and Providing Passage between home and hospital; (2) Facilitating family caregivers in Attending Patient's Personal Care; (3) Sharing knowledge by communication with family caregivers and using teaching and learning as a tool for Exchanging Information, Collaborating with HCT to Provide Personal Care, and Participating in Therapeutic Health Care Regimens; (4) Promoting understanding between family caregivers and nurses in support of the category of Making Sure HCT Takes Care of Patient's Needs to decrease both family worry and nurse stress; and (5) Promoting or Taking care of family members in support of the category of taking care of self. Overall, communication is a key to implementing the intervention principles. Further refined clinical protocols will be developed, based on the findings of the study.

Although making sure was in the dimension of working Together with HCT, it had a different flavor when compared to the other three categories under the same dimension. Making sure the HCT takes care of the patient's needs may decrease family worry, but it also may increase nurses' stress and produce tension between the family and the nurses. The key intervention here is for the family caregiver and nurse to communicate and understand each other's expectations and underlying meanings in order to establish a trusting relationship and, in turn, to decrease family worry and nurses stress. Actually, N3 gave a good example of how to establish a trusting relationship. She said:

> What I try to do is meet as many of their needs as I can, and take a little time initially to talk to them and let them know that I am their friend and I understand how they're feeling. Because then they feel like I'm on their side and they don't have to continue to struggle for my attention...I think that if you can try and let them [family members] know that you understand something of what they're going through, then they can relax and then they will trust you.

Specific interventions can be developed based on the strategies of communication. For example, F7 said: "If there was something I should know or should be doing that I wasn't doing or didn't know, they [RNs] should tell me." This supported the format of the original clinical protocols, in which nurses tell family members what the patient's needs are, what nurses are going to do, and what the family can do. Then, nurses can present choices to family caregivers about various possible types of participation and explain that the family can participate at any level where they feel comfortable. The level of participation can change during the patient's hospitalization. Nurses can discuss any stress and worry issues with the family and clarify their questions. Nurses can let family members know they and their input are valued by the HCT. Most important, nurses can begin establishing a relationship of trust from the very beginning during the admission process.

Hospital environmental modification may need to be considered in family participation. An environment needs to be created in such way that family caregivers feel welcomed and comfortable to participat in the care. In addition, a family-nurse exchange mail box should be available in each patient's room and the family rest room to facilitate the information exchange between family and nurses. Primary nurses should open the box once a day and communicate with family caregivers regarding the input. Communication as a key intervention strategy in family participation matches the findings of Collier and Schirm's (1992) study. A teaching program is needed to train nurses how to provide family-centered nursing care to elderly patents and their families.

The findings of this study showed that family participation in the hospital care for elders not only benefits the families and patients in the short term (such as patients' feeling of being cared for, preventing and caring for patients' dysfunctional syndrome, decreased family worry about patients' health status and care), but also benefits families and patients in the long term way (such as family preparedness for home care after discharge). In other words, family caregiving in the hospital has both its own values (family-centered nursing care) and long-term home care implications. Because family caregiving usually increases as the patient returns home, it is important to understand the phenomenon of family participation in the hospital care for elders and to find a way to facilitate participation. As Collier and Shirm (1992) pointed out: "there is an urgent need to broaden the conception of the family role in the acute care setting and to build a better bridge to the family who manages illness care in the home" (p. 56). Based on Strauss and Corbin's (1988) chronic trajectory theory, the family is central to chronic illness management.

Implications for Theory and Research

The findings of this study indicate that family participation in hospital care for elders is a complicated phenomenon. This dissertation study was only the first step of a research program which aims to understand the phenomenon of family participation in hospital care for elders. Therefore, the study served as a preliminary piece of work for adapting the Family Caregivng Model (Archbold & Stewart, 1988) from home to hospital setting. The findings of this study indicated that there were few differences in the nature of family caregiving between these two settings, and few differences existed concerning the major concepts and their relationships. The most salient difference in the hospital setting was more sharing and communication between nurses and family caregivers on a daily basis, due to the patient's acute illness. In terms of relationships among concepts, a few refinements were made, such as considering family worry and patient preferences as mediating variables between antecedent factors and the core elements instead of considering them as antecedent (patient preferences) and consequence (family worry) variables (Archbold and Stewart, 1988). Family worry and patient preferences were considered mediating variables because they depended on some of the factors that existed prior to the patient's admission, such as characteristics of nurses and hospitals.

Recommendations to strengthen the research in completing the model adaptation are: (1) further development of the content categories of family participation actions, family worry, and patient preferences by focusing on the less developed categories as a result of this study; (2) further development of the emerging concepts, such as patient worry and role expectations; (3) a replication study focusing on minority populations to explore the different values related to family participation in the hospital setting; and (4) a longitudinal study to track long term outcomes of the patient and family, especially because family preparedness was indicated by this study as one of the consequences of family participation. The design of the longitudinal study would be based, in part, on Corbin and Strauss' chronic illness trajectory theory, which assumes that family caregivers continue shaping the patient's trajectory even when the patient is hospitalized. Actually, the finding of this study in terms of continuity of life patterns is congruent with Corbin and Strauss's chronic illness trajectory theory.

In the investigator's program of research on family participation in hospital care for elders, this study completed Phase 1. The next phase will focus on scale development and evaluation based on the findings of this study. Thus this study provided a building block for future research.

Strengths and Limitations

Strengths

This study filled some existing gaps in the literature and indicated directions for future research in the area of family caregiving in hospital as well as the transitional stage from hospital to home. In existing literature on family caregiving, the majority of home caregiving literature has focused on family caregiving burden. Less literature has examined what family caregivers do in terms of their role. Further, the underlying meaning of what is going on in what caregivers do has not been a focus, except studies of Bowers (1988), Hasselkus (1988), and Langner (1995). This study anticipated meaning or what's going on by using a qualitative design. As a result, continuity of life patterns and values of patients, family caregivers, and nurses were found. In addition, Lofland and Lofland's analytical approach in social settings was used effectively to enable this finding.

Limited studies were found addressing issues on family caregiving in the transitional stage from hospital to home (Bull, 1990; Oberst & James, 1985;

Obserst & Scott 1988). These studies focused on follow up care and addressed some discharge planning issues for clinicians. However, there was no connection made between how family participation in hospital care affected families' follow up care at home, family preparedness, and patient outcomes. This dissertation study started to fill the existing gaps by looking into the outcome of family preparedness for follow-up home care.

In the hospital setting, the majority of hospital caregiving literature focused on family needs, often as viewed from the nurses' perspective, and was limited to critical care units. This study asked a broader angle and examined not only a segment of hospital care, but also the whole hospital experience, as well as the long term picture of life experience at home. Therefore, hospitalization is viewed as an episode in the long term practice of family life and caregiving. Family caregivers' purpose was to maintain continuity of their life pattern in the hospital by using the five process themes and the three dimensions of Family Participation Actions. This study did not focus on what family needs were, but on what family members did. It did not focus on what the nurse did to meet family members' needs, but rather on what family members did in the hospital.

Family caregivers provided care to patients, worked together with HCT, and took care of themselves.

Another strength of this study was the inclusion of family participation from admission to discharge. This shifted the approach from a traditional "near sighted" view of one segment of critical care settings, to a "broader sighted" view of family participation in the hospital as an episode of their long-term practice (either as a family caregiver or as a family member). The strength of this study design was using the multiple data sources and methods to explore the concepts and their relationships.

Limitations

One limitation of this study is the small sample, which limited the generalizability. Limited ethnic diversity was also a shortcoming. A future study may need to include old-old hospitalized patients to compare difference family participation with the patients who are in the young-old age group.

Also, more explicit evidence needs to be obtained in the next study on such variables as the rates of dysfunctional syndromes in elderly inpatients. Other methods, such as chart review, may be needed to obtain such information. In addition, patient's recovery course is a possible variable to be included in future studies.

Another limitation of this study was the exclusion of the patients whose families did not visit in hospital. Some of these families may have done "long-distance caregiving" by telephone and other means. This is another area for further exploration.

In addition, family participation provided more positive consequences than negative ones in the interviews of this study. One possible explanation is a power issue. Perhaps denial as an coping mechanism also contributed. For example, when a wife (F1) was asked about worry during her husband's hospital stay, she said no worry, nurses would take good care of him during the night. However, when she was asked about the similar question after her husband was discharged home, she said she worried about her husband during the night when she was not at his bedside. Therefore, when interviewing patients and family caregivers regarding the quality of nursing care, the timing of the interview may influence their response. Because caregivers may perceive their positions as vulnerable while the care receipients were in the hospital, their evaluation of the quality of nursing care may differ depending on whether they are interviewed during the hospitalization or after the hospital stay.

Nurses provided some important data related to worry. However, because some of the nurses were not matched with the patients and their family caregivers, they provided some unsure statement from their experience of what family members would worry about. In strengthen this study, the researcher would have asked the nurse to give an example from her experience to illustrate what she mentioned about family worry, or asked her what kind of objective signs she saw that suggested family caregivers were worried about things, such as the technical tasks.

Conclusions

The family role in hospital care for elders is not a well established one in American culture because nurses are the formal caregivers in those settings. However, in the future, due to the emerging aging phenomenon, hospital restructuring, shortening of hospital stay, and health care trends for shifting from hospital to home, family caregiver preparedness for such changes becomes crucial for maintaining long term family caregiving at home. The focus of research and practice has began to shift from the older person alone to the family system. The number of families providing long-term care to older relatives is expected to increase substantially in the next few decades. In this conceptual framework, family participation in the hospital care for elders was considered as an episode in the long term practice of family life and caregiving at home.

In the future, the highly technical aspects of hospital care will increase, but the patient's hospital stay will be shorter. As a result, current hospital care will become home care in the future. Evidence from this study indicated that family participation in hospital care would help the family to be more prepared for follow up care at home. In other words, family participation in hospital care for elders had both short term outcomes of family centered nursing care and long term outcomes for follow up home care. Jillings (1981) pointed out that "the development of tools for systematic assessment and care planning can facilitate the extension and allow the nurse to become more proficient in the care of the individual, not as an isolated patient, but as a member of a large group---his family" (p. 31). Therefore, understanding the phenomenon of family participation and developing a systematic assessment tool for family participation in the hospital care for elders is timely and much needed.

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APPENDIX A

Protocol to Enhance Family Involovment in Elderly Patient Care In An Acute Hospital Setting

Contents:

DRAFT OF PAMPHLET FOR FAMILY MEMBERS

NURSE-FAMILY CARE IN REDUCING ELDERLY DYSFUNCTIONAL SYNDROME

INTRODUCTION

Over 40% of all United States hospital beds are occupied by adults over 65, and each year the acuity level of elderly patient raises. Available evidence suggests that 20-40% of patients aged 65 or older suffer functional deterioration during hospitalization for an acute illness. We call this phenomenon the dysfunctional syndrome, which we define as a decline in functioning and quality of life that occurs during therapy of an acute illness or acute exacerbations of chronic illness. The dysfunctional syndrome includes the following problems: acute confusion, incontinence, nutrition problems, skin breakdown, injury, and etc. For many elderly patients, the dysfunctional syndrome probably prolongs hospital stays, decreases quality of life, and leads to institutionalization.

Although nurses are the major cargivers in hospital care, family has an unique role to play which can not be substitute by nurses. Appropriate family involvement in elderly care can help patient's in reducing the dysfunctional syndrome and increasing the satisfactions of families and nurses in patient's care. Three types of family involvement are commonly seen in the Geriatric unit based on how much time and visits that family made for the patients, such as high involvement (7 days per week and 8 hours a day), medium involvement (2-4 times per week and 3-4 hours per visit), or little involvement (0-1 times per week and 1-2 hours per visit). No matter how much you involved in the patient's care, you always can make your visit efficient and improve the patient's care in referring to the protocol. Your care is special for your sick family member, and are most valued and appreciated by nursing staff. let us work together and be a partner team in the care for your elderly sick family members.

DRAFT OF ASSESSMENTR PROTOCOL TO ENHANCE FAMILY PARTICIPATION

ASSESSMENT PROTOCOL

PATIENT
- -Age
- -Gender
- -Illness condition
- -Allergies
- -Reason for admission
- -Physical assessment
  - nutrition
  - elimination: bowel & urinary
  - skin
  - mobility
  - physiological comfort: pain, sleep
- -Psycho/social comfort
  - cognitive impairment
  - anxious
  - impairment communication
  - substance abuse
  - grieving
  - powerlessness
- -Safety-Environmental/physiological
  - at risk for fall
  - at risk for infection
  - at risk for respiratory dysfunction
  - at risk for circulatory dysfunction

FAMILY

-Person to contact_____
-Age______
-Gender_____
-Relationship______
-Phone_____
-Address___________
-Occupation__________Work per week_______ day/evening
-Transportation__________
-Health status_________
-Quality of relationship with patient_________
-Social support system__________
-Plan to visit: times per week__________
hours per visit__________
-Things you concern the most_________________

-Prior cargiving experience ___________

Please describe your sick family members "usual" behaviors, patterns, and preferences during daily activities in home care from your knowledge:

Kind of food: like____________________ dislike__________
Kind of liquid: like_____________dislike_______________
Taking medicine with ____________(kind of liquid)
Taking medicine time______________________________
Eating patterns____________________________________
Elimination patterns: urinary______________
stool________________
Activity patterns__________________________
Cues for better communication_________________
Tips for managing behavior problems_____________
Things that patient like to do__________________
Things does not like to do______________________
Things can make patient calm______________________
happy_____________________
upset_____________________

Anything you would like to add____________________

DRAFT OF INTERVENTION PROTOCOL

INTERVENTION PROTOCOL

- -Orientation to hospital environment
  - To patient
    - call light
    - operation of bed and siderails
    - smoking policy
    - use of phone
    - bathroom
    - meal schedule
  - To family
    - visiting hours
    - phone number for the bedside and nursing station
    - family bathroom and cafeteria
    - parking information
    - unit name and direction
    - welcome family to visit
    - encourage family to ask questions
    - encourage family and patient to fill in the evaluation questionnaire for quality of care and put into the box in the nursing station
    - if you have further questions or more tips and concerns about the patient's care, please write a note and put it in family-nursing communication box (on the wall of each patient's room), and nurses will open it once a day

-Nurse-family care for patient's care in reducing elderly dysfunctional syndrome (see handout--nurse-family protocol from A to E, and go though with family)

According to the intervention protocol, family may contact with nurse when come in visit, and may choose one or more problems to work with in providing the care for the sick family member based on the his or her current condition and the family's wish. Some family members may choose not to participate. your decision will be respected by nursing staff no matter what you have made.

DRAFT OF INTERVENTION PROTOCOL

NURSE-FAMILY CARE PROTOCOL
A. URINARY INCONTINENCE

Urinary incontinence is a condition in which involuntary losses of urine occur, causing a social or hygienic problem. Recent survey shows that the prevalence is about two in ten among elderly who are institutionalized.

A (1) Basic Guidelines

1. Patients with evidence of confusion will be assessed for possible causative within 24 hours, which includes physiological factors, such as urinary tract infection, benign prostatic hypertrophy, weakened pelvic floor, fecal impaction; use of medications, such as diuretics; psychosocial factors, such as patient's mental status changes and lack of assistance when needed; and environmental factors, such as toilet location.
2. Correct or minimize the above factors
3. Maintain fluids at 1200cc, avoid caffeine. Attempt to increase fluids to 1500cc if not contraindicated, and limited fluids intake in the evening after 8pm.
4. Follow a toileting schedule. Begin with schedule of early morning, 20 minutes after meals and before bed (encourage patients to attempt to void even if no urge). Record episodes of incontinence, plan a schedule based on the patients pattern of incontinence.
5. Perform Kegel exercises. Kegels can be described as tightening the buttocks together. Repeat these exercises 10 times TID
6. Identify and record the patients need for caregiver assistance or assistive devices such as a bedside commode. Avoid diapers if possible.
7. Locate toilets close to patient areas, provide privacy and adequate light, clothing that facilitate self-care. Answer the light on time when patient needs assistance for toileting.

Sample Schedule

Time	Hydration	Exercise	Activities
0800	120cc	Kegel 10X	assist to drink and toilet
1000	240cc		offer opportunity to void
1200	360cc	Kegel 10X	offer fluids voiding opportunity
1400	360cc		offer fluids voiding opportunity
1700	360cc		offer fluids voiding opportunity
2000	120cc stop fluids	Kegel 10X	offer fluids voiding opportunity
2400			offer voiding opportunity
0600			offer voiding opportunity

A (2) Mutual Contract In Nurse-Family Care

1. The primary nurse contacts with the family and invites family to make following decisions:

(1) In your opinion, how relevant is this problem in the patient's care?

not relevant______________
some relevant______________
very relevant____________

(2) Would you like to participate the care of this problem?
Yes___________ No_________
If your answer is No, please skip (3).

(3) Which area(s) of patient's care would you like to participate?

a. Teaching-learning activities__________
  -toileting schedule
  -Kegel exercises
b. Cargiving activities_________
  -identify underline factors
  -maintain fluids intake
  -establish and follow the toliet schedule
  -identify and record the patients need for cargiver assistance
  -assist patient in toileting if needed
c. Emotional support___________
  -positive assurance for patient's performance
  -touch, eye contact, verbal or written notes for emotional support
  -encourage for patient's self-care

(4) Anything else do you like to add for better care of your sick family member for his/her urinary incontinence?
____

2. Your decisions are well respected by the nursing staff no matter what you made. please specify your reasons for not being able to visit the patient or participate in the care_________________________
____

Please list how can nurses be most helpful to you in your situation
____
____

NURSE-FAMILY CARE PROTOCOL
B. CONFUSION

Cognitive deficits are not a normal part of aging. Acute changes in cognitive function constitute an emergency in geriatric patients. Confusion may be acute and reversible. Even patients with dementia may experience acute confusion states during hospitalization. Confusion is viewed as maladaptive behavior which occurs as a consequence of alterations in the individual's internal and/or external environment. The reported incidence of confusion among hospitalized, elderly patients was from 5% to 61%. The patients with surgery and/or hip fractures have high percentage with confusion.

B (1) Basic Guideline

1. Patients with evidence of confusion will be evaluated in daily for possible causative factors including medications; physical actors, such as impaired mobility, impaired mental status, and sensory deficit; environmental factors, such as changes in sounds, lights, or social contacts, and use of restrain.

2. Assess mental status q2h & intervention.

3. Warmly greet patient at eye level with handshake, touch on shoulder or hand. Integrate the reality information about person, place, time during the care.

4. Communication patterns will be repetitive using simple words and gestures.

5. Daily patient care routines will consistent as much as possible.

6. Assess usual time, amount & type of TV, radio, music, & religious services enjoyed by patient, and daily routine habits, such as timing and method of bathing, oral care, activity & rest periods. Provide interventions using above information.

7. Arrange hearing aid/eyeglasses in use/accessible to patient

8. Monitor environment, such as room lighting appropriate to time of day, activity, & patient preference, and window blinds raised in am, & closed in evening.

9. Ask patient about placement of personal items in room at least 1x, and encourage family to bring in personal possessions, own slippers, bathrobe, pictures and place them where can be seen by patient.

10. Phone family/friends for patient to help orient & calm patient, or read letter to patient when patient bored or anxious and family is not available.

11. Change position q2 hours and prn

B (2) Mutual Contract In Nursing-Family Care

1. The primary nurse contacts the family and invites families to make following decisions:

(1) In your opinion, how relevant is this problem in patient's care?

not relevant________
some relevant____________
very relevant_______

(2) Would you like to participate the care of this problem?

Yes_________ No________
If your answer is No, please skip #(3).

(3) In which area(s) of the patient's care would you like to participate?

a. Teaching-learning activities__________
   - offer information of patient's daily routine habits

b. Cargiving activities___________
   - identify risk factors
   - Communication pattern
   - monitor environment
   - bring in patient's familiar items

c. Emotional support________
   - talk with the patient even he is confused
   - Touch, holding hands, eye contact, verbal or written notes for emotional support
   - continuing usual pattern of interaction with the patient and family traditions, such as birthday or anniversary celebrations

(4) Anything else do you like to add for better care of your sick family member in the hospital?

2. Your decisions are well respected by the nursing staff no matter what you have made. Please specify your reason for not being able to visit the patient or participate in the care_____________________

Please list how can nurses be most helpful in your situation____

NURSE-FAMILY CARE PROTOCOL
C. NUTRITION

Good nutrition has been identified as a vital component of health care for hospitalized elderly patients. Malnutrition, widespread among the elderly places them at increased risk for infection, anemia, dehydration, electrolyte imbalance and other disease. Risk factors of poor nutritional status include the presence of various acute or chronic diseases and conditions, inadequate or inappropriate food intake, poverty, dependency/ disability, and chronic medication use.

C (1) Basic Guidelines

1. Nutritional screening on admission by nursing to identify risk factors of resent weitht loss (>10 lbs. in 3 months or serum albumen levels below 3.5 mg./dl).

2. If nutrition screen indicates pitnents at risk for malnutrition, wight loss or loss albumin, initiate dietician consult.

3. Assess patients' usual food intake pattern and preferences of food.

4. Consume a nutritionally-balanced diet including appropriate amounts of 4 basic food groups, i.e. milk, meat or other protein, fruit-vegetable, starches/grains, and fiber

5. Patients will take greater than 1200 kilocalores daily and a minimum of 2 grams of sodium unless contraindicated by medical condition.

6. Monitor and maintain admission weight (except for diuresis).

7. Offer a variety of nutritional snacks to patients over a twenty-four hour period based on patient preference and per hospital routines.

8. Request patients to perform oral care before meals. Elderly patients as part of the normal aging process loose taste buds. Providing oral care before meals enhances taste as well as stimulating digestive juices. Soft toothbrushes and dilute mouth wash should be used. Dentures should be cleaned and placed before meals.

C. (2) Mutual Contract In Nursing-Family Care

1. The primary nurse contacts with the family and invites family to make following decisions:

(1) In your opinion, how relevant is this problem in patient's care?

Not relevant______________
some relevant__________________
Very relevent_____________

(2) Would you like to participate the care of this problem?

Yes__________ No______________
If your answer is No, please skip #(3).

(3) Which area(s) of patient's care would you like to participate?

a. Teaching-learning activities_________________
  -offer information of patient's daily routine habits
b. Caregiving activities__________________
  -encourage patient to eat
  -help patient to sit up for meal if needed
  -assist patient in pre-meal activities (oral and dentures care)
c. Emotional support___________________
  -sit with the patient during meal
  -verbal or written note for emotional support
  -continuing usual patterns of interaction with the patient and family routine for meal, such as religious pray if patient used to.

(4) Anything else do you like to add for better care of your sick family member in the hospital?___________________

2. Your decisions are well respected by the nursing staff no matter what you made. Please specify your reason for not being able to visit the patient or participate in the care ___________________

____

____

Please list how can nurses be most helpful in your situation _____

____

____

NURSE-FAMILY CARE PROTOCOL
D. IMMOBILITY

Immobilization occurs commonly among elderly hospitalized patients. Actually, the legitimate reasons for immobilization is very few, such as severe blood loss, fresh trauma, head injury, and hip fractures. However, other factors that cause immobilization in the hospital include environmental barriers such as bedrails, restraints, high beds, and lack of staff to help with mobility, cognitive impairment, central nervous system disorders, pain with movement, affective disorders, sensory changes, and overprotective family or support system. Common consequences of immobility are bowel and bladder incontinence, bedsores, emotional trauma, depression, sleep disorder, and potential electrolyte imbalances.

D. (1). Basic Guideline

1. Identify risk factors for immobilization

2. Assess patients physical functions (ability to change and control body position) and mental status every shift.

3. Encourage patient to mobilize frequently

4. Plan a schedule for patient's mobilization, and connect mobilization with daily activities, such as up in chair for all meals, walk to the toilet three times a day.

5. Place call light in patient's reach and answer the call light promptly.

6. If patient uses walker, cane, or wheelchair at home, obtain same for patient in hospital.

7. Place frequently used items within patient's reach

8. Encourage family to assist patient mobilization .

9. Help the immobilized patient in selecting one or two appropriate exercises methods and assist patient to do the exercise. The methods include followings: in bed, deep breathing, nick rolls, knee to chest, pelvic tilts, head raising in prone and supine positions, unilateral leg lifts; exercise that can be done in a chair are deep breathing, head rolls, knee to chest, head to knee, shoulder rolls and lifts, weight shift (hip to hip), leg lifts, ankle rotation and dorsiflexion.

10. Assess patient's pain level and keep patient pain free.

11. Coach patient or teach family how to help patient with pain to mobilize, for example, instruct patient who are in pain to move slowly and smoothly while deep breathing to ease pain and anxiety.

12. Patient in bed who is assessed to be at risk for developing pressure ulcers should be repositioned at least every 2 hours.

13. For patient in bed, positioning devices such as pillows or foam wedges should be used to keep bony prominences (such as knees or ankles) from direct contact with one another.

14. Patient in bed who are completely immobile should use devices that totally relieve pressure on the heels, most commonly by raising the heels off the bed.

15. Use lifing devices such as a trapeze or bed linen to move patient in bed who cannot assist during transfers and position changes.

D. (2). Mutual Contract in Nursing-Family Care

1. The primary nurse contacts with the family and invites family to make following decisions:

(1) In your opinion, how relevant is this problem in current care of your sick family member?

Not relevant_______
somewhat relevant___________
Very relevant______

(2) Would you like to participate the care of this problem?

Yes______________No_______________
If your answer is No, please skip #(3).

(3) Which area(s) of patient's care would you like to participate?

a. Teaching-learning activities__________________
  - -offer information of patient's daily routine habits on mobilization, unique way to get in or out of bed
  - -learn from nurses how to help patient who are in pain to move
  - -help nurses to identify appropriate exercise methods or put together a schedule for mobilization

b. Caregiving activities_____________________________
  - -assist patient to mobilize as planed
  - -identify risk factors

c. Emotional support_________________________________
  - -positive assurance and verbal encourage
  - -touching, taking with the patient
  - -taking patient out of floor and doing something meaningful and enjoyable, such as listening to singing

(4) Anything else do you like to add for better care of your sick family member in the hospital? __________________________________
____

2. Your decisions are well respected by nursing staff no matter what you have made. Please specify your reasons for not being able to visit the patient or participate in the care____
____

Please list how can nurses be most helpful in your situation_____
____
____
____

NURSE-FAMILY CARE PROTOCOL
E. FALLS

Hospitalized elderly are at special risk of falling. Risk factors include physiological decline associated with the aging process, acute illness superimposed on existing chronic disease, drugs, and an unfamiliar environment, such as when starting new drugs, orthostatic hypotension, poor judgement, confusion, sensory deficit, environment hazards, and inadequate lighting.

E (1). Basic Guideline

1. Identify risk factor for falls by assessing the history of previous falls, presence illness condition, drug intake, complaints of neurological symptoms, reports of comfort.

2. Assess patient's mental status every day.

3. Assess patient's physical functioning includes pulse and blood pressure, observation of postural sway and walking gaits, determination of the ability of transfer, ambulate, and use mobility aids and assistive devices.

4. Orientate patient and ask patient to arrange his glasses, hearing aid, and mobility aids. Make sure the patient has a big call lights and knows how to use it.

5. Place bed in lowest position with rails up.

6. Make sure patient has nonskid shoes or slippers.

7. Check patient every 2 hours during night if high risk.

8. Monitor environment, such as adequate sources of lighting, particularly at night. raised toilet seats, clear walking surface to the bathroom, and wheelchairs with seat belts.

9. Carefully use restraints system if necessary, the needed for restraints should be reviewed every 24 hours, and restraints should be removed for remobilization of patients every 30-45 minutes.

10. Use of volunteers or a family member to assist new patients to adapt to the hospital and its routines.

11. Teach patient and/or family about medications that may cause confusion, dizziness, or weakness, such as sleeping pills, pain relievers, tranquilizers, diuretics, or blood pressure pills.

12. Encourage and teaching family members how to assisting with mobility, and reorienting the patient. Communication with family about patient's condition change to prevent from falls.

E. (2). Mutual Contract In Nursing-Family CAre

1. The primary nurse contacts with the family and invites family to make following decisions:

(1) In your opinion, how relevant is this problem in current care of your sick family member?

Not relevant____________________
Somewhat relevant_________________
Very relevant____________________

(2) Do you like to participate the care of this problem?

Yes____________ No_______________
If your answer is No, please skip (3).

(3) Which area(s) of patient's care would you like to participate for this problem?

a. Teaching-learning___________________________
   - offer information for history assessment
   - help nurses to identify risk factors
   - learn how to assist patient and reorient patient

b. Caregiving activities_______________________
   - monitor environment
   - visit and spend time with patient, especially on admission
   - reorient and assist patient to walk
   - bring in patient's sleepers from home if possible

c. Emotional support______________________________
   - holding patient's hands
   - talking with the patient
   - positive assurance

(4) Anything else do you like to add for better care of your sick family member in the hospital? __________________
____

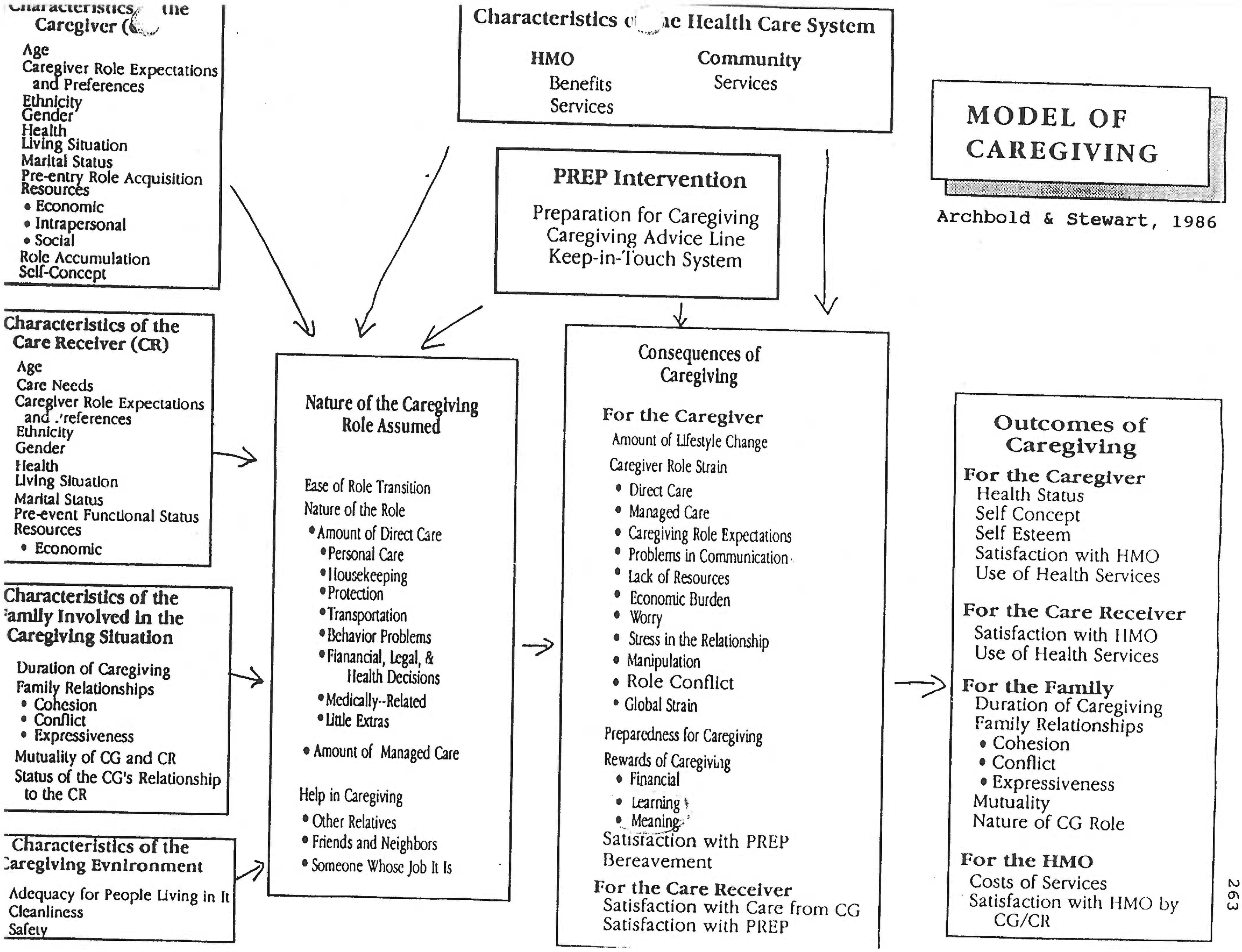
2. Your decisions are well respected by nursing staff no matter what you have made. Please specify your reasons for not being able to visit the patient or participate in the care _
____
____

Please list how can nurses be most helpful in your situation ____
____
____

THANK YOU!

Appendix B

Family Caregiving Model (Archbold & Stewart, 1986)



MODEL OF CAREGIVING

Archbold & Stewart, 1986

Characteristics[illegible] the Caregiver ([illegible]

Age
Caregiver Role Expectations and Preferences
Ethnicity
Gender
Health
Living Situation
Marital Status
Pre-entry Role Acquisition
Resources
- Economic
- Intrapersonal
- Social

Role Accumulation
Self-Concept

Characteristics of the Care Receiver (CR)

Age
Care Needs
Caregiver Role Expectations and Preferences
Ethnicity
Gender
Health
Living Situation
Marital Status
Pre-event Functional Status
Resources
- Economic

Characteristics of the amily Involved in the Caregiving Situation

Duration of Caregiving
Family Relationships
- Cohesion
- Conflict
- Expressiveness

Mutuality of CG and CR
Status of the CG's Relationship to the CR

Characteristics of the aregiving Environment

Adequacy for People Living in It
Cleanliness
Safety

Characteristics o[illegible]e Health Care System

HMO
Benefits
Services

Community
Services

PREP Intervention

Preparation for Caregiving
Caregiving Advice Line
Keep-in-Touch System

Nature of the Caregiving Role Assumed

Ease of Role Transition
Nature of the Role
- Amount of Direct Care
  - Personal Care
  - Housekeeping
  - Protection
  - Transportation
  - Behavior Problems
  - Fianancial, Legal, & Health Decisions
  - Medically--Related
  - Little Extras
- Amount of Managed Care

Help in Caregiving
- Other Relatives
- Friends and Neighbors
- Someone Whose Job It Is

Consequences of Caregiving

For the Caregiver
Amount of Lifestyle Change
Caregiver Role Strain
- Direct Care
- Managed Care
- Caregiving Role Expectations
- Problems in Communication
- Lack of Resources
- Economic Burden
- Worry
- Stress in the Relationship
- Manipulation
- Role Conflict
- Global Strain

Preparedness for Caregiving
Rewards of Caregiving
- Financial
- Learning
- Meaning

Satisfaction with PREP
Bereavement

For the Care Receiver
Satisfaction with Care from CG
Satisfaction with PREP

Outcomes of Caregiving

For the Caregiver
Health Status
Self Concept
Self Esteem
Satisfaction with HMO
Use of Health Services

For the Care Receiver
Satisfaction with HMO
Use of Health Services

For the Family
Duration of Caregiving
Family Relationships
- Cohesion
- Conflict
- Expressiveness

Mutuality
Nature of CG Role

For the HMO
Costs of Services
Satisfaction with HMO by CG/CR

APPENDIC C

Summary of Adaptation of Archbold & Stewart's Family Caregiving Model In the Home Setting to Caregiving In the Hospital Setting

Summary of Adaptation of Archbold & Stewart's Family Caregiving Model in the Home Setting to Caregiving in the Hospital Setting

CONCEPTS EXIST IN A&S MODEL	CONCEPTS ADOPTED FROM A&S MODEL	CONCEPTS MODIFIED FROM A&S MODEL	CONCEPTS ADDED IN A&S MODEL
1. Antecedent variables			
-Characteristics of the caregiver	-Characteristics of the caregiver		-Characteristics nurses
-Characteristics of the care receiver	-Characteristics of the care receiver		
-Characteristics of the dyadic relationship	-Characterictics of the dyadic relationship		
-Characterictics of the environment		-Family caregiving from home to hospital	
-Characterictics of the health care system		-Characterictics of organization	
2. Nature of the caregiving role assumed			
-Ease of role transition			
Nature of the role		-Actual family participation -Nonparticipation -Appropriate participation -Inappropriate participation	-Patients - & family members preference about participation
-Help in caregiving			

CONCEPTS EXIST IN A&S MODEL	CONCEPTS ADOPTED FROM A&S MODEL	CONCEPTS MODIFIED FROM A&S MODEL	CONCEPTS ADDED IN A&S MODEL
3.Consequences of caregiving		Consequence of family caregiving during & after hospitalization	
For the caregiver			
-Amount of lifestyle change			
-Caregiver role strain ... .worry .global strain ...		-Family caregiver role strain from worry -Frustration -Exhausted feeling	
-Preparedness for caregiving	-preparedness for caregiving		
-Rewards of caregiving			
-Satisfaction with PREP			
-Bereavement			
For the care receiver			
-Satisfaction with care from caregiver	-satisfaction with care		
-Satisfaction with PREP			
			-Decreased dysfunctional syndrome rate -Injury -delayed self-independess For Nurses -job saticifaction For Hospital -decrease length of stay
4.Outcomes of caregiving.			

Appendix D

Findings From Preliminary Studies (Li, 1992ac)

Indicators/Categories of Family Paticipation (Li, 1992ac)

Categories	Items
Treatment-related	(a) Frequent contact with staff
	(a) Providing historical information (i,e. pattern of bowel movement)
	(o) Help patient to take medicine
	(o) Help patient to make decision on treatment or arrangement after discharge
Emotional/spiritual	(a) Bring family pictures
	(a) Bring pets
	(a) Bring stuffed animals
	(o) Kiss & hug patient
	(a) Verbal express "I love you"
	(a) Positive assurance "You really look good today"
	(m) Talk with patient
	(m) Share feelings with patient
Extra	(a) Visit
	(m) Spenting time with patient
	(o) Back rub
	(o) Holding hands
Enrichment	(a) Anniversary & birthday party
	Bring whole extended family to visit
	(a) Take patient out for "pass"
	(m) Do something they may routinely do at home
	(a) Take patient downstairs to listen to music
Physical/personal comfort	(o) Help patient out of bed
	(m) Help patient to set up the tray
	(o) Help patient to go to bathroom
	(o) Help patient bathe
	(m) Bring food from outside within the diet prescribtion

(a): new items (12)
(o): adopted items from Archbold & Stewart's family caregiving scale (8)
(m): modified items from archbold & Stewart's family caregiving scale (6)

Indicators/Categories of Family Role Srtain from Worry
(Li, 1992b)

Categories	Items
Worry about patient	(m) Illness (o) Mood (a) Mental condition (a) prognosis (a) comfortable level (a) Push the button as needed (a) When family is at the bedside (a) When family is away from the hospital (a) When family is in the waiting room during the patient's treatment procedures
Worry about the care	(a) Treatment plan (a) Quality of nursing care (o) Enough information from doctors (o) Enough information from nurses (a) Adequate nursing care (a) Nurses answer the light on time (a) Left on the toilet too long (a) Handled roughtly in patient's care (a) Lying in a cold and wet bed (o) Decision making of putting the patient in a nursing home (a) When family is at the bedside (a) When family is away from the hospital
Worry about ownselff	(o) Own ability to continue talking care of the patient when discharging to home (o) Own future (o) Financial situation

(a): new items (12)
(o): adopted items from Archbold & Stewart's worry scale (7)
(m): modified item from Archbold & Stewart's worry scale (1)

APPENDIX E

Summary of Selected Research on Family Caregiving For Elders in Home Setting

AUTHORS/DATA	SAMPLE	DEF. CONCEPT	CATEGORIES/ITEMS
Archbold Stewart Harvathh Lucas (1986)	50 spouse caregivers convenience home setting	nature of caregiving role: the amount and type of direct and managed caregiving tasks performed by the caregiver for the care receiver	Personal care (alpha=.81) feed life/transfer assist bathing clean incontinence brush teeth assist dressing help nights check skin help toilet assist hair care Houskeeping (alpha=.87) prepare meals change linens do housekeeping Protection (alpha=.53) assist walking keep one eye on protect falls check in on Transportation (alpha=.58) do shopping accompany shopping take med. appts. take other places Financial legal & health decision (alpha=.70) decide health help legal matters assist banking odd jobs assist forms help decide finances Behavior problems (alpha=.70) handle crying handle paranoia handle aggression listen repetitive question handle wandering remind who & where

AUTHOR/DATA	SAMPLE	DEF.CONCEPT	CATEGORIES/ITEMS
			Medically related (alpha=.21) assist meds. handle pain Little extras (alpha=.58) sit spend time participate leisure hold hands Managed care (alpha=.73) find out services get services manage services
Albert (1991)	52 caregivers random subset of 650 adult child caregivers	caregiver tasks	three dimensions competency Location Impairment-type expain feed be with services cheer sleep simple task groom doctor wander independent dress bed toilt medicines meals mood decision mobility membory friends phone look good listen finances

AUTHOR/DATA	SAMPLE	DEF.CONCEPTS	CATEGORIES/ITEMS
Bowers (1987)	60 interviews (27 parents 33 of their caregivers) Theoretical sampling	Caregiving is defined by the meaning or purpose a attributes to a behavior rather than by the nature or demands of the behavior itself	5 caategories: Anticipatory behaviors or decisions that are based on anticipated, possible needs of a parent Preventive activities carried out by offspring for the purpose of prevening illness, injury, complications, and physical and mental deterioration. e.g., altering the physical environment to increase satety Supervisory it is observed in situations where identifiable care is given to a patient. Activities include arranging for, checking up, making sure, setting up, and checting out Instrumental hands-on caregiving: doing for, assisting, providing, and giving Protective the purpose of protective caregiving is to protect the parent from the consequences of that was not or could not be prevented. (congnitive decline)

AUTHORS/DATA	SAMPLE	DEF.CONCEPT	CATEGORIES/ITEMS
Cicirelli (1983)	141 adult children with disrupted marriages (divorced, widowed, remarried) was compared with that of 164 adult children with intact marriages	caregiving services	3 types of services __Primary__ homemaking housing income maintenance personal care home health carte __Secondary__ transportation psychological support social & recreational activities spiritual support protection bureaucratic mediation __Tertiary__ reading materials career education enrichment employment
Horowitz (1985)	131 adult children caregivers to an old frail parent	caregiving type of assistance	escort/transportation houshold chores meal preparation errands/shopping personal care health care financial management linkage financial support emotional support
Oberst Thomas Gass Ward (1989)	47 caregivers who were caring for spouses (53%) or parents (30%) care receivers were out-patients at a cancer center	caregiving activities	transportation emotional support managing illness related finances/ paper work structuring activities monitoring/reporting systems managing behavior treatments assisting mobility personal care

AUTHOR/DATA	SAMPLE	DEF.CONCEPT	CATEGORIES/ITEMS
Stoller (1990)	173 caregivers (76.1% relatives, 23.9% friends or neighbors)	caregiver tasks	cooking shopping light chores heavy chores laundry financial management dressing bathing using toilt
Stoller Earl (1983)	753 elderly people from 2 non-metro politan areas	need assistance for specific task areas	food parenaration shopping bathing toileting heavy chores light chores dressing/grooming

APPENDIX F

Summary of Selected Research on Family Caregiving For Elders in Hospital Setting

AUTHORS/DATA	SAMPLE	DEF.CONCEPT	CATEGORIES/ITEMS
Haggmark (1990)	67 relatives in a hospital	involvement of relatives	frequency of visit duration of visit
Halm Titler (1990)	Critical Care Units patients (n=77) family members (n=58) nurses (n=81) physicans (n=8)	role of family members during visiting periods	providing emotional support helping pateint eat backrub or bath reading mails completing tasks desired by the patient and family or suggested by the staff calming touching the patient participating in care as desired with guidance from the nursing staff hands-on care such as suctioning, oral and Hiskman line care
Hickey Lewand-owski (1988)	226 CCU nurses in 4 hospitals	family participation	encouraging pt. to drank helping pt. eat reading to patient helping pt. stay oriented helping pt. deal with fear bringing pt. food from home being told vital signs sitting with pt. participating decision make being told lab. result participating care planning giving pt. a back rub assisting with pt.'s bath helping change pt.'s cloth making decision ab. care supporting pt. during upsetting procedures supporting pt. during painful procedure helping change with bed helping pt. hold still during procedure helping clean up an incontinent patient assisting with tracheostomy care help with dressing changes

AUTHORS/DATA	SAMPLE	CONCEPT	CATEGORIES/ITEMS
Laitinen (1992)	18 elderly patients 7 caregivers	paticipation in informal care	dressing sitting exercising walking out standing up/ getting into bed using the toilet eating drinking caring for hair caring for teeth caring for hand and nails caring for feet and nails caring for skin giving emotional support making the bed reading other: singing
Sharp (1990)	74 nurses 60 relatives of elderly mentally ill patients	relatives' involvement	helping with ADL's feeding washing toileting dressing bathing

Appendix G

Letters of Support for access to Study Participants

memo:

DATE: July 15, 1993

TO: Hong Li

FROM: Peg Shepherd, PhD, RN, Nurse Researcher, University Hospital

RE: Proposed research: "Family Participation in Hospital Care of Elders"

After reviewing your proposed research and discussing your proposal with you, I am confident that University Hospital can provide you will the clinical access you request. Although as we discussed, our population of elderly patients is smaller than that of most community hospitals, we certainly have a sufficient number to meet the requirements of your study. In addition, your research questions are clearly of interest to hospital nursing. I look forward to hearing about your progress and results.

As per our discussion, we will each follow through in these ways:

1. I will contact Clinical Coordinators and/or Department Directors for 8C (cardiac surgery; cardiology) and 9C (neurology; neurosurgery; ENT surgery) as well as those for our critical care and emergency departments. Once I have identified one of these people willing to be your primary clinical contact person, I will let you know. Their responsibility will be to assist you in gaining access to the specific clinical population and nursing staff on their unit.

2. I will need a copy of your final proposal when that is complete. I also need you to fill out the attached form and return it to me before you begin data collection.

3. Before beginning data collection, you will need to make arrangements to communicate with nursing staff on the relevant clinical units about your research project and expectations of them. This communication may be either written or verbal (e.g., by attending staff meetings to present your study). That part is up to you and your clinical contact person to negotiate.

4. Once you have completed your study, it will be your responsibility to arrange a time (either through me or through your clinical contact person) to present your findings to the nurses at University Hospital.

Good luck with this project. Let me know if I can be of further assistance.

DEPARTMENT OF VETERANS AFFAIRS
Medical Center
3710 Southwest U.S. Veterans Hospital Road
Portland OR 97207

In Reply Refer To:

March 22, 1993

118-P

Hong Li, R.N.
1245 S.W. Grover St., #105
Portland, Or 97201

Dear Hong,

From our recent discussion, I understand that you are planning to develop a tool to measure family participation in the care of elderly hospitalized patients. I would be pleased to help you identify potential subjects to participate in your research, including patients and their families as well as registered nurses.

Please let me know when you are ready to proceed.

Joyce K. Holohan-Bell

Joyce K. Holohan-Bell, RN, MSN,CS
Clinical Nurse Specialist, Gerontology

Appendix H (Part 1: VA Hospital)

Consent Forms

Interviews
- With family members
- With elderly patients
- With nursing staff

Participant Observation
- With family members
- With elderly patients
- With nursing staff

Department of Veterans Affairs

VA Research Consent Form

Subject Name: ____________________ Date: __________

Title of Study: Family Participation In Hospital Care of Elders

Principal Investigator: Hong Li, RN. MS. VAMC: __________

Description of Research By Investigator

Study Purpose

The purpose of this study is to learn about family participation in the care of hospitalized elderly relatives and family worry during such hospital stays. This area of research has significant implications in terms of the quality of hospital care for elderly patients and their families.

Procedures

If you agree to participate, you will be interviewed on two separate occasions. The first time Ms. Li will interview you in the hospital. The interview will take about 1/2 to 1 hour. Ms. Li will be asking you questions about the kind of things you have been doing, and would prefer to do, to assist your relative during a hospital stay. The second interview will take place after your relative is discharged from hospital. Ms. Li will interview you on the phone about 15 to 30 minutes. Ms. Li will ask you questions about the kinds of things you did, and would prefer to do, to assist your relative during discharge from the hospital.

Confidentiality

The results of your participation in this study may be used for publication or for scientific purpose, but your identity will not be disclosed unless you give separate, specific consent to this, or unless as required by law.

Risk and Benefits

Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you. Participating in this interview may provide some benefits for you. For example, some family members report that talking to someone about their situation is helpful.

Subject's Identification (I.D. plate or give Name-last, first, middle)

To be used for interviews with family members

VA FORM
JAN 1990 **10-1086**

Department of Veterans Affairs

VA Research Consent Form

Continuation Page 2 of 3

Subject Name: ______________________ Date: __________

Title of Study: Family Participation In Hospital Care of Elders

Principal Investigator: Hong Li, RN. MS VAMC: __________

Treatment in Case of Injury, source of additional Information

Every reasonable effort to prevent any injury that could result from this study will be taken. In the event of physical injuries resulting from the study, medical care treatment will be available at this institution. For eligible veterans, compensation damages may be payable under 38 USC 251 or, in some circumstances, under the Federal Tort Claims Act. For non-eligible veterans and non-veterans, compensation would be limited to situation where negligence occurred and would be controlled by the provisions of the Federal Tort Claims Act. For clarification of these laws, contact District Counsel at (503) 326-2441. You have not waived any legal rights or released the hospital of its agents from liability for negligence by signing this form.

Any person participating in a study at the Department of Veterans Affairs Medical Center, Portland, Oregon is encouraged to contact Dr. Dennis J. Mazur, Chairman, Subcommittee on Human Studies, to discuss any issue related to their research study participation. Dr. Mazur can be reached through the Research Service (503) 220-8262 extension 6620.

Your signature below indicates that you understand that the Department of Veterans Affair Medical Center, your investigators, and the sponsors of this research study bear no responsibility for any costs you incur at other hospitals, clinics, or care institutions related to this study or to any of your medical conditions.

Your Right as a Participant

Your participation in this study is voluntary, and you may withdraw from this study at any time without prejudice to your relative or to any future medical care with this institution or with the Department of Veterans Affairs (VA).

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

Department of Veterans Affairs

VA Research Consent Form

(Continuation Page 3 of 3)

Subject Name: ______________________ Date: __________

Title of Study: Family Participation In Hospital Care of Elders

Principal Investigator: Hong Li, RN. MS. VAMC: __________

RESEARCH SUBJECTS' RIGHTS: I have read or have had read to me all of the above. Dr. Ms. Hong Li has explained the study to me and answered all of my questions. I have been told of the risks and/or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

I understand that I do not have to take part in this study, and my refusal to participate will involve no penalty or loss of VA or other benefits to which I am entitled.

The results of this study may by published, but my records will not be revealed unless required by law.

In case there are medical problems or questions, I have been told I can call Dr. Debbie Burton at 6015 during the day and Dr.__________ at __________ after hours. If any medical problems occur in connection with this study the VA will provide emergency care.

I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Signature of Subject

Date

Signature of Witness

Witness (print)

Signature of Investigator

IF MORE THAN ONE PAGE IS USED, EACH PAGE (VAF 10-1086A) MUST BE CONSECUTIVELY NUMBERED AND SIGNED.

VA FORM
JAN 1990 **10-1086**

Department of Veterans Affairs

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Principal Investigator: Hong Li, RN. MS. VAMC: __________

Description of Research By Investigator

Study Purpose

The purpose of this study is to learn about family participation in the care of hospitalized elderly relatives and family worry during such hospital stays. This area of research has significant implications in terms of the quality of hospital care for elderly patients and their families.

Procedures

If you agree to participate, you will be interviewed on two separate occasions. The first time Ms. Li will interview you in the hospital. The interview will take about 1/2 hour. Ms. Li will be asking you questions about the care given by your relatives and nurses during your hospitalization, and your preferences about what your relatives and nurses do to assist you. The second interview will take place at your home after you are discharged from the hospital. Ms. Li will interview you on the phone about 15 minutes. Ms. Li will ask you questions about the kinds of things your relative did, and what you would prefer your relatives and nurses to do, to assist you during your discharge from the hospital.

Confidentiality

The results of your participation in this study may be used for publication or for scientific purpose, but your identity will not be disclosed unless you give separate, specific consent to this, or unless as required by law.

Risk and Benefits

Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you. Participating in this interview may provide some benefits for you. For example, it will give you an opportunity to share your opinions about improving your care in the hospital.

Subject's Identification (I.D. plate or give Name-last, first, middle)

To be used for interviews with elderly patients

VA FORM
JAN 1990 10-1086

Department of Veterans Affairs

VA Research Consent Form

Continuation Page 2 of 3

Subject Name: ______ Date: ______

Title of Study: Family Participation In Hospital Care of Elders

Principal Investigator: Hong Li, RN. MS VAMC: ______

Treatment in Case of Injury, source of additional Information

Every reasonable effort to prevent any injury that could result from this study will be taken. In the event of physical injuries resulting from the study, medical care treatment will be available at this institution. For eligible veterans, compensation damages may be payable under 38 USC 251 or, in some circumstances, under the Federal Tort Claims Act. For non-eligible veterans and non-veterans, compensation would be limited to situation where negligence occurred and would be controlled by the provisions of the Federal Tort Claims Act. For clarification of these laws, contact District Counsel at (503) 326-2441. You have not waived any legal rights or released the hospital of its agents from liability for negligence by signing this form.

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Your Right as a Participant

Your participation in this study is voluntary, and you may withdraw from this study at any time without prejudice to yourself or to any future medical care with this institution or with the Department of Veterans Affairs (VA).

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VA Research Consent Form

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In case there are medical problems or questions, I have been told I can call Dr. Debbie Burton at 6015 during the day and Dr.__________ at__________ after hours. If any medical problems occur in connection with this study the VA will provide emergency care.

I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Signature of Subject	Date
Signature of Witness	Witness (print)
Signature of Investigator	

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Description of Research By Investigator

Study Purpose

The purpose of this study is to learn about family participation in the care of hospitalized elderly relatives and family worry during such hospital stays. This area of research has significant implications in terms of the quality of hospital care for elderly patients and their families.

Procedures

If you agree to participate, you will be interviewed in the hospital at a time convenient for you. The interview will take 1/2 hour. Ms. Li will be asking you questions about your observation and opinions about what kind of things family members do in participating in the hospital care of their elderly relatives.

Confidentiality

The information you share with the investigator will be handled in a manner to ensure confidentiality. Only the investigator and faculty dissertation advisors will have access to your responses. The results of your participation in this study may be used for publication or for scientific purpose, but your identity will not be disclosed unless you give separate, specific consent to this, or unless as required by law.

Risk and Benefits

Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you. Participating in this interview may provide some benefits for you. For example, some nurses reports that talking to someone about their experiences is helpful.

To be used for interviews with nursing staff

Subject's Identification (I.D. plate or give Name-last, first, middle)

Department of Veterans Affairs

VA Research Consent Form

Continuation Page 2 of 3

Subject Name: ______ **Date:** ______

Title of Study: Family Participation In Hospital Care of Elders

Principal Investigator: Hong Li, RN. MS **VAMC:** ______

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VA Research Consent Form

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Title of Study: Family Participation In Hospital Care of Elders

Principal Investigator: Hong Li, RN. MS. VAMC: __________

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____
Signature of Subject

____
Date

____
Signature of Witness

____
Witness (print)

____
Signature of Investigator

IF MORE THAN ONE PAGE IS USED, EACH PAGE (VAF 10-1086A) MUST BE CONSECUTIVELY NUMBERED AND SIGNED.

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Department of Veterans Affairs

VA Research Consent Form

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Description of Research By Investigator

Study Purpose
The purpose of this study is to learn about family participation in the care of hospitalized elderly relatives and family worry during such hospital stays. This area of research has significant implications in terms of the quality of hospital care for elderly patients and their families.

Procedures
If you agree to participate, Ms. Li will be present during a time when you visit your relative in the hospital. This observation may last from less than an hour to several hours. Ms. Li will observe interactions among you, your relative, and the nurse. Occasionally, Ms. Li may ask you to tell her your opinions about the care provided to your relative.

Confidentiality
The results of your participation in this study may be used for publication or for scientific purpose, but your identity will not be disclosed unless you give separate, specific consent to this, or unless as required by law.

Risk and Benefits
Some of the observation and questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you. Participating in this study may provide some benefits for you. For example, some family members reports that sharing their experience with someone is helpful.

Subject's Identification (I.D. plate or give Name-last, first, middle)

To be used for participant observation with family members

VA FORM
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Department of Veterans Affairs

VA Research Consent Form

Continuation Page 2 of 3

Subject Name: ______________________ Date: __________

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Your Right as a Participant

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If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

Department of Veterans Affairs

VA Research Consent Form

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Subject Name: ______________________ Date: __________

Title of Study: Family Participation In Hospital Care of Elders

Principal Investigator: Hong Li, RN. MS. VAMC: __________

RESEARCH SUBJECTS' RIGHTS: I have read or have had read to me all of the above. Dr. Ms. Hong Li has explained the study to me and answered all of my questions. I have been told of the risks and/or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

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The results of this study may by published, but my records will not be revealed unless required by law.

In case there are medical problems or questions, I have been told I can call Dr. Debbie Burton at 6015 during the day and Dr.__________ at __________ after hours. If any medical problems occur in connection with this study the VA will provide emergency care.

I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Signature of Subject ______________________ Date __________

Signature of Witness ______________________ Witness (print) __________

Signature of Investigator ______________________

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VA FORM
JAN 1990 **10-1086**

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VA Research Consent Form

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Procedures

If you agree to participate, Ms. Li will be present during a time when your family member visits you in the hospital. This observation will last from less than an hour to several hours. Ms. Li will observe interactions among you, your relative, and the nurse. Occasionally, Ms. Li may ask you to tell her your opinions about the care you received.

Confidentiality

The results of your participation in this study may be used for publication or for scientific purpose, but your identity will not be disclosed unless you give separate, specific consent to this, or unless as required by law.

Risk and Benefits

Some of the observations and questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you. Participating in this study may provide some benefits for you. For example, some patients report that they enjoy talking with someone about their experiences.

To be used for participant observation with elderly patients

Subject's Identification (I.D. plate or give Name-last, first, middle)

VA FORM
JAN 1990 **10-1086**

Department of Veterans Affairs

VA Research Consent Form

Continuation Page 2 of 3

Subject Name: ____________ Date: ____________

Title of Study: Family Participation In Hospital Care of Elders

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Every reasonable effort to prevent any injury that could result from this study will be taken. In the event of physical injuries resulting from the study, medical care treatment will be available at this institution. For eligible veterans, compensation damages may be payable under 38 USC 251 or, in some circumstances, under the Federal Tort Claims Act. For non-eligible veterans and non-veterans, compensation would be limited to situation where negligence occurred and would be controlled by the provisions of the Federal Tort Claims Act. For clarification of these laws, contact District Counsel at (503) 326-2441. You have not waived any legal rights or released the hospital of its agents from liability for negligence by signing this form.

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Your Right as a Participant

Your participation in this study is voluntary, and you may withdraw from this study at any time without prejudice to you or to any future medical care with this institution or with the Department of Veterans Affairs (VA).

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

Department of Veterans Affairs

VA Research Consent Form

(Continuation Page 3 of 3)

Subject Name: ______ Date: ______

Title of Study: Family Participation In Hospital Care of Elders

Principal Investigator: Hong Li, RN. MS. VAMC: ______

RESEARCH SUBJECTS' RIGHTS: I have read or have had read to me all of the above. Dr. Ms. Hong Li has explained the study to me and answered all of my questions. I have been told of the risks and/or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

I understand that I do not have to take part in this study, and my refusal to participate will involve no penalty or loss of VA or other benefits to which I am entitled.

The results of this study may by published, but my records will not be revealed unless required by law.

In case there are medical problems or questions, I have been told I can call Dr. Debbie Burton at 6015 during the day and Dr.______ at______ after hours. If any medical problems occur in connection with this study the VA will provide emergency care.

I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

Signature of Subject

Date

Signature of Witness

Witness (print)

Signature of Investigator

Or Signature of Guardian
(If patient is cognitively
impaired or confused)

Date

IF MORE THAN ONE PAGE IS USED, EACH PAGE (VAF 10-1086A) MUST BE CONSECUTIVELY NUMBERED AND SIGNED.

VA FORM
JAN 1990 10-1086

Department of Veterans Affairs

VA Research Consent Form

Subject Name: ______________________ **Date:** __________

Title of Study: Family Participation In Hospital Care of Elders

Principal Investigator: Hong Li, RN. MS. **VAMC:** __________

Description of Research By Investigator

Study Purpose

The purpose of this study is to learn about family participation in the care of hospitalized elderly relatives and family worry during such hospital stays. This area of research has significant implications in terms of the quality of hospital care for elderly patients and their families.

Procedures

If you agree to participate, Ms. Li will be present during a time when your patient has family visitor(s) in the hospital. This observation will last from less than an hour to several hours. Ms. Li will observe interactions among the patient, family member, and you. Occasionally, Ms. Li may ask you to tell her your opinions about the care provided to your patient by you and by the family members.

Confidentiality

The information you share with the investigator will be handled in a manner to ensure confidentiality. Only the investigator and faculty dissertation advisors will have access to the written notes. The results of your participation in this study may be used for publication or for scientific purpose, but your identity will not be disclosed unless you give separate, specific consent to this, or unless as required by law.

Risk and Benefits

Some of the observations and questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you. Although participation in this study may not have direct benefits for you personally, it will help us understand better the way that nurses and family members participate in the care of hospitalized older persons.

Subject's Identification (I.D. plate or give Name-last, first, middle)

To be used for participant observation with nursing staff

Department of Veterans Affairs

VA Research Consent Form

Continuation Page 2 of 3

Subject Name: ____________________ Date: __________

Title of Study: Family Participation In Hospital Care of Elders

Principal Investigator: Hong Li, RN. MS VAMC: __________

Treatment in Case of Injury, source of additional Information

Every reasonable effort to prevent any injury that could result from this study will be taken. In the event of physical injuries resulting from the study, medical care treatment will be available at this institution. For eligible veterans, compensation damages may be payable under 38 USC 251 or, in some circumstances, under the Federal Tort Claims Act. For non-eligible veterans and non-veterans, compensation would be limited to situation where negligence occurred and would be controlled by the provisions of the Federal Tort Claims Act. For clarification of these laws, contact District Counsel at (503) 326-2441. You have not waived any legal rights or released the hospital of its agents from liability for negligence by signing this form.

Any person participating in a study at the Department of Veterans Affairs Medical Center, Portland, Oregon is encouraged to contact Dr. Dennis J. Mazur, Chairman, Subcommittee on Human Studies, to discuss any issue related to their research study participation. Dr. Mazur can be reached through the Research Service (503) 220-8262 extension 6620. Your signature below indicates that you understand that the Department of Veterans Affair Medical Center, your investigators, and the sponsors of this research study bear no responsibility for any costs you incur at other hospitals, clinics, or care institutions related to this study or to any of your medical conditions.

Your Right as a Participant

Your participation in this study is voluntary, and you may withdraw from this study at any time without prejudice your position in this institution or with the Department of Veterans Affairs (VA).

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

Department of Veterans Affairs

VA Research Consent Form

(Continuation Page 3 of 3)

Subject Name: ______________________ Date: __________

Title of Study: Family Participation In Hospital Care of Elders

Principal Investigator: Hong Li, RN. MS. VAMC: __________

RESEARCH SUBJECTS' RIGHTS: I have read or have had read to me all of the above. Dr. Ms. Hong Li has explained the study to me and answered all of my questions. I have been told of the risks and/or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

I understand that I do not have to take part in this study, and my refusal to participate will involve no penalty or loss of VA or other benefits to which I am entitled.

The results of this study may by published, but my records will not be revealed unless required by law.

In case there are medical problems or questions, I have been told I can call Dr. Debbie Burton at 6015 during the day and Dr.__________ at __________ after hours. If any medical problems occur in connection with this study the VA will provide emergency care.

I understand my rights as a research subject, and I voluntarily consent to participate in this study. I understand what the study is about and how and why it is being done. I will receive a signed copy of this consent form.

____
Signature of Subject

____
Date

____
Signature of Witness

____
Witness (print)

____
Signature of Investigator

IF MORE THAN ONE PAGE IS USED, EACH PAGE (VAF 10-1086A) MUST BE CONSECUTIVELY NUMBERED AND SIGNED.

Appendix H (Part 2. OHSU Hospital)

Original Consent Forms

Interviews
- With family members
- With elderly patients
- With nursing staff

Participant Observation
- With family members
- With elderly patients
- With nursing staff

ORS#3596
5/25/94

3021

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM

TITLE:	FAMILY PARTICIPATION IN HOSPITAL CARE OF ELDERS
PRINCIPAL INVESTIGATOR:	Hong Li, RN, MS Doctoral student School of Nursing Oregon Health Sciences University Phone: (503) 228-0971
RESEARCH ADVISOR:	Barbara J. Stewart, PhD Professor School of Nursing Oregon Health Sciences University Phone: (503) 494-3835
CONSENT FORM:	To be used for interviews with family members of elderly patients who are involved in the care of their relatives in hospital settings

Study Purpose

The purpose of this research study is to learn about family participation in the care of hospitalized elderly relatives and family worry during such hospital stays.

Procedures

If you agree to participate, you will be interviewed on two separate occasions. The first time Ms. Li will interview you in the hospital. The interview will be audiotaped and will take about 1/2 to 1 hour. Ms. Li will be asking you questions about the kind of things you have been doing, and would prefer to do, to assist your relative during a hospital stay. The second interview will also be taped but will take place after your relative is discharged from hospital. Ms. Li will interview you by phone for about 15 to 30 minutes. Ms. Li will ask you questions about the kinds of things you did, and would prefer to do, to assist your relative during discharge from the hospital.

Confidentiality

The interviews will be audio-tape recorded and written notes will be kept. The tapes will be transcribed, with all personal identifying information deleted in the transcription process. The audio tapes will be destroyed after transcription is complete. Personal identifying information will be deleted from the written notes. The information you share with the investigator will be handled in a manner to ensure confidentiality. Neither your name nor your identity will be used for publicity or publication purposes.

Risks And Discomforts

Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you.

Benefits

You may not personally benefit from participating in this study. Some family members report that talking to someone about their situation is helpful.

Cost of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your participation in this study.

Liability

The Oregon Health Sciences University, as an agency of the state, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

Your Right as a Participant

Participation in this research project is completely voluntary and you may refuse to participate and may withdraw from this study at any time without affecting the care your relative receives at the OHSU hospital.

You will receive a copy of the consent form.

________ I have read what is written above and agree to be in this study.

________ I have had read to me what is written above and agree to be in the study.

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

____

signature   Date

____

Witness Signature   Date

ORS #3596
6/16/95 -

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM: FAMILY PARTICIPATION IN HOSPITAL CARE OF ELDERS

PRINCIPAL INVESTIGATOR:	Hong Li, RN, MS Doctoral student School of Nursing Oregon Health Sciences University Phone: (503) 228-0971
RESEARCH ADVISOR:	Barbara J. Stewart, PhD Professor School of Nursing Orgon Health Sciences University Phone: (503) 494-3835
CONSENT FORM:	To be used for interviews with elderly patients.

<u>Study Purpose</u>

The purpose of this study is to learn about family participation in the care of hospitalized elderly relatives and family worry during such hospital stays. This area of research has significant implications in terms of the quality of hospital care for elderly patients and their families.

<u>Procedures</u>

If you agree to participate, you will be interviewed once within one week of period of time after you are discharged from hospital. The interview will take about 1/2 hour and may take place at your home or somewhere you preferred. Ms. Li will be asking you questions about the care given by your relatives and nurses during your hospitalization, and your preferences about what your relatives and nurses do to assist you during your hospitalization including the discharge process. Sometimes, more than one interview may be needed as data analysis indicated.

<u>Confidentiality</u>

The interviews will be audio-tape recorded and written notes will be kept. The tapes will be transcribed, with all personally identifying information deleted in the transcription process. The audio tapes will be destroyed after transcription is complete. Personally identifying information will be deleted from the written notes. The information you share with the investigator will be handled in a manner to ensure confidentiality. Only the investigator and faculty dissertation advisors will have access to your responses. Any publications, including the dissertation report, will include necessary precautions to protect your identity.

Risk and Benefits

Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you. Participating in this interview may provide some benefits for you. For example, it will give you an opportunity to share your opinions about improving your care in the hospital.

Cost of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your participation in this study.

Liability

The Oregon Health Sciences University, as an agency of the state, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

Your Right as a Participant

Participation in this research project is completely voluntary and you may refuse to participate and may withdraw from this study at any time without affecting the care you receive at the OHSU or VA hospital.

________ I have read what is written above and agree to be in this study.

________ I have had read to me what is written above and agree to be in the study.

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

____
signature Date

____
Witness Signature Date

ORS # 0596
5/25/94

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM

TITLE:	FAMILY PARTICIPATION IN HOSPITAL CARE OF ELDERS
PRINCIPAL INVESTIGATOR:	Hong Li, RN, MS, Doctoral student School of Nursing, Oregon Health Sciences University Phone: (503) 228-0971
RESEARCH ADVISOR:	Barbara J. Stewart, PhD professor School of Nursong Oregon Health Sciences University Phone: (503) 494-3835
CONSENT FORM:	To be used for interviews with nurses who have experience in taking care of elderly hospitalized patients.

Study Purpose

The purpose of this research study is to learn about family participation in the care of hospitalized elderly patients and family worry during such hospital stays.

Procedures

If you agree to participate, you will be interviewed in the hospital at a time convenient for you. The interview will be audiotaped and will take 1/2 hour. Ms. Li will be asking you questions about your observation and opinions about what kind of things family members do in participating in the hospital care of their elderly relatives.

Confidentiality

The interviews will be audio-tape recorded and written notes will be kept. The tapes will be transcribed, with all personal identifying information deleted in the transcription process. The audio tapes will be destroyed after transcription is complete. Personal identifying information will be deleted from the written notes. The information you share with the investigator will be handled in a manner to ensure confidentiality. Neither your name nor your identity will be used for publicity or publication purposes.

Risk And Discomforts
Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you.

Benefits
You may not personally benefit from participating in this study. Some nurses reports that talking to someone about their experiences is helpful.

Cost of Participation
There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your participation in this study.

Liability
The Oregon Health Sciences University, as an agency of the state, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

Your Right as a Participant
Participation in this research project is completely voluntary and you may refuse to participate and may withdraw from this study at any time without affecting your position at the OHSU or VA hospital.

You will receive a copy of the consent form.

________ I have read what is written above and agree to be in this study.

________ I have had read to me what is written above and agree to be in the study.

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

signature Date

Witness Signature Date

ORS #6596
5/25/94

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM

TITLE:	FAMILY PARTICIPATION IN HOSPITAL CARE OF ELDERS
PRINCIPAL INVESTIGATOR:	Hong Li, RN, MS Doctoral student School of Nursing Oregon Health Sciences University Phone: (503) 228-0971
RESEARCH ADVISOR:	Barbara J. Stewart, PhD Professor School of Nursing Oregon Health Sciences University Phone: (503) 494-3835
CONSENT FORM:	To be used for participant observation with family members who are involved in the care of their relatives in hospital settings.

Study Purpose

The purpose of this research study is to learn about family participation in the care of hospitalized elderly patients and family worry during such hospital stays.

Procedures

If you agree to participate, Ms. Li will be present during a time when you visit your relative in the hospital. This observation may last from less than an hour to several hours. Ms. Li will observe interactions among you, your relative, and the nurse. Occasionally, Ms. Li may ask you to tell her your opinions about the care provided to your relative.

Confidentiality

Written notes will be kept. Personal identifying information will be deleted from the written notes. The information you share with the investigator will be handled in a manner to ensure confidentiality. Neither your name nor your identity will be used for publicity or publication purposes.

Risk And Discomforts

Some of the observation and questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you.

Benefits

You may not personally benefit from participating in this study. Some family members reports that sharing their experience with someone is helpful.

Cost of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your participation in this study.

Liability

The Oregon Health Sciences University, as an agency of the state, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

Your Right as a Participant

Participation in this research project is completely voluntary and you may refuse to participate and may withdraw from this study at any time without affecting the care your relative receives at the OHSU or VA hospital.

You will receive a copy of the consent form.

________ I have read what is written above and agree to be in this study.

________ I have had read to me what is written above and agree to be in the study.

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

____
Signature Date

____
Witness Signature Date

DRS #3.6
5/25/94

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM

TITLE:	FAMILY PARTICIPATION IN HOSPITAL CARE OF ELDERS
PRINCIPAL INVESTIGATOR:	Hong Li, RN, MS Doctoral student School of Nursing Oregon Health Sciences University Phone: (503) 228-0971
RESEARCH ADVISOR:	Barbara J. Stewart, PhD Professor School of Nursing Oregon Health Sciences University Phone: (503) 494-3835
CONSENT FORM:	To be used for participant observation with elderly hospitalized patients.

Study Purpose
The purpose of this research study is to learn about family participation in the care of hospitalized elderly relatives and family worry during such hospital stays.

Procedures
If you agree to participate, Ms. Li will be present during a time when your family member visits you in the hospital. This observation will last from less than an hour to several hours. Ms. Li will observe interactions among you, your relative, and the nurse. Occasionally, Ms. Li may ask you to tell her your opinions about the care you received.

Confidentiality
Written notes will be kept. Personal identifying information will be deleted from the written notes. The information you share with the investigator will be handled in a manner to ensure confidentiality. Neither your name name nor your identity will be used for publicity or publication purposes.

Risk And Disconforts
Some of the observations and questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you.

Benefits
You may not personally benefit from participating in this study. Some patients report that they enjoy talking with someone about their experiences.

Cost of Participation
There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your participation in this study.

Liability
The Oregon Health Sciences University, as an agency of the state, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

Your Right as a Participant
Participation in this research project is completely voluntary and you may refuse to participate and may withdraw from this study at any time without affecting the care your relative receives at the OHSU or VA hospital.

You will receive a copy of the consent form.

________ I have read what is written above and agree to be in this study.

________ I have had read to me what is written above and agree to be in the study.

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

Signature	Date	Witness Signature	Date

Or Guardian Signature	Date	(If patient is cognitively impaired or confused)

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM

TITLE:
FAMILY PARTICIPATION IN
HOSPITAL CARE OF ELDERS

PRINCIPAL INVESTIGATOR:
Hong Li, RN, MS
Doctoral student
School of Nursing
Oregon Health Sciences University
Phone: (503) 228-0971

RESEARCH ADVISOR:
Barbara J. Stewart, PhD
Professor
School of Nursing
Oregon Health Sciences University
Phone: (503) 494-3835

CONSENT FORM:
To be used for participant observation with nursing staff who have experience in taking care of elderly hospitalized patients.

Study Purpose

The purpose of this research study is to learn about family participation in the care of hospitalized elderly relatives and family worry during such hospital stays.

Procedures

If you agree to participate, Ms. Li will be present during a time when your patient has family visitor(s) in the hospital. This observation will last from less than an hour to several hours. Ms. Li will observe interactions among the patient, family member, and you. Occasionally, Ms. Li may ask you to tell her your opinions about the care provided to your patient by you and by the family members.

Confidentiality

Written notes will be kept. Personaly identifying information will be deleted from the written notes. The information you share with the investigator will be handled in a manner to ensure confidentiality. Neither your name nor your identity will be used for publicity or publication purposes.

Risk And Disconforts

Some of the observations and questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you. Although

Benefits

You may not personally benefit from participating in this study. It will help us understand better the way that nurses and family members participate in the care of hospitalized older persons.

Cost of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your participation in this study.

Liability

The Oregon Health Sciences University, as an agency of the state, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

Your Right as a Participant

Participation in this research project is completely voluntary and you may refuse to participate and may withdraw from this study at any time without affecting your position at the OHSU or VA hospital.

You will receive a copy of the consent form.

________ I have read what is written above and agree to be in this study.
________ I have had read to me what is written above and agree to be in the study.

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

______________________________ ______________________________
Signature Date Witness Signature Date

Appendix H (Part 2. OHSU Hospital)

Revised Consent Forms

Interviews
  - With family members
  - With elderly patients

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM: FAMILY PARTICIPATION IN HOSPITAL CARE OF ELDERS

PRINCIPAL INVESTIGATOR:
Hong Li, RN, MS
Doctoral student
School of Nursing
Oregon Health Sciences University
Phone: (503) 228-0971

RESEARCH ADVISOR:
Barbara J. Stewart, PhD
Professor
School of Nursing
Oregon Health Sciences University
Phone: (503) 494-3835

CONSENT FORM:
To be used for interviews with family members of elderly patients who are involved in the care of their relatives in hospital settings

Study Purpose

The purpose of this study is to learn about family participation in the care of hospitalized elderly relatives and family worry during such hospital stays. This area of research has significant implications in terms of the quality of hospital care for elderly patients and their families.

Procedures

If you agree to participate, you will be interviewed once within one weeks period of time after your elderly relative is discharged from the hospital. The interview may take place at your home or somewhere you preferred. The interview will take about 1 hour. Ms. Li will be asking you questions about the kind of things you have been doing, and would prefer to do, to assist your relative during a hospital stay including the process of discharging from hospital. Sometimes, more than one interview may be needed as data analysis indicated.

Confidentiality

The interviews will be audio-tape recorded and written notes will be kept. The tapes will be transcribed, with all personally identifying information deleted in the transcription process. The audio tapes will be destroyed after transcription is complete. Personally identifying information will be deleted from the written notes. The information you share with the investigator will be handled in a manner to ensure confidentiality. Only the investigator and faculty dissertation advisors will have access to your responses. Any publications, including the dissertation report, will include necessary precautions to protect your identity.

Risk and Benefits

Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you. Participating in this interview may provide some benefits for you. For example, some family members report that talking to someone about their situation is helpful.

Cost of Participation

There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your participation in this study.

Liability

The Oregon Health Sciences University, as an agency of the state, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

Your Right as a Participant

Participation in this research project is completely voluntary and you may refuse to participate and may withdraw from this study at any time without affecting the care your relative receives at the OHSU hospital.

________ I have read what is written above and agree to be in this study.

________ I have had read to me what is written above and agree to be in the study.

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

________________________________ ________________________________

signature Date Witness Signature Date

OREGON HEALTH SCIENCES UNIVERSITY

CONSENT FORM: FAMILY PARTICIPATION IN HOSPITAL CARE OF ELDERS

PRINCIPAL INVESTIGATOR:	Hong Li, RN, MS Doctoral student School of Nursing Oregon Health Sciences University Phone: (503) 228-0971
RESEARCH ADVISOR:	Barbara J. Stewart, PhD Professor School of Nursing Orgon Health Sciences University Phone: (503) 494-3835
CONSENT FORM:	To be used for interviews with elderly patients.

Study Purpose

The purpose of this study is to learn about family participation in the care of hospitalized elderly relatives and family worry during such hospital stays. This area of research has significant implications in terms of the quality of hospital care for elderly patients and their families.

Procedures

If you agree to participate, you will be interviewed once within one week of period of time after you are discharged from hospital. The interview will take about 1/2 hour and may take place at your home or somewhere you preferred. Ms. Li will be asking you questions about the care given by your relatives and nurses during your hospitalization, and your preferences about what your relatives and nurses do to assist you during your hospitalization including the discharge process. Sometimes, more than one interview may be needed as data analysis indicated.

Confidentiality

The interviews will be audio-tape recorded and written notes will be kept. The tapes will be transcribed, with all personally identifying information deleted in the transcription process. The audio tapes will be destroyed after transcription is complete. Personally identifying information will be deleted from the written notes. The information you share with the investigator will be handled in a manner to ensure confidentiality. Only the investigator and faculty dissertation advisors will have access to your responses. Any publications, including the dissertation report, will include necessary precautions to protect your identity.

Risk and Benefits
Some of the questions may touch on sensitive experiences that may be upsetting to you. You are free to decline to discuss any topics which may be uncomfortable for you. Participating in this interview may provide some benefits for you. For example, it will give you an opportunity to share your opinions about improving your care in the hospital.

Cost of Participation
There is no charge for participating in this study. No reimbursement or compensation will be given to you as a result of your participation in this study.

Liability
The Oregon Health Sciences University, as an agency of the state, is covered by the State Liability Funds. If you suffer any injury from this research project, compensation would be available to you only if you establish that the injury occurred through the fault of the University, its officers or employees. If you have further questions, you should call Dr. Michael Baird at (503) 494-8014.

Your Right as a Participant
Participation in this research project is completely voluntary and you may refuse to participate and may withdraw from this study at any time without affecting the care you receive at the OHSU or VA hospital.

________ I have read what is written above and agree to be in this study.

________ I have had read to me what is written above and agree to be in the study.

If you have questions about this research, or your rights and responsibilities as a research participant, you should first contact Hong Li at (503) 228-0971. If you have further questions you may contact Dr. Stewart, PhD, Professor of Nursing, (503) 494-3835.

______________________________ ______________________________
signature Date Witness Signature Date

Appendix I (Part 1)

Proposed Guidelines for Preliminary Interviews

Family Member ID# Qual___

FAMILY MEMBER INTERVIEW
(Addapted from Archbold & Stewart, 1991)

School of Nursing
Oregon Health Sciences University
Portland, Oregon 97201

Hong Li, RN, MS, Doctoral Candidate

Date of Interview: ____________________
Time Begin: ____________________
Time Ended: ____________________

General Probes:
1. So...
2. It seems to me you are saying
3. How are you feeling?
4. That helps me understand your situation.
5. I am glad you told me that.
6. That's very helpful.
7. I appreciate your showing me, telling me...

Interview with Family Members

Hello. My name is Hong Li. I am from the School of Nursing at the Oregon Health Sciences University.

Before we begin the actual interview, I would like for us to go over what this interview is about. Then we can get the consent forms signed and proceed with the interview. Is that okay with you?

1. EXPLAIN THE STUDY USING THE CONSENT FORM AND SUMMARIZE THE MAIN POINTS.

2. HAVE RESPONDENT READ AND SIGN THE FORM.

Do you have questions about the interview of this consent form? I would like you to sign two copies of the forms, and I will sign them too. One copy is for you to keep. I will keep the other copy for my records.

3. GIVE ONE OF THE SIGNED COPIES TO THE RESPONDENT.

I think we are ready to go ahead with the interview. It will work best if you and I can do the interview in a room that is private.

4. MOVE TO PRIVATE LOCATION.

During this interview, I will be asking you some questions about your__________ (Insert Relationship), Mr., Mrs., or Ms. __________ (Family Name of Patient). When I do so, how do you like me to refer to him/her? Would you like me to use his/her first name, family name, or just refer to him/her as your ____________(Insert Relationship)?
Caregiver reply: preference for care receiver's name_____________

During this interview, I want you to be as comfortable as possible. If we need to stop and take a break, or if you need to check on _______ (patient), please let me know. Remember that you my refuse to answer any questions or discontinue the interview at any time.

Do you have any questions before we begin?

5. TURN ON TAPE RECORDER AND BEGIN INTERVIEW.

Interview with Family member

I. The General Caregiving Situation

1. Could you start by telling me a little bit about (patient) as a person, both before he/she was hospitalized and now.

II. Caregiving Experiences

When a patient stays in the hospital, some family members want to participate in the hospital care of the patient, some family members may not. What is it like for you to be a family member of an elderly patient during during his/her hospitalization?

Now I'd like to ask you about some of the things you do to help (patient). I am interested in how your day goes in caring for (patient) in the hospital. In answering these questions, imagine that I am coming in to take care of (patient) and you want to make sure that I understand how to do things your way.

1. Your Day In (patient)'s Admission?

2. Your Day In Emergency Room with the (Patient)?

3. Your Day In Intensive Care Unit with the (Patient)?

4. Your Day Yesterday (on the regular unit)?
Would you please describe to me what your day yestreday was like? or the last day you were here.
PROBES;
-Would you please describe to me what it was like the last time you provided care for (patient)?
-Was this a typical day?
-Is that your typical schedule?

5. Getting Up in the Morning
What exactly do you do to help (patient) when he/she wakes up in the morning?
PROBES:
-Tell me what is involed. How are you involved?
-If you are invoved in the morning care, would you please explain why you do these activities (you preferred or wanted to do; patient preferred you to do; nurses asked you to do; or no one else to help)
-How does that go for you?
-How does that go for him/her?
-How do you think (patient) feels or reacts at this times?

-What information would you like to have nurses know if you are not here for (patient's) morning care?
-What information did you learn from nurses regarding the morning care?
-What do you worry about his/her morning care? (When you are here or at home?).

6. Meals: Are you involved in meals for (Patient)?
PROBES:
-Tell me what is involved. Take me through an actual meal, perhapes lunch or dinner last time you were here?
-(repeat above PROBES for Question 5).

7. Drinking: Do you help (patient) with fluid drinking?
PROBES: (repeat as Question 5).

8. Dressing: Do you help (patient) with dressing?
PROBES: (repeat as Question 5).

9. Walking: Do you help (patient) with walking?
PROBES: (repeat as Question 5).

10. Medications, Shots or Dressing Change: What about medications, shots or dressing change? Are you involved in these activities?
PROBES: (repeat as Question 5).

11. Bathing: Do you ever help (Patient) with bathing?
PROBES: (repeat as Question 5).

12. Hair Care: Do you help (Patient) with hair care?
PROBES (repeat as Question 5).

13. Skin Care: Do you help (patient) with skin care?
Probes (repeat as Question 5).

14. Bowel or Bladder Accidents: Do you ever have to help (Patient) because of bowel or bladder accidents?
PROBES: (repeat as Question 5).

15. Behavioral Problems: Does (patient) ever have behavior problems, for example, confusion, crying spells, wandering off, yelling or hitting?
PROBES:
-Tell me what that's like. How do you handle that?
-(repeat as Question 5).

16. Bedtime: Do you ever participate in the bedtime care for the (patient)?
PROBES: (repeat as Question 5).

17. Enjoy and Look Forward To: Are there any other things that you do to comfort (patient) or for his/her pleasure, that both you and (patient) enjoy and look forward to?
PROBES:
-Please describe, in as much detail as possible.

18. Something else do you do to help (patient)?

19. Do you worry about your relative during his/her hospitalization? If so, what are your worries?

III. Relationship With Nurses

1. Have there been any problems related to your participation in the care of your elderly relative during his/her hospitalization? Can you tell me about some time(s) when this happened?

2. In your opinion, what is the best way of handling the issues or problems you mentioned above?

3. Are you participating in the way you would like to be?
(more, less, nature of tasks)
Probe: how could nurses help you participate in the hospital care of your relative in the way you'd like to participate?

4. Tell me about a time when the nurse was helpful...

5. Tell me about a time when the nurse was not helpful...

6. Are there other question that you think I should ask regarding family participation in the hospital care of elderly patients?

Thank you very much for participating in this interview.

SECOND INTERVIEW BY PHONE WITH FAMILY MEMBER

Hello! Mr./Mrs./Ms. __________, my name is Hong Li. I am doing a study about family paticipation in the care of hospitalized elderly relatives. I talked with you when your relative was in the hospital recently, and you agreed to participate in this second interview. This interview will take about 15 minutes of your time on the phone. I will ask you questions about the care you received from your relatives, and what kinds of things you would prefer your relative and nurses to do, to assist you when you were discharged from hospital. Would you like to answer my questions now or another time? It is up to you.

1. How did your day go when (patient) was discharged from the hospital? What kinds of things did you do as part of the hospital discharge?

2. Did anything else come up after our first interview regarding your paticipation in the (patient's) hospital care?

3. Looking back over the hospitalization, what things did you worry most about?

4. Do you think your participation in the (patient's) hospital care made difference to the patient? yourself? nurses? and the hospital?

5. What advice would you give to other families who have an older relative in the hospital and are thinking about whether they want to participate in the hospital care of their relative?

Thank you very much for participating in this study!

Patient ID # Qual_____

PATIENT INTERVIEW

School of Nursing
Oregon Health Sciences University
Portland, Oregon 97201

Hong Li, RN, MS, Doctoral candidate

Date of Interview: ______________________

Time Begin: ______________________

Time Ended: ______________________

Interview with Patients

FIRST INTERVIEW WITH PATIENTS

1. When a patient like you is in the hospital, some family members sometimes visit the patient and sometimes participate in the hospital care of the patient. What is it like to have your family members or friends participate in your care in the hospital setting?

Probes: (1) feelings
(2) preferences
(3) who

Which family members or friends would be most likely to visit or assist you in the hospital? Please list up to five people who are the most likely to visit and their relationship to you.

	First Name/Initials	Relationship to You
1		
2		
3		
4		
5		

(4) what do they do when they visit?

Following is a list of types of help that family members might help with. Write in the initials of the people listed above. For each type of help, check ( ) the person you would prefer to help you.

Would you like this family member or friend to help out

Type of help	Name/ Init.	1	2	3	4	5	Nurse
1. eating							
2. dressing							
3. walking							
4. Bowel/bladder accidents							
5.Others							

2. Are there any parts of your care that you would not want your family members or friends to help with? Examples?

3. What are the things that you would rather have family members or friends help with instead of nurses? Examples?

4. Are there other questions that you think I should ask about family participation in the hospital care of patients?

SECOND INTERVIEW BY PHONE WITH PATIENT

Hello! Mr./Mrs./Ms. __________, my name is Hong Li. I am doing a study about family paticipation in the care of hospitalized elderly relatives. I talked with you when you were in the hospital recently, and you agreed to participate in this second interview. This interview will take about 15 minutes of your time on the phone. I will ask you questions about the care you received from your relatives, and what kinds of things you would prefer your relative and nurses to do, to assist you when you were discharged from hospital. Would you like to answer my questions now or another time? It is up to you.

1. Did any of your relative go to the hospital when you were discharged from the hospital?
If yes, who were they?

2. What kinds of things did your relative do to assist you during your discharge from the hospital?

3. What kinds of things would you prefer your relatives to do, to assist you during the process of your discharge from the hospital?

4. Is there any advice you would like to give about how family members and nurses can best help a person in the hospital?

Thank you very much for participating in this study.

Nurse ID# Qual________

NURSE INTERVIEW

School of Nursing
Oregon Health Sciences University
Portland, Oregon, 97201

Hong Li, RN, MS, Doctoral candidate

Date of Interview: ______________________
Time Begin: ______________________
Time Ended: ______________________

Interview with Nurses

1. What is it like to have family members participate in the care of elderly patients in the hospital setting?

Probes: (1) what specific activities do they do?
(2) how frequent do they help out?

For each of care activities you mentioned, indicate why you think family members participate in that activity.
(Probe: family member preferred or wanted to do; patient preferred family members to do; nurse asked family member to do; no one else to help)

Care Activities	Explanation of why family member did activity
1.eating	
2.dressing	
3.walking	
4.others	
.	
.	
.	
.	
.	
.	
.	
.	
.	
.	

(3) feelings
(4) tell me about a situation in which a family member participated a lot in the care of one of your older patients.
(5) tell me about a situation in which a family member participated a small amount in the care of one of your older patients.

2. What are the main things that you think families are worried about during hospitalization of their older ratives?

3. Are there any things that families do not currently do to help in the hospital care of elder patients that you think would be helpful to have them participate in?

4. Are there any issues or concerns that you have about family participation in the hospital care of elderly patients?

Interview with Nurses (Continue)

5. In your opinion, what is the best way to handle the issues you mentioned about family participation in the hospital care of elderly patients?

6. What role do you think the RNs should play in helping family participate in the care of elderly patients in hospital setting?

7. Are there any hospital policess about family participation in the hospital care of patients? What are they?
   Probes: written, unwritten, way in which it should change?

8. Do you think hospital staffing patterns influence family participation in the hospital care of their older relatives? If yes, please explain.

9. Are there more questions that you think I should ask about family participation in the hospital care of elderly patients?

Thank you very much for participating in this study!

Appendix I (Part 2)

Revised Guidelines for Preliminary Interviews

Family Member ID# Qual___

FAMILY MEMBER INTERVIEW
(Addapted from Archbold & Stewart, 1991)

School of Nursing
Oregon Health Sciences University
Portland, Oregon 97201

Hong Li, RN, MS, Doctoral Candidate

Date of Interview: ____________________
Time Begin: ____________________
Time Ended: ____________________

General Probes:

1. So...
2. It seems to me you are saying
3. How are you feeling?
4. That helps me understand your situation.
5. I am glad you told me that.
6. That's very helpful.
7. I appreciate your showing me, telling me...

Interview with Family Members

Hello. My name is Hong Li. I am from the School of Nursing at the Oregon Health Sciences University.

Before we begin the actual interview, I would like for us to go over what this interview is about. Then we can get the consent forms signed and proceed with the interview. Is that okay with you?

1. EXPLAIN THE STUDY USING THE CONSENT FORM AND SUMMARIZE THE MAIN POINTS.

2. HAVE RESPONDENT READ AND SIGN THE FORM.

Do you have questions about the interview of this consent form? I would like you to sign two copies of the forms, and I will sign them too. One copy is for you to keep. I will keep the other copy for my records.

3. GIVE ONE OF THE SIGNED COPIES TO THE RESPONDENT.

I think we are ready to go ahead with the interview. It will work best if you and I can do the interview in a room that is private.

4. MOVE TO PRIVATE LOCATION.

During this interview, I will be asking you some questions about your_________ (Insert Relationship), Mr., Mrs., or Ms. _________ (Family Name of Patient). When I do so, how do you like me to refer to him/her? Would you like me to use his/her first name, family name, or just refer to him/her as your ___________(Insert Relationship)?
Caregiver reply: preference for care receiver's name____________

During this interview, I want you to be as comfortable as possible. If we need to stop and take a break, or if you need to check on _______ (patient), please let me know. Remember that you my refuse to answer any questions or discontinue the interview at any time.

Do you have any questions before we begin?

5. TURN ON TAPE RECORDER AND BEGIN INTERVIEW.

(revised on 4/21/95)

Interview with Family member

I. The General Caregiving Situation

1. Could you start by telling me a little bit about (patient) as a person, both before he/she was hospitalized and now.

II. Caregiving Experiences

When a patient stays in the hospital, some family members want to participate in the hospital care of the patient, some family members may not. What is it like for you to be a family member of an elderly patient during during his/her hospitalization?

Now I'd like to ask you about some of the things you do to help (patient). I am interested in how your day goes in caring for (patient) in the hospital. In answering these questions, imagine that I am coming in to take care of (patient) and you want to make sure that I understand how to do things your way.

1. Your Day In (patient)'s Admission?

2. Your Day In Emergency Room with the (Patient)?

3. Your Day In Intensive Care Unit with the (Patient)?

4. Your Day Yesterday (on the regular unit)?

Would you please describe to me what your day yestreday was like? or the last day you were here.

PROBES;

-Would you please describe to me what it was like the last time you provided care for (patient)?

-Was this a typical day?

-Is that your typical schedule?

5. Getting Up in the Morning

What exactly do you do to help (patient) when he/she wakes up in the morning?

PROBES:

-Tell me what is involed. How are you involved?

-If you are invoved in the morning care, would you please explain why you do these activities (you preferred or wanted to do; patient preferred you to do; nurses asked you to do; or no one else to help)

-How does that go for you?

-How does that go for him/her?

-How do you think (patient) feels or reacts at this times?

-What information would you like to have nurses know if you are not here for (patient's) morning care?
-What information did you learn from nurses regarding the morning care?
-What do you worry about his/her morning care? (When you are here or at home?).

6. Meals: Are you involved in meals for (Patient)?
PROBES:
-Tell me what is involved. Take me through an actual meal, perhapes lunch or dinner last time you were here?
-(repeat above PROBES for Question 5).

7. Drinking: Do you help (patient) with fluid drinking?
PROBES: (repeat as Question 5).

8. Dressing: Do you help (patient) with dressing?
PROBES: (repeat as Question 5).

9. Walking: Do you help (patient) with walking?
PROBES: (repeat as Question 5).

10. Medications, Shots or Dressing Change: What about medications, shots or dressing change? Are you involved in these activities?
PROBES: (repeat as Question 5).

11. Bathing: Do you ever help (Patient) with bathing?
PROBES: (repeat as Question 5).

12. Hair Care: Do you help (Patient) with hair care?
PROBES (repeat as Question 5).

13. Skin Care: Do you help (patient) with skin care?
Probes (repeat as Question 5).

14. Bowel or Bladder Accidents: Do you ever have to help (Patient) because of bowel or bladder accidents?
PROBES: (repeat as Question 5).

15. Behavioral Problems: Does (patient) ever have behavior problems, for example, confusion, crying spells, wandering off, yelling or hitting?
PROBES:
-Tell me what that's like. How do you handle that?
-(repeat as Question 5).

16. Bedtime: Do you ever participate in the bedtime care for the (patient)?
PROBES: (repeat as Question 5).

17. Enjoy and Look Forward To: Are there any other things that you do to comfort (patient) or for his/her pleasure, that both you and (patient) enjoy and look forward to?
PROBES:
-Please describe, in as much detail as possible.

18. How did your day go when (patient) was discharged from the hospital? What kinds of things did you do as part of the hospital discharge?
-Tell me the details about what happened on the day (patient) was discharged from hospital?
-When was your relative discharged from hospital?
-What did you do for him during the discharge procedure? and rationale?
-How did that go for you?-How did that go for him?
-How do you think the (patient) respond to your help during discharge?
-What information did you learn from the nurses about how you should take care of the patient at home?
-On discharge, what did you worry about? (7/12/94)

19. Something else do you do to help (patient)?

*20. What things do you think about when you participate in your relative's care in the hospital?
*Probes: tell me about the time when you did...
what can make it different in term of your participation?

21. Are there any other things concerning your relative that you worry about during his/her hospitalization? If so, what are your worries?

22. Looking back over the hospitalization, what things did you worry most about?

23. Do you think your participation in the (patient's) hospital care made difference to the patient? yourself? nurses? and the hospital?
(Revised after F04 interview) -helpful or not helpful?
-in which way?

24. What advice would you give to other families who have an older relative in the hospital and are thinking about whether they want to participate in the hospital care of their relative?

III. Relationship With Nurses

1. Have there been any problems related to your participation in the care of your elderly relative during his/her hospitalization? Can you tell me about some time(s) when this happened?

2. In your opinion, what is the best way of handling the issues or problems you mentioned above?

3. Are you participating in the way you would like to be?
(more, less, nature of tasks)
Probe: how could nurses help you participate in the hospital care of your relative in the way you'd like to participate?

4. Tell me about a time when the nurse was helpful in terms of your participation in the hospital care of your relative.

5. Tell me about a time when the nurse was not helpful in terms of your participatioin in the hospital care of your relative.
-in which way (shortage of nurses) effect your participation?

*6. How do nurses get along with you? How do you get along with nurses and how do tou get along together?

*7. In general, what do you think nurses should do to help family members to participate in their elderly patients' care in the hospital?

8. Are there other question that you think I should ask regarding family participation in the hospital care of elderly patients?

Thank you very much for participating in this interview.

____Patient ID # Qual_____

PATIENT INTERVIEW

School of Nursing
Oregon Health Sciences University
Portland, Oregon 97201

Hong Li, RN, MS, Doctoral Candidate

Date of Interview: ____________________________
Time Begin:___________________________________
Time Ended: __________________________________

Interview with Patients (Revised 4/21/95)

1. Who has come to visit you while you have been in the hospital?
   -How often do they visit you?
   -Where do they live?

2. Tell me about the kinds of things you have needed help with while you have been in the hospital? (for example, have you needed help in taking a shower or changing clothes or talking to the doctor or nurses?)

3. Of the things you need help with, which ones have your family members helped out with while you have been here in the hospital?
   -Are there any other things your family members do to help you? (What about your husband, wife, daughter, etc. What does each one do to help?)

4. Of those things you have needed help with, are there some things that you prefer to have your family help with and are there other things you would not want your family members to help with?
   -Are there some things that you prefer to have the nurse help you with rather than your family?
   -Are there any things that you would rather have family members help with instead of nurses? Examples?

5. Did any of your relative go to the hospital when you were discharged from the hospital?
   If yes, who were they?

6. What kinds of things did your relative do to assist you during your discharge from the hospital?
   7/12/94: How did you feel about assistance or lack of assistance during discharge?

7. What kinds of things would you prefer your relatives to do, to assist you during the process of your discharge from the hospital?

8. Tell me how you feel when your family members visit or help you with something in the hospital?
   -What about their visit made you feel better?
   -Did anything about their visit make you feel worse?
   -Are there any specific things they do to make you feel better?
   -Are there any special things your family does for you that you both count on and look forward to during this hospitalization?

9. Tell me how do you think about family memebers come to visit and help their sick elderly relatives in the hospital?
   -If it's helpful, in which way? Please give me an example.
   -If it's not helpful, tell me about that please. or how did that go?
   -Did your family member' visit and help in your hospital stay make any different to you?

10. What difference do you see between the care your received from your family member and the care you received from the nurses in your hospital stay?

11. What are the most important things that you think family members can do to help someone like you who is in the hospital?

12. Is there any advice you would like to give about how family members and nurses can best help a person in the hospital?
7/4/94 probes for question#4:
-Do you like to give advice to other family member about how can they be best help to an elderly relative in the hospital?
-What advice do you like to give them?
-Do you like to give advice to nurses about how can they be best help family members to participate in the hospital care?
-What advice do you like to give them?

Thank you very much for your participating in this study!

_______________Nurse ID# Qual_______

NURSE INTERVIEW

School of Nursing
Oregon Health Sciences University
Portland, Oregon, 97201

Hong Li, RN, MS, Doctoral candidate

Date of Interview: _______________
Time Begin: _______________
Time Ended: _______________

Interview with Nurses

*Demograghic Information

How well do you know the family? to what extend?
Have they been admitted before?
How often do you take care of this patient?

1. What is it like to have family members of (your patient) participate in the care of elderly patients (pt's name) in the hospital setting?

Probes: (1) what specific activities do they do?
(2) how frequent do they help out?
*(3) if it's helpful, in which way?

For each of care activities you mentioned, indicate why you think family members participate in that activity.
(Probe: family member preferred or wanted to do; patient preferred family members to do; nurse asked family member to do; no one else to help)

Care Activities	Explanation of why family member did activity
1.eating	
2.dressing	
3.walking	
4.others	
.	
.	
.	
.	
.	
.	
.	

(3) feelings

*Probes: what do you feel when family member is here to help?
how do you think patient's feel when he/she has visits?

(4) tell me about a situation in which a family member participated a lot or being helpful in the care of your older patients (the patient's name).

(5) tell me about a situation in which a family member is not being helpful in the care of your older patients (the patient's name).

2. What are the main things that you think families are worried about during hospitalization of elderly patient (the patient's name)

3. Are there any things that families do not currently do to help in the hospital care of elder patients that you think would be helpful to have them participate in for your patient (the patient's name)?

4. Are there any issues or concerns that you have about family participation in the hospital care of elderly patients (the patient's name)?

Interview with Nurses (Continued)

5. In your opinion, what is the best way to handle the issues you mentioned about family participation in the hospital care of elderly patients (the patient's name)?

6. What role do you think the RNs should play in helping family participate in the care of elderly patients (particular of the patient) in hospital setting?

*7. What relationship between nurses and family members in current practice? and what kind of relationship between nurses and family members would you like to see ideally in practice?

Probes: how do you relate to the family member?
how the family member relates to you?
how do you get along?

8. Are there any institutional rules or regulations about family participation in the hospital care of patients? What are they?

Probes: written, unwritten, way in which it should change?

9. Do you think hospital staffing patterns influence family participation in the hospital care of their older relatives? If yes, please explain.

*10. What factors do you think would be associated with family members' decision making in participating in the patient's care in hospital?

9. Are there more questions that you think I should ask about family participation in the hospital care of elderly patients?

*(new questiones added on meeting of 4/21/95)

Thank you very much for participating in this study!

Appendix J

Demographic Data

Demographic Data

WITH FAMILY MEMBERS

Number: ________________________
Age (year): ______________
Gender: ________________________
Race: ___________________
Relation to Patient: Son/daughter___________
Spouse___________________
Other___________________

Education Level: __________________________
Employment: _______________________________
Visit per week: ___________________
Patient's Length of Stay: ____________________
Length of caregiving: _________________________
Health: _____________________________

Demographic Data

WITH PATIENTS

Number: ______________________
Age: ______________________
Gender: ___________________
Marital status: _______________
Race: ______________________
Length of stay: ____________________
Illness condition: __________________
Sources of Admission: ____________________
Insurance coverage: ________________________

Demographic Data

WITH NURSES

Number: ____________
Age (Year): ____________
Gender: ____________
Education Level: ____________
Job Position: ____________
Length of Employment (Year): ____________

Appendix K

Communittee on Human Research Approval

(VA Hospital and OHSU)

VA MEDICAL CENTER
Report of Subcommittee on Human Studies
Meeting Date: May 4, 1994

Protocol: Family Participation in Hospital Care of Elders
Principal Investigator: Li, Hong R.N.
VA Responsible Staff Member: Burton, Debbie Ph.D., R.N.
Recommendation: ***Approval with Modifications*** (9-0) At this time the Subcommittee finds no ethical or scientific concerns with this study. A corrected consent form should be returned to Research Service (151P) with the following modifications:

1. On all consent forms:

   Under ***Study Purpose*** (page 1, para. 1, line 5) **delete the sentence** This study will last about one year.

Please highlight any changes on the consent form and/or protocol if applicable and return to Elizabeth McElligott at VAMC (151-P)

OREGON
HEALTH SCIENCES UNIVERSITY
3181 S.W. Sam Jackson Park Road, Portland, OR 97201-3098
Mail Code L106, (503) 494-7887 Fax (503) 494-7787

Institutional Review Board/Committee on Human Research

DATE: May 25, 1994

TO: Hong Li, MS 7c-VA
Barbara Stewart, Ph.D.

FROM: The Committee on Human Research mwhite

SUBJECT: ORS#: 3596
TITLE: Family Participation in Hospital Care of Elders.

This confirms receipt from you of the revised consent form(s), and/or answers to questions, assurances, etc., for the above-referenced study.

It satisfactorily meets the recommendations made by the Committee on Human Research. The proposal to use human subjects is herewith approved. It is requested that the date of this memo be placed on the top right corner of the first page of the consent form. This is the approval date of this revised consent form.

Investigators must provide subjects with a copy of the consent form, keep a copy of the signed consent form with the research records, and place a signed copy in the patient's hospital/clinic medical record (if applicable).

Approval by the Committee on Human Research does not, in and of itself, constitute approval for implementation of this project. Other levels of review and approval may be required, and the project should not be started until all required approvals have been obtained. Also, studies funded by external sources must be covered by an agreement signed by the sponsor and the Oregon Board of Higher Education.

If this project involves the use of an Investigational New Drug, a copy of the protocol must be forwarded to the Pharmacy and Therapeutics Committee (Pharmacy Services - Investigational Drugs, OP-16A).

Thank you for your cooperation.

OREGON
HEALTH SCIENCES UNIVERSITY
3181 S.W. Sam Jackson Park Road, Portland, OR 97201-3098
Mail Code L106, (503) 494-7887 Fax (503) 494-7787
Institutional Review Board/Committee on Human Research

DATE: June 16, 1995

TO: Hong Li, MS VAMC 7C-VA

FROM: Dawn Goodman Dawn
Committee on Human Research L-106

SUBJECT: ORS# 3596
TITLE: Family Participation in Hospital Care of Edlers.

This confirms receipt and approval of the following materials:

3 corrected consent forms

Thank you for making the suggested changes. It is requested that the new date of this memo be placed on the top right corner of the first page of the consent forms. This is the approval date of these revised consent forms.

Thank you for your cooperation.

Appendix L

Support for the Analysis in Interview Data Bits: Family Participation Actions

FAMILY PARTICIPATION ACTIONS

DEFINITION: The concept of family participation actions refers to the caregiving actions performed by a family caregiver including verbal and nonverbal interactions with the patient, health care team (HCT) and other family members in the hospital setting for the purpose of maintaining continuity of life patterns for the patient and family.

1100. Providing Care to Patients

The first dimension, family providing care to patients, includes four categories: (1) being there; (2) performing usual family practices in the hospital; (3) providing passage between home and hospital; and (4) attending to the patient's personal care. The above four categories were grouped into the same dimension because they are all the caregiving actions performed for the patient by a family caregiver.

1110. Being there

DEFINITION: This category refers to the family caregiver's presence with the patient for varying lengths of time, sometimes lasting all day or around-the-clock. The caregiver's presence conveys that there is somebody who cares for and supports the patient. It serves as a foundation for family actions and continuity of life patterns during the hospital stay as well as having inherent value itself. The actions include being present staying there with the patient, and waiting for the patient during treatment.

F--P	F07 P4 29-31	"I don't know what I could say I did to help him that day. Just hope the presence was soothing"	-I hope my presence was smoothing to my family member
F--P	F011 P1 46 P2 1-3	"So I stayed with him a lot, around the clock"	I stayed with him or her around o'clock
F--P	F011 P2 12	"I went to see him and stayed with him everyday	I..stayed with him every day
F--P	F011 P3 20-21	"So I stayed with him through that stay in the hospital"	I stayed with him through his stay in the hospital
F--P	F011 P4 22-26	"We were there from 2:00 in the morning until 8:00 in the morning at the	I was there with my family member during admission

		University. Then we came down here and we were in the hospital from about 8:00 in the morning in the Emergency Room, until about, didn't get up to the room until about 4:00"	I stayed with my family member while we waited to get into the room
F--P	F011 P6 29	"I come every day. I come in at 7:00" in at...	-I come every day
F--P	F011 P8 46	"I leave around 7:00"	-I leave late
F--P	F011 P9 3-4	"Yeh, 7:00 to 7:00. If the kids come, I don't get out until about a quarter to nine"	-On a typical day when you are here, how long are you here from when to when? ___Am to____Am Pm Pm hospital
F--P	F011 P18 4-5	"I feel that if by being here I can get things done for him"	-By being there, I can get things done for My family Member
F--P	F07 P3 30-35	"Well I got to go with him until they took him at quarter to twelve. So I was in the same room all the time.	-I companies my family member all the time until the nurse took him or her to surgery -I waited in the surgical area during the time of my family member's surgery
F--P	P07 P3 3	"Her mother was there all the time"	-My family member is being with me all the time
F--P	F07 P4 45-47	"He know we were there	-My family

		and talked to us"	member knew I was there when he or she came back from recovery room
F--P	P06 P1 11-14	"I'd say, she was there every day"	-My family members visited Everyday
F--P	N01 P1 21-23	"Well we've had variety of people. We've had some that just come and, you know, sit at the bedside and they're with the person,"	-Family member just come and sit at the bedside being with the patient
F--P	N01 P2 38-42	"We have others that Come here every day".	
F--P	N01 P5 38-46	"The situation. We have a gentleman right now on the floor that, how old, I don't remember how old he is. He's probably in his middle to late 60s. Who I think is of a Spanish descent. Who has a very supportive family. His wife and the daughters of some combination are here every night that I am here. It's only Monday and Tuesday, but they're here every night that I'm here. And they're here on typical hours at his bedside".	-Family members are here on typical hours at their sick relative's bedside
F--P	N02 P1 20-24	"They are very dedicated most of the time. They're usually here at the crack of dawn. They come in at, you know, 6:00 and they don't go home until the day is over. So they are usually tired. But	-Family members come here and stay from morning to evening

F--P	N03 P1 41-44	"[Family members] being there"	Family member is being there
F--P	N06 P2 1-10	"She stay there. Most when I've been there she has been. She comes in the late morning and stays the rest of the day" "She was always with him and helped him whenever she could"	-Family member stays with the patient whole day -Family member stays with patient
F--P	N07 P1 36	"And keeping him company"	-Family member keeps the patient company

1120. Performing usual family practices in the hospital.

DEFINITION: This category refers to actions performed by family caregivers including verbal and nonverbal interactions for the patient's well-being and maintenance of their family relationships. Action sub-categories are (a) maintaining linkages, (b) doing enjoyable activities, (c) providing reassurance, and (d) engaging in religious practices.

1121. Maintaining linkage

DEFINITION: This sub-category refers to actions performed by caregivers in connecting the patient with everyday life and the outside world. The actions include talking and chatting with the patient by phone or in person, calling other family members and arranging for other family members to visit according to the patient's preferences, and using reading materials such as newspapers, magazines, and books.

F--P	P021 P4 22-25	"She later went back At about, she stayed here about three or four hours. Then she left and went back. and now she's coming again today"	-My wife stay with me
F--P	P011 P2 36-42	"(My wife, daughter), granddaughter, and son-in-law came to visit me"	-My family members came to visit me
F--P	P011 P3 31-35	"(My daughter has been) come to visit me every other night.	-My daughter come to visit me pretty often
F--P	P021 P2 20-34	"(My wife, son-in-law), my daughter visited me"	-My family members visited me
F--P	P031 P1 39-41	"Just my husband (come to visit me). I told him, I said not to come until I'd been here a few days. My son's coming this afternoon. My son's family will be coming eventually, but I said not to rush them"	-My family member come to visit me as much as I wanted them to
F--P	P051 P1 3	"My wife, son, and	-My family

		daughter-in-law (came to visit me)"	members come to visit me
F--P	P051 P3 1-3	"There wasn't anything to do that I know of. He mostly visited"	-My family member visited me
F--P	P06 P1 3-6	"My daughter and granddaughter. My wife, of course. My daughter-in-law, two daughter-in-law. My brother (came to hospital visited me)"	-My wife and extended family members came to visit me
F--P	P06 P1 11-14	"About every day three days my daughter would he there. My brother would be there probably every four days or something"	-My family members visit Me a lot
F--P	N01 P2 38-46	"We have some, some family members that come in and they maybe come in once a week, like on a Sunday or something. And they just visit for a little bit and talk with the person. Maybe take them outside a little"	-Family member varies on how freq. They come To visit
F--P	F011 P9 29-30	"They talk with him.	-I talk with my family
F--P	F06 P3 44-46	"Some of the time, yes, when he was not too tired to talk. And read books, things like that"	-I talked with my family member when he or she was not too tired to talk
F--P	N02 P2 8-9	"Well they talk to them (patients) a lot"	-Family member talks to patient
F--P	F011 P16 4-7	"I make sure I call [relatives] from the hospital here so he can talk to them"	-I call relatives from the hospital so he or she can talk to them

F--P	F021 P5 27	"I called him from my home up here just to check on him"	-I called my family member from my home up here to check on him
F--P	F031 P2 24-27	"Chatter. That's about it. Told her what was happening at home and things like that, you know. Calling her oldest girl and telling her. She's down in California, our oldest daughter and our son"	-I chatter with my family member -I told my family member what was happening at home and things like that -I called my children who are not in the town and let them know what's going on with my family member in the hospital
F--P	F06 P5 47-48 P6 1-5	"Yes. In the last two days, he would like to have visitors in the last few days" "We have his brother here, and his brother lives 100 miles from here. And the daughter in law has the baby with the operation and they come to visit"	-We have visitors here when my family member feels ready for it
F--P	P011 P3 21	"We talk about other relatives that are too far away to see"	-We talked when I have visitors
F--P	P031 P1 9-10	"My daughter called me [patient] from California"	-My family member called me from outside town
F--P	P031 P2 31-33	"And he (my husband) there and doze off. But he will tell me the news and what's going on at the house and how's my daughter	-My family member just sit there -My family member tell

		doing with cooking the meals. And he will tell me these things, which I worry about"	me these things which I worry about
F--P	N07 P2 18	"Talked to him" (Family members talked to the patient)	-Family member talked to patient
F--P	OB1 P2 40-45	"There are several cards hang on the wall. One of them from the patient's daughter on which wrote: What this card remind you eating, please Dad, I love you". One of the hand made card from his granddaughter. Another one from his son and one from his friend.	-Family member sends get well cards to patient -Family member posted get well cards on the well where the patient can see
F--P	F07 P7 29-32	"Sometimes when he was awake I would read little articles that I thought would be of interest to him"	-I read little articles from newspaper which I thought would be interest to my family member when he or she is awake
F--P	OB7 P2 20-30	"P07 is resting. F07 is sitting in her chair and reading the Oregonian newspaper. N07 stood up and pointed a news to her husband. P07 opened his eyes and listening to her reading to her husband. P07 opened his eyes and listening to her reading."	-Family member sits with the patient -Family member read the newspaper to the patient

F--P	F06 P5 42-43	"I gave him books, he read them in the last two days"	-I brought in books for my family member to read
F--P	F06 P6 28-32	"So I went down brought him magazines"	-I brought magazines for my family member
F--P	F07 P7 36-40	"I would take a paper from here each day. I mean, when I went up in the morning I would take the paper that we'd gotten the day before so I could see what was going on here" (The family caregiver reads article from the newspaper to her husband)	-I brought a newspaper every day with me to hospital

<u>1122. Doing enjoyable activities</u>

Definition: This sub-category refers to pleasant or meaningful actions conducted by either the family caregiver or both caregiver and patient based on a history of home experience to enrich everyday life during the hospital stay. Enjoyable activities tend to be specific to the individual.

F--P	F011 P11 30-31	"Well, I'm looking forward to taking him outside again.... And I did take him downstairs yesterday to the canteen, Brought him a small bag of popcorn" (The patient wanted the popcorn and the wife brought it to him as a gift)	-I take my family member to other parts of the hospital for an enjoyable activity
F--P	F021 P4 40-42	"Well see they let him go home last Friday and then I brought him back Monday" (Pt. enjoyed going home on the weekend	-I took my family member home for short period of time with Doctor's permission and I brought him or her back
F--P	F041 P5 8-10 37-40	"I got him to go down to the Rec Room and shoot pool... It was something he was looking forward to" "That's about the only happy thing he's done in the last few year... I think it was very much fun for him"	-I helped my family member to do something he or she was looking forward to
F--P	F07 P12 29-39	And so we sat in the visitors lounge a long time where we could look out over the river"	

F--P	P011 P4 37-46	"The other night we were down on the first floor to a wheelchair party"	-My wife pushed me in a wheelchair to go downstairs for something enjoyable
F--P	P012 P3 18-20	"They [his son's family] come down to the hospital and picked me up. It takes about 2 or 3 hours. We went to Eugene and went to this lake down there and we fished (on Father's day" (The patient likes fishing)	-My family members took me out for an enjoyable activity
F--P	P021 P7 28	"My daughter brought me a hamburger" about everything she can do, you know"	-My family member brought me a some food from outside
F--P	P031 P2 30-31	"He (my husband) brought me flowers"	-My family member brought me flowers
F--P	N02 P4 36-40	"Yes. Actually quite a few people make a big to do over the birthdays. Father's Day was a big day. And they usually, they have like a big banner and bring in the whole family. Including the kids. I've seen lots of kids, young kids. Even before their first birthday"	-Family member celebrate meaningful days with patient at the bedside
F--P	N03 P3 18-23	"Yes. Sometimes they bring in a lot of things. Sometimes they bring in nothing for a special event. Other times they decorate the whole room and bring presents and cakes. And sometimes	-Family member brings in a lot of things -Family member celebrates

		other people come. I've seen a few very celaborate birthdays. I've seen many where they do something and I've seen many where dthey o nothing. So I've seen all kinds."	the special event for the patient at the bedside
F--P	OB1 P3 21-28	"A cookie jar on the patient's bedside. The wife told me that she brought it for her husband for the gift long time ago. The jar is white color and looks like a cow. When open the lid, it can make noise like a cow. The patient likes it a lot and are very familiar with it. This was the reason she brought it at his bedside.	-Family member brings in meaningful items from home
F--P	F011 P10 17-23	"Today is my birthday. And he wants to take me out, wants me go out for dinner with him.	-My husband wants to take me out for dinner on my birthday
F--P	F041 P14 36-48	"I don't know of anything in particular, other than the pool thing. Seems like that's kind of excited him the last couple of days. Oh, maybe watching football games. He kind of likes that. So I would think that maybe he would look forward to doing that with me. Or bowling. He likes sports, and every now and then they bowling on television. I know that he would like me to be able to sit down and watch that with him, something	-I found there is particular thing that my family member would look forward to doing that with me

		like that"	
F--P	P011 P3 38-39	"And we go to town to eat in a restaurant"	-We go to town to eat in a restaurant
F--P	P011 P4 1-5	"As a matter of fact, today is my wife's birthday. And we're going out for dinner"	-We go out for eat dinner on my wife's birthday
F--P	N01 P2 24-29	"We've had people that have brought in like a family pet or they've taken their family member downstairs to see the pet if it's in the car. Which I think is emotional helpful at times for the person if they're very attached to one of their pets".	-Family member brought in family pets for emotional support
F--P	OB1 P3 4-8	"When do we have to leave at supper?" the patient asked. (today is the wife's birthday, they are going out for dinner). "About 5pm" the wife said. "Is the kid go with us?" the patient asked. "They can't make it" she said.	-Family member talks with the patient

1123. Providing reassurance

DEFINITION: This sub-category refers to actions performed by family caregivers using verbal or non verbal behaviors to help put the patient at ease. The actions include explaining what HCT were trying to do for him. Reassure him that he was going to get, and physical contact with the patient.

F--P	F011 P4 31	"I just more or less tried to keep him calm"	I tried to keep him calm
F--P	F011 P4 35-36	"Tell him what they were trying to do for him. Reassure him that he was going to get help"	I told my family member what they are trying to do for him or her I reassured my family member that he/she was going to get help
F--P	F011 P14 16	"When he dozes off, he will talk, call me. And I just reassure him I'm there"	-I reassure him or her I'm there
F--P	F06 P4 4-5	"I held his hand one day after he..."	-I held my family member's hand
F--P	N03 P1 41-44	"[Family members] talking to them [patients] and reassuring them"	-Family member talks to patient
F--P	N03 P1 41-44	"and reassuring them" (family caregivers reassure the patients)	-Family member reassure the patient
F--P	N01 P2 20-21	"Actually being supportive to the patient mentally"	-Family member provide mental support to patient"
F--P	OB7 P2 8-9	"Wait and see, the meds will work" F07 said.	-Family member assures the patient

1124. Engaging in religious practices

DEFINITION: This sub-category refers to actions performed by family caregivers by doing religious activities for the patient. Family actions on behalf of the patient are oriented toward seeking or involving religious or spiritual resources. The actions include praying with or for the patient, or reading the Bible or other religious writings to the patient

F--P	F011 P9 30	"They pray with him so that he can get better"	-I pray with him so that he can get better
F--P	F041 P10-18	"I've been reading the Bible to him while he eats breakfast. Help prepare him for eternity. ... And so I've been praying for him and encouraging him spiritually"	-I've been praying for my family member
F--P	P011 P3 30-31	"She (the patient's daughter) and her husband pray for me"	-My family members pray for me

1130. Providing passage between home and hospital

DEFINITION: This category refers to caregiving actions performed by family caregivers including gathering up patients and their medications and belongings during both the admission and discharge process as well as the hospital stay, bringing in and taking back patients and their personal belongings, and helping the patient to physically settle in during admission.

1131. Gathering up

DEFINITION: This sub-category refers to caregiving actions performed by family caregivers in managing patients, organizing their personal belongings, and collecting medications during the discharge process.

F--P	F032 P1 1-2	"And got all her stuff organized"	-I got all his or her Stuff organiaed
F--P	F012 P1 26-28	"and then make sure that I got other things I needed to take home with"	-I made sure that I got other things I needed to take home with
F--P	F012 P2 20-22	"Just loaded all the stuff he had accumulated while we were here.	-I loaded all the stuff he had accumulated While we were In the hospital
F--P	F042 P1 20-23	"I helped Dad get his belongings together"	-I helped my get his or her Together
F--P	F06 P8 40	"I got his clothes"	-I got my family member's
F--P	F07 P15 15-29	"I went in and the nurse came and said: Get him dressed. She would do it or I could do it. So I said: Well, we can do it"	-Nurse offered me care options for my family member during discharge

F--P	F07 P15 15-29	"When we got him all dressed, ..."	-I helped my family member get dressed during discharge
F--P	P022 P1 42	"Well she gathered my stuff up" [to go home]	-My family member gathered my staff up
F--P	P022 P2 1-2	"She got my clothes and got ready and everything.	-My family member helped me to get ready for discharge
F--P	P022 P2 23-25	"My wife, she gathered all my clothes. Laundry and staff like that. Got them all before she left and took them down and put them in the car you know, stuff in the car"	-My family member gathered my stuff and put them in the car
F--P	P052 P1 23-26	"She got my clothes all gathered up and gathered up all my hardware and got all my medicines together. Helped put all the things in the bag"	-My family member gathered up my clothes and medications when I was being discharged
F--P	P06 P4 43-50	"They have to go get the clothes" [when the patient was being discharged]	-My family member gathered my clothes up
F--P	OB6 P1 6-9	"I asked the patient where was his wife, he told me that his wife moved some of his personal belongings to the car, and she would be back later"	-Family member helps the patient to gather his or her personal belongings and parked them in the car

F--P	OB6 P2 23-26	"N06 left the room, and CNA came with a wheelchair to take patient down stairs. F06 and their friend gathered the patient's bags and followed the wheelchair and left.	-Family member carries patient's bag to the car
F--P	F07 P15 1-4	The nurse said... one of us could go to the pharmacy and pick up his prescriptions"	
	P15 11-15	"My daughter went to the pharmacy and picked up the prescriptions"	-I went to the pharmacy and picked up the prescriptions for my family member
F--P	P012 P1 12-13	"She picked up the medication from the pharmacy"	-My wife picked medication from the pharmacy
F--P	F012 P1 39-41	"I took the prescription down to the pharmacy and filled"	-I took the prescription down to the pharmacy and r

1132. Bringing and taking

DEFINITION: This sub-category refers to caregiving actions performed by family caregivers in transporting patients and their personal belongings during admission and discharge process as well as the hospital stay.

F--P	F032 P1 35-36	"Just went down to the car and drove her home"	-I went down to the car and drove my family member home
F--P	F032 P1 1-2	"Just to see she got Home"	-I made sure My family Member got home
F--P	F012 P2 20-22	"Then I took him done with the wheelchair"	-I took him out with the Wheelchair
F--P	F011 P2 28	"We went to take him to the hospital"	I took him to the hospital
F--P	F011 P3 6	"I brought him home"	I brought him home
F--P	F011 P4 8	"I brought him in to the Emergency Room"	I brought him to the Emergency Room
F--P	F042 P1 20-23	"And took him home"	-I took my Family member Home
F--P	F06 P8 42	"I took him home"	-I took him or her home
F--P	F07 P15 17-29	"And so, the nurse helped us to the door but the daughter had to go for the car. So it was going to take her a little time so she called and had an aid come, or went back and got an aid come and stay with us and bring us to the car.	-I helped my family member to get in the car
F--P	F07 P15 1-4	"We got there, and we went into the room and saw him. so then	-I went to the hospital to get my

		I went up the desk and said that we are here to get him.	family member home
F--P	P012 P1 12-13	"She drove me home"	-My wife drove me home
F--P	P021 P4 22-25	"My wife brought me up here and brought me back. Brought me up at 10:00"	-My family member drive me back and Forth
F--P	P022 P1 23	"My wife and daughter come and got me (on discharge day)"	-My family members come to pick me up on the discharge day
F--P	P031 P1 45	"My son brought me here"	-My family member took me to the hospital
F--P	P031 P2 3	"He probably will take me home"	-My family member takes me home
F--P	P032 P1 11	"My husband (come to pick me up on discharge day)"	-My family member comes to pick me up
F--P	P032 P1 23-24	"He just carry my bag on and drove me home"	-My family member helps me to carry my bag and drove me home
F--P	P052 P1 4	"My wife come and picked me up"	-My family member comes and picked me up
F--P	P06 P4 30	"She did [come in] and A friend came to drove The car"	-My family member and a friend came to hospital to pick me up
F--P	P06 P5 7-8	"She brought car around so you didn't have to go out"	-My family member brought car around and neared the door

F--P	P07 P4 17-18	"Well there aren't much they done. come and got us and that's about it"	-My family member came and drove me home
F--P	P07 P4 27-28	"Helped me get in the house when we got home"	-My family member helped me get in the house when we got home
F--P	N01 P2 5-16	"Bring in like may be things from home that are helpful like assistive devices"	-Family member bring things from home which is helpful
F--P	F021 P10 33-34	"I brought his clean pajamas and I brought him some new night shoes"	-I brought my family member some personal things he or she needs in the hospital
F--P	F031 P5 35-36	"Oh we brought some stuff. An extra set of clothing. Those pajamas are, you know"	-I brought some stuff in for my family member
F--P	F031 P5 40-42	"We brought some extra clothing for her to exchange. And I'll take back the clothes she had been wearing and my daughter will wash and I'll bring them back"	-I took back the dirty clothes and brought clean clothes in
F--P	N03 P9 8-26	"And so they are family members who come with them. They drive them here from Southern Oregon, Eastern Oregon, Montana, Idaho, Washington. And sometimes farther away than that"	-Family member drives patient to hospital

<u>1133. Settling in</u>
DEFINITION: This sub-category refers to caregiving actions performed by family caregivers in helping patients to get situated in the new places during admission process.

F--P	F041 P3 4-9	"I admitted him downstairs and brought him to the level, or up here in Geriatrics, the sixth level, that first day. And we just got him ready and put him in a room with three other people"	-I helped my family member at the Admission Office and companies him or her to the floor and bedside
F--P	F041 P3 35-40	[When he was admitted] "I think we helped him get undressed and put on his pajamas that they had given us. Yeh, we couldn't get the right size. we had to keep trying different sizes. Yeh, just whatever he needed we helped him with"	-I helped my family member get undressed and put on his pajamas -I helped my family member with whatever he or she needed
F--P	P021 P4 39	"She takes care of my clothes" [when the patient was admitted]	-My family member help me taking care of my clothes
F--P	P021 P6 26-27	"She hung all my clothing, put it in a locker" [when the patient was admitted]	-My family member help me taking care of my clothes

1140. Attending to patient's personal care
DEFINITION: This category refers to family caregivers providing care in the patient's daily activities by carrying on and modifying usual care routines from the home to hospital, and/or starting new caregiving actions during the hospital stay. These caregiving actions serve to individualize the patient's care in the content areas of (a) eating, feeding, and drinking; (b) moving and transferring; (c) bathing, showering and hygiene care, including clean up and hair care; (d) toileting; and (e) dressing.

1141. Helping
DEFINITION: This sub-category refers to verbal and nonverbal actions performed by family caregivers in facilitating the patient in their daily activities and doing things partially or completely to meet the patient's individualized personal care needs including (a) eating, feeding, and drinking; (b) moving and transferring; (c) bathing, showering and hygiene care, including clean up and hair care; (d) toileting; and (e) dressing.

F--P	F012 P3 42-44	"I just plan to do things [personal care] for him that he could not do for himself"	-I do things for my family member that he or she couldn't do for him or herself
F--P	F012 P4 4	"I just took care of his personal care"	-I take care of my family member's personal care
F--P	N02 P1 20-24	"They are usually here in the morning to help get them ready for the day"	
F--P	F041 P3 47-50 P4 1-3	"He needs help taking off these, Depends, they're called diapers that he's wearing. And he has a real hard time on and off. So I would change that for him, and have been changing, even while he was living with us"	-I helped my family member change his or her diapers

F--P	F011 P6 38-43	"I help him with the urinal ... And I take him to the bathroom if he needs a bowel movement"	-I help him with the urinal. -I take him or her to the bathroom if he or she needs to have a bowel movement
F--P	F07 P9 13-15	"I'd help him in the bathroom"	-I help my family member to go to the bathroom
F--P	P011 P5 18-19	"She takes me to the bathroom. And then she stands and assures me that I get the (commode) toilet"	-My wife helps me to the bathroom
F--P	P07 P2 20	"Helped me to the bathroom"	-My family member helped me to the bathroom
F--P	N03 P2 1-9	"Yes, sometimes they'll help them go to the bathroom. They'll help them onto the commode or	-Family member helps the patient go
F--P	F07 P12 1-5	"Well I'd put his, he wore socks a lot of times, or footies, and help him get them on and off. [And when he was up to the bathroom], I'd help him get his clothes back up and stuff"	-I help my family member with his or her socks -I'd help my family member get his or her clothes back up
F--P	P07 P2 16	"Helped me dress"	-My family member helped me to dress
F--P	N02 P1 24-26	"They help them get dressed usually"	-Family member helps pt. get dressed

F--P	F011 P10 46- P11 1-4	"His hands don't want to work good with the buttons...He's got several shirts that snap, I try to buy ones with snaps, he can snap them"	-I try to buy shirts with snaps so he can snap them because his hands don't want to work well with the buttons
F--P	OB1 P3 27-33	"F07 asked for wash clothes and a pair of pants. I went out and got some for her. F07 cleaned P07's bottom and tried to put his pants on. F07 needed help to lift P06's bottom in order to put his pants on and I assisted her, and made P07 comfortable in bed and put cover on him.	-Family member helps patient to clean up after going to bathroom -Family member helps the Family member makes the patient omfortable
F--P	F041 P10 35-40	"I mean, I might salt his food or I might put cream in his coffee, something like that. But that's about it"	-I might put cream in his or her coffee
F--P	F07 P10 5-6	"I fed him quite a bit of the time"	-I fed my family member quite a bit of the time he or she needs to be fed
F--P	P021 P7 34	"(my daughter) Get coffee or something like that"	-My family member gets me something to drink

F--P	N07 P1 34-36	"She's been feeding him and getting him things while he was on bed rest.	-Family member feeds the patient and gets him or her things while he was on bed rest
F--P	N07 P2 18-19	"She fed him lunch and ... That's all there's been a need for.	-Family member fed the patient
F--P	OB1 P3 34-38	Then F07 helped him to eat by feeding him with spoon.	-Family member feeds the patient in bed
F--P	OB1 P1 44-49	"She stood beside the table, open The lid and explained What kind of food was In the tray" [Patient nearly blind]	-Family member explains to patient what Were in the lunch tray Because the Patient's poor vision
F--P	OB1 P3 2-3	"What's this" the patient pointed the food. "Jello salad" The wife answered" [The patient nearly blind]	-Family member answers the patient's question
F--P	OB1 P2 7-11	"The wife is sitting in the chair after helping the patient set up his tray, and watching him to eat. "You got some food next to your mouth", she said. The patient used his hand to wipe it . The wife said: "you've got it".	-Family member watches patient while he or she is eating

F--P	F011 P5 41	"I helped with his feedings"	-I helped my family member with meals
F--P	F011 P6 33-34	"I help him with his breakfast. I get it all set up for him so he can feed himself"	-I help him or her with his meals I get the food all set up so he or she can feed him or herself
F--P	F011 P7 37	"I gave him lunch. I cut it up for him and he'll feed himself"	-I give him or her lunch -I cut the food for my family member;then he or she will feed him or herself
F--P	F011 P8 35	"I stay until supper and I help him with his supper"	-I stay until supper so I help him with his meal
F--P	F011 P14 16	"Hand him his glass for drinking"	-I hand him or her glass for drinking
F--P	F07 P2 44-45	"I would hold his milk and juice and sit and helping him drink"	-I help my family member drink something
F--P	F07 P3 2	"Just help him eat"	-I help my family member eat
F--P	F07 P11 43-46	"When he was laying down, it was very difficult. So he needed straw to get in" [helped drink]	-I help my family member to drink with straw
F--P	P011 P6 39-42	"She helped me feed myself for breakfast"	-My wife helped me feed myself

F--P	P031 P4 9-11	"My daughter does cut my meat and things like that. She asks me if I want it cut and if I do say yes, because she wants to do it"	-My family member help me to cut my meal if she wants to do it
F--P	P06 P3 11-19	"Well she would help me when I went to eat, you know. Feed me rather than, it was kind of a struggle to eat, in the bed particularly. I could sometimes get up and sit in the chair, so I would need aid to get in the chair. But I could eat better in the chair than I can in the bed because, didn't have to reach so far"	-My family member feed me after my surgery
F--P	P07 P2 12	"Helped me eat"	-My family member helped me to eat
F--P	N01 P1 23-28	"They help, you know, Set up their tray"	-Family member helps set up tray
F--P	N02 P1 24-26	"They help them eat if they need help with that"	-Family member helps pt. to eat
F--P	N03 P1 26-41	"For a patient who isn't, the patient who has been healthy up until the time they come into the hospital, people can help with eating, with feeding them, too"	-Family member helps patients with eating or feeding
F--P	OB1 P1 44-49	"The patient opened his eyes and said: "I am Hungry". The wife Removed his cover, and Helped him to sit up at The bedside. Then pushed The table in front of him"	-Family member helps patient to sit up at The the bedside

F--P	OB1 P2 3-6	"She put the salt in the dish and buttered the Bread. The wife put the Special spoon into his Right hand. The patient used the spoon to pick up the food into his mouth slowly"	-Family member helps the patient to set up the tray.
F--P	OB1 P2 18-20	"The patient said: 'Honey!'the wife came over to the bedside and rearranged the food in the tray' [So that the food is under where his special spoon]	-Family member helps the patient to eat by rearranging The food in tray
F--P	OB1 P2 36-39	"The patient stopped chewing and looked at her. "Hard piece" "a hard piece in my mouth" he said. The wife wiped it out with a napkin."	-Family member helps the The patient to remove a hard piece from his or her mouth
F--P	OB1 P3 13-20	"The patient lay down by himself. "All done?" the wife asked, and stood up to his bedside to help him. "Put your arms down" the wife said. The patient was grapping the trapege on the head of his bed. He put his hands down and the wife covered him with the cover sheet"	-Family member helps the patient to get comfort-
F--P	OB1 P3 34-38	"F07 holds a cup with straw to P07's mouth and helped him drink milk.	-Family member helps the patient to drink in bed

F--P	N03 P9 8-26	"That, you know, help with the bath and help with moving and help with feeding"	-Family member helps patient with bath -Family member help patient with moving -Family member help patient with feeding
F--P	F011 P5 45	"I helped with, giving showers to him"	I helped with his showers
F--P	F011 P7 6-7	"I shave him and comb his hair"	-I shave him -I comb his or her hair
F--P	F011 P16 25-27	"One thing I've noticed, not this time, I think he's still afraid to wash himself down here (gallbladder surgical insicion), so I have to"	-Because my family member is uneasy about washing around the incision, I do that for him or her
F--P	N03 P1 26-41	"Sometimes the caregiver will bathe them"	-I give bath to my family member
F--P	N03 P3 30-45	"I've seen many people give baths to the patients"	-Family member give bath to the patient
F--P	F011 P11 18	"I put lotion on him"	-I put lotion on his or her skin
F--P	F07 P14 1-8	"I had some lotion. And his feet are always so dry"	

F--P	F011 P10 17-23	"So I gave him a haircut this morning so he wouldn't look too shabby when we went out"	-I have given him a hair cut before we went out for my birthday dinner
F--P	F06 P7 10	"I combed his hair"	-I combed my family member's hair
F--P	P011 P6 39-42	"She cut my hair this morning"	-My wife cut my hair
F--P	F011 P7 6-7	"I help him brush his teeth. He brushes them, but I got to hold him"	-I help my family member brush his or her teeth -When my family member brushes his or her teeth, I hold to hold him or her to prevent falls -I support my family member while he or she is standing up
F--P	F041 P7 1-10	"If he's still cleaning himself when I get here, I help him a little bit, you know, find the things he wants, or spray his hair for him, or, you know, whatever. So probably when I'm not here he does more for himself than when I am here I would think. Just because he thinks it's easier for me to do it than for him to do it"	-I help my family member to find the things he wants -I spray my family member's hair for him -When I am not here my family member does more for him or herself when I am here
F--P	F07 P5 26-27	"I wash his face or, you know, give him water"	-I help my family member to wash face

F--P	F07 P5 41-50	"And then I helped him brush his teeth and comb his hair and stuff after he come back and then took his razor so he could shave"	-I helped my family member brush teeth and comb his or her hair -I brought in his razor so he could shave
F--P	P011 P6 39-42	"She helped me brush my teeth.	-My wife helped me brush my teeth
F--P	N01 P1 23-28	"They help get the person cleaned up"	-Family member helps to get the pt. clean up
F--P	N01 P6 3-6	"And they assist him with, you know, all sorts of things. From helping him, you know, probably get cleaned up .."	-Family members helped their sick relative cleaned up -Family members helped their
F--P	N02 P1 24-26	"They help them get cleaned up.	-Family member helps pt. cleaned up
F--P	P06 P5 17-18	"(My wife) helped me out of the chair"	-My wife helped me transferred from the chair to
F--P	F011 P7 21	"I help him sit up and he transfers very well to a chair without his leg"	-I help him or her to sit up
F--P	F011 P7 28	"He's got a drop foot. So we get that going and get him up"	-I help my family member to get up and get going

F--P	F06 P6 30-31	"Then helping him get out of bed to the chair"	-I heled my family member get out of bed to the chair
F--P	N01 P1 23-28	"They helped the person get out of bed"	-Family member helps the pt. get out of bed
F--P	N01 P2 21-24	"Physically helping them, out of bed like I say, get out of bed and do these kinds of things. Taking them outside and getting them out of this environment.	-Family member help patient out of bed -Family member takes his or her sick person out of the
F--P	N01 P6 3-6	"They help patient getting out of bed and into a chair and going into the bathroom"	-Family member helps patient transfer to chair -Family member helped their sick relative to go to the bathroom
F--P	N03 P1 26-41	"Sometimes, they'll help with turning"	
F--P	OB7 P3 13-15	"F07 started to straighten the patient's bed sheet"	-Family member straighten the bed sheet for patient's comfort
F--P	F041 P16 2-7	"Like taking him for a walk"	-I took my family member for a walk
F--P	F06 P5 38	"I assisted him walking"	-I assisted my family member with his or her walking
F--P	F041 P3 35-40	"I put him in a wheelchair and helped him physically up to the sixth floor"	-I helped my family member transferred him to floor

F--P	P051 P2 29-30	"She wheels me up and down the hallway"	-My family member wheels me up and down the hallway
F--P	OB1 P1 17-20	"The wife unlocked the patient's wheelchair, and pushed the wheelchair back to the patient's room through the hallway. Then turning to the left corner to the patient's room"	-Family member pushed the wheelchair and sent patient back to the room
F--P	OB1 P1 26-38	"The wife pushed the wheelchair to the bedside, removed the blanket from his lap (the patient's left leg was amputated under the knee). Then she helped the patient to grab the rail of the bed with his one hand, she stood in front of him and supported his another arm. The wife said: "Okey! (pt.'s name)". The patient stood up and turned his body to sit in the bed with the help of his wife. He then laid down with his wife's help his wife picked up his legs to the bed)."	-Family member helps patient to transfer from the wheelchair to the bed -Family member helps the patient to cover patient
F--P	OB1 P3 39-52	"About 12:40, ... The wife went to his bedside, and open the cover sheet. The patient sit up with holding the trapege. The wife put his broots on his right foot first, and then put his left half leg on (very skillful). The patient asked:"You got it on?" "Yes" the wife	-Family the bed Family member helps the patient to transfer to the wheelchair

		said. "Now stand up for me". The patient stood up with the help of his wife and transferred to the wheelchair. The wife put both of his legs on the wheelchair. Then put a blanket on his lap."	-Family member puts a blanket on patient's lap to keep him warm
F--P	F06 P8 26-33	"Always like keep his hair combed and he had sweating times and I used the wet cloth to wipe and keep him comfortable.	-I always keep my family member's hair combed -When my family member had sweating times and I used the wet cloth to wipe -I help my family member to get comfortable
F--P	P021 P8 3-4	"They both help me. Both (wife and daughter) of them are very good to me. Say one does more than other. They really help"	-My family members help me
F--P	P022 P2 35-37	"My daughter, she helps quite a bit. She'll help me without any trouble at all. And my daughter-in-law too, she helps us"	-My other family members help me too

1142. Encouraging

DEFINITION: This sub-category refers to family caregivers using verbal and nonverbal actions to reinforce or motivate the patients in performing their daily living activities for independence or behaviors leading to more health or independence. The actions include reinforcing patients' eating and moving.

F--P	F041 P10 35-40	"We don't force him, but we do encourage him (to eat as much as he can). But we don't help him eat".	-I encourage my family member to eat as much as he or she can
F--P	F041 P5 37-40	"I didn't have to persuade him to get out of bed and go down there (to shoot pool). [It was something he was looking forward]"	-I encourage my family member to get out of bed by doing fun thing with him
F--P	F07 P10 25-50	"I'd say: why don't you have this or why don't you have that. And just kind of pushed it on him"	-I pushed food and liquid on my family member
F--P	OB1 P2 21-30	"Try some jello salad" the wife feed him a spoon of jello into his mouth. "No more" he said, "No more, I don't like it". "Try some meat" the wife said"	-I encourage my family member to eat
F--P	OB1 P3 13-20	"The wife sitting in the chair and said: "eat the bread with butter on it".	-Family member encouraged patient to eat
F--P	OB7 P2 3-6	"P07 still closed his eyes and lying in his bed. F07 walked to pt's left side and looking at he menu and food. "We should feel hungry, the food looks good" F07 said to P07"	-Family member encourages patient to eat
F--P	F041 P6 44-45	"I had to encourage him to get out of bed"	-I encouraged my family member to get out of bed

1143. Doing little things

DEFINITION: This sub-category refers to verbal and nonverbal actions performed by family caregivers in being comforting to the patient and attending to patient's detailed individualized care needs as desired by either the patient or the family caregiver.

F--P	N03 P1 41-44	"Often a big help is just being comforting to the patient... and doing little things for them"	-Family member is being comforting to the patient -Family member is doing little things for the pateint
F--P	F07 P7 18-20	"And get anything whenever he needs it"	-I get anything whenever my family member need it
F--P	P051 P2 38-39	"She got me whatever I need"	-My family member helps me with whatever I need
F--P	P011 P4 29-33	"Well, (my wife) just put this thing (a blanket) on my lap. It's warm"	-My wife put a blanket on my lap to keep me warm
F--P	P07 P3 3	"They (my daughters) did run errands"	-My family member run errands

1200. Working together with health care team

The second major dimension of Family Participation Actions refers to verbal and/or nonverbal caregiving actions performed by family caregivers in interacting with the health care team and serving as a team member.

1210. Exchanging information between family & health care team

Definition: Refers to verbal and/or nonverbal actions performed by family caregivers in exchanging information between family caregivers and health care team members.

1211. Family to health care team

DEFINITION: This sub-category refers to verbal and nonverbal actions performed by family caregivers in presenting information based on their experiences of caring for or living with the patients to the HCT members, in order for the HCT to provide patients with individualized care. The actions include offering information to the team about patients' habits and ways the patient liked things to be done, and answering questions for the patient.

F--P	F011 P5 1-2	"That's the one thing I warned the surgeon about (patient's medical allergies)	-I warned hospital staff about medications that might cause problems for my family member
F011 P12 45-46 & P13 1-9		"I had warned them when we came in that he'd had the Demerol and he was having a reaction to it. And I asked them to take him out of the room because he was confused. As soon as we left, then I told the nurse, I said: I think you are going to have to take him out of the room. The poor man, there were three other men (in the same room). ...I had warned them, the evening shift that they might have to do that.	-I asked nurse to do something for my family member to handle his behavior problem

F--P	F041 P10 48-50	"He seemingly does have a little bit of a problem swallowing. I've been telling the doctors about it" (The patient had this problem before came to the hospital)	-I've been telling the doctors about my family member's swallow problem
F--P	F012 P3 16-18	"I was there to answer the details he wouldn't remember"	-I was there to give the answer he or she wouldn't remember
F--P	F041 P3 22-40	"I helped him answer the questions by the admitting office down there. Some of the questions he didn't understand. We use new terminology today that he's familiar with a lot of times at his age. And so some of the questions were hard for him to answer. But he can answer if they're maybe rephrased in the right wording for him"	-I helped my family member answered the questions by the admitting office
F--P	F021 P4 1-2	"I just sat there and they would ask questions you know, ask him questions and they'd ask me questions"	-I helped my family member to answer the questions which asked by hospital staff
F--P	P07 P27-28	"She answered all the questions"	-My family member answered all the questions
F--P	N01 P2 20-29	"That's the majority	-Family member

		of the things I can think of this providing information that is helpful"	providing information
F--P	N02 P2 9-11	"A lot of times they [family members] work as their [patients] advocate in many things".	
F--P	N01 P4 26-29	"I have a family right now that will, it's usually, it's the daughters of a father that we have right now. And they'll come and say: My dad won't ask for this. Can you please ask him if he needs like something for pain. He won't ask".	-Family member advocate for his or her sick relative
F--P	N06 P1 27-37	"It was very nice because especially Mrs. G. She is giving us the information I did not realize that pattern of the patient. Often I would ask "are you in pain?". He would say:"No, I am okay". Mrs.G would tell me he usually says that even when he was in pain. She knew that in fact he was in pain, so I can give him some meds for pain that would help him when he was really in pain"	-Family member provided information to nurse for pain management
F-N-P	F07 P8 29-31	"I just told them pretty much his habits and the way he likes things"	-I told nurses about my family member's habits and the way he or she likes things"
F--P	N01 P2 5-16	-"Some get quite involved with the doctors and provide like information on, well this is maybe like a daughter, this	-Family member provide information to team

		is what my dad at home, or this is what my mom does at home kind of thing. And provide information that's helpful for the team: the doctor, nurses, the therapist. Some provide just general information as to their diet, what they like and what they don't like"	
F--P	F012 P7 25-38	"I think the first thing they should know is that he couldn't see without his glasses, or his contact, he got to Have one or another. And they have to deal wearing it. If___ without his leg, he can't do it, it had to be brought to him. And for his morning meals, he can't open the box of cereal up and needs to pour into his bowl for him. And cut up whatever needed to be cut off. Then he can feed himself"	-I shared with nurse what I usually do at home for my family member's personal care -I let the nurse know how I usually do at home for my family member's personal care OR: -I shared with the nurses care the special needs of my family member -I let the nurses know what parts of personal care my family member can or can't do it
F--P	F012 P10 43-51	"I think it would depend upon whether he had diarrhea or anything like that. But basically I just wanted them (RNs) to understand that he can't see to do some of the things for	-I would like to let nurses know about my family member's functional level

		himself, he can't wait for himself if he had to go for bowel movement"	

<u>1212. Health care team to family</u>
DEFINITION: This sub-category refers to the actions preformed by family caregivers when receiving information and obtaining new skills or observing the treatment or therapy for continuity of patient care. The actions including listening and talking to HCT, learning about medication, skills, treatment, and keeping up with the medication list.

F--P	F012 P6 9-18	"He doesn't really know what he is taking in terms of medication go. I had the list of everything if they changed his medication that I revised the list so I was keeping up with changes that the Doctors making them. So when we got ready to leave, I know what medication have already had on him that wouldn't be extra on him"	-I keep track of my family member's medication changes
F--P	F012 P5 7-14	"Well, the quite few things. We learned different ways to use his insulin. It changed since the last time we've seen the doctors. we found you don't draw up the NPH before you draw up the regular. You draw the Regular first, then the NPH"	-I learned different ways to draw insulin
F--P	F012 P1 24-28	"Then they had talked with me about the medications. I've gotten some of them"	-The nurse talked with me about the medications when my family member is being discharged

F--P	F042 P1 11-23	"I checked him out at the nurse's station, and the nurse that was on duty and one of the head nurses over the geriatric's department said: How was my dad and I. And talked to us for about half an hour, I think, going over the different medicines that they were sending home with him so I would know when to give it to him and what to expect"	-I cheked my family member out at the nurse's station -The nurse talked to us and going over the different medicines that being sent home with my family member
F--P	F06 P8 40-42	"[I got his clothes] and listened to the nurses for the discharge instruction, and took him home"	-I listened to the nurse for the discharge instruction
F--P	F07 P8 35-39	"I learned a lot of things about treatment and stuff that, you know, that I wouldn't know. That Doctors and nurses know. And then about how he should get up and move around and all"	-I learned a lot of things about my family member's treatment and follow up care
F--P	P052 P2 40-41	"She (RN) explained all the medicines to her (my wife) and everything"	-My family member learned from nurse about my medicine when I was discharged
F--P	OB6 P1 39-51	"N06 said to both F06 and P06 that she had went though the materia with the patient, but she would repeat one more time with the F06. N06 started with discharge medications. She asked the patient how often to take each of	-Family member learns about follow up care in the procss of dicharge

		the three medications? and repeated the names (comudin, digiox, and reglan) of medication, what its for and side effects. N06 indicated what time each meds should be taken and what and when he had always taken in the hospital during that day"	
F--P	OB6 P2 3-22	"Next, N06 mentioned that about P06's swallow problems, Dr. was notified and will see the patient in the follow up appointment on next Monday. N06 asked the F06 to remind Dr. about this issue during the appointment. N06 then said here were the papers we had. Patient could not lift more than 5 lbs. When you drive home from here to Alaska, make sure to get out of the car every 1 or 2 hours for circulation... Incision care, if Temperature increase call your dr. Watch diet for low salt, and watch for s/s of diabetes. N06 asked if there was any questions? and kept eye contact with both F06 and P06. No questions and Thanked N06 for her care and help. N06 said please call me if you have more question before 3:30 that day"	-Family member learns about follow up care

F--P	F012 P5 20-24	"These some of the newer things we learned. And of course they have come up some adaptive equipments for him to feed himself which made easier for him"	-We learned some new things from nurses -We learned about some equipments for my family member which made it easier foe his or her care
F--P	F042 8-14	"But as far as any other kind of care at home, they gave us, let's see, an apparatus to help him get up from the toilet. I don't know what you would call it. Some kind of bars, you know, to where it's easier to hold himself, push himself up to get off the toilet"	-Some equipments are being sent to home for assisting my family member daily activities
F--P	F06 P9 10-11 16	"I think I learned something like all the meals that was helpful" "Like what I said his manual and excercess"	-I learned something about my family member's care from nurses
F--P	OB6 P2 3-22	"Exercise start to walk from the week 1, and increasing the time for walking"	
F--P	OB7 P1 45-48	"Several minutes later, N07 open the door (after inserting a Doculax supporstary into the patient's rectum) F07 went back in the room and asked:"Should he call for help if he needs help to go to the bathroom?" "Yes, he may need help,	-Family member asks the nurse question for her appropriate participation

		may put the light on" N07 said, and then left.	
F--P	P07 P27-28	"(My wife) asked a lot of questions"	-My family member asked a lot of questions for me
F--P	F041 P12 26-29	"I asked the doctor that was here yesterday or the day before about sleeping aids and such as that, and he says that they weren't giving him any"	-I asked the Doctor about my family member's medications
F--P	OB7 P1 32-36	"N07 said:"your sugar is 262" F07 asked:"isn't it fascinating that the sugar goes up so quick? What did you say how much that the sugar was?" "262" N07 answered."	-Family member asks question about the patient's condition

1220. Collaborating with health care team to provide personal care

DEFINITION: This category refers to verbal and nonverbal actions performed by family caregivers to supplement nurses and to smooth things out for the patients' personal care. The actions include environmental modification, and reporting patient's input to nurses.

F--P	OB7 P2 36-41	"Then she removed her chair outside the door because the chair was placed on the path to the bathroom. Then F07 was standing to pt's bedside and waiting.	-Family member makes things easy for nurse to take care of the patient
F--P	N06 P2 1-10	"Just, helping nursing staff and helping the patient, too. We'll start his bath and we got called away, she will finish the bath. Yes, just the activities of daily living, and just do whatever she could"	-Family member finished giving a bath to the patient while nurse was called away
F--P	N06 P2 42-50	"Well, probably has to call with the last one, because we would set up to wash him and she would be at the room and she would let us to do our job but if there is a break, she would go ahead and step in and do it. So it was after we left the room, no body there"	-Family member would go ahead and step in and finish the task after nurses were called out
F--P	OB1 P3 39-40	"The wife tighten the tray and put the lid back on the dish plate.	-Family member helps cleaning

F--P	N03 P2 1-9	"Or sometimes they'll help us. Sometimes it's a two-person job to help somebody get into the bathroom or get onto the commode. So they will be the second person and we don't have to call for another nurse or aid to help.	-Family member helps nurses to assist patient with walking when two people assistant is needed
F--P	N06 P3 46-50	"The walking, like on the weekends, we don't have time always to walk him as often as we want as the first several time somebody has to assist him. She did that"	-Family member helps patient to walk when nurse is busy
F--P	OB1 P3 32-38	"It is about 12:20, the patient is taking a nap. The wife removed the table from the bedside. At this time, the RN came in and asked the wife "how did he do?" "He ate everything, no jello" the wife answered. The RN said Okay and wrote on the bedside chart and then left.	-Family member answered nurse's question for the patient
F--P	F06 P5 31-34	"the last three days, he got to the shower by himself. I got him soap and shaver, so he could shave himself"	-I got my family member soap and shaver, so he could shave himself when he was able to take a shower by himself
F--P	P06 P4 43-50	"By that time, you're at a point where you don't have all the stuff hooked up to you and everything. Actually, the nurse usually does that,	-My family member helped me to take shower

		but I think she helped me the last day I was in there. There wasn't anything attached"	
F--P	F07 P5 41-50	"The first day he got up I believe they took him to the shower. I stayed outside and they helped him"	-I let the nurse helped my family member because that was the first day he or she got up after surgery
F--P	N03 P2 1-9	"They'll help them, as long as we've checked them first and know that they can walk safely to the bathroom with one person, then we'll let them, let their caregiver help them to the bathroom"	-Family member helped the patient to the bathroom after checking with the nurses
F--P	OB7 P2 36-41	"P07 opened his eyes and said he wanted to go to the bathroom. F07 pushed the light on"	-Family member pushes light for pt
F--P	OB1 P3 19-20	"P07 still in the bath-, room and F07 said she pushed the light on and had been waiting for the help.	-Family member pushed light for the patient
F--P	F07 P15 15-29	"[When we got him all dressed], then we to call and they would help us out"	-I got my family member all dressed up when he was discharged
F--P	F07 P12 17-25	"Well, I always, before he started to walk up there. They told him when he could start in. They were really good. Either a nurse or somebody, an aid or someone, would stay out with him walking. So alone, I think we only	-I let nurses to help my family member walking after his surgery -I help my family member walking after getting

		walked like to the visitor's lounge there"	permission from nurses
F--P	P06 P3 23-29	"When they told you that you could start walking, she would hold my arm. But I always had all these tubes and other things in me that I had to drag along. I had to drag the equipment along with it. So it was quite a chore to get ready for just a little walk"	-My family member held my arm and helped me to walk after I was told to walk
F--P	N06 P1 41-50	"Well, any time she hears that something he should be doing something, she would enforce that. Dr. said he should walk more, so she got him up and help him walk,"	-Family member helps the patient in his or her recovary by following Dr.'s recommendations -Family member helps patient to walk
F--P	N06 P3 6-12	"Just remending him to do things, like the urinal, his urine output drop off and we put foley catheter in. After we took the cath. out, she did always remind him to use urinal. So if he is heading to the bathroom, she always remind him to use urinal.	-Family member remends the atient to follow the Dr.'s recommendation

F--P	N07 P3 4-8	"[I think she has done everything that's appropriate]. As he gets stronger, she'll be able to walk with him. But he needs us to walk with him right now"	-Family member helps the patient when it is appropriate

1230. Participating in therapeutic health care regimens

Definition: Refers to verbal and nonverbal actions performed by family caregivers in helping the patient in his or her recovery process according to the health team's recommendations and facilitating the patient to follow the medical regimes. The actions including assessing patient's symptoms by asking question to patient, providing interventions by bringing in appropriate medications from home changing dressing for patient's incision, calling for treatment or technique assistant when needed, reminding, encouraging and doing for the patient to follow the treatment plan.

F--P	F011 P5 27-29	"I went with him on some of the tests so I could observe what was going on"	I went with him on some of the tests so I could observe what was going on
F--P	F012 P1 45	"I took him down there myself" (PT)	-I took my family member to physical therapy by myself
F--P	F011 P7 31-33	"He goes to physical therapy. I take him down there. And watch what they're doing so if I have to help him I know what to do for him"	-I take him or her to therapy -I watch what the staff are doing so I know what to do for him or her
F--P	N02 P1 26-32	"Some family members even go to therapy with with the patient. We have a lot of patients that go to ccupational therapy and physical therapy. And some are are so involved that they want to go and participate in that too"	-Family member goes to therapy with the patient

F--P	F07 P15 1-8	"He's had so much trouble with his feet. And he had crackles between his toes for several days so I've been remembered to tip them and now pretty much healed up now"	-I take care his feet
F--P	OB7 P2 14-18	"N07 came in with a syringe in her hand. "16 units of regular insulin" N07 said. F07 asked: "isn't it too much?"	-Family member asks question to nurse about the patient's treatment
F--P	F06 P8 30-33	"When he said he had gas pain on his stomach, I would see if something can be done to help him"	-I would see if something can be done to help him
F--P	OB7 P2 10-12	"F07 sit in the pt's bed and asked him:"Do your fingers feel numb now?" "little bit" P07 said.	-Family member assesses patient
F--P	F011 P6 4-5	"I had to bring in his insulin from home because he's not on humulin"	I had to bring in MED from home for him or her
F--P	N03 P1 26-41	"Sometimes they'll help give their medicines"	
F--P	OB1 P3 9-12	"The RN comes in and said to the patient: "here is your medicine". The wife gave him a couple of water, the patient swallowed the pills. The RN smiling to the wife and left"	-Family member helps patient to take pills

F--P	F011 P17 2-3	"And that was probably the only time I've ever put on his call button, was when he threw up the feeding tube"	-I pushed on the button when I think the nurse need to come quickly
F--P	OB1 P2 51-52	"It is 12:15. The wife said to the patient, "about 15 minutes, I'll get you ready for physical therapy".	-Family member reminds patient for his or her treatment
F--P	OB1 P3 39-52	"About 12:40, the patient to waken up. The wife said:"Hello, Hello! ready to go to the therapy?" "I guess so" he said.	-Family member helps the patient to stand up from
F--P	F041 P16 2-7	-[Family caregiver] taking him [patient] down for rehabilitation"	-I took my family member done for rehabilitation
F--P	OB1 P4 3-7	"At about 12:45, the wife pushed the wheelchair with the patient on to the 6D nursing station, and got his medical chart. They went to down stairs for his physical therapy"	-Family member pushed wheelchair with the patient -Family member obtained patient's chart from nursing desk -Family ember ccompany the patient to Physical Therapy

F--P	N03 P5 34-46	"But sometimes the family member can get a patient to take medicine when we can't. Or they can get them to take it fast, you know within five minutes, and it might take us half an hour.	-Family member can get a patient to take medicine when nurse can't
F--P	F06 P6 31-32	"Helped with his breathing excise, you know, things like that"	-I helped my family member with his or her breathing excise
F--P	F011 P6 40-43	"I was dressing his incision"	-I help my family member to dress his or her incision
F--P	N06 P1 46-49	"She encourage him to breath by using the insenimiter several times per hour to begin with. So she would hand it to him and make sure he did it.	-Family member helps patient to do breathing excerse filled
F--P	N01 P2 5-16	"If there is an eating disorder or something there, sometimes they're able to bring in food that we can't supply here.	-Family member brings food

1240. Making sure that health cares team take care of patient's needs

DEFINITION: This category refers to verbal and nonverbal actions performed by family caregivers in interacting with health care team members or patients to make sure patient's personal care needs are being met and to keep the patient from getting lost in the shuffle of a large institution. The actions include making sure the patient receives adequate care by watching, observing, or asking questions to either patients or HCT members regarding the patient's personal care needs.

F--P	F07 P17 32-35	"Well yes, I liked to be there and know what's going on because I figure if it's me or my family, if I have to step on somebody's toes, I would"	-If I have to step on somebody's toes, I would for my family member
F--P	F07 P11 26-27	"I had mentioned it (pt's dinner tray was missing) to two or three different people	-I make sure my family member gets his tray on time (keeping pt. from getting lost in the shuffler of a large institution)
F--P	N02 P1 31-32	"They try to make sure they're comfortable"	-Family member tries to make sure patient is comfortable
F--P	N02 P4 19-25	"They're only here to make sure that we're doing our job right. e.g, taking care of their father they want him taken care of. Making sure he gets things done. They just watch to make sure it's done right.	-Family members there to make sure if the patient's care done right

F--P	N01 P1 10-12	"And others are only there to make sure that you're caring for them (the patients) appropriately.	-Some family members are here to make sure nurses are caring for patient appropriately
F--P	OB1 P2 46-50	"The nurse said the patient's sugar was little up. "Do you know if the jello is sugar free?" the wife asked"	-Family member asked question to nurse for the patient
F--P	F011 P11 26-28	"And I have to watch his feet for those little sores. I watch that. Pressure, on any part of his body. I'm always watching"	-I watch his feet for little sores -I watch pressure sores on any part of body
F--P	OB7 P3 13-15	"Then she open the bathroom door a little bit and asked P07 if he was alright.	-Family member checks with the patient who is in the bathroom
F--P	F011 P6 38-43	"I see that he gets a shower, if need be"	-I make sure that he or she has a shower
F--P	F06 P7 1-2	"I made sure he had something to drink"	-I made sure my family member had something to drink
F--P	OB1 P2 21-30	"The patient is still eating. The wife is setting in the chair at bedside and watching him to eat. 'How are you doing?' she sked"	-Family member is checking on the patient

F--P	OB1 P3 34-38	"F07 asked P07 if he wants to drink something"	-Family member assesses patient's needs
F--P	F011 P14 16	"Just make sure he has cold water"	-I make sure my family member has cold water
F--P	OB7 P3 39-43	"F07 shaken the water container and put it back on the table. I asked if she thought the water was too warm? She said:"I think he needs fresh cold water" I went out and got him ice water"	-Family member make sure the patient has cold water

1300. Taking care of self

DEFINITION: The third major dimension of Family Participation Actions refers to caregiving actions performed by family caregiver in interacting with other family members or taking a break for themselves to meet either or both family caregiver and the patient's needs.

F--P	F011 P13 22-24	"When I left, some of other relatives came to stay with him while I went home and showered"	-I make sure some other relatives or friends stay with him or her when I have to go home or to work
F--P	F011 P8 30-32	"After [physical] therapy then he (patient) rests. And I usually go down and work the jigsaw puzzle or crossword puzzle, or something like that"	-I take a break for my self during the day I am here with my family member
F--P	F011 P13 32-34	"I said: I have to leave early sometimes. I'll make it at 7:00 just so that I can get home and kind of relax and unwind"	-I left little early sometimes so I can get home relax and unwind
F-F-P	F07 P5 47-50 P6 1-5	"I don't like the traffic so each day, one of the kids or grandkids, somebody, pick me up in the morning and somebody else came and get me in the evening"	-My other family members would drive me back and force to the hospital every day
F--P	P07 P1 28-31	"They (my two daughters) came every evening to pick her (my wife) up".	-My family members drive my wife back and force to the hospital everyday
F--P	N03 P9 8-26	"When they come from such a distance, then the family is not going to their own home at night"	

Appendix M

Support for the Analysis in Interview Data Bits: Patient Preferences

Patient Preferences

DEFINITION: Patient preference refers to the elderly patients' personal choices based on their role privilege in family participation actions. In this study, patient preferences were perceived by multiple parties: family caregivers, elderly patients themselves, and nurses. The language that reflected elderly patients' personal choices included such phrases as preferring or not preferring, wanting or not wanting, asking or not asking, and happy to have a specified individual do a given type of caregiving actions. The reasons given for patients' personal choices, as perceived by family caregivers, patients, and nurses included: getting care done on time according to patient's habits or beliefs, meeting individual care needs, and making the patient comfortable.

Reference	Quotes	Possible Items
P06 P4 1-2	"Do you prefer your daughters to do anything or brother?" "Just whatever they want"	-I prefer my daughters or brother do whatever they want
<u>1100. Being there</u>		
P031P1 5-9	"Well it depends on the illness. Now if I've had my operation, I would like to have them come in day and night. but now that I'm just going through And adjustment and rehab not to bother me".	-How often I want my family to visit me depends on My illness treatment
F011 P14 24-29	"Once I leave, he accepts it. Now, a couple of nights ago, he didn't want me to leave. He wanted me to stay. And so I stayed until about 9:00 and, the kids had come. And then we all left together. And he seemed to be accept it at 9:00. But he just didn't want me to leave, so I said: Okay, I said: I'll stay"	-I stay with my family member as long as he wants in the evening

1120. Performing usual family practices in hospital

1121. Maintaining linkage

N01 P3 12-19	"There have been times like a patient has said: Can you call my son. Or, you know, can you do this. And they actually ask us to initiate calling the son and having the son or somebody come in and see them"	-I asked nurse to call my family member to come in and see me
N02 P3 17	"[Bringing in family visit] I think they do that because the patient asks them to"	-I asked my family member to bring in Family visitors
P06 P6 4-7	"[Family] Be supportive, gettting there at a convienient time, and leaving when they saw you [pateints] are tiring."	-I prefer my family member to visit me at a convienient time, and leave when they see me being tired
P011 P1 30-42	"Do you prefer to have family visit you?" "Yes, Yes" "Whom do you prefer to visit? I mean your wife, daughters and sons?" Yes" "do you want all of them?" "Oh, yes, equally"	-I prefer all my family members to visit me equally
P031 P1 21-41	"Do you prefer them to come to visit you?" "sometimes, yes, sometimes no...Well they have their other business. If it's serious I would want them here every night. The illness is the main part of it, the reason they should come"	-If I am seriously ill, I would want my family member here every night -If I am here for rehab. I don't want my family member to be here that often because they have their other buiness
	"Just my husband. I told him, I said not to come until I'd been here a few days. My son's coming this afternoon. My son's family will be coming eventually,	-I told my family member not to come until I'd been here for a few days

	but I said not to rush them"	
P031 P2 22-24	"We have friends, but they're not visiting friends I wouldn't say. We have friends call me, but we didn't tell them I was in the hospital. didn't want them to know"	-I don't want my friend to know I am in the hospital

1121. Doing enjoyable activities

N01 P5 18-24	"[Bringing in pet] I think ..and/or the patient has asked that, you know: Oh I'd really like to see my dog or whatever and so they asked a family member to bring it in"	-I asked my family member to bring in the pet for me
F011 P12 30-36	"And I did take him downstairs yesterday to the canteen. Brought him a small bag of popcorn" "He wanted some popcorn"	-I took my family member done stairs to the canteen because he or she wanted some popcorn

1123. Providing reassurance

1124. Engaging in religious practices

1130. Providing passage between home and hospital

1131. Gathering up

P012 P1 46-52	"What kind of thing did you prefer your wife to do in assisting you during the hospital discharge process?" "Just about everything" "well, she has to, I can't find the way around in the hospital...I need my wife to help me almost everything I do"	-I prefer my wife to do almost everything for me during discharge because my physical limits

(Patient's preference on family role in FP perceived by patient)

P022 P2 19-26	"What do you prefer your wife or daughter to do when you were discharged from the hospital?" "My wife, she gathered	-I prefer my wife to take care of my personal belongings when I was discharged

	all my clothes, laundry and stuff like that. Got them all before she left and took them down and put them in the car you know, staff in the car"	from the hospital
P06 P5 22	"During discharge, what kinds of things did you prefer your wife or your friend to do?" "Nothing other than what they did"	-I prefer my family member to do what they did for me during The discharge

1132. Bringing/taking

P032 P1 38-41	"What kind of things do you prefer your husband to do during the discharge process?" "Well, he just...who the person talk with me and take me home. That's about it, and that's what he did"	-I preferred my family member to talk with me and take me home

1133. Settling in

1140. Attending to patient's personal care

1141. Helping

P07 P3 35-40	"They [RNs] can put you to bad a lot better" "so they make you less hurt?" "Yeh" because they	-I prefer nurse to put me to bed because they can do a better job
P07 P4 1-3	"Are there something that you prefer to have your wife do rather than the nurse?" "Feed me for one thing, when I was laying flat on my back"	-I prefer my family member to feed me when I need help to eat

P07 P3 10-16	"I prefer my wife most of the times [about providing personal care]". It's real interesting up there. The order nurse could get to you and go right on and not seem to bother them a bit. But those younger nurses they had little problem with that... they just didn't want to grab a hold like the old, experienced" " Yeh, they were hesitant [about providing personal care]"	-I prefer my family member to help me in my personal care -I prefer an older nurse more than younger one
P051 P3 8-30	"Do you prefer that the nurse help you or your wife (bathing)?" "My wife" "Do you prefer your son help you with your bath?" "No" "Is there anything that you prefer the nurse help you rather than your wife?" "Medicine" "Are there other things that you would rather have your wife do than the nurse?" "I don't know. Can't think of anything out of hand, but there probably is"	-I prefer my wife help me bathing -I don't prefer my son help me bathing -I prefer the nurse to give me medicine
F041 P7 28-29	"Well both (patient asked and family member perference), but most generally it's because he asks"	-My family member asked me to do things for him or her
P011 P4 19-20	"I prefer my wife. I, we have a very good relationship. No bickering, no fighting"	-I prefer my wife to help me
P011 P6 7-15	"Is there any other things you prefer your wife do with your care in the hospital?" "No, there's no difference between her and nurse" "No difference?" "No, I have no preference"	-I have no preference between my wife and nurse in terms of providing care to me

P011 P7 6-12	"Your friends come in, do you want them to help you to do things?" "No. Very independent in that respect"	-I do not prefer my friend to do things for me
P021 P6 12-17	"If you need help with your care, do you prefer your wife to do it of nurse to do it in the hospital?" "My wife, yes. When I need a nurse, I expect her to come on time. Most of them do"	-I prefer my wife to help me with the care
P021 P8 25-33	"I don't like my daughter to do it (help to go to the bathroom). But my wife is alright" "I don't want my daughter in on something like that, you know. If she had to she would. I know she would"	-I don't like my daughter to help me to go to bathroom
P021 P8 39-42	"Well, there's nobody there where I'm at, I prefer a nurse to do it. If they're there and not doing anything. I'll let them do it. I mean as far as nursing, like giving medicine or something like that"	-I prefer a nurse to do the care for me if they're there and not doing anything
P021 P10 11-21	"No. Things like that, personal. I don't want her (my daughter) to do it. My wife, but not my daughter"	-I don't like my daughter to do my personal care -It's okay with me if my wife helps in my personal care
	"How about your son?" "He's alright"	-It's okay with me if my son helps in my personal care
P021 P10 36-37	"How about your friend? If your friends come to visit you, do you prefer him?" "No. I don't ever ask him to do anything"	-I don't ever ask my friend to do anything in my care

Appendix N

Support for the Analysis in Interview Data Bits: Family Worry

Family Worry

DEFINITION: Family worry refers to the cognitive and affective reaction family caregivers experienced when the elderly relative has been admitted as a patient in hospital. Family worry is conceptualized as one type of role strain from being a family caregiver of an elderly patient. It is defined as felt difficulty in fulfilling the family member and/or caregiver obligations because of worry. Also, family worry is viewed as a sign of family caring about the elderly relative.

2100: Worry About Patient's Health Status

DEFINITION: This dimension refers to the family caregiver's felt difficulty in fulfilling the family member and/or caregiver role because of worry about the elderly patient during his or her hospitalization.

Reference	**Data excerpts**	**How much do you Worry about:**
F011 P14 43-44	"I worry (about if he would get better and about how he's behaving. Giving them a hard time or cooperating"	-whether your family member will get better? -how your family member is heaving in the hospital?
F021 P7 44-46 P8 1-6	"I worry about him all the time. About his leg and you know he can't walk that good, and the dizzy part, he's being dizzy. And his mind, you know. I worry about that because there's time he forgets what he's talking about and he'll be talking to you and you don't know what he's talking about. He won't start at the beginning of anything. He'll want to start in the middle of it. And you'll say, now what are you talking about? I don't know what he is talking about. So he has to go back and tell me what he's talking about. So, it bothers me"	-your family member's physical and illness condition? -about your family member's mental status? -When you are not with your family member, how often do you worry about him or her? 0 Never 1 Rarely 2 Sometimes 3 Most of the time 4 All of the time

F022 P1 17, 23	"Well, (I worry about) his mind and his walking", and "his leg, you know, getting his leg straightened up"	-about your family member's mind? -about your family member's physical condition?
F06 P9 25-29	"(I worry about) that he was stable, the biggest worry is if he was stable. Because like I said the first Sunday, he had first shock and on the second Sunday he lost his blood pressure"	-about your family member's unstable health condition -unpredictable changes in his or her health?
F07 P17 1-4	("What worried you the most? Did you worry about him during the night when you were at home?")"Well, the first night more, yes"	-your family member during the night? -your family member during the first night?
N06 P4 10-15	"Mr. G's urine output once dropped off, she was very worried about that. She didn't know what medically happened with him. She was at the the motor-home (RV) during the night and she couldn't sleep. She was definitely concerned"	-your family member's condition change
N07 P2 34-41 N07 P2 38-40	"Anybody would be worried about how he is going to recover from the surgery. But now most of that worry is over because he's had the surgery and I think people are more concerned before the surgery happens. But he had diabetes, so she's probably worried about his diabetes control"	-your family member's recovery -your family member's adverse reactions to treatment -your family member's illness

F032 P2 16-23	"Oh, I really wasn't worried. I know they were helping her. I mean if she were in for operation or something, then that would be concerned. As she was in for therapy, I knew that everything they did were helping her. There were no worry"	-How much your worry is reduced because your family member is here for rehabilitation and you know the staff are helping her or him?
F07 P17 4-10	("Did you worry about his diabetes?") "Yes, but I did feel they would keep pretty much on top of that. Because, you know, after surgery the sugar always gets, really goes up and stuff" (This family member had the same surgery, same doctor, same hospital 2 years ago)	-How much your worry is reduced because your knowledge about what would happen? -How much your worry is reduced because your past experience with surgery -How much your worry is reduced because you exhibited a non-anxious calm presence?

2200. Worry about patient's care received from health care team
DEFINITION: This dimension refers to the family caregiver's felt difficulty in fulfilling the family caregiver role because of worry about the elderly patient's care received from the health care team during his or her hospitalization, including whether the patient may get help on time and get his or her individual needs met.

Reference	**Data excerpts**	**How much do you Worry about:**
F011 P14 42-44	"Oh, Yeh. I worry about if he would get good care	-whether your family member is getting good care?
F012 P1 36-45	"I think I worry the most about during night. He didn't seem too good and that he would be not able to get the nurses if he needed some help. That was the only worry I had. But he didn't seem to have too many problems"	-about your family member during night when you are not with him or her? -your family member not being able to get the nurse if he or she needs some help?

F012 P3 1-6	"Only in the night because during the day I was here to get everything he needed, so he didn't have to wait for the nurses to get here they are busying working with other patients. Just the night time I primarily concerned"	-about your family member during the night?
F012 P8 10-21	"I worried if he got his shower. That's important to him....When I was there, I helped him to get it. But I knew if I was not there, I know it would be while before they could get it for him. He wouldn't be comfortable"	-your family member getting his or her needs taken care of in a timely manner? -about whether your family member is comfortable when you are not there?
F012 P9 18-42	"What did you worry about his meal and drinking care if you were not there?" "I know if I was not there to help cut it up that it wouldn't get down. In most of the time, I have found when the nurses do came in, they just opened up all the food package, the sugar package, and just pulled on everything. They don't stop to realize that everybody tastes isn't to the point they you like a lot of sweet on things... They just want to get the things set up, so they can move to the next patient. So it was done in a hurry, and they should do it so the patient's taste would like it, but don't have the time to do it"	-about the nurses being too busy to take care of your family member's needs? -about nurses who don't adjust their care to your family member's preferences?

F021 P8 15-19	"No I don't worry about him while he's up here because I feel like that he's in good hands. You know what I mean. Because of the doctors and everything. So I don't worry that much about him while he's here"	-How much is your worry reduced because you feel your family member is in "good hands" at the hospital? 0 My worry is not reduced at all 1 A little 2 Some 3 Quite a bit 4 A great deal
F031 P8 1-4	"No (worry), because I think she's being cared for and it's great to be learning some things to facilitate her movements. No, it's at home, not too much worry"	-How much is your worry reduced because of knowing that he or she is being cared for? -How much is your worry reduced because of learning things that I can do to help me family member to get butter?
F041 P15 23-28	"I've not had much worry since he's been here. I think he's had very good care here. We've been very impressed, honestly, with the doctors and nurses. Their level of concern for our father has been extremely good"	-How much your worry is reduced because you think your family member has had very good nursing care here -How much your worry is reduced because you've been impressed with the doctors and nurses? -How much your worry is reduced because the level of concern by staff for my family member has been extremely good

F07 P8 45-50	("Do you worry about his morning care if you are not here?) "Well, I felt like he was where, you know, able to punch his buzzer, and that he probably would get anything he really needed. He might get impatient or if something was a little longer. But I didn't think there was anything going to be that serious that, you know that he wouldn't get attention soon enough"	-How much your worry is reduced because you belief that family member will get anything he or she really needs from nurses -How much your worry is reduced because you acceptance of reality of nursing care and confidence in nursing care
F07 P17 4-10	("Did you wprry about his diabetes?") "Yes, but I did feel they would keep pretty much on top of that."	-How much your worry is reduced because your knowledge about what would happen? -How much your worry is reduced because you felt HCT will keep pretty much on top of the treatment?

2300: Worry About Future Care For Patient By Family Caregiver

DEFINITION: This dimension refers to family caregiver's felt difficulty in fulfilling the family caregiver role because of worry about how they will manage in the future.

Reference	**Data excerpts**	**How much do you Worry about:**
F011 P15 24-25	"Oh I just try to be sure I eat good so that I can keep my strength up"	-your own health?
F011 P15 29-32	"I don't, right now, I don't worry about a nursing home. I wouldn't put him in a nursing home if I could take care of him myself. I would just go to an apartment where if I needed help I'd have it available"	-your family member's nursing home placement?

F021 P8 28-37	"Well sometimes I worry about what am I going to do, you know, If I get sick I can't take care of him. And I definitely don't want him to go into a nursing home. I've seen too much of a nursing home. I don't want nursing home. And I worry about that, you know. Well, what am I going to do if I get to where I can't take care of him. Because I can't hardly do what I do on account of my back. Even when I'm washing dishes, I can't finish my dishes. I wash a few dishes and then I'll have to sit down and then I'll get up and try to finish them again, you know"	-what you are going to do if you get sick and can no longer take care of your family member at home? -if your family member going into a nursing home? -about your own health condition?
F041 P1 1-6	"I'm not worried about it at all. I think in the hospital here, it's okay. There's a life here, but it's not the real life. When he (his father) gets to the house and his real life, then I'll be concerned"	-what will happen when your family member returns home
N02 P6 37-42	"A lot of family members are also really worried about treatment, like if there was a dressing change that we were trying to teach them to do so that they could do it at home. They're worried about, I guess technical tasks. They worry that they're not going to do it right"	-your family member's treatment? -the technical caregiving tasks that you need to learn from nurses and to perform at home

2400. Worry About Finance

DEFINITION: This dimension refers to the family caregiver's felt difficulty in fulfilling the family caregiver role because of worry about their financial situation.

Reference	**Data excerpts**	**How much do you Worry about:**
F021 P9 1-4	"I worry about our finances because lots of times we just don't have the money to, we just live from month to month, you know"	-about your finances?