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EXPLORING THE LIVED EXPERIENCE OF INDIVIDUALS WITH
ACUTE INFECTIONS TRANSITIONING IN THE HOME WITH SUPPORT
BY AN ADVANCED PRACTICE NURSE USING TELEHEALTH

A DISSERTATION SUBMITTED TO THE GRADUATE DIVISION OF THE
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By
Michelle L. Marineau

Dissertation Committee:

Lois Magnussen, Chairperson
Charon Pierson
Jillian Inouye
Victoria Niederhauser
Michael Weinstein

UMI Number: 3198369

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I dedicate this dissertation to my husband.

To Richard, who was responsible for
encouraging me down the path of
pursuing my Ph.D. and has been
there to support me every
step of the way.

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ABSTRACT

The use of telehealth in individual's homes is increasing in the United States in an effort to cut cost by limiting admissions to hospitals and/or reduce length of stay. This increase has not been driven by conclusive research findings in support of this technology; furthermore, the majority of research conducted has been in the area of chronic disease management. It is important to expand the knowledge base related to transitioning from an acute illness in the home with telehealth from the individual's perspective.

Due to the lack of empirical data available, phenomenology was used to explore the individual's perceptions in the use of this new health care delivery model. In exploring this new phenomenon, eidetic phenomenology was used to capture the essential structure of the lived experience as told by individuals who had been enrolled in a pilot quantitative telehealth study over the past two years.

The purpose of this study was to describe the "lived experience" of individuals with acute infections transitioning in the home with support by an advance practice nurse (APN) using telehealth in an effort to avoid a hospitalization or to promote an earlier discharge. Purposeful sampling was used to enroll the sample of ten participants.

Major findings of this study consisted of three Theme Categories: Initial Response, Engaging in Care, and Experiencing the Downside. The essential structure as it relates to the health/illness transition that occurs when an individual with an acute infection is discharged from the hospital to the home supported by telehealth technology revealed an overall positive experience from the ten participants. There was one negative experience in a participant who had two separate telehealth enrollments. This knowledge adds valuable information to future health care providers from the individual's perspective as it relates to

understanding the transitional process that occurs with an acute illness from the hospital to the home with support by an APN using telehealth.

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CHAPTER ONE

INTRODUCTION

This chapter provides an introduction to the background of telehealth and the author's personal interest in implementing this technology, definition of concepts, research question and the method. Telehealth is a rapidly growing field that has primarily been used to assist in the management of individuals with chronic illnesses. Therefore, research that does exist in the field of telehealth is in chronic disease management with no existing research to support its use in the treatment of acute infections (Friedewald & Pion, 2001; Haily, Roine, & Ohinmaa, 2002). In addition, there is no information about the effect of the use of this technology on the lived experience of individuals recovering from an acute illness at home with telehealth.

As our population ages, the use of telehealth in individual's homes in the United States is increasing in an effort to provide high-quality, cost-effective care. This has resulted in policies and changes in the health care delivery system that can be seen worldwide (Ehrenfeld, 1998). Unfortunately, there is a lack of sufficient evidenced-based research that clearly supports the benefits of this technology (Whitten, Mair, & Haycox, 2003; Hailey et al., 2002; Currell, Wainwright, & Lewis, 2000). It is essential that we explore the impact of telehealth from the individual's perception to assure that high quality care is not hindered.

Background of Telehealth

Telehealth is an integrated system that defines healthcare activities being carried out at a distance (Wootton, 1996). It refers to a technique of delivering healthcare where communication with the individual is achieved at a distance, rather than in person. Other

synonyms for telehealth include: E-health, telemedicine, telecare and telehomecare. All of these imply the concept of removing time and distance barriers with the potential to increase access and decrease cost while sustaining high quality health care. There are two types of telehealth techniques: those that are pre-recorded and those that occur in real-time (Wainwright & Wootton, 2003). This paper will focus on the care given in real-time, requiring that the provider and the individual are present during the interaction and will use the term “telehealth”.

There has been increased interest in telehealth in the past ten years although the concept has existed since 1909 when Wilhelm Einthoven transmitted electrocardiographs for remote consultations via the telephone network system. In 1924 the magazine *Radio News* had a cover depicting a “radio doctor”. Over the past decade, telehealth has been primarily used in rural areas, military health applications, correctional facilities requiring high security, and for transmission of images between hospitals and specialty physicians (Jenkins & White, 2001).

Wainwright and Wootton (2003) recently conducted a review of the literature and identified that 45% of all telehealth research is with the chronic disease management of diabetic clients; 15% hypertensive clients; 10% depressive clients; 9% congestive heart failure (CHF) clients; 9% asthma clients; 6% dementia clients; 2% chronic obstructive pulmonary disease (COPD) clients; 2% renal failure clients; 1% liver disease clients and 1% arthritis clients. The goal of chronic disease management typically involves preventing emergency room visits and hospitalizations, decreasing the number of home nursing visits and engaging clients in self-care management of their condition.

Coleman (2002) has identified that nearly 200 telehealth projects were active in 1999 in the U.S. alone with a projected growth of 40% annually over the next ten years. Costs for telehealth may reach 15% of all health care expenditures by the year 2010. With this projected rapid growth it is essential that telehealth is driven by research that supports the psychosocial and physiological needs of the individual and not just the cost-benefits of implementing this technology for an ever-increasing aging population with escalating health care cost and demands.

Definitions of Concepts and Terms

APN

In this study, advanced practice nurse (APN) refers to a nurse with advanced education at the Master's level and credential as a board certified family nurse practitioner holding an APN license in the state of Hawaii. This individual has an expert knowledge base to make complex medical and nursing decisions with a substantial degree of autonomy and independence with a high level of accountability. The three APNs who provided the care that was preliminary to this study are working in collaboration with a physician who is a board certified infectious disease specialist. Additionally, the APNs have specialized education with two of the three APNs having four years experience each in the field of managing individuals with acute infections.

Acute Infections

Acute infections, for the purposes of this research, were limited to individuals with severe cellulitis, urinary tract infection, and community-acquired pneumonia. Co-morbid conditions existed in some participants with diabetes the most common co-morbidity. Participants were excluded from the telehealth provision if they required intensive care

monitoring for a life-threatening acute infection. Life-threatening acute infections tend to occur in elderly individuals with other co-morbidities and result in the participant being ill enough to require hospitalization to administer medication (i.e., intravenous antibiotics) along with close monitoring by the APNs for complications.

Telehealth

Telehealth is defined as healthcare activities carried out in real time over a Plain Old Telephone System (POTS) using the APN to assess the physiological and psychological status of the individual and support the family members in the holistic care of the participant during their health/illness transition from an acute infection. This care includes the holistic interventions conducted by the APN via telehealth which mimics all the essential components that would be accomplished in the hospital with the exception of being able to physically touch the participant. The family members assist in moving the instruments, (e.g., stethoscope across the posterior lung fields) and the same clinical data is gathered (i.e., vital signs, oxygen saturation, daily weights and blood sugar) that would be gathered if the participants were hospitalized. Family members record vital signs and other pertinent data at various times of the day similar to the hospital setting, but at times that are best for the individual rather than the rigid structured times in the hospital environment⁶⁺. Teaching interventions are accomplished via telehealth with many opportunities to optimize and support the self-care abilities of participants and families.

Health/illness Transition

The health/illness transition relates to a disturbance in bodily functions that results in physiological distress causing the individual and/or family members to seek assistance with health care. An acute infection results in varying degrees of instability requiring

adaptations and change to survive the illness event with critical points and events that may occur during this process. Health outcomes of this process are mastery of new skills or behavior to manage the acute infection and may result in an identity reformulation, particularly when the individual is able to master new skills to better manage an underlying chronic disease process.

Lived Experience

To understand (or explore) the lived experience requires capturing the essential structure that is actually lived out by an individual through reflection and remembrance of the experience and is the goal of this research. The researcher distills the lived experience into a textual expression of its essence (vanManen, 1990).

Personal Interest

My practice, for the majority of my nursing career, was in an area of Northern Michigan where there were never enough resources and medical personnel to meet the health care needs of the population. This has led to my intense interest in pursuing alternative methods of health care delivery to maximize resources available to the community. In Northern Michigan, I initiated the opening of a Nurse-Managed Health Center at our college so that the elderly and students in our community could have access to health care without driving 50-100 miles. The problem arose when I needed to refer an individual to a specialist. I attempted to develop a proposal with Michigan State University to accomplish these referrals via telehealth. Unfortunately, bureaucratic obstacles prevented this proposal from ever becoming a reality. In 1999, I made the decision to move to Hawaii to explore new challenges.

For the past five years I have been working in an exciting and challenging position as an APN treating individuals with acute infections at Kaiser Permanente. Our team consists of three APNs, a physician who is board certified in infectious disease, and a team of registered nurses. We have been treating persons who normally would be hospitalized with acute infections in an Ambulatory Treatment Center (ATC) located at the hospital. We have been successful in treating these individuals in their homes with daily to weekly visits to the ATC. We believe that these individuals have fewer complications due to a decreased exposure to nosocomial infections and that they resume their normal activities of daily living quicker than the individuals who are hospitalized. We are unified in our belief that the people we serve have unique capabilities that we can mobilize to achieve an optimum state of wellness.

Between September of 2003 and December of 2004 we were able to give our participants the option of having their health care rendered via telehealth supported by the APN instead of being hospitalized. These individuals entered into our telehealth program via four pathways. 1) directly from the emergency room; 2) directly from the ATC; 3) within the first twenty-four hours of hospitalization 4) after more than one day of hospitalization in an attempt to result in an earlier discharge from the hospital.

Eron, King, Marineau and Yonehara (2004) conducted a study with these forty-seven individuals that primarily examined clinical outcomes, cost savings, patient satisfaction and return to activities of daily living (ADL) using a hospital case-control in the treatment of individuals with acute infections. The groups were matched according to age, gender, primary diagnosis and co-morbidities. This study demonstrated comparable clinical outcomes, considerable cost savings by averting or shortening hospital days, and a

more rapid return to ADLs. A patient satisfaction questionnaire was implemented after the two interventions using a five-point Likert scale to specifically explore the patients perceived sense of safety and comfort while recovering from an acute illness using telehealth compared to the hospital control group. The telehealth group verbalized a greater sense of comfort recovering at home in a retrospective telephone survey questionnaire. Patients' responses related to safety, however, indicated that they would have felt safer in the hospital (Eron, King, et al., 2004). This could have enormous implications regarding the future use of telehealth with this patient population.

I was concerned that we were missing valuable clinical data regarding our participants' perceptions and acceptance of this new technology being used to treat their acute infection. Qualitative methods of research using eidetic phenomenology could reveal each participant's perspective in transitioning from the hospital to the home with the assistance of the APN and telehealth. The goal of phenomenological research is to describe the phenomenon as accurately as possible, remaining true to the facts. Ragin, Nagel and White (2004) stated "qualitative researchers tend to gravitate to the study of phenomena that are under-theorized or outside the scope of existing theory"(p.11).

Research Question and Method

In this study, phenomenology sought to describe the lived experience as it relates to the health/illness transition that occurs when an individual with an acute infection is discharged from the hospital to the home with support by an APN using telehealth in an effort to avoid a hospitalization or to promote an earlier discharge. This approach is used to describe phenomena that are difficult to capture through quantitative methods. By identifying the individuals' perceived needs and concerns we may be able to optimize the

nursing care rendered with this technology and exclude individuals who may prefer the hospital environment. Phenomenology was the preferred approach for this study because of the lack of quantitative and qualitative research available exploring how this new technology affects individuals' lived experience and ultimately their ability to successfully transition when they have an acute infection.

The quantitative data that has been collected on our participants needed to be explored in more depth, specifically as it relates to participants' ability to transition from illness to health using telehealth in place of hospitalization and/or an earlier discharge. By analyzing the data using an eidetic approach, data-generated themes emerged, providing a thick description of the essential structure of the lived experience. This knowledge will be valuable to health care providers, providing an awareness of the participant's needs during their health/illness transition, specifically as it relates to their individual perceived needs and concerns recovering from an acute illness with the support of an APN via telehealth.

This research sought to specifically answer the question: What is the lived experience of individuals with acute infections transitioning in the home with support by an APN using telehealth in an effort to avoid a hospitalization or to promote an earlier discharge?

This phenomenological research included two specific aims:

- To describe the lived experience of individuals with an acute infection transitioning in the home with support by an APN using telehealth.
- Identify individuals' perceived needs and concerns when transitioning from an acute infection in their home with support of an APN using telehealth.

CHAPTER TWO

CONCEPTUAL ORIENTATION

The purpose of this chapter is to first analyze the concept of transition and then to describe in detail Meleis, Sawyer, Im, Messias and Schumacher's (2000) middle-range theory that was used as a conceptual orientation to specifically explore the properties and patterns of response of the health/illness transition within the context of telehealth (see Appendix A). This provided a conceptual orientation to guide the researcher's project by identifying key concepts of the health/illness transition that can then be related to the individual with an acute infection who is discharged from the hospital to the home with support by an APN using telehealth in an effort to avoid a hospitalization or to promote an earlier discharge.

Walker (2001) discussed the decreased length of hospital stay common in most countries in a qualitative study of the Australian health care system. The results focused with a greater emphasis on the concept of transition and how it relates to the recovery process. She states, "recovering patients are patients in transition with all that implies" (p. 215). The decreased length of hospitalization has resulted in families being expected to provide more complex care to ill family members (Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000). Telehealth may be an essential tool in assisting families in the health/illness transition of their loved ones.

The concept of the health/illness transition using telehealth has not been examined. Several authors have noted the importance of the concept of transition for nursing. Meleis and Trangenstein (1994) strongly assert that facilitating transition should be the focus for the discipline of nursing and a central concept in nursing (Chick & Meleis, 1986;

Schumacher & Meleis, 1994). McCubbin (1999) views the concept of transition as an integral part of nursing practice.

The review of literature began with a search of PubMed using “Transition” 73,914 articles returned. It was then narrowed to search “AND Illness” (536) OR “Home care” (119) “AND Hospital” (82). CINAHL yielded 1,277 using “Transition” which was then narrowed to search “AND Illness” (244) OR “Home care” (99) “AND Hospital (102). Wiley Science Direct yielded 3,132 with “Transition” and 5 with “Transition AND Illness. Ebsco yielded 26 using “Transition AND Illness” and 48 using “Transition AND Hospital”. Cochran yielded 79 using “Transition AND Illness”. Digital Dissertations yielded 26 with “Transition AND illness.” The searches included articles from 1980-2004. After reviewing the abstracts and eliminating the inappropriate articles, 122 were read in their entirety. The criteria for inclusion in the review was telehealth that was conducted in “real time” and articles that addressed access to care, self-care and discharge from the hospital with transition as a major concept. This resulted in 45 references used for this concept analysis.

All 45 articles were examined for essential attributes of the concept of transition in relationship to the proposed middle-range theory of transition (Meleis, et al. 2000) using telehealth as the context for the concept. In addition the articles were explored for a definition of the concept of transition, the surrogate terms and relevant uses of the concept of transition, and to identify the antecedents and consequences of the concept as it relates to the health/illness transition. The majority of articles represented the discipline of nursing (N=32) with one article from business, eight from medicine and four from psychology. Eighteen articles looked specifically at the concept of transition as it relates to the practice of nursing. Fourteen articles that addressed some aspect of transition also addressed access

to care, self-care and discharge from the hospital that addressed some aspect of transition. Seven of the articles looked at antecedents to transition and six looked at some aspect of transition directly related to telehealth with the primary variable studied “patient satisfaction.” The articles were organized by year and then alphabetically by author. Several of the articles referenced the work done by Meleis but none of the recent articles written on transition cited their proposed middle-range theory (Meleis, et al., 2000).

Rodgers’ evolutionary method (Rodgers, 2000) was used to conduct the concept analysis of transition. Rodgers views one of the primary functions of concept analysis as the identification of the concept attributes to facilitate categorizations. Core attributes (properties) that define the concept are necessary to clearly communicate and categorize the phenomena. This research examined the concept of transition as it specifically relates to customizing care rendered by the APN via telehealth. The core attributes are not static in nature and the definition of the concept “may change over time, by convention or by purposeful redefinition to maintain a useful, applicable, and effective concept” (Rodgers, p. 81).

Definitions of Transition

Definitions of transition in nursing literature date back to 1957 when Tyhurst was the first to introduce the dictionary definition of transition into mental health literature. It was defined as “a passage or change from one place or state or act or set of circumstances to another” (Tyhurst, 1957, p.150). At this time he identified the attributes of transition to include: A phase of turmoil; disturbances in bodily functions, mood and cognition; symptoms of psychological distress and altered time perspective. Golan (1981) defined transition as “moving from one stage or event in life to another with varying degrees of

instability in the adaptive process” (p.12). Schlossberg (1981) defined transition as “an event or nonevent that results in changes in relationships, routines, assumptions, and/or roles within the settings of self, work, family, health and economics” (p. 4). All the definitions proposed on transition from 1957 to the present have the universal attribute of a process that occurs over time (Schumacher & Meleis, 1994).

Chick and Meleis (1986) defined transition as the “passage or movement from one life phase, condition, status, or place to another” (p. 239). Specifically, transition requires a change in health status, in role relations, in expectations, or abilities over a span of time (Meleis & Trangenstein, 1994). Tomlinson defined transition as “a movement from one state to another that is accompanied by change in roles, relationships, or patterns of behavior” (Tomlinson, 1996, p. 287).

Selder (1989) stated “a life transition is initiated when a person’s current reality is disrupted”(p. 437). This disruption requires the individual to reorganize or reconstruct their current reality which initiates the transition process. She determined the primary antecedent to transition was a disruption in one’s reality. She focused on the resolution of uncertainty to motivate a person through restructuring their reality. The attributes of the concept were focused on reducing the uncertainty and included: confronting circumstances, acknowledging of the disrupted reality, information-seeking behavior, and engaging in the transition to normalize their reality. The goal of the transitional process is to regain the integrity of the self. In examining Meleis et al.’s. (2000) middle-range theory Selders’ (1989) work has many similar dimensions. Both emphasize the need for the individual to be aware and engage in the transitional process. The health care provider needs to assess for reactivation (time span), critical points and events, and examine the individual’s ability

to move towards the reformulation of their identity as the primary criteria for a healthy outcome.

Murphy (1990) reviewed the literature and defined the concept of transition as arising from two major theoretical perspectives. The first is the developmental lifespan where the focus is more on the assimilation of change rather than the event itself. The second is life events that cause crisis points or disequilibrium between two stable periods of time. “Both definitional perspectives suggest that human responses to transition are complex and can be affected by many factors” (Murphy, p. 2). The five types of transitions (Meleis & Trangenstein, 1994) that nurses should focus on are: developmental transition, family developmental transition, situational transition, health/illness transition and organizational transition. Murphy condenses these into developmental, situational, and health illness transitions. This chapter will focus on the health/illness transition that occurs when an individual with an acute infection is discharged from the hospital to the home supported by the APN with telehealth in an effort to avoid a hospitalization or to promote an earlier discharge from the hospital.

When an individual is experiencing an acute illness requiring hospitalization it forces both the individual and family members to move into a transitional phase with the antecedent to transition the illness event. “Changes in health and illness of individuals create a process of transition, and the individual in transition tends to be more vulnerable to risks that may in turn affect their health ” (Meleis et al., 2000, p.12). “A transition will occur if the disruption of a reality necessitates reorganizing or reconstructing the existing one” (Selder, 1989, p. 437).

Meleis and colleagues have been publishing work on the exploration of the concept of transition since 1986. Several authors have worked in collaboration with Meleis over the years including: Chick & Meleis, 1986; Meleis & Trangenstein, 1994; Schumacher & Meleis, 1994 and most recently Meleis et al., 2000 describing a middle-range theory for transition (see appendix A). This framework provides the conceptual orientation used to analyze the health/illness transition within the context of telehealth. Additional data in the literature as it relates to the work of Meleis and colleagues will also be examined and related to an individual with an acute infection discharged from the hospital to the home supported by the APN with telehealth in an effort to avoid a hospitalization or to promote an earlier discharge from the hospital.

Meleis et al. (2000) and other researchers (Golan, 1981; Selder, 1989; Tyhurst, 1957; & Walker, 2001) have stated that transitions are complex and multidimensional. After years of research Meleis and colleagues have identified common essential properties of the transition experience. These include: awareness, engagement, time span, critical points and events, and change and difference. A discussion of these properties as they relate to telehealth will be included.

Properties (Attributes)

Awareness

Chick and Meleis (1986) stated that in order for individuals to enter transition they must first be aware of the transitional event. One example of a transitional event involving the property of awareness is when an individuals and/or family members recognize that they are ill and seeks health care. There may be multiple transitional events in addition to seeking health care.

One aspect of transition may relate to the individual transitioning from the hospital to the home when they are ill. This transition may not be related to personal choice as in the case of individuals with an acute illness who are not given the option to stay in the hospital until recovery is achieved. During this period of transition from the hospital to the home, the individual and family members may have a sense of not feeling safe, feeling disoriented and feeling threatened (Weaver, Perloff, & Waters, 1998). In addition to location, there can be multiple psychological stressors that reflect the diversities and complexities of the transition experience. These may include - adjusting to a new diagnosis, experiencing the illness event, changing expectations related to how the health care providers can best meet one's needs, and changes in the individuals' and family members' roles.

Engagement

The ability of the individual or caregiver to engage is dependent on the awareness of the transitional event (Meleis et al., 2000). Engagement is the degree to which the person is involved in the transition process. This is the stage in which they are seeking information and are proactive. Assessing caregiver and individual needs and responding to this information seeking is important during the proactive stage of the transitional process.

Time Span

Time span is the flow and movement over time that results in transition. Bridges (1991) views transition as passages or processes to which rites, rituals, and ceremonies are attached. He describes three distinct phases: endings characterized by several negative features, reassessment, and new beginnings or a period of stability. His conceptualization applies to both developmental and situational types of transition. This time span is

constantly in a state of flux or change that require the nurse to continually reassess how the individual and family members are moving through their transition from illness to health.

With the discharge from the hospital, the individual and family members become aware of the need to cope with additional change that may affect the transitional process they are in and/or initiate the transitional process. Meleis et al. (2000) identified that transitions are not “discrete or mutually exclusive” (p. 18). When exploring migrations scholars they found they were having at least two types of transitions occurring simultaneously. Meleis et al. (2000) identified the importance of reactivation in discussing latent transition and the need to continually reassess individuals’ outcomes.

Critical Points

Critical points and events are the periods of vulnerability an individual and or family using telehealth may experience during the transitional period (Meleis et al., 2000). Selder (1989) identifies that when reality has been disrupted, there often is a sense of not being safe and a feeling of being threatened. There is extensive material in the literature on the topic of care giving, but little attention has been devoted to the critical period of time immediately following hospitalization. In a study of mothers cared for by their daughters, there were fewer difficulties in managing their mother’s post hospitalization care when the daughters were able to obtain information and could problem-solve with the health care providers on a daily basis. They were also more likely to have established routines (Bull & Jervis, 1997).

Implementing telehealth with the expertise of the APN as an immediate available resource could facilitate these critical points through assisting in self-care strategies and supporting of the caregivers on a daily and emergent basis (Meleis et al., 2000).

Schumacher et al. (2000) identified that caregivers need professional assessment and guidance to develop confidence in their roles at critical periods in care giving. The first critical period occurs when the individual is sent home with telehealth to manage the acute illness. There are future potential critical points as the illness progresses to recovery or complications requiring interventions, including role strain that may occur in the caregiver. Access to health care providers is key during this time period, which individuals could have via telehealth with the push of a button (Marineau, 2005b).

Change and Difference

In Meleis et al.'s (2000) proposal for a middle-range theory there was a shift from their earlier works stating that "change and difference" are essential properties of transition. "Although similar, these properties are not interchangeable, nor are they synonymous with transition. All transitions involve change, whereas not all change is related to transition" (Meleis et al., 2000, p. 19). Transition results in a more permanent change that tends to be slower in its process and more complex than change. The acute illness may bring on an abrupt change in an individuals' behavior (i.e., a person who presents with pneumonia may abruptly stop smoking due to difficulty in breathing) but this may not be a long-term process of transition.

"Transitions are both a result of and result in change in lives, health, relationships, and environments" (Meleis et al., 2000, p.13). In this context, change could also be thought of as both an antecedent and consequence of transition. Meleis and Trangenstein (1994) distinguished transition from change with transition having a sense of flow or movement that extends the concept of change. Change is seen as more abrupt and to be used instead of, or to substitute one behavior for another. "At the individual

and family levels, changes occur in identities, roles, relationships, abilities, and patterns of behavior” (Meleis & Trangenstein, 1994, p. 257).

Another property of transition is confronting differences, which could involve being perceived as different, “feeling different, or seeing the world and others in different ways” (Meleis et al., 2000, p. 20). To reformulate one’s identity requires both transitioning through change where the person is reformulated as both the result of change and the result in change. Individuals need to perceive they are indeed different from their prior identities once reformulation has occurred. “In examining transition experiences, it may be useful for nurses to consider an individual’s level of comfort and mastery in dealing with change and difference” (Meleis et al., 2000, p. 20).

The properties of transition provide many opportunities for the APN to interact with individuals and facilitate a smooth progression through their health/illness transition when recovering from an acute infection. The Rodgers (2000) method of concept analysis also involves identifying surrogate concepts, related concepts and antecedents to the concept being explored. These steps further assist in the exploration of the concept being analyzed.

Surrogate Concepts

Adaptation to situational change, adaptation to role change, adaptation to organizational change and adaptation to health/illness change may meet all the attributes of transition to qualify as a surrogate concept. Except for the earlier works of Meleis where “change” was identified as a surrogate concept, and then later changed to an attribute, there was no evidence of a stated surrogate concept in the literature. Selder’s (1989) work implied “resolution of uncertainty” as a surrogate concept to transition.

Related Concepts

The concept of transition may be related to and congruent with the concepts of “adaptation, self-care, self-efficacy, unitary development, expanding consciousness, and human becoming” (Meleis & Trangenstein, 1994, p. 255). Many theorists (e.g., King, 1981; Levine, 1973; Orem, 1985; Roy, 1984; & Watson, 1988) incorporate these related concepts, thus adding support for transition as a central concept in nursing (Chick & Meleis, 1986; Meleis & Trangenstein, 1994; Schumacher & Meleis, 1994). Other related concepts that were encountered in the literature included: Shifting of self-care; restructuring one’s reality; life changes; and uprooting and development. All of these concepts share some attributes with transition, but none address all of the attributes.

Antecedents to Transition

Occurrences in one’s life or circumstances that are most likely to be antecedents to the process of transition include: Illness, recovery, birthing, death, loss, immigration, migration, hospitalization, pregnancy, retirement and maturation (Chick & Meleis, 1986). The focus of this research was on the antecedent of change in health status resulting in the individual with an acute illness being treated in the home with telehealth.

Meleis et al.’s (2000) middle-range theory explores the patterns of response when examining the concept of transition. These patterns of response involve both process indicators and outcome indicators that can be used to by the APN to evaluate and intervene early to assist in achieving a positive transition.

Patterns of Response

Process Indicators

Consequences occur after the illness event when transition has begun. Meleis et al. (2000) identified that making a healthy transition involves both process and outcome

indicators that can guide the nursing process. Since transition is a process over time, assessing these indicators for movement toward health or illness would allow the APN to intervene early and promote a positive transition. Tomlinson states that “a central assumption of transition theorists is that change involves reorganization and reintegration of meaning, identity and role taking, all significant factors in determining nursing actions with individuals’ response to health change” (Tomlinson, 1996, p. 287). Process indicators that indicate a healthy transition include: developing confidence and coping, location and being situated, and the need to feel connected and interacting with their health care providers and/or significant others.

Developing confidence in their ability to do self-care activities is an important part of the transition process. Chick and Meleis (1986) identified that a transition occurring in an environment that is unstable will impede the transitional process. It is imperative that the APN assess the home environment and the support system of the individual before setting up telehealth.

To assess their ability to cope with the situation there must be an appraisal of the significance of the illness to the individual and family members. Support resources must be explored, as well as an assessment of individuals’ abilities to adapt, such as mastery of illness care and what coping skills they will use to engage in this transition to home care (King, et al., 2001).

Schumacher and Meleis (1994) identified that emotional distress can occur during transition, resulting in feelings of isolation, inability to concentrate and feeling overwhelmed. Murtaugh and Litke (2002) in their study of elders identified four potential negative transition outcomes related to acute and long-term care settings. They included:

Emergency Room visits, potentially avoidable hospital admissions, hospital admission for any reason, and return to any institutional setting after being discharged into the community. They recommended better integration of the supportive care provided for the elder population transitioning from an acute and/or long-term care setting to decrease emergency room visits and readmission to institutions after being discharged into the community. The effect of location on the elderly population can significantly impact their ability to successfully transition.

Location may have different effects on different individuals according to their perception of health/illness, culture, gender and other variables yet to be identified. Some individuals may prefer to be in their homes to recover from an illness and will move more rapidly to resuming their normal activities of daily living in that setting (Eron & Passos, 2001). Marineau (2005a) identified the importance of using telehealth as an intervention strategy with individuals suffering from dementia to prevent their psychological and subsequent physiological deterioration that results when they are taken away from their familiar home environment. This author has found several individuals who refused to participate in the telehealth pilot program verbalizing that they preferred the dependent environment of the hospital. Both environments require an atmosphere of connectedness and caring with their health care providers.

The need to feel connected and interacting with health care providers has been an important indicator of a positive transition from illness to health (Meleis et al., 2000). Communication is a key element that could be accomplished on a daily basis by the APN via telehealth with the individual in their home environment surrounded by family members. Planning must occur before and during the transition to identify problems,

needs and issues that may arise in the transition process. This daily planning and preparation could include anticipatory guidance for critical events.

Doing anticipatory planning for each phase of the transitional process that the individual may encounter may be especially helpful. Cowan and colleagues (1991) have done extensive research in anticipatory guidance interventions during the transition to parenthood. Their work supports the need to study transition to gain a better understanding of family adaptation and identify and intervene with strategies that contribute to its success.

There are important implications for discharging an individual home with telehealth who does not have the social support system to assist in the recovery process. The lack of a support system could be due to the family member working out of the home for much of the day. Another variable could be a spouse who is elderly and/or has health care needs of their own that makes it impossible for them to administer the care necessary for the individual to recover in the home with the assistance of telehealth.

Outcome Indicators

Meleis et al. (2000) have identified two primary indicators from their research: mastery of new skills to move positively through the transition process and fluid integrative identities. These constitute health outcomes of the transitional process. There is a wide variation regarding when a transitional process is complete. If examined too early, one may be dealing with process indicators. If the researcher waits too long after the transition has been completed, he/she may be dealing with another life event of the individual (Meleis et al., 2000).

Mastery is defined as the completion of a transition in which the individual has been able to demonstrate mastery of a new skill or behavior to manage a new situation or

environments (Meleis et al., 2000). Mastery is unlikely to be seen early in the transitional process but tends to occur near the completion of the transition process. An example would be a telehealth participant who was initially non-compliant with their diabetic regimen. They may ultimately be motivated by their acute illness to assume management of their chronic disease process and have blood sugars meeting their target range.

Transition has been connected with the identity reformulation. Selder states that in the later stages of transition “all report a resurgence of integrity, the reemergence of the sense of self” (Selder, 1989, p. 440). This reformulation is viewed as fluid and dynamic rather than stable and is referred to in Meleis et al.’s (2000) middle range theory as fluid integrative identities. These individuals demonstrate mastery in their daily care activities, ownership of their underlying chronic disease process and have confidence in their self-care abilities. Morse and Carter (1995) gave a vivid description of a burn patient who works through the transition of loss over time and reaches her reformulated sense of self by realizing that she has a future and much to offer others.

In conclusion, the health/illness transition is indeed a complex and multidimensional concept, with several unique attributes that manifest as individuals progress through the process, which are identified by patterns of response involving both process indicators and outcome indicators. In the context of telehealth, there may be two or more distinct health/illness transitional processes. One transitional process may be encountered as the individual moves from the dependent hospital environment to the home, a second transitional process occurs as they fully assume self-care abilities required to manage their acute infection which may also involve better management of their underlying chronic disease processes. Additional health/illness transitional events may be

experienced by the individual related to their chronic disease process, such as, coping with a terminal illness, beginning chemotherapy, hemodialysis and/or dealing with caregiver role strain. Telehealth supported by the APN may be an important strategy to assist them in all these transitional processes.

CHAPTER THREE

LITERATURE REVIEW

The purpose of this chapter is to explore the current literature related to research conducted using telehealth with individuals with acute infections.

The initial search terms were with PubMed using “Telehealth OR Telemed OR Telecare” and 6,013 articles returned. It was then narrowed to search “AND Home care (416) OR Home health” (519) “AND Wound OR Wounds (39) OR Cellulitis (41) OR Pneumonia (0) OR Asthma” (10). CINAHL yielded 277 using “Telehealth OR Telemed OR Telecare AND Home care OR Home health” with “AND Wound OR Wounds OR Cellulitis (39) OR Pneumonia (0) OR Asthma” (11). Wiley yielded 21 using “Telehealth OR Telemed OR Telecare” and 0 articles with wound, cellulitis or pneumonia. Science Digest yielded 261 using “Telehealth OR Telemed OR Telecare” and 0 articles with wound, cellulitis or pneumonia. Ebsco yielded 131 using “Telehealth OR Telemed OR Telecare” and 0 articles with wound, cellulitis or pneumonia. Cochran had 286 with the use of “Telehealth OR Telemed OR Telecare. A time frame was specified using the last five years since this is a new technology that has only recently been financially reasonable to use in an individual’s home. The telemedicine journals were hand searched (*Telemedicine Journal & e-Health* and *Journal of Telemedicine & Telecare*) with an additional two current articles found.

The focus of the search was on the use of this technology with individuals with acute infections requiring hospitalization rather than individuals with chronic disorders alone. Only two studies were found that included subjects with a high level of acuity. One was done in Italy on patients with restrictive airway disease (Maiolo, Mohamed, Fiorani, &

Lorenzo, 2003). The second was a study done at Kaiser Permanente in which this author was the co-investigator of a quantitative study looking specifically at the same participant population that will be used for this qualitative study (Eron, King et al., 2004).

The search goal to include primarily subjects who had wounds/cellulitis, pneumonia and pyelonephritis was attempted since these are the diagnostic criteria for inclusion of subjects for both the previous quantitative study and this qualitative study. Other than the earlier study in which this author participated there were no other research studies identified in the search that used this technology for managing pneumonia and pyelonephritis and the wounds managed were primarily chronic venous stasis ulcers or decubitus ulcers. The latter were included because it was felt the data would be helpful to see how the technology worked in assessing the wounds over POTS which was the same technology used for the participants in this study. Asthma and COPD studies were also included since they provided data that were closely related to data that would be monitored with pneumonia (i.e., oxygen saturation). Articles were included that specifically looked at patient satisfaction and/or return to activities of daily living in the use of telehealth in the home.

Articles were excluded that discussed teleradiography or echocardiogram and articles on chronic management of diabetes (which represents approximately 45% of the research data). Studies were excluded when there were no phone or video interactions and just consisted of data transmission to a computer over the phone or Internet lines. Studies were also excluded where the individual was seen in a health care facility rather than in their home. The result was 43 articles that met the inclusion criteria. Less than half of the articles were research based with identified independent and dependent variables. All but

one study used a pilot/feasibility approach. The majority of the articles were descriptive in nature with a discussion of various concepts as they relate to the field of telemedicine. Seven of the remaining articles included a systematic review of the literature.

Synthesis of the Literature Review

The focus of the literature reviewed encompasses the last five years. The review was limited to this time period because the quality and the feasibility of having the video technology of “face-to-face” interactions in the home has been a recent occurrence. The studies done prior to this time period had prohibitive cost and equipment problems so did not fit the inclusion criteria for this literature review (the individuals would have had to travel to a clinic site to access this technology).

The primary outcomes in the studies were related to patient/provider satisfaction and cost effectiveness. The intervention was replacing “face-to-face” interactions in the home with telehealth that was supported by a nurse. None of the studies used an APN to support the telehealth interactions.

One of the studies reviewed cited an explicit theoretical model (Demiris, Speedie, & Finkelstein, 2001). The value-expectancy model was used to explore patients’ perceptions as they relate to the congruency between expectations of care and perceptions of the care received using telehealth as the delivery method. The 28 participants in this study had scores that demonstrated congruency between expectations of care and perceptions of care that were statically significant after experiencing telehealth.

The intervention was targeted to increase self-care activities with four of the nineteen studies reviewed (Agrell, Dahlberg, Jerant, 2000; Dansky & Bowles, 2002; Johnston, Wheeler, Deruser, & Sousa, 2000; Vesmarovich, Walker, Hauber, Temkin, &

Burns, 1999). Johnston et al. (2000) was the only study that actually used “self-care” as a quality indicator measurement. The goal of this study was to replace some in-person home visits with telehealth visits without compromising client care or raising home health care costs. The groups were comparable in age, gender, primary diagnosis, prior home health nursing visits and caregiver support. At discharge from the home care services, clients in the control and intervention group did not differ in their knowledge regarding their condition, compliance with medication regimen, or ability to move toward self-care.

Patient Satisfaction

One group in Canada conducted research with children suffering from complex problems being discharged from the hospital with serious chronic conditions. Prior to the study they observed parents having a difficult time transitioning with their child from the high tech hospital environment to an abrupt decrease in access to health care providers at discharge. Their telehome care program was specifically designed to improve the transition from the hospital to the home with access via videoconferencing to pediatric nurses located in the hospital. They specifically looked at satisfaction for care delivered at home compared to hospitalization. Their results indicated a strong preference for telehome participation (59%) with no difference in the care received at the hospital when compared to care delivered with telehealth (Dick, Bennie, Barden, Daniels, & Young, 2004).

Of these nineteen studies, sixteen looked at patient satisfaction using questionnaires, telephone interviews or mailed surveys. Only two studies (Demiris et al., 2001; Yip, Chang, Chan & Mackenzie, 2003) tested their instrument for reliability and validity. The purpose of the first study (Demiris et al., 2001) was to measure patients’ perceptions of telehealth before and after they participated in it. The same research group

(Finkelstein, Speedie, Demiris, Veen, Lundgren, & Potthoff, 2004) recently conducted an additional study and demonstrated that elderly homebound patients were more satisfied with their home health care program when telehealth visits were added to their face-to-face home visits with the home health care nurse.

One study demonstrated conflicting results when measuring patients' perception of comfort and safety against a hospital control group (Eron, King et. al., 2004). Overall, the remaining sixteen studies all reported positive patient and/or provider satisfaction with the technology. This satisfaction was reflected in easier access, increased sense of security (one study reflected a decreased sense of security when compared to a hospital control group), empowerment, increased understanding of their disease process, increased self-management skills, not wanting to "give it up" and perceiving that they were special, like "being on TV"(Singh, Donoghue, Soon & 2002, p. 5). A threat to the validity of data obtained is that all of the studies except four (Caplan, Ward, Brennan, 1999; Dansky et al., 2002; Demiris et al., 2001; Maiolo et al., 2003) included nonrandomized subjects who were obtained by a volunteer method. This type of recruitment leads to the assumption that the individuals who would rate this health care delivery method poorly could have been excluded from the study.

Studies ranged in sample size from 1- 212 with nine of the fifteen studies having 28 or fewer subjects. Johnston et al. (2000) was cited by several articles that critiqued the literature as the only randomized control research trial done in the field of telehealth with an adequate number (212) of subjects (Coleman, 2002; Hersh et al., 2001; Wootten, 2001). The majority of studies looking at telehealth in the home have been pilot trials and

feasibility studies with small sample sizes. These studies reflect small heterogeneous samples with limited ability to generalize.

There were minimal studies that addressed ethical considerations. Only one of the studies mentioned institutional review board (IRB), ethical considerations and informed consent (Eron, King et. al., 2004). There are real ethical implications if a clients are forced to use telehealth when they would prefer a traditional “face-to-face” interaction.

Systematic Reviews

Whitten et al., (2003) did a systematic review of the cost effectiveness of telehealth. The results of 55 studies assessing the costs and benefits of telehealth indicated that 36% demonstrated that telehealth saves money, 20% demonstrated that it saved time and money, 16% demonstrated that cost-effectiveness is achieved if a certain threshold is met, 13% demonstrated that more work is needed to assess cost-effectiveness accurately, and 7% found that telehealth does not save money. They concluded that the studies investigating the cost effectiveness were generally small and of poor quality. The author reported that at the time of their publication there was not enough high quality evidence that telemedicine is better than the usual health-care delivery method. An executive summary report to congress for telemedicine (Executive Summary, 2001) identified that the lack of research related to cost savings and patient/provider satisfaction may be due to the relatively small number of telehealth projects used in any one specialty with the lack of a standard evaluation methodology to study these concepts across small groups and projects.

Mair & Whitten (2001) reviewed research related to patient satisfaction in patients involved in real time interactive video. They identified 32 studies conducted world wide. Study methods used were simple survey (26 studies), qualitative methods (1 study) and

exact-method-not-specified (5 studies). All studies reported positive patient satisfaction but the authors noted that all of the studies had methodological problems.

Hersh and colleagues (2001) did a systematic review exploring telehealth interventions in the home-and office/hospital. A total of 25 studies were reviewed. Their conclusions were that the strongest evidence for using telehealth was in the home-based arena in the areas of chronic disease management, hypertension, and AIDS. Their recommendations were that further controlled randomized trials must be done to determine the greatest field of efficacy.

Hailey et al. (2002) (screened 1,323 abstracts) in a review of the literature to investigate the evidence for benefits of telehealth. They selected 66 articles that met criteria and grouped them into 11 areas of applications (with 17 of the articles done in the field of radiology, pathology and ophthalmology) and a hospital, clinic or home settings. Thirty-seven studies demonstrated advantages in using telehealth over the traditional (“face-to-face”) approach; 13 studies demonstrated advantages and disadvantages; 11 demonstrated that any advantages were unclear; and 5 found the traditional approach held advantages over telehealth.

Currell, Urquhart, Wainwright, & Lewis (2000) reviewed seven trials involving 800 clients examining telehealth versus face-to-face patient care looking specifically at the effects on professional practice and health care outcomes. The interventions involved video consultation between the hospital consultant and the general care practitioners to manage patient care. These interventions were well accepted by the patients. They found no analyzable data regarding the cost effectiveness of this type of intervention using telehealth.

There is a need to be aware of the ethical issues regarding privacy/confidentiality, patient/caregiver perceptions and cultural considerations that should be addressed when conducting research in this field (Singh et al., 2002). Telehealth results in a change in the client/provider encounter requiring investigation of the need for different communication skills and approaches to information giving using this technology (Hersh et al., 2001; and Government Update, 2001). These issues should be addressed as they relate to age, gender and culture.

None of the studies have looked at long-term outcomes in the use of this technology. This may result in a re-focusing of the scope of telehealth with new research questions emerging. None of the studies have explored the concept of transition applying telehealth specifically to individuals' abilities to move from illness to health using telehealth when they are acutely ill. Few studies have used a qualitative approach in this area to gain greater insight into common themes that may emerge regarding participant/provider perceptions of barriers, facilitators and satisfaction with this method of health care delivery.

Conclusions

Telehealth may have the potential to increase participants' satisfaction by having more frequent opportunities to make treatment changes, promote self-care strategies, and observe the status of the disease process. With these frequent interactions there could be more educational opportunities to teach self-care activities and empower individuals to take control of their disease process, which should result in a positive health/illness transitional process.

Delivery of health care via telehealth has the potential to be positively related to participant satisfaction by increasing individuals' self-care activities resulting in a sense of empowerment over their disease process. This has advantages over hospitalization by taking the individual out of the dependent role of the hospital environment. For individuals who would need to come into the ambulatory treatment center (ATC) for daily monitoring it would decrease their travel time and result in greater satisfaction with their care. However, telehealth used as a replacement for hospitalization when an individual is acutely ill may result in a decrease in patient satisfaction due to a perception of feeling unsafe in the home environment without a health care provider physically present. The acutely ill individual may also have insufficient internal and/or external resources to deal with the technical challenges of interacting with the APN via telehealth (see appendix B).

Research in the area of telehealth used for chronic conditions has shown an increased sense of security perceived by the patient by connecting with the health care providers through this technology. Eron, King et al. (2004) documented that patients suffering from an acute infection using telehealth perceived a decreased level of security when compared to a hospital matched control group. Individuals transitioning from an acute illness may have different levels of satisfaction to telehealth treatment when compared with those who are dealing with a chronic illness.

A few of the research studies implied the use of a self-care model in the implementation of their telehealth programs (Agrell et al., 2000; Dansky & Bowles, 2002; Johnston et al., 2000; Vesmarovich et al., 1999). By integrating Orem's model into a telehealth practice on a daily basis, providers would be able to do a frequent assessment of the individuals' strengths to assume self-care strategies and mobilize the available

resources and support systems to keep them out of the dependent hospital environment. The nurse using telehealth could be the supporting force to assist in regulating self-care deficits, while maintaining individuals in the comfort of their own environment.

Levin (1973) emphasized that it is also important to understand that health is culturally determined. Health is not an entity by itself, but is defined through the ethos and beliefs of the group to which the individual belongs. This becomes exceedingly important in delivering telehealth in Hawaii where such a diverse cultural population resides. Telehealth may not be appropriate to use based on the person's culture or, support system, especially as it relates to safety consideration and perceived or real need for dependency when they are ill (Eron, Marineau et al., 2004).

Safety factors will dictate that telehealth cannot be used with individuals who do not have adequate support systems in place. The acuity of these individuals will mandate some level of direct patient care to be done by family members in place of the nurse. It is not an assumption that all individuals would possess sufficient internal resources to be able to restore their level of health through just telehealth; care will need to be augmented by family members and/or a respite worker.

In summary, there are very few studies that explore the individual's perceptions and attitudes towards the use of telehealth in intervening with chronic illnesses and no studies to date exploring interventions with acute infections, with the exception of the recent quantitative study conducted by this author.

CHAPTER FOUR

METHODOLOGY

Phenomenology was used in this study to describe the lived experience of individuals with acute infections transitioning in the home with support by an APN using telehealth in an effort to avoid a hospitalization or to promote an earlier discharge. The purpose of this chapter is to describe the method used in this study. The specific eidetic approach of phenomenology as a method will be addressed. Topics will include the research design, setting and sample, data generation, data management, data analysis and qualitative rigor.

Eidetic Phenomenology

Eidetic phenomenology was chosen for this study because it seeks to understand another's experience by reducing particular facts to general essences. Husserl (1980) believed that it is essential that we first get to the "roots" of knowledge to discover, "How do we know what we know?" This researcher felt that this was an important beginning point when addressing the new phenomenon of telehealth in meeting the needs of the individual with an acute infection.

There are two major assumptions when examining a phenomenological approach. First, individual perceptions provide us with evidence about the world as it is lived. The "lived experience" is critical to phenomenology. Second, human existence as "being in the world" is meaningful specifically as it relates to the individual's relationships with things, people, events and situation (Morse & Richards, 2002). Eidetic phenomenology is specifically interested in understanding the structure of the life-world or the lived experience.

Eidetic phenomenology, a descriptive qualitative research methodology, and hermeneutic phenomenology, an interpretive qualitative research method, arise from two different but related schools of thought. The goal of eidetic phenomenology is to describe the essential structure of the lived experience after presenting an exhaustive description of the phenomenon under study. This researcher achieved this goal by living with the data, holding prior biases or preconceptions in abeyance (bracketing), while examining it from various perspectives. This researcher then identified potential themes, looking at all possible alternatives before arriving at the essential description (Munhall, 2001).

Bracketing is the process used in eidetic research to visualize the individual as they are without presuppositions. Husserl (1980) used bracketing to assist the researcher to see and understand observations without tainting the observations with personal biases. This allows the researcher to get to the roots of the beginnings of the knowledge itself, “How do we know what we know?” This method is concerned with the wholeness, looking at the phenomenon from many sides, angles, and perspectives to arrive at the essences of the experience. There must be an acknowledgement of the researchers own subjectivity and subsequent bracketing of personal beliefs and all prior knowledge about the topic.

Hermeneutic phenomenology differs from eidetic in that it has both descriptive and interpretive elements (Heidegger, 1962). The primary distinction between the two methods is that hermeneutic (or Heideggerian) phenomenology maintains that presuppositions should not (and cannot) be eliminated by brackets. Rather, it contends, these presuppositions bring about the possibility of interpretations (Ray, 1994). This approach advocates that the researcher remain orientated toward the phenomenological question

without a prescribed method but rather has a discovery-oriented approach (van Manen, 1990).

This researcher has had a long-standing personal interest in the field of telehealth and has been immersed with many of the participants of this study for the past two years using this technology. Based on being a co-investigator in the telehealth quantitative study and the review of the literature on the subject of transition and telehealth, this researcher has made assumptions and held pre-existing ideas based on the phenomenon of individuals with acute infections transitioning in the home supported by the APN and telehealth. Bracketing allowed this researcher to identify her presuppositions, reflect on the experience and then describe the critical structures that are being examined. The bracketed assumptions and pre-existing ideas consisted of the following:

- Individuals have unique capabilities that the APN can appeal to in empowering them to an optimum state of wellness using telehealth to assist in the transitional process of health/illness.
- Telehealth supported by the APN can assist in more frequent observations to make treatment changes, promote self-care strategies and allow observance of the status of the disease process that should result in a positive health/illness transitional process.
- Telehealth participants feel a greater sense of comfort in their homes and will recovery faster from an acute illness.
- Telehealth participants feel less safe in the home when compared to the hospital environment when recovering from an acute illness.
- Some individuals may prefer the dependent environment of the hospital when recovering from an acute illness.

- Safety factors dictate who telehealth should not be used in individuals with acute illness that do not have adequate support systems in place in the home.

The researcher's role in conducting an eidetic phenomenological study is to attempt to understand the person's perception of how they see their world to understand the lived experience. This researcher has a personal interest to seek to intimately connect with this phenomenon through the individuals' perceptions of how they viewed transitioning with the assistance of the APN via telehealth. This approach allowed the researcher to go to the homes of the participants and immerse herself completely in their memory of the lived experience of telehealth. This researcher was able to look, listen, see, hear, and touch from many perspectives to capture the essential structure of their experience.

Phenomenology views an individual in the lived world as having differences qualitatively based on individual situations. Questions are intended to uncover meaning, for example, "What does this mean to you? How did the experience affect you? What changes do you associate with the experience? What thoughts stood out for you? Have you shared all that is significant with reference to the experience" (Moustakas, 1994, p. 116)? This form of inquiry is incompatible with a focus group format where the group is the unit of analysis. The philosophical focus of phenomenological research is on the subjective rather than the objective nature as a means of seeking understanding of the life-world of human beings (Donalek, 2004).

Research Design

Eidetic or descriptive phenomenology was used as the research method for this study. Specifically this study focused on the lived experience of acutely ill participants as it related to the health/illness transition when they are discharged into the home using

telehealth with support by an APN, in place of hospitalization or in an effort to promote an earlier discharge from the hospital.

Setting and Sample

The interviews for this study were conducted in the participants' home with the exception of one participant who preferred to be interviewed at the hospital during her chemotherapy. Participants were recruited by phone from the telehealth pilot program located at Kaiser Permanente in Hawaii that began in September of 2003 and was completed in December of 2004 with 47 participants enrolled. The author was a co-investigator of this project and conducted telehealth visits with the majority of the enrolled participants.

The pre-existing telehealth pilot program gathered quantitative data regarding participants cared for by APNs with telehealth who would normally have been hospitalized with their acute infections. The participants were excluded if they required intensive care monitoring with a life-threatening acute infection. The participants in the telehealth pilot program had a mean age of 70 years. The diagnoses they most frequently presented with were severe cellulitis, urinary tract infections and community-acquired pneumonia, with the most common co-morbidity being diabetes. The participants were ill enough to require hospitalization to administer medication (i.e., intravenous antibiotics) along with close monitoring by the APN for complications. These participants were recruited into the telehealth pilot program via four possible pathways: 1) directly from the emergency room; 2) directly from the ATC; 3) within the first twenty-four hours of hospitalization 4) after more than one day of hospitalization in an attempt to result in an earlier discharge from the

hospital. This current study gathered qualitative data from the participants in the previous study to complete the description of this population.

Phenomenology does not seek to control for variables such as age, race, gender, etc., therefore, sampling was done by a purposive means, using a convenience sample from the telehealth pilot research program at Kaiser Permanente in Hawaii. Purposive sampling is considered to be the most important kind of non-probability sampling to identify participants. Participants are selected by looking for those who have experienced the phenomenon (Welman and Kruger, 1999) of recovering from an acute infection in the home with telehealth. The sample for this qualitative study was ten participants. This was determined by saturation of the data according to the criteria outlined by Denzin (1989). Data collection was conducted until there was redundancy in categories and no new categories emerged. This was confirmed by peer review indicating that all categories were saturated after analyzing the ten transcribed interviews.

The criteria for selection required that the participants had been included in the telehealth program over the past two years and were capable of articulating their experience in English. A two year period was chosen to allow for adequate time for the participant to reflect on the experience and decrease the likelihood of the participant encountering another acute illness that might have made it difficult to articulate the telehealth experience. The participants were contacted by phone by the author to determine an interest in participating in the proposed study. There were no incentives used to encourage participation in this study.

Data Generation

Human Subjects

Approval from the IRB was obtained through both Kaiser Permanente (Appendix D) and the University of Hawaii (Appendix E) prior to initiating this study. Subjects were recruited by phone and were informed that their participation was voluntary and would in no way influence their future health care at Kaiser Permanente. A consent form describing the purpose of the study was reviewed with the subject at the first interview in their home. Subjects were informed that they could withdraw from the study at any time. Assurance of anonymity and confidentiality was maintained throughout the duration of this study. Only the author of this study and the transcriptionist had identifying personal information and were bound by confidentiality not to reveal any personal information about the participants in this study. All tape-recorded interviews were locked in a secure place; only the author of this study and the transcriptionist had access to these tapes. There was no identifying patient information on the tapes or transcripts. A number with the date of the interview was assigned to each tape and transcript. The subjects' name, medical record number or social security number was not used to label each interview. Written consent to participate was filed in a separate locked secure place. Tape recordings and transcripts will be destroyed one year after the completion of the study. Subjects were informed of the results of this study at the third interview and are aware that the study may be published with no identifying information included in any future publications (see Appendix F).

Data Collection Procedure

All 47 of the participants who were enrolled in the telehealth pilot program at Kaiser Permanente (there were 49 cases with 47 participants; two participants were

enrolled in the study on two separate occasions) were attempted to contact. These participants had been rendered care in the telemedicine pilot program by the author of this study and/or the other two APNs involved in the preexisting study. The initial contact to participate in this study was by telephone. Three of the participants had moved to the mainland, four of the participants had expired, and two of the participants would only agree to a short interview by phone so were excluded. One ninety-year-old participant stated, “I would love to help dear, but I am afraid I really do not remember the experience.” One individual was hospitalized and wanted to participate but felt too ill to give an interview at the time of contact. One individual agreed to participate and an interview date and time was set up; at the designated time he was not present. The family members stated he would call to reschedule, but he never contacted the researcher, so was excluded. Sixteen of the forty-nine participants were not even contacted to enroll due to the researcher’s knowledge that the participants were too debilitated and/or suffered from severe dementia, with only the family members able to articulate the experience. The nine remaining individuals were unable to be reached by phone with no answer; five had answering machines but did not return the researcher’s phone messages. This resulted in ten remaining participants who agreed to enroll in the study.

Demographic data from the existing demographic data enrollment in the pre-existing telehealth pilot program (see Appendix F) was verified and updated for this research at the first home visit. Background information related to age, diagnoses, comorbidities, gender, ethnicity, home living situation and educational level was examined in this study.

The study included three home interview visits per subject. The first interview was conducted between July 24, 2005 and August 9, 2005. The interviews lasted from 10 to 22 minutes and were tape recorded. The researcher posed open-ended questions to the participant to elicit their lived experience of the health/illness transition that occurred with telehealth. The goal of the interview was to hear the participant's descriptions of their lived experience using telehealth supported by the APN when they were acutely ill, the interviewer did not determine the content to be discussed. Five of the ten participants did not have a family member present during the interview. Significant others' comments were not transcribed. The researcher encouraged the participants to narrate their lived experience of transition as freely as possible with minimal interruptions. In two of the interviews, the significant other wanted to contribute to the interview, which resulted in interruptions. This made it difficult for the researcher to focus entirely on the participant's interview. This open approach enabled the participants to "talk story" (a Hawaiian-English term meaning an open-ended, relaxed description of events to one or more people) and formulate their own thoughts and feelings regarding what it was like for them to recover from an acute illness with telemedicine in place of hospitalization. An interview guide was used as necessary to prompt further exploration of the recollections of the participant's lived experience.

The second visit was conducted two to four weeks after the first interview had been transcribed and analyzed. Additional questions were formulated to assist the participant in expanding on their thoughts and feelings described in the first interview. These visits were tape recorded for any significant additional comments participants wanted to contribute after reflecting on the first interview. The goal of the second visit was to allow the

participant to make clarification, changes and/or corrections. Seven of the ten participants allowed the researcher to return for the second and third visit. One of the participants with terminal cancer decided to move back to the mainland to be close to his family, but allowed the researcher to validate findings and ask additional questions to clarify meanings from the first interview by telephone. One of the participants scheduled a visit in her home with the researcher in Waimea, but was not home at the pre-arranged time. Multiple attempts were made to reschedule the visit but the phone had been disconnected. The last participant, with stage four cancer, had spontaneously decided to go to India for one month. The researcher attempted to validate the data by e-mail correspondence but did not get a reply.

Interview Guide

At the first visit the interview began with the following statement: “I would like to hear about your thoughts and feelings using telehealth when you were ill.”

Broad questions were needed to facilitate obtaining a full description of the participant’s experience such as:

- Can you recall who initially approached you about telehealth? What were your initial thoughts and feelings about the information they presented?
- Can you remember any specific person, event or visit that stood out for you?
- How did your significant others feel about you going home with telehealth? What were their thoughts and feelings about the experience?
- Who was here for you when you came home? Who helped out with the telehealth encounters?
- What thoughts stood out for you during your telehealth encounters? Describe what they were like?

- Have you shared all that is significant with reference to the telehealth experience?
(Moustakas, 1994).

The third visit was scheduled after all interviews were transcribed and analyzed to allow the participant to read the concluding themes derived from the study and the essential structure that had been determined. These visits occurred one to two weeks after the second visit. This allowed the participant to have final input regarding their impressions and/or questions. The third visit was not tape-recorded. All of the remaining seven participants allowed the researcher to return for the final home visit.

The author of this study wrote observational notes within two hours of conducting all of the visits. These notes outlined how the interview was initiated, the setting in which the interview took place, and other details, including any distractions that occurred during the interview. Attention was focused on recording the participant's voice intonations, facial expression and physical gestures during the interviews. The content of the conversation that took place before and after the interview was also included to set the tone of the interview. Finally, the researcher's reflections of the whole interview process were recorded.

Data Management

Each of the interviews was transcribed verbatim by a Kaiser transcriptionist. The researcher compared the transcribed data with the audiotape and made the necessary corrections. The tapes were placed in a locked drawer. The transcribed interviews were stored on the researchers' personal computer and a disk that was locked in a drawer. The transcriptionist was instructed to replace any personal identifiers with "xxx" to protect the anonymity of the participants.

Data was entered into a computer software program on the researcher's personal home computer ("Qualrus") to assist in organization. Qualrus is one of the newest programs that attempts to bring artificial intelligence to qualitative research (Ragin et al., 2004). The author of this study used Qualrus to systematically index and organize the data to allow for reliability and flexibility in retrieving the data in different ways. This software was not used to analyze the data. Each segment was analyzed according to Colaizzi's seven-step process by the author of this study and one other researcher who has extensive experience in conducting qualitative research studies. Each interview generated additional themes with final generalizations made by the two researchers using Colaizzi's (1973) qualitative data analysis procedure.

Field notes were utilized as a secondary form of data. Four types of field notes were utilized: 1) Observational notes – using all the researcher's senses (vision, smell, touch, hearing) in making observations, 2) Theoretical notes – using the researcher's reflections on the experiences in an attempt to derive meaning, 3) Methodological notes- having the researcher critique and/or remind herself of the process, and 4) Analytical notes- regarding the researchers periodic summary and/or progress reviews. Each of these was a step toward data analysis using Colaizzi method (1973) of qualitative data analysis.

Data Analysis

Steps of Data Analysis

Step One

All of the individual's descriptions were read, referred to as protocols, to make sense of the content and gain a feeling for them (Colaizzi, 1973). This step was done to get a sense for the whole. The tapes were listened to several times and the transcripts were

read numerous times to get a feeling for each of the whole interviews. Once all the interviews were completed, the whole process was completed again to try and stay as true as possible to the interviewee's meaning. General impressions were noted on each interview with additional questions listed to ask in order to elicit elaboration from the interviewee at the second interview.

Step Two

Each protocol were reviewed and phrases and/or sentences were extracted that directly related to the phenomenon. This stage was done to extract significant statements. Meaning units were highlighted and stated in the words of the subjects. Meaning unit were then entered into the software program Qualrus. For the most part, the literal words were retained. If there was ambiguity or uncertainty as to whether a statement contained a significant statement it was included even if it was redundant.

Step Three

Each significant statement was examined and meanings were formulated. This step was critical. The researcher was very careful not to leave the data set and to formulate meaning that was not connected with the data. Each of the significant statements were explored and then the researcher identified those that were clearly relevant to the phenomena being studied. At this point the statements that were clearly irrelevant were not recorded. A peer researcher went over each of the transcripts to verify that the significant statements were relevant to the lived experience as it relates to the health/illness transition that occurs when an individual with an acute infection is discharged from the hospital to the home with support by an APN using telehealth in an effort to avoid a hospitalization or to promote an earlier discharge.

Step Four

The researcher examined and organized the formulated meanings into a cluster of themes. This was also a critical phase that involved examining the various meanings of the text, and having extensive evidence to provide support for the choice of relational themes which related back to the original protocols. This involved validating each relational theme with the data set. At this point bracketed presuppositions were reviewed, trying to stay as true to the phenomena as possible. Formulated meanings were identified, combining common themes into clusters of relevant meaning. The observation notes were reviewed again, so as not to lose sight of all the researcher's senses. Again, a peer researcher and the Chair of the Dissertation Committee validated that the relevant meanings fit in the identified clusters.

Step Five

All the results were integrated into an exhaustive description of the phenomena by identifying themes from the formulated meanings. No themes were discounted or eliminated prematurely.

Step Six

An effort was made to formulate a statement of identification from the exhaustive description of the phenomena. All the above steps were repeated for each interview, and the themes common to all the interviews, as well as the individual differences were examined. Great care was taken not to cluster themes together when there were significant differences. Once the theme categories, clusters, themes and sub-themes were determined, each of the direct significant statements were coded and entered into the software program

Qualrus. This program assisted in organizing the 321 significant statements into the appropriate theme categories, theme clusters, themes and sub-themes.

Theme categories are concrete entities that emerge from analysis of the interviews which involves reading and rereading the data. They are then aggregated into units of theme clusters that are further derived from smaller units of behavior, observations, or verbal expressions into themes and then sub-themes (DeSantis & Ugarriza, 2000).

Step Seven

The researcher returned to the study subjects to validate the findings. This was a critical last step to confirm that the description of the phenomena was complete. The second interview was conducted to verify the analyzed interview of the participant and additional questions were directed to clarify statements made in the first interview. The third interview was the final validation with the subjects when they could view the completed analysis of all ten interviews and make final input into the process.

Initial data from other instances with interchangeable examples were verified to determine when saturation was reached. The interview with participant number six provided a new thematic category (experiencing the down side). Four additional participants were interviewed, for a total of ten participants, with no new thematic categories or clusters indicating saturation had been reached. This was verified by a peer reviewer and the Chair of the Dissertation Committee. The results of this compilation of common elements extracted from the experiences of the telehealth study participants resulted in an identification of the essential structure of this phenomena.

Qualitative Rigor

Trustworthiness in qualitative research refers to the validity of the data collection procedure. Colaizzi's (1973) method of data analysis was used in this research. This ensured rigor without sacrificing the relevant findings of qualitative research. Like quantitative research, there needs to be a systematic collection of data that allows for a critical analysis by others of the procedures and findings used to collect the data. There are specific techniques used to assess the trustworthiness of qualitative research. The following are key concepts that were used in assessing the trustworthiness of the qualitative findings of this study.

Credibility

Credibility requires prolonged engagement with persistent observations made to capture the essence of what the respondents are communicating. When comparing this approach to quantitative research, credibility represents the internal validity of the study. This was an important step to ensure that the data was represented in a way that did not distort the participant's lived experience. Four variables were key when checking for credibility in this qualitative study: prolonged engagement, persistent observation, external check with peers and testing the findings through member check.

This author has had prolonged exposure with the topic of telemedicine and has been an active participant and observer in a pilot telemedicine program for the past two years, which enhances the credibility of this study by the research having depth and understanding of the participants subjective experience. Knowing that having prolonged exposure may also result in being an "insider" that could lead to problems with biases in the data analysis process, the researcher bracketed these presuppositions, biases, and personal influences

during the analysis to ensure that the experiences described are from the participant's perspective.

Persistent observation was achieved through the interview that was conducted in the patient's home environment to gain knowledge of the participants' cultural and personal space. The time was flexible to allow for "talking story" to assist in a free flow of the patients' thoughts and feelings and gain trust. Nine of the ten participants had already established a trust relationship with the researcher through the pre-existing quantitative research study and the telehealth visits conducted in the past.

Recording observational notes of the interviewing process making persistent observations, and then living with the data through reflection and journaling assisted the researcher in entering the lived experience of the individuals. This allowed data to emerge that may have appeared hidden on a superficial level.

An external check of the data was done by meetings with a peer reviewer and the Chair of the Dissertation Committee. Testing the analysis of the findings with the participants in the second and third interview provided data through member checking.

Transferability

Transferability refers to the ability to replicate the study in an attempt to see if the same findings emerge. The researcher must provide a thick description, or enough data about the entire study so that the reader can judge the applicability of the results. This establishes the external validity of the study. In this study, a thick description of the process and the outcome of the data was provided. This was accomplished with a detailed accounting of how the data were managed and analyzed through each of the steps to produce the essential structure of the lived experience.

Confirmability and Dependability

Confirmability mimics the concept of objectivity in quantitative research. This required the researcher to remain neutral in observing and reporting the findings. Auditable refers to the ability to audit the qualitative research process. A clear audit trail was provided from the raw data to the actual reporting of the findings. The audit trail establishes dependability and reliability of the study (Krefting, 1991).

Confirmability and dependability of the data were enhanced by checking each transcript against the original tape for accuracy and the use of Qualrus software to assist in the organization of first the protocols, then sentences, significant statements and eventually the cluster of themes to ensure that meaning was not lost in such a large data set. The Colaizzi (1973) method of qualitative data analysis required a last step where each participant was asked to validate the findings at the end of the study that further ensured credibility and confirmability. Field notes were a secondary form of data along with a detailed audit trail to assist in addressing the dependability and confirmability of this study.

In summary, the specific eidetic approach of phenomenology was the method chosen to explore the lived experience as it relates to the health/illness transition that occurs when an individual with an acute infection is discharged from the hospital to the home with support by an APN using telehealth in an effort to avoid a hospitalization or to promote an earlier discharge will be addressed. Topics included in this chapter were outlining the research design, setting and sample, data generation, data management, data analysis and qualitative rigor.

CHAPTER FIVE

RESULTS

The purpose of this chapter is to describe the essential structure of the lived experience as it relates to the health/illness transition that occurs when an individual with an acute infection is discharged from the hospital to the home with support by an APN using telehealth in an effort to avoid a hospitalization or to promote an earlier discharge. Included in this chapter is a description of the sample followed by an exhaustive description of the results of the analysis of the data and the essential structure of the phenomenon.

Description of the Sample

Ten participants from the telehealth pilot program at Kaiser Permanente of Hawaii participated in this study. Five were female and five were male. The age range was 49 years old to 81 years old ($M=62$). Six of the participants identified their ethnicity as Caucasian, one Japanese, two Filipino and one Hawaiian. Educational levels ranged from some high school to college graduate. All ten of the participants identified at least one support person at home to assist them in their telehealth encounters.

Six of the ten participants presented to the telehealth program with a community-acquired pneumonia (CAP). One of the six participants with CAP spent eight days in the intensive care unit (ICU) with acute respiratory distress syndrome (ARDS) prior to enrolling in the telehealth program. One had a urinary tract infection with bacteremia. The remaining three participants presented with cellulitis; the location of the cellulitis was either facial, hip or foot. The participants were enrolled between the dates of December 10, 2003 to December 10, 2004. The number of days that they were on telehealth ranged from

4 to 13 days (M=7.5) with one participant being placed on telehealth in December 10, 2003 and then again on February 3, 2004 for an exacerbation of an infection of the hip. The most common co-morbidity was diabetes with four of the participants having this disease process. Three of the participants had moderate/severe renal disease; three had COPD, one had CHF, and two had identified malignancies. Table 1 summarizes the sample description.

Table 1: Demographic Data of Study Participants

Study No.	Co-morbidities	Educa-tion Level	Sup-port	Ethni-city	Gender	Age	Presenting Diagnoses	Date enrolled	# Tel. Days
#101	Diabetes & Renal Disease	Some High Sch.	Wife	Filipiono	M	62	Cellulitis Facial	11/30/04	7
#102	None	Some High Sch.	Wife	Cauca-sion	M	81	CAP	12/10/04	4
#103	COPD Diabetes Renal Disease	2 yr. Col-lege	Hus-band	Hawaiian	F	59	CAP	01/22/04	7
#104	None	Col-lege Grad.	Wife	Cauca-sion	M	76	CAP	11/07/04	7
#105	COPD	2 yr. Col-lege	Wife	Cauca-sion	M	67	CAP	10/21/04	4
#106	Renal Disease	High-Sch.	Hus-band	Japan-ese	F	61	UTI & Bacteremia	01/22/04	9

Table 1: (Continued) Demographic Data of Study Participants

Study No.	Co-morbidities	Educa-tion Level	Sup-port	Ethni-city	Gender	Age	Presenting Diagnoses	Date enrolled	# Tel. Days
#107	Malignancy	College	Husband	Caucasian	F	49	Cellulitis Hip	12/10/03 02/03/04	4 5
#108	Diabetes	Some High Sch.	Husband	Caucasian	F	77	Cellulitis	05/24/04	8
#109	Diabetes	2 yr. College	Husband	Filipino	F	50	CAP & ARDS	01/27/04	5
#110	CHF	2yr. College	Wife	Caucasian	M	51	CAP	10/02/04	13

The participants in this study had varied backgrounds in their past and present hospital experiences. Hospitalizations ranged from one to five episodes in the past year. Two of the participants had never been hospitalized (other than childbirth) prior to entering into the telehealth study, with one of these participants entering the study from the doctor's office. One of these two participants had spent eight days in the ICU with ARDS two days prior to enrolling in the study. Two of the participants had been healthy prior to being diagnosed with cancer resulting in three hospitalizations in the year prior to enrolling in the study and ongoing chemo and radiation therapy. Three of the participants were on dialysis in the past, present or future. One was a recipient of a kidney transplant and off dialysis, one was still on dialysis, and one was hospitalized between the first and second visit to have access placed to begin dialysis.

Exhaustive Description of the Results of the Analysis of Data

The exhaustive description of the phenomenon of the lived experience as it relates to the health/illness transition that occurs when an individual with an acute infection is discharged from the hospital to the home with support by an APN using telehealth in an effort to avoid a hospitalization or to promote an earlier discharge resulted in 321 significant statements. The formulated meanings of these significant statements resulted in 22 sub-themes, 31 themes, 10 theme clusters and 3 theme categories. The exhaustive description of the theme categories, theme clusters, themes, and sub-themes follow.

Theme Category: Initial Response

The first theme category is the Initial response. This category focused on when the participants were first introduced to telehealth to avoid a hospitalization or promote an earlier discharge. There were 81 significant statements involving this category. None of the participants had heard of this health care delivery method before. Two theme clusters describe this category: Painting the picture and Feelings connected with enrolling in telehealth. Table 2 presents the theme category Initial Response, with its two theme clusters and themes.

Table 2. Theme Category: Initial Response

Theme Category	Theme Clusters	Themes
Initial Response	Painting the picture	Living with illness Confronting mortality Trusting the health care Organization
	Feelings connected with Enrolling in telehealth	Weighing the pros and cons of enrolling Confidence in primary care doctor recommending telehealth Sharing decision with significant other Feeling special- chosen to participate Feeling like a guinea pig new health care delivery Feeling excitement

Theme Cluster: Painting the Picture

During the interview the participants painted the picture of living with their illness, concerns with confronting mortality and wanting to discuss their trust of the health care organization.

Theme: living with illness

Eight of the ten participants wanted to describe to the researcher their encounters of living with the illness that brought them to the telehealth experience.

05: I was really sick that time in the hospital, I lost a lot of weight, I was real weak and right now I am back up to 160 when I came out of the hospital I was all the way down to 134 pounds.

09: One of the people in administration said you are here because you are really sick and you can not breathe on your own. As soon as they took the tube out of my throat- I said, "I want to go home."

One of the participants felt it important to start at the beginning and specifically lay out the details of his illness in chronological order.

04: It started in California. They took me to the emergency room and they did an x-ray and they found that I had blocked, ascending coronary artery and the left ascending artery had three loops in it that were constricted, but the x-ray also showed cancer on the right lobe. It's like the crab was here with one leg reaching out into the wall of the upper right lobe.

Theme: Confronting mortality

Two of the participants verbalized concerns regarding mortality. One was 81 years-old and the other participant was 49 years old at the time of her illness. The first was elderly and confronting dealing with the loss of several of his family members and friends, and now questioning if his health was failing; the other was a previously healthy middle-aged woman who unexpectedly was placed in the ICU. Both expressed feeling an awareness of the fragility of life.

09: My mom was really sick and she hated being in the hospital too. She died when she was 49. Yeah. I did not share this with anyone, because I did not want them to think that I was superstitious, but you know when I turned 50 – it was like, OK I am going to pull through this thing OK.

The older participant tried to inject a note of humor in an attempt to make light of his feelings.

02: I'm going to be 81, you see. And I can't die because there is no openings. You know, even if they kill me, I'm still coming back. But you know, I appreciate what you doctors and you, whatever you folks doing for me, I really appreciate it.

Theme: Trusting the Health Care Organization

At the end of each interview the researcher asked if there was anything else about the telehealth experience they wanted to share. Two of the participants felt it important to express their feelings about trusting the health care organization that enabled them to participate in the telehealth experience.

08: So we always had Kaiser, always been. And my husband was a government worker, so we have a good plan. You know people talk about Kaiser sometime, "Oh, I hate Kaiser because you have to wait there." Well, all you have to do is be patient, you know. I wouldn't change plans for nothing.

09: And you know, I think, I just think, I just had a fantastic treatment. You know, I've been, actually almost all my life, from when I was young all the way till when I was like about 40, I had HMSA, so just in the past recent years, I had Kaiser, you know, and I was really fascinated with the care. I really liked it.

Theme Cluster: Feeling Connected with Enrolling in Telehealth

All of the participants provided data that supported the theme cluster connected with enrolling in telehealth. There were six themes that emerged: Weighing the pros and cons, Confidence in their primary doctor recommending telehealth, Sharing the decision to enroll with their significant other, Feeling special – chosen to participate, Feeling like a guinea pig in a new health care delivery model and feeling excitement.

Theme: Weighing the pros and cons of enrolling

Four of the participants described weighing the pros and cons prior to enrolling in the telehealth pilot program. Although the overwhelming attitude seemed to be relief at the possibility of being monitored at home, there was an awareness of possible risks in leaving the safety of the hospital environment.

03: When I first heard about it, I was kind of like, I questioned the hook-up because it is so far away from the hospital.

04: I was very, uh – well, my feelings were affirmative. I could see all the up sides and very few down sides.

06: Cause I knew I was going home and I just said we can do this and you don't have to come back in every day, and so that was when I was really, yeah, you know, that was , you know, when it was presented I thought it was great!

Theme: Confidence in primary care doctor recommending telehealth

One participant expressed that his confidence in his primary doctor recommending telehealth and giving him the choice was the motivating force to him enrolling.

10: I'm very fortunate to have doctor_____ as my doctor because if there was anybody else, she says things like, "What are we going to do." You know whereas other doctors say "What I'm going to tell you, you have to do."

Theme: Sharing decision with significant other

Four of the ten participants discussed sharing the decision to enroll in the telehealth pilot program with their significant other and two expressed that they thought they really enjoyed it.

01: She never know anything about this new method of being home and contacting the nurses and hospital, she liked it, she liked it.

05: We both thought that was fine, you know. I'm glad to do it.

Theme: Feeling special – chosen to participate

Two of the participants expressed that they felt very special to be able to participate in the telehealth program.

08: Special! You know I was getting all this people coming to my house to take care of me- one giving me IV's and one checked how I tried to walk. So I felt very special- you know – I never going to forget this.

08: And I think they told me that I was one of, they only had seven of those machines at that time, and I was one that got it. I was real lucky!

09: I made mention to my sister that I told you that in Los Angeles, and she was kind of like astounded, too. We're here in Los Angeles and you know, I never, we don't really have that kind of stuff going on down here.

Theme: Feeling like a guinea pig in new health delivery model

One participant expressed initial concern about being a part of an experiment and used the analogy of feeling like a guinea pig. She was the only participant that expressed this concern. She was definitely the sickest of the participants, having just spent eight days in the ICU for ARDS.

09: He told me that I think you're going to do better at home with this stuff. I never quite understand, yeah. I thought like maybe I was a guinea pig for studies, but I really liked it.

At the second visit the researcher asked for clarification regarding in what way she felt like a guinea pig with the following response.

09: I think that because in the beginning that it was something new so I thought I would be part of an experiment. So I never realized that the doctor had to look to see if I was in the condition to go home with it and that I had support. It was nothing like I felt used or anything or felt coerced into it.

Theme: Feeling excitement

Six of the ten participants verbalized an initial response of feeling excitement regarding enrolling in the telehealth pilot program. They were involved in a new method of care that enabled them to recover at home. None of the participants had heard of this health care delivery method prior to being selected.

01: New and interesting!

06: I was excited. I thought it was great!

08: That was unreal, like, I couldn't believe it and people don't believe when I tell them. I still talk about it, you know. I'll never forget that!

10: I just think it was a wonderful thing. IT was the best thing I've ever heard of in my life!

Theme Category: Engaging in Care

The second theme category is Engaging in care. This category focused on the ten participant's lived experience while they were participating in the daily telehealth visits. There were 222 significant statements. All the participants contributed statements to this category in the following five theme clusters: Feeling they were there for me, Feeling cared for by team members, Feeling confidence in care delivered, Pushing the idea- wanting to go home, and Avoiding visits to clinic/ATC. Table 3 presents the theme category Engaging in Care, with its five theme clusters, themes, and sub-themes.

Table 3. Theme Category: Engaging in Care

Theme Category	Theme Clusters	Themes	Sub-themes
Engaging in care	Feeling they were "there for me"	Feeling family's	
		acceptance of	
		telehealth	
		Viewing family as	
		substitute nurse	
	Feeling cared for by team members	Good to me	
		Feeling monitored	
		and reassured by	
		the APN	

Table 3. (Continued) Theme Category: Engaging in Care

Theme Category	Theme Clusters	Themes	Sub-themes	
Engaging in care	Feeling cared for by team members	Reaching understanding		
		Preparation for visit	Timing of visit	
	Feeling confidence in care delivered			Easy to use
				Feeling concern re: appearance
		Feeling connected to the hospital		Treatment changes in a timely manner
		Desire to do it again		Feeling safe
				Self in future
				Others to have
		Experiencing reception difficulties		
	Pushing the idea - wanting to go home		“There’s no place like home”	Feeling family enhances recovery
Feeling comfortable				
Desiring privacy				
Feeling in control				
			Restful environment	

Table 3. (Continued) Theme Category: Engaging in Care

Theme Category	Theme Clusters	Themes	Sub-themes
Engaging in care	Pushing the idea wanting to go home	“There’s no place like home” Feeling dislike for the hospital	Music healing Environment depressing Needs not met Bad food Catching sickness Expensive Interruptions in rest
	Avoiding visits to clinic/ATC	Avoiding the drive Having difficulty with mobility Disliking the wait time Preparing for visit	Dressing up

Theme Cluster: Feeling they were there for me

All of the participants verbalized feelings regarding the importance of a support person when they came home early from a hospitalization and/or prevented a hospitalization with telehealth. The themes that emerged were feelings related to the

family members' acceptance of telehealth and viewing the family member as a substitute nurse. Two of the participants expressed that this should be a priority when enrolling someone in the telehealth program.

02: Well, I was blessed with her. I forgot everything and I look to her when the nurse talk to me.

10: You have, the first thing and the most important thing, the first thing that came to my mind when you said this, and the first thing that my wife said, who, my wife is just wonderful, is that you have to have a good support system first.

10: You have to have a spouse, a parent, a child, whoever, that will help you to stay, you know, be sure you take the medication at the right time, the right amount of medication, I mean , you know, especially things like IV and things like that, you have to do.

Theme: Feeling family's acceptance of telehealth

Four participants provided data supporting the importance of their family's acceptance of telehealth. All of the responses were positive regarding the experience.

02: I see the picture on the machine and what she follow, even her, she enjoyed doing it.

06: Yeah, cause he's the one who would shuffle me back and forth everyday, so yes, he liked that aspect of it.

07: He was happy. He was happy with it.

09: My daughters liked it and my husband because we're close family and you know, it kept us at home, but yet it enabled Kaiser to take care of me and help me get well.

Theme: Viewing family as substitute nurse

Eight of the participants verbalized feelings related to a family member being a substitute nurse while they were recovering at home on telehealth. A criterion for enrollment in the Kaiser pilot program was that a family member was expected to assume responsibilities that normally are within the role of the nurses in the hospital. They were seen in that light by the participants.

02: Her, she is just like a nurse. But, I thank God I have her and she is a great help to me. I thank God I was blessed when I met her.

05: And my wife had to do that, you know, the purge, oh, the coupling in my wrist, right? Hang up the IV bag, okay, and then purged again.

08: Every morning at 6:00 a.m., she would come here and help me get shower and get a bath, and set me up for the day, and get all my medications that I needed you know. I got used to it after that, after the first day I felt a little bit uncomfortable because I never stripped in front of my children.

10: Basically, our bedroom back there, was just like a hospital room, in essence. So it was just, uh, and my wife is a very good nurse.

Theme Cluster: Feeling Care for by Team Members

Eight of the ten participants verbalized feelings related to feeling cared for by the members of the telehealth team. The three themes that emerged from their significant statements were: good to me, feeling monitored and reassured by the APN, and reaching understanding.

Theme: Good to me

Six of the participants consistently verbalized some aspect of “good” when describing the care rendered by the telehealth team members.

01: Well I forget who they were now but they were all good, especially the person that came out to the house and brought the machine.

02: It’s the person with the machine.

03: I think I was treated good when I went in there and then they came and hooked it up and they was really nice about everything.

04: Yeah they were both very knowledgeable, very pleasant, not obtrusive. They were good nurses.

08: Everybody was so generous and you know, I cannot say it enough about the treatment I got from you folks.

Theme: Feeling monitored and reassured by the APN

Feeling monitored by the APN was important to two of the participants to get the reassurance that things were going okay. Because, even though they were happy to be home, they were aware that there was an element of risk to their situation and the worries were never completely gone.

06: I liked the fact that, you know, cause I had this rash, or this redness, and the infection underneath the skin, and that was really nice to be able to actually look at it and tell me, “no it’s fine.” You know, because it was kind of , it was kind of scary.

06: So it was kind of nice to check in and know that it took my temperature, and all those other vital signs were there. That was really good, because I wasn't real sure if I was well or not. I enjoyed that aspect of it.

10: And of course, you know, everybody on that side that was involved was very good. I mean they just, you know, that sounds good, this sounds good, blood pressures fine, this is okay, that's good, great, any questions, no problems.

Theme: Reaching understanding

Two of the participants verbalized the importance of the APN taking the time to explain everything until they were comfortable with the equipment and had full understanding.

01: I could stay home and still get the understanding you guys gave me when I had to call in to verify how I was feeling and the way you guys explained to me was very good.

02: The nurse, they explained everything to me. She really explained everything- with my age and medicine- it is hard for me to understand. It hard for me to catch on to everything. She had patience, she had a lot of patience!

Theme Cluster: Feeling Confidence in Care Delivered

There was an overwhelming verbalization by all the participants in the study regarding their feelings of confidence in the care that was delivered over the telehealth technology. There were 75 significant statements made in this theme cluster with 16 themes and 22 sub-themes.

Theme: Preparation for visit

Preparing for the visit was expressed by seven of the participants. The sub-themes that emerged were Timing of the visit, Easy to use and Feeling concern regarding appearance. The timing of the visit was a concern to two of the participants with one commenting on how timely the visit was (04) “The only down side is the preparation in the morning to receive the call, which is nothing. Yet, your phone call itself is maybe half an hour.” One elderly participant’s concern was forgetting the visit (01) “The only thing a certain time we communicated to each other what time we would be on tomorrow and sometime I would forget and then they call me on the land line to remind me and then we get connected again.”

One participant spoke of the telehealth being complicated at first but rapidly became easy, (01) “the first time was complicating to me but each time became easier.” Two participants commented on how easy they felt the telehealth was to use. (6) “Your telemedicine was not scary. It was easy.” (10) “I just sat right there, you know, in the loveseat right there and had the machine right there on the table, you know. It was a very simple thing.”

One participant was genuinely concerned regarding who might be seeing her on the other side of the telehealth. She commented, (07) “the only drawback that I felt was I needed to have my make-up before I was contacted cause I didn’t want anybody to see what the real me looks like.” When asked for clarification on the researchers second visit she stated, “Yes, it was important. I did not know who might see me and I wanted to look my best – I did not want to look a mess.”

Theme: Feeling connected to the hospital

Nine of the ten participants verbalized feelings related to Feeling connected to the hospital with a sub-theme of Feeling safe and that treatment changes were made in a timely manner by one of the participants. Three of the participants compared it to a face-to-face intervention emphasizing the importance of being able to see the nurse.

01: It was like speaking to you like I am speaking to you right now, because I could see you on the machine and you could see me too and this was very good.

05: I felt a terrific thing to do down there and get the information over that telemedicine machine every morning and speak to the nurse and can see each other, you know.

08: It was good cause they can see everything in my room, you know, and I would shine the camera there and they would check my foot from there.

Three of the participants compared the telehealth as being equal to being in the hospital.

01: That was good as I said it was like being in the hospital talking to you and you talking to me and we looking at each other, it was something good.

02: Because the treatment I have on the machine was just like I was in the hospital.

03: It's like having home care versus having to come to the hospital all the time or being in the hospital.

Two of the participants verbalized the importance of having their vital signs and heart and lung sounds auscultated to give them the reassurances they needed that they were well.

09: Yeah, and I'm like, you know, trying to make like I'm okay. I'm not going to move, I'm not wheezing, you know, I didn't think it was that sensitive. You know, the material, the equipment. You know, I could never fool that stuff.

10: Heart and lungs. And so, that would be the only part that I would not, you know, not be able to do myself because I don't know what it's supposed to sound like.

A sub-theme that emerged in 'Feeling connected to the hospital' was 'Feeling safe.' Three of the participants verbalize feeling safe being monitored by telehealth. (03) "But as long as I was talking with them and going over things with them, I felt comfortable and safe. (07) "And then because it was monitored then, you know, I felt very safe." (04) "Even though you're sicker than hell, you know. And to have a support program as near as your phone, it's a bonus." (07) "Yeah, I felt secure that I wasn't just being dropped off at home; that there was someone there to monitor me. I didn't feel pushed out or abandoned."

One participant was very confident that the telehealth was responsible for communicating important information to his physician to result in timely treatment changes. His story provided data addressing the sub-theme 'Treatment changes in a timely manner.' (04) "I was accessing what was going on in my body into the hospital system. The medical system. So that the physicians that were in charge of my care would know what was going on day to day if they so chose. And it gave me confidence in that if anything was going on in my body was giving me trouble, I would be able to report it and it would be acted upon, so I had confidence that I was that far away from remedial help if I needed it. So those were the main benefits."

Theme: Desire to do it again

Five of the participants expressed a desire during their interview to be able to have access to telehealth again in the future if they needed it.

01: I sure would like to do it again if anything happened.

02: If I can have the machine always here, I be happy.

07: That was my preference, yeah, and if I had to do it all over again, I would do all over again.

Within this theme five participants verbalized their concern that others have access to this technology with the sub-theme ‘Desire for others to have it.’ (01) “I think everyone should try it. It really helps you, if never had it before – it is a good thing!” (02) “I enjoyed the machine and I wish everybody have it.” (03) But, I think that would help a lot of people feel more comfortable to be monitored at home, you know.” (04) “I think it has more benefits than it has negatives. I can’t see any patient receiving that care and not benefiting.” (10) “I think, you know, I think that it should be done more.”

Theme: Experiencing reception difficulties

Four of the participants experienced telehealth reception difficulties during one or more of their telehealth visits. The Kaiser pilot program was placed on hold in December of 2004 due to the numerous reception difficulties that were experienced during the telehealth visits. These consisted of complete blackouts requiring the family members to bring the participant to the ATC for monitoring; and/or one or more attempts at redialing the home. Three participants had to be withdrawn from the Kaiser pilot program due to the inability to obtain a reliable connection. None of the participants stated that they were distressed by these technical difficulties.

03: So everything, you know, turned out good.

07: No, as long as I heard her voice, that was good enough for me.

09: The blood pressure cuff broke. You know, she made sure everything was set up and the only thing that she had to leave and come back and give me another one was that blood pressure cuff.

10: I think there was one time where we had to hang up and recall or something – Oh, it didn't make me feel bad at all.

Theme Cluster: Pushing the Idea – Wanting to go Home

All ten of the participants verbalized the importance of wanting to recover in their home with 77 significant statements. There were two theme categories: “There’s no place like home” and ‘Feeling dislike for the hospital.’ Within these two themes there were 6 sub-themes in each of the two themes.

Theme: “There’s no place like home.”

All of the participants expressed in various statements that there was “no place like home” when discussing ‘wanting to go home.’ There were 6 sub-themes that emerged when discussing this theme: Feeling family enhances recovery, Feeling comfortable, Desiring privacy, Feeling in control, Restful environment, and Music healing.

Three participants discussed the sub-theme of feeling ‘family enhances recovery.’ (09) “It just gave me more incentive to get better.” (10) “I think that most people, if given the chance or the opportunity, would get better faster at home than they would in the hospital.” Five participants verbalized feeling more comfortable in their home when they were sick. (04) “And, it’s just more comfortable being at home in our own environment.”

(05) “Oh, I don’t know - I think it was right – I was ready to go home. I was happy to sit back there in the den and my wife could take care of me and it was right.”

One participant addressed the need to have privacy to recover, (09) “I felt a little bit that I didn’t have that much of my privacy (in the hospital). But when I came home and they had that thing set up, I felt more private. It wasn’t like they were invading or imposing (with the telehealth) they always asked when the best time was and this helped me get better since I could have my privacy but could still know they would be there.”

Three of the participants verbalized having more freedom and control in their home environment than when they were hospitalized. (02) “Real comfortable, I wasn’t nervous, I could just feel relax, I do not know how to say it but I feel more at home here, I have more freedom than in the hospital.” (04) “Well, you really, you’re constricted in your movements, and everything that you’re used to is not at hand (in the hospital).” (09) “Like I wanted to have a little bit more control that knowing that I could be in my own place and that would help me get better. Having more control of my life- that’s what helped me get better!”

Three of the participants verbalized the importance of the home being a restful environment to recover in (01) “It’s not like home, home is one place you can relax.” (05) “It was well, it was more peaceful here. I was more comfortable, I could sleep better.” (10) “You know, given that they are in a good environment, of course, which is a very peaceful place.” One of these participants spoke to the last sub-theme, Music healing (10) “I listen to this healing music that is very spiritual. Upon me getting sick a Buddhist friend of mine gave me this music. This music is very different, very spiritual. I listen to it every day when I am not feeling well.”

Theme: Feeling dislike for the hospital

Two of the ten participants did not verbalize any specific dislike of the hospital environment. The remaining eight all expressed a general dislike of being hospitalized, (07) “I just don’t like staying in the hospital.” (01) “I don’t like being in the hospital.” (10) “Cause I really, just really detest hospitals.” When questioned by the researcher what they specifically dislike about the hospital environment 6 sub-themes emerged: Environment depressing, Needs not met, Bad food, Catching sickness, Expensive and Interruptions in rest.

One participants verbalized feelings regarding the sub-theme ‘environment depressing’ stating that the hospital actually caused her to become depressed (09) “At the hospital, I was quite depressed cause I’m not a person to, you know, to stay in the hospital. Two participants felt that their needs are not met in the hospital (03) “sometimes you can buzz and you just keep waiting until they decide to come, you know.” Three participants felt the food was bad or would be better at home. “(04) “And you’re on a hospital diet, which the food isn’t that great. No hospital food is that great!” (07) “Food is better at home.” Three participants verbalized concern regarding catching sickness while in the hospital. (02) “The hospital has so much sickness and you sit next to the person and you start to get their sickness.” (07) “I was just so afraid that if I stayed too long, that I might get something else wrong, so I wanted to get out of this situation (the hospital).” One participant verbalized concern that going to the hospital increased the overall health care costs speaking to the sub-theme of Expensive (10) “I think if you can stay home instead of being in the hospital, even though I have very good insurance, that insurance will continue to rise as people spend more time in hospitals.”

The last sub-theme that the participants were able to identify as relating to their dislike of the hospital was Interruptions in their rest. Five of the participants felt that they were not able to rest due to frequent interruptions in the hospital. (01) “At the hospital every so often you got to give blood, checking you up all the time and you can not sleep cause you are always getting interrupted, someone checking your pulse.” (103) “They bother you all the time. Because they have a timing. You know, like when they do their checkups and all this, when they come in on a new shift, they don’t give consideration to the person who just feel asleep, and they come and wake you up to take, what, your blood pressure! And unless you’re dying from blood pressure, I’m pretty sure that blood pressure can wait until you get up.” (105) “Glad they did that cause I wanted to get home out of the hospital. ‘Cause that guy I was with in the hospital, he was a contractor. He was yak, yak, yakking on this two cell phone and all I heard was him all day long!” (10) “Schedules and things – when I was in the hospital before, they used to wake me up to give me sleeping medicine.”

Theme Cluster: Avoiding Visits to Clinic/Ambulatory Treatment Center (ATC)

Six of the participants verbalized their preference to do telehealth to avoid having to visit the clinic and/or ATC to be monitored for their illness. There were 19 significant statements with four themes that emerged from their comments. These four themes were: Avoiding the drive, Having difficulty with mobility, Disliking the wait time and Preparing for the visit.

Theme: Avoiding the drive

Four of the participants identified the drive to the clinic or ATC as a negative factor.

01: I have hard time driving to the clinic cause I have bad eyesight – because of my diabetes.” This same participant identified the distance as also being a negative factor.

01: Especially those people who live in the country like I do.

Two participants identified traffic as a major obstacle.

02: I rather have the machine than going over there and fighting the traffic.

Theme: Having difficulty with mobility

Three of the participants felt that the physical effort to get to and from the clinic/ATC would be a hardship.

02: I cannot walk too much, but if I have to go to doctors, I have no choice.

04: It would put an additional physical strain on me.

06: It was at that time, really hard to get here, just physically, to walk in, and stuff.

Theme: Disliking the wait time

Two of the participants verbalized negative feelings related to long wait times when going to the clinics.

01: I call and set the time and you guys were available and it was not something that I had to wait for my time to see the nurse.

03: I didn't have to wait in the waiting room. Sometimes that can be really uncomfortable when you are sick.”

Theme: Preparing for the visit

In contrast to the participant who felt she needed to make herself look presentable for the telehealth visit, another person shared her dislike of having to prepare for a visit to the clinic setting.

03: I was in my home and I could stay in my old clothes. I didn't have to dress up to see a doctor.

Theme Category: Experiencing the Downside

The last theme category is experiencing the down side. The data that supported this category was presented by one participant who had a positive experience with her first telehealth encounter but had a negative experience with her second encounter (06) "I was thinking about it the other day after I talked to you and I think I had two experiences, I think, because of the two different times that I used it. One of the times I was really happy to do it, 'cause then I could go home and I was ready to go home. But the one time I think I had the feeling of being sent home to early." There were 18 significant statements involving this category. Two theme clusters describe this category: Feeling too sick to go home and Being sent home to early. Table 4 presents the theme category Experiencing the Down Side, with its two theme clusters and themes.

Table 4. Theme Category: Experiencing the Down Side

Theme Category	Theme Cluster	Themes
Experiencing the down side	Feeling too sick to go home	Making the decision Receiving second choice health care Wishing I wasn't doing it
	Being sent home too early	Needing to come back Stressors at home Being sent home with a babysitter

Theme Cluster: Feeling too Sick to go Home

Although only one participant verbalized actually experienced feeling too sick to go home during her telehealth encounters; four other participants talked about the concept of readiness to go home from the hospital

04: When I am totally bored, I can walk around I can get to the bathroom on my own. I have always been ready to go home before the doctor thought I was ready – I guess he is too conservative.

There were three themes that emerged from this theme cluster: Making the decision, Receiving second choice health care and Wishing I wasn't doing it.

Theme: Making the decision

The participant who actually encountered feeling too sick to go home did not feel a part of the decision process.

06: It was just the second time, I was really too sick to be going home. And I was kind of too sick to really even fight about it, so I just did it...

Three participants alluded to the concept of making the decision to go home from the hospital in defining when they felt too sick to go home.

04: It means feeling to lethargic to get up.

05: I don't have any energy and I don't feel like eating and I have a bad attitude. I just want to relax.

01: The hospital is alright if you are really sick.

Theme: Receiving second choice health care

Only the one participant who personally experienced the downside of telehealth verbalized about this theme.

06: But I sort of felt like I was getting a second choice in health care. Like I said, I felt like I was just being shuffled out of my bed, 'let's send her home and give her some other type of treatment.' It's kind of like you're going, you know, 'we're going to send you home' and kind of, 'were going to give you this' So it wasn't really that process, you know, I didn't feel like I was being sent home because they wanted me to use the telemedicine equipment. So that kind of colored my feelings toward using the equipment and everything like that." This participant tried to expand more on her feelings about the experience.

06: In fact, again, I don't think that it really had anything to do with telemedicine. It was, um, just, I was really too sick to be going home, so that was just sort of the, I think, that I didn't really feel that it was proper treatment for me.

Theme: Wishing I wasn't doing it

Again, only the one participant experienced this theme.

06: I came home and it was kind of like, every time I, you know, pop up and, you know, talk to you guys on the phone (telehealth), I was kind of wishing I wasn't doing it.

Theme Cluster: Being Sent Home too Early

Only one participant verbalized actually experiencing the downside of her telehealth by being sent home too early. One other participant verbalized that he felt telehealth would not be appropriate.

04: Unless they were sent home prematurely and they really needed a much closer, hands-on type of treatment, but when you think of that, you say, well, then they should really be in there (the hospital).

The participant who actually experienced being sent home too early had three themes: needing to come back, stressors at home and feeling unsafe.

Theme: Needing to come back

Only one participant described a situation of being sent home and ultimately needing to be re-admitted to the hospital

06: The second time, I was still really sick and I did end up coming back into the hospital.

Theme: Stressors at home

Again, only one participant verbalized the frustration of having to face the stressors while feeling too sick to cope.

06: So I think I look a lot healthier than I am, and I finally learned to say, look, I'm not well enough to go home. Cause when I go home I have to go chasing the cat and run Manoa and if I grow too thin, then I have to do the whole process of 'am I sick enough to' – and it is a long process.

Theme: Being sent home with a babysitter

The same participant verbalize her concerns of being sent home too early with the theme Being sent home with a babysitter.

06: I think I had the feeling of being sent home too early, you know, kind of like being sent home with a babysitter, when I felt, I should be, I should have still been in the hospital. I wasn't ready to go home.

Essential Structure

The essential structure as it relates to the health/illness transition that occurs when an individual with an acute infection is discharged from the hospital to the home supported by the APN with telehealth in an effort to avoid a hospitalization or to promote an earlier discharge revealed an overall positive experience from the ten participants interviewed, with one negative down side in a participant who experience two separate telehealth enrollments, one positive and one negative.

The transitional process begins with an initial response to this new health care delivery method to assist them in their recovery when they are acutely ill. This response begins with a desire to paint the picture of the illness that brought them to the health care facility and initiated the referral to the telehealth pilot program. Participants have a variety of feelings connected to enrolling in telehealth: feeling the need to weigh the pros and con, being satisfied with just the recommendation from their primary care provider whom they

trust; wanting to share the decision of enrolling with their significant other, feeling like a “guinea pig” in an experiment, and expressing feeling special and excited regarding being chosen for this new way of delivering care.

Participants experience many variables that assist in their health/illness transitional process as they recovered in their home from an acute illness. Feeling that they have a family member who is “there for them” is critical to their recovery process. The family’s acceptance of the telehealth and the family’s role in acting as a “substitute nurse” are essential.

Participants need to feel cared for by the members of the telehealth team. It is important for them to feel understood by the team members as they adjusted to this new way of accessing care. Feeling monitored by competent, good nurses is reassuring and engaging for the individuals.

Participants feel a sense of confidence in the care that is delivered over this technology. It is important for the visits to be at a designated time and that it is easy to use the equipment. Participants feel connected to the hospital. This enhances their feelings of safety and confident that treatment changes will occur in a timely manner. Participants feel the telehealth interactions are equivalent to face-to-face interactions because they can see the nurse. Reception difficulties did not decrease their confidence in being monitored with none of the participants verbalizing anxiety or concern regarding their safety. Participants express the desire to have telehealth available to them and others, feeling a real comfort in being monitored at home.

Participants attracted to enrolling in this study have an overwhelming desire to recover from their illness in their home. Participants feel “there is no place like home” and

feel that family is key in enhancing their recovery process. Home is a more restful environment where they feel in control, private, and comfortable.

The participants' experiences showed that the hospital environment is not the optimal environment for all individuals transitioning from an illness. The environment may actually delay the recovery process due to nosocomial infections, needs not being met, poor appetite, interruptions in rest, feeling depressed and disempowered in the hospital setting.

Participants also may be attracted to enrolling in a telehealth program to avoid daily visits to the clinic. Motivating factors include avoiding the drive, not having to contend with long wait periods, not having to prepare for the visit and eliminating the physical strain on an acutely ill individual to go to the clinic.

There is a down side to the telehealth experience. Some participants may be too sick to go home. They may not want to engage in the telehealth experience feeling more comfortable in the dependent hospital environment when they are acutely ill. They may feel they are getting a second choice in health care when they are too acutely ill to participate in the telehealth encounters and may wish they were not doing it. They feel they are being sent home prematurely and have difficulty addressing the stressors at home. Being sent home too early also results in feeling unsafe in the home environment and fear they may need to come back to the hospital. Having to return to the hospital results in the individual having to address the question "Am I sick enough to go?", which is stressful and energy depleting.

In summary, this chapter described the analysis of data from ten interviews. This analysis produced 22 sub-themes, 31 themes, 10 theme clusters and 3 theme categories

supported by direct quotes from the interviews. A synthesis of this exhaustive description resulted in the essential structure of the phenomenon of the lived experience as it relates to the health/illness transition that occurs when an individual with an acute infection is discharged from the hospital to the home with support by an APN using telehealth in an effort to avoid a hospitalization or to promote an earlier discharge. Topics included in this chapter were description of the sample followed by an exhaustive description of the results of the analysis of the data and the essential structure of the phenomenon.

CHAPTER SIX

CONCLUSIONS AND IMPLICATIONS

This chapter will begin with presenting the relationship of the results of this study to the concept of transition and the review of the literature of telehealth. It will conclude with a discussion of the limitations of this study, implications for the profession of nursing and recommendations for future research in this area.

Relationship of Results to the Concept of Transition

The concept of the health/illness transition using telehealth to assist an individual with an acute illness has not been examined in the literature. The middle-range theory for transition (see appendix A) proposed by Meleis et al. (2000) was used as a conceptual orientation to guide this research project. The results of this study demonstrated congruence with the proposed essential properties, and process indicators of the transition experience outlined in their middle-range theory (Meleis et al., 2000).

The transition conditions of facilitators and inhibitors was not evaluated in this study. Meleis et al. (2000) identified that there are personal and environmental factors that can act as barriers or facilitators to achieving a healthy transition. This study did not seek to define facilitators as it related to meaning, cultural beliefs and attitudes, socioeconomic status, preparation and knowledge, community conditions and societal conditions in the individuals who chose to participate. It would be impossible to make general statements regarding facilitators and inhibitors because the individuals who had barriers that would have inhibited a healthy transition may have selectively excluded themselves as participants in this study. The participants in this study were too small and diverse of a group to make generalizations as they relate to personal and environmental factors.

Theme Category: Initial Response

This theme category is consistent with the property of awareness (Meleis et al., 2000). In this study the participants had a need to tell their story or “paint the picture” of the illness that brought them to the hospital or clinic. This involved experiencing the illness event and adjusting to their new diagnosis. When they made the decision to enroll in the telehealth pilot program, they weighed the pros and cons and wanted to share the decision with a family member who would be involved in their home care.

Theme Category: Engaging in Care

This theme category reflected many of the properties in the middle-range theory (Meleis et al., 2000) including engagement, time span and critical points. In the engagement period the participant is seeking information and is proactive. The study participants verbalized their feelings of confidence in the care rendered via telehealth as being directly related to feeling monitored, and having interactions equivalent to face-to-face interactions that assisted in their feeling comfortable and secure. During the time span that they were being monitored on telehealth, they felt that treatment changes would be implemented in a timely manner and that they were reassessed on a daily basis similar to being in the hospital environment. This was important in addressing the critical points and events that may occur when dealing with an acute illness.

This theme category was congruent with the patterns of response in this middle-range theory (Meleis et al., 2000). Process indicators that result in a healthy transition included: developing confidence and coping, location and being situated, and the need to feel connected, and interacting with their health care providers and/or significant others. The participants in this study had an overwhelming response of feeling confident in the

care delivered via telehealth even when there were reception difficulties. The participants felt that the control that they had over their environment assisted in their recovery process. The decision they made to recover with telehealth rather than be hospitalized indicated their desire to be an active participant in their recovery process through self care activities. Due to their acute care process self care activities were verbalized by the participants in this study as a the family unit engaging in self care rather than the individual as stated in Meleis et al.'s (2000) middle-range theory.

They expressed fear the hospital may cause delays in their recovery process due to nosocomial infections, needs not being met, poor appetite, interruptions in their rest and feeling depressed and disempowered in the hospital environment.

The participants in this study verbalized repeatedly that “there is no place like home” as a preferred environment to recover in when they were ill. They felt that home was a more restful environment, that having family members close by was key to their recovery process, and they expressed a real comfort in being monitored at home when they were acutely ill.

The need to feel connected and interacting with health care providers is identified as an important indicator of a positive transition (Meleis et al., 2000). The participants in this study wanted to have a specific time to connect to telehealth and know that they could access the hospital for critical events and timely treatment changes. They verbalized feeling connected to the hospital and cared for by the telehealth team members.

Feeling that they had a family member who was “there for them” was a key factor in their transitional process. It was important to them that the family members who assisted them in the telehealth experience accepted this delivery method and enjoyed the telehealth

visits. They viewed each of these family members as a substitute nurse during their recovery from the acute illness.

Theme Category: Experiencing the Down Side

This theme speaks to the complexity and multidimensional aspects of the transitional process. Transitional experiences are not unidimensional, each transition has the potential to be multidimensional with its' own unique complexities (Meleis et al., 2000). The individual in this study was concurrently coping with a diagnosis of terminal cancer, dealing with the new regimen of chemotherapy and radiation treatments. Additional stressors could be related to lack of resources at home and issues related to readiness for discharge. Meleis et al. (2000) middle-range theory may not adequately capture the individual experiencing multidimensional transitional experiences.

Selder (1989) identifies that when reality has been disrupted, there often is a sense of not being safe and a feeling of being threatened. This was clearly demonstrated in this study by the individual in this study who felt she was too sick to go home and was being sent home to a demanding environment too early. She verbalized a lack of physiological and psychological reserve to assume self care responsibilities necessary to recover at home. Having to then return to the hospital caused an additional transition and the distress of questioning "Am I sick enough to go back to the hospital."

In summary, the results of this study did support the properties and process indicators of the Meleis et al. (2000) middle-range theory in nine of the ten participants. The study participants did not verbalize specific support regarding the outcome indicators of mastery and identify reformulation. The focus of the interviews was on the lived experience of transitioning with telehealth during their acute illness. This may have not

been a sufficient time period to complete the transition process since they were only monitored for a total of four to thirteen days. Their comments were focused on first being presented with the option to enroll and how they felt transitioning in their home. It was encouraging that they expressed the desire to do telehealth again in the future if they had an illness event and were hopeful that others had access to telehealth for their health care needs.

Relationship of Results to the Review of the Literature on Telehealth

There were no other research studies identified in the review of literature, other than the study that this author previously participated in, using this technology to treat individuals with acute infections in place of hospitalization. In comparing this research to other existing reported findings there is a real question of transferability because the existing studies primarily described implementing telehealth to manage chronic diseases more effectively (Friedewald et al., 2001; Whitten et al., 2003; & Haily et al., 2003). Treating individuals with chronic disease versus an acute illness with this technology may result in significantly different findings, particularly as they relate to an individual's ability to transition with telehealth in place of hospitalization. There is a strong emphasis in the literature related to the use of telehealth to manage chronic diseases increasing self-management activities. Individuals with acute disease processes may lack both the physiological and psychological resources necessary to engage in self care activity. The other existing studies in the literature have not used an APN to support the telehealth interactions which also hinders the ability to transfer these findings to this study.

Theme Category: Initial Response

This study presented an Initial Response of feeling special. This supports the findings of Singh et al. (2002) that reported the individual perceiving that they were special like, “being on TV”, (p. 5). The remaining areas of needing to weigh the pros and cons, being satisfied with the recommendations from their primary care provider whom they trusted, wanting to share the decision of enrolling with their significant other and feeling like a guinea pig in an experiment were not found in the literature. This could be due to the level of acuity; but could also be due to the limited number of qualitative studies in the area of telehealth. The majority of the articles in this area are descriptive with five-point Likert Scales used to measure patient satisfaction.

Theme Category: Engaging in Care

This study demonstrated a strong response related to feeling confident in the care rendered via telehealth and feeling cared for by the telehealth team members. This is consistent with several other findings in the literature. Dick et al. (2004) patient satisfaction findings from parents whose children with serious conditions were transitioning from the hospital to the home using telehealth documented parents having a strong preference for telehealth with no reported difference in the care received in the hospital. Demeris, et al. (2001) conducted the only study specifically designed to measure patients’ perceptions of telehealth before and after they participated in it. Their elderly patient population also evaluated telehealth positively. Even though they were somewhat intimidated by the technology they felt that the nurses gained an increased understanding of their medical problems over the television. Agrell, et al. (2000) also rated telehealth positively. Patients in this study perceived that the presence of the telehealth equipment

implied the nurse was available 24-hours-a-day, despite education given to the patient that this was not true. This “appeared to create a feeling of greater security for patients enrolled in the telehealth” (Agrell et. al, 2000, p. 414).

In this study, wanting to have access again in the future was related to having feelings of confidence in the telehealth experience. This was consistent with the findings of Singh et al. (2002) that reported the individuals not wanting to give it up.

This study found that it was extremely important for the participants to have a family member support them in the telehealth intervention and act as a substitute nurse as they recovered from their acute illness. The family was required to assist in bathing, giving medication, administering IV antibiotics, etc. There were no articles in the existing literature that called for this level of family support to address the comprehensive needs of an individual recovering from an acute illness in place of hospitalization.

Several of the studies agreed with the findings of easier access, increased sense of security and empowerment (Caplan et al., 1999; Danky et al., 2002; Demeris et al., 2001; & Maiolo et al., 2003). They did not specifically address some of the issues raised by the participants in this study that were demonstrated wanting to go home from the hospital environment with telehealth. Participants in this study were motivated to enroll in the telehealth pilot program in an effort to be in the comfort and privacy of their homes supported by their family.

Theme Category: Experiencing the Down Side

The only area in the literature supporting this theme was in the quantitative study that this author participated in using the same population pool from the telehealth pilot program (Eron, King et al., 2004). That study measured patients’ perceptions of safety and

comfort using a five-point Likert scale. The hospital control group felt safer but not as comfortable when compared to the telehealth group. The telehealth group felt more comfortable but not as safe when compared to the hospital control group. This data relates to the findings in the present study where one of the participants felt too sick to go home and believed she was sent home too early. The result for this participant was that she wished she wasn't in the telehealth program, and she did have to return to the hospital.

In summary, results of this study that supported the literature were the Theme Categories: Initial Response, Engaging in Care, and Experiencing the Down Side. There is limited transferability because this patient population involves an acutely ill population using this technology in place of hospitalization, versus an attempt to use telehealth in supporting a chronic disease population. A final major difference in this study was that the participants were supported in the telehealth program by an APN, as compared with other studies that reported patients being supported by non-advanced degree nurses and/or other personnel.

Limitations of the Study

A limitation of this study is that only participants who volunteered to enter the telehealth pilot program in an effort to avoid a hospitalization or to promote an earlier discharge were included. This would lead to the assumption that the individuals who would not transition well would be excluded from this study. A second limitation was that, because phenomenology is used to answer questions about the lived experience of individuals, family members who supported the participants in this study were not interviewed. They may have had a different perception of the experience than the perception portrayed by the participant. Possibly their stories would provide an even

clearer picture of the total experience of living with telehealth. In addition, this researcher had a pre-established relationship with nine of the ten participants from the previous study. This may have resulted in them feeling a desire to present their telehealth experience in a positive light. Finally, three of the ten participants were not able to validate the analysis portion of the research that resulted in the essential structure because they became unavailable during the study.

Implications for the Profession of Nursing

Telehealth has the potential to be an enormous resource in addressing the health care needs of our communities. In choosing individuals for whom this technology would be appropriate, one must explore the barriers and the facilitators as they relate specifically to the individual and their family members. Telehealth may not be appropriate for every individual and could actually hinder the health/illness transition process if the individual is too sick to go home and and/or sent home too early.

The first implication to be considered is the need for nurses to understand transition from the perspective of the person. Some individuals may feel adequately supported by their family and the telehealth technology with the support of an APN; while others may prefer the dependent environment of the hospital.

The second implication is the need for health care professionals to redefine the standard of care related to hospital length of stay based on the individual's and their family's need for support. As technological advances continue to improve the ability to monitor acutely ill individuals in the home, telehealth will become more feasible and cost effective. We must clearly examine the risks and benefits from the individual's perspective, gaining their input regarding the optimum environment for their recovery. It is

important that the individual and family members are comfortable with this health care delivery method. If it is solely driven by cost effectiveness, there is the risk of individual's perceiving that they are being pushed out of the hospital too fast, receiving a second choice health care.

The third implication is the importance of the nurse assessing the ability of the family members to provide support and to act as a substitute nurse for individuals with significant levels of acuity. There needs to be a mechanism for the individual and family members to access that telehealth team twenty-four hours day to give them support for any critical events that can occur with this level of acuity. It is too stressful for them to feel that the families' only option for urgent care for the individual is to be rushed to the Emergency Room.

The fourth implication is the role of the APN in the telehealth field. The APN played a pivotal role in assisting individuals with a significant level of acuity to recover faster in the home. The physician played a role in initiating the telehealth experience but the APN was the sole support during all of the participants telehealth visits. This study demonstrates that there is clearly a patient population who would prefer to recover from an acute illness in their home supported by their family and an APN via telehealth. One participant verbalized the benefit of treatment changes being made in a timely manner while he was on telehealth. He suggested the APN had a power base connection with the physician that would result in changes being acted on quicker via telehealth then if he was reporting the same symptoms to the staff nurse when he was hospitalized. The APN possesses advanced clinical assessment skills with a higher intuitive sense to intervene early due to her years of experience, expertise and educational level. He/she may be the

critical factor in transitioning individuals with this level of acuity from a distance via telehealth.

Recommendations for Future Research

Based on the results of this study, future research should be conducted in four areas: the family's perception of caring for an acutely ill family member in the home via telehealth supported by an APN; the APN's perception of caring for an acutely ill individual in the home via telehealth; the individual's perception of recovering at home with telehealth supported by an APN with ethnic groups to determine specific culturally competent interventions when implementing this technology; and replication of this study to include individuals with acute disease processes other than infectious disease processes.

The first recommendation is to conduct a study of the family's perception of caring for an acutely ill family member in the home via telehealth supported by an APN. During this study several of the family members wanted to be interviewed and/or interrupted or corrected responses given by the telehealth participant. The individual may have been too ill to remember key themes that could be important when implementing this technology. The family members may exhibit role strain that needs to be addressed by an APN, but was not recognized by the participants in this study because of their focus on recovering from their illness.

The second recommendation is to conduct a study of the APN's perception of caring for an acutely ill individual in the home via telehealth. This researcher was extremely surprised at the participant's lack of concern regarding reception difficulties that occurred during the telehealth visits. During episodes of reception difficulty the researcher assumed that the participant was experiencing the same level of distress that she was

feeling. There were many strategies that this researcher used to portray a caring presence during use of telehealth and to safely assess the participant from a distance. This would be valuable information to disseminate to other health care professionals using this technology for a higher acuity patient population.

The third recommendation is to conduct a study of the participants' perception of recovering at home with telehealth supported by the APN separated by ethnicity to determine specific culturally competent interventions when implementing this technology. Four ethnic groups were represented in this study. It would be interesting to conduct this study with one ethnic group to determine if there are specific interventions that could be shared with other health care professionals to enhance the success of their health/illness transition.

The fourth recommendation is to replicate this study to include individuals with acute disease processes other than infectious disease processes. All of the participants of this study had acute infectious disease processes that hindered the transferability of the findings to other individuals with acute disease processes using telehealth in place of hospitalization.

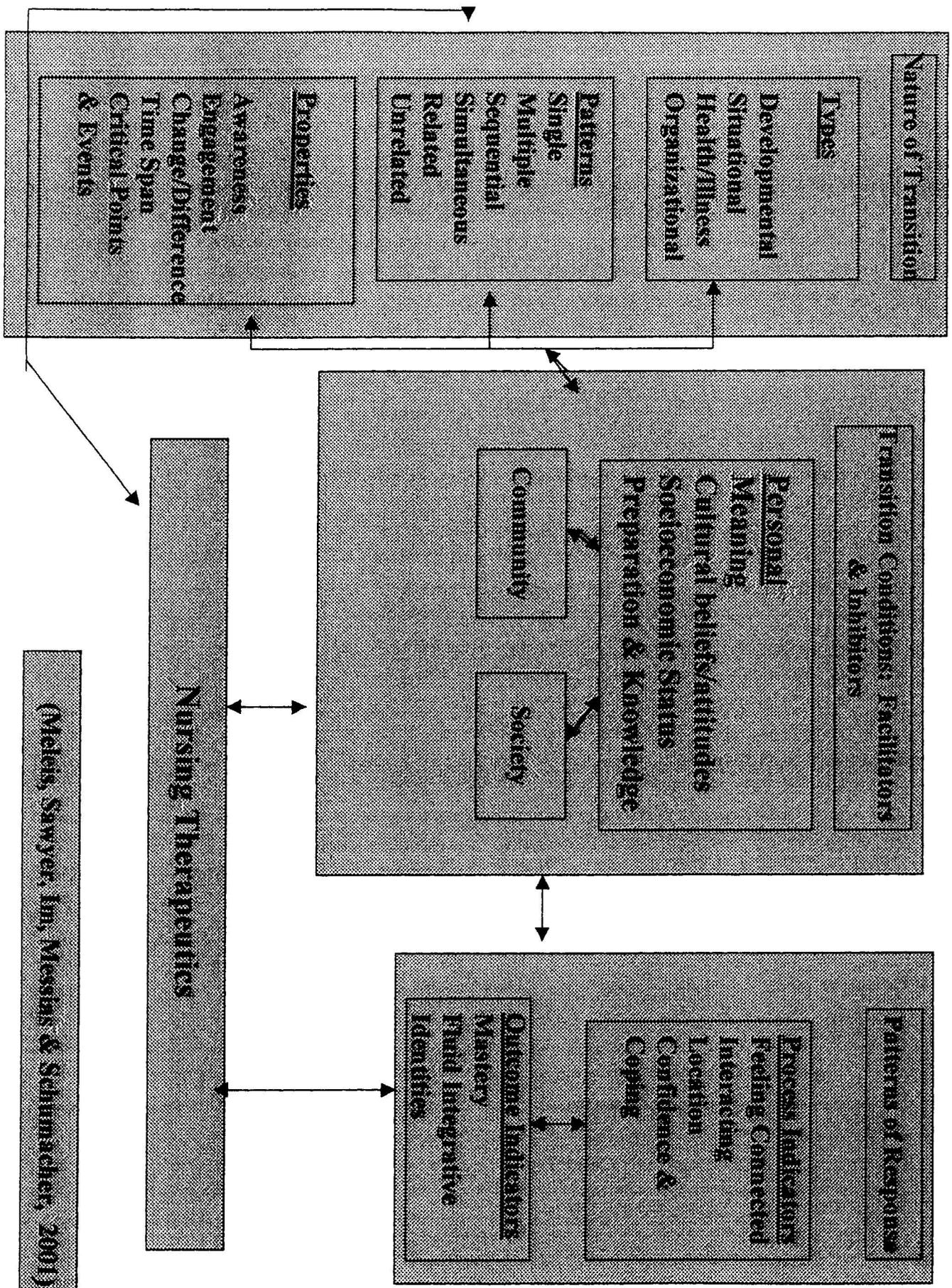
In summary, this chapter presented a discussion of the relationship of the results of the concept of transition and the review of literature on the uses of telehealth. The study supported the properties and process indicators of Meleis et al. (2000) middle-range theory. The study participants did not verbalize specific support regarding the outcome indicators of mastery and identify reformulation. The study was difficult to compare to the review of the literature since the reports have been limited to treatment of individuals who suffer from a chronic disease. The use of this technology with acute illnesses may result in

significantly different findings particularly as it relates to an individual's ability to transition with telehealth in place of hospitalization. The existing studies in the literature have not used APNs to support the telehealth interactions which also hinders the ability to transfer those findings to the findings of this study.

Limitations of this study were that only participants who volunteered to enter the telehealth pilot program in an effort to avoid a hospitalization or to promote an earlier discharge were included. Family members who supported the participants in this study were not interviewed and may have had a different perception of the experience than the perception portrayed by the participant. The data may have been skewed because the researcher was one of the APN's providing care during the telehealth program. Further, three of the ten participants were not able to validate the analysis portion of the research because they became unavailable during the study.

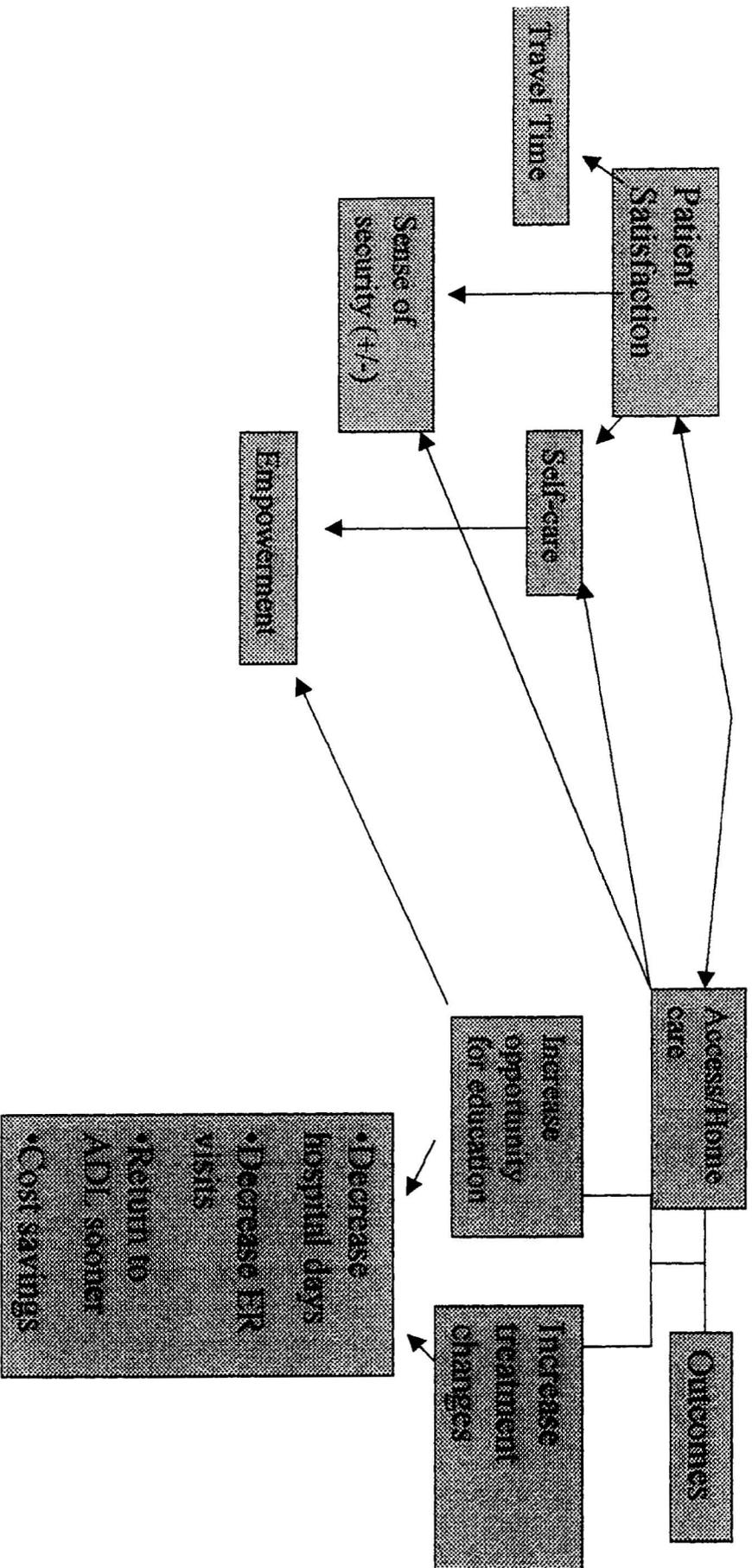
Recommendations for further research included: The family's perception of caring for an acutely ill family member in the home via telehealth supported by an APN, the APN's perception of caring for an acutely ill individual in the home via telehealth, the individuals' perceptions of recovering at home with telehealth supported by an APN separated by ethnicity to determine specific culturally competent interventions when implementing this technology, and replication of this study to include individuals with acute disease processes other than infectious disease processes.

Transition: A Middle-Range Theory

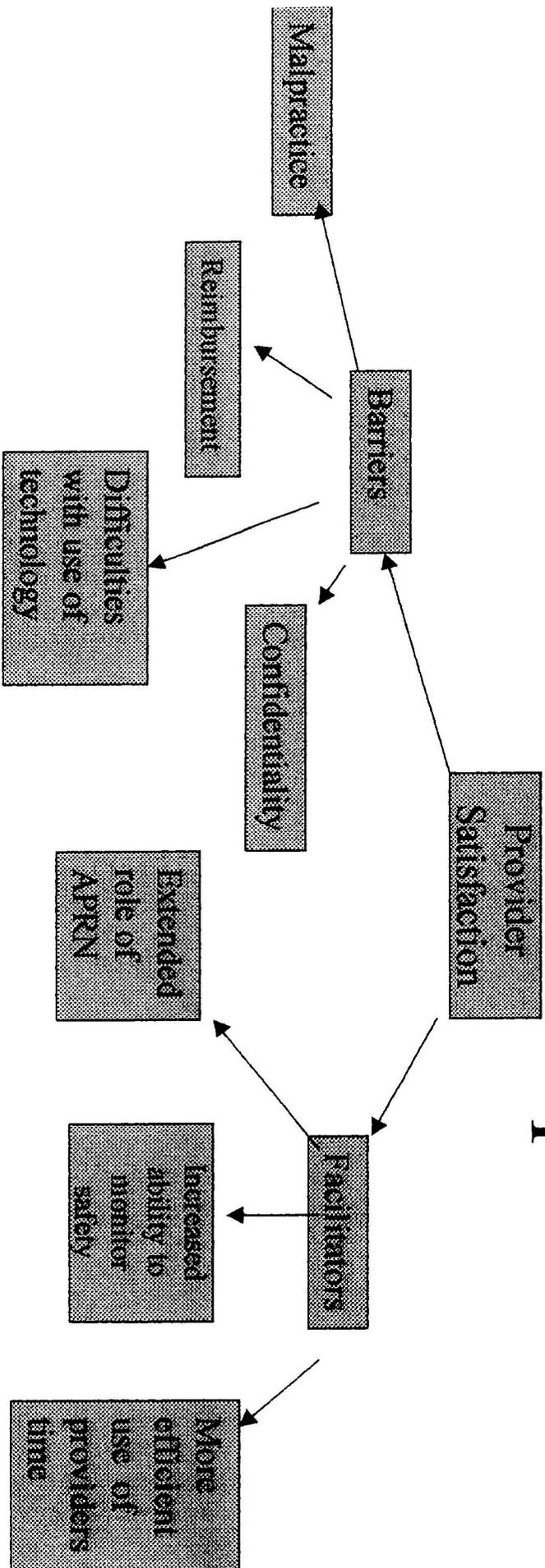


(Meleis, Sawyer, Im, Messias & Schumacher, 2001)

Telemedicine Concepts



Telemedicine Concepts



Addendum: Patient and Provider Satisfaction are positively interrelated!

Appendix C

UNIVERSITY OF HAWAII

Committee on Human Studies

MEMORANDUM

March 22, 2005

TO: Michelle Marineau, NP
Principal Investigator
Nursing Department

FROM: William H. Dendle
Executive Secretary



SUBJECT: CHS #13606- "Exploring the Lived Experience of Clients with an Acute Infection Transitioning in the Home with Telemedicine"

Your project identified above was reviewed by the Chair of the Committee on Human Studies through Expedited Review procedures. The project qualifies for expedited review by CFR 46.110 and 21 CFR 56.110, Category (7) of the DHHS list of expedited review categories.

This project was approved on March 18, 2005 for one year. If in the active development of your project you intend to change the involvement of humans from plans indicated in the materials presented for review, prior approval must be received from the CHS before proceeding. If unanticipated problems arise involving the risks to subjects or others, report must be made promptly to the CHS, either to its Chairperson or to this office. This is required in order that (1) updating of protective measures for humans involved may be accomplished, and (2) prompt report to DHHS and FDA may be made by the University if required.

In accordance with the University policy, you are expected to maintain, as an essential part of your project records, all records pertaining to the involvement of humans in this project, including any summaries of information conveyed, data, complaints, correspondence, and any executed forms. These records must be retained for at least three years from the expiration/termination date of this study.

The CHS approval period for this project will expire on March 18, 2006. If your project continues beyond this date, you must submit a continuation application to the CHS at least four weeks prior to the expiration of this study.

We wish you success in this endeavor and are ready to assist you and your project personnel at any time.

Enclosed is your certification for this project.

Enclosure

**Protection of Human Subjects
Assurance Identification/IRB Certification/Declaration of Exemption
(Common Rule)**

Policy: Research activities involving human subjects may not be conducted or supported by the Departments and Agencies adopting the Common Rule (58FR28003, June 18, 1993) unless the activities are exempt from or approved in accordance with the Common Rule. See section 101(b) of the Common Rule for exemptions. Institutions submitting applications or proposals for support must submit certification of appropriate Institutional Review Board (IRB) review and approval to the Department or Agency in accordance with the Common Rule.

Institutions must have an assurance of compliance that applies to the research to be conducted and should submit certification of IRB review and approval with each application or proposal unless otherwise advised by the Department or Agency.

1. Request Type <input checked="" type="checkbox"/> ORIGINAL <input type="checkbox"/> CONTINUATION <input type="checkbox"/> EXEMPTION	2. Type of Mechanism <input checked="" type="checkbox"/> GRANT <input type="checkbox"/> CONTRACT <input type="checkbox"/> FELLOWSHIP <input type="checkbox"/> COOPERATIVE AGREEMENT <input type="checkbox"/> OTHER: _____	3. Name of Federal Department or Agency and, if known, Application or Proposal Identification No. Kaiser Permanente
4. Title of Application or Activity "Exploring the Lived Experiences of Clients with an Acute Infection Transitioning in the Home with Telemedicine"		5. Name of Principal Investigator, Program Director, Fellow, or Other Michelle Marineau, NP

6. Assurance Status of this Project (Respond to one of the following)

- This Assurance, on file with Department of Health and Human Services, covers this activity. Assurance Identification No. F-3526, the expiration date October 15, 2005 IRB Registration No. IORG0000163
- This Assurance, on file with (agency/dept) _____, covers this activity. Assurance No. _____, the expiration date _____ IRB Registration/Identification No. _____ (if applicable)
- No assurance has been filed for this institution. This institution declares that it will provide an Assurance and Certification of IRB review and approval upon request.
- Exemption Status: Human subjects are involved, but this activity qualifies for exemption under Section 101(b), paragraph _____.

7. Certification of IRB Review (Respond to one of the following IF you have an Assurance on file)

- This activity has been reviewed and approved by the IRB in accordance with the Common Rule and any other governing regulations. by: Full IRB Review on (date of IRB meeting) _____ or Expedited Review on March 18, 2005
 If less than one year approval, provide expiration date _____
- This activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by the Common Rule will be reviewed and approved before they are initiated and that appropriate further certification will be submitted.

8. Comments

CHS #13608

9. The official signing below certifies that the information provided above is correct and that, as required, future reviews will be performed until study closure and certification will be provided.		10. Name and Address of Institution University of Hawaii at Manoa Office of the Chancellor 2444 Dole Street, Bachman Hall Honolulu, HI 96822	
11. Phone No. (with area code) (808) 958-5007	12. Fax No. (with area code) (808) 538-3954	15. Title Compliance Officer	
13. Email: dandle@hawaii.edu	14. Name of Official William H. Dandle		
16. Signature 		17. Date March 22, 2005	

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Appendix D



Joan L Holup
07/07/2005 06:07 PM

To: mmarineau@hpu.edu, Michelle L Marineau/HI/KAIPERM@KAIPERM
cc:
Subject: Communication from the KPHI IRB

This is your official IRB letter.

Principal

Investigator: Marineau, Michelle L. NP

Re: Exploring the lived experience of clients with acute infections transitioning in the home supported by the advanced practice nurse with Telehealth

Study ID: HI-05MMari-01

Date: 07/07/05

IRB Expiration Date: 07/05/2006

Dear Ms. Marineau:

On July 6, 2005, the Kaiser Permanente Hawaii Institutional Review Board (IRB) approved your research application to conduct the referenced study. This study is approved for one year. It is renewable (upon your request for continuing review by the IRB) before this approved period is expired.

There are changes to the consent form and HIPAA Authorization form you originally submitted. The IRB felt these changes were necessary for approval. The approved consent form and HIPAA Authorization form are appended to this letter for your use. **Do not retype these forms.** The Medical Research Participants' Bill of Rights has been attached. This document must be given to each prospective research participant with the consent form and HIPAA Authorization form.

The IRB requires that you obtain the signature of Olivia Castro (in addition to the signature you have obtained from Paula King) prior to study initiation. Please forward this signature to the IRB for our files.

Federal regulations require that all studies be reviewed at least annually. It is your responsibility to ensure that you apply for reapproval at least one month prior to this study's expiration date.

If your study or study-related documents require modification, you must seek IRB approval for these changes before they are implemented. In addition, you must promptly notify the IRB of any unanticipated serious adverse events affecting research participants or controls as well as any complications that occur during any experimental procedure associated with this study.

You are also required to be in compliance with all Kaiser Permanente Hawaii Standard Operating Procedures (SOPs). The SOPs are found on the following internal website:
<http://web.hi.kp.org/irb/sop.asp>.

Please note, it is your responsibility as the KP- investigator to inform all study staff (specifically outside

Appendix D (cont.)

investigators) of all IRB actions.

Sincerely,
Joan Holup, MA
Institutional Review Board
Administrator



HI-05MMari-01 cf.doc HI-05MMari-01 HIPAA form.d Rights of Candidate flyer.do

Appendix E- Part I

Principal Investigator: Michelle Marineau APRN
Kaiser Permanente
3288 Moanalua Road
Honolulu, Hawaii 96819
michelle.l.marineau@kp.org

Phone: (808) 432-7793

Sponsor: PhD. in Nursing Dissertation
University of Hawaii Manoa

INFORMED CONSENT To Participate In A Research Study

Introduction

You are being invited to participate in a research study being conducted by Michelle Marineau, an Advanced Practice Registered Nurse (APRN) with Kaiser Permanente. You are being invited to participate because you have been a participant in the Tele-Homecare Hospital Study in the last two years. The procedures of that study have allowed for the measurement and transmission of health information from your home to a receiving station in the hospital.

This study is part of Ms. Marineau's required work for her doctoral degree in Nursing. She expects to enroll between 8 and 12 people into this study.

Purpose of the study

The purpose of this study is to find out how participants from the Tele-Homecare Hospital Study feel about the use of the "telehealth" process while being monitored by the APRN.

Procedures

If you agree to be in the study and sign this consent form, the principal investigator will come to your home three times over a period of six months. These three visits are described below. In general, the principal investigator will ask you to talk about your thoughts and feelings when you were at home on telehealth. She will ask you to talk about what it was like for you recovering at home in place of being hospitalized.

Visit 1

The first visit will take about one hour. During this visit, you will be interviewed by the principal investigator. The interview will be tape-recorded. The tape recording will not have your name, initials, or other personally-identifying information on it. Instead the principal investigator will put a number code and the date of the interview on the tape.

Visit 2

The second visit will take twenty to thirty minutes. During this visit, the principal investigator will show you how your tape-recorded statements from the interview were written down. You will see some of your statements written word for word from the tape recording to paper. You will be asked if you agree with how your statements were written and if you would like to change anything that you said or that you see in writing. You will have the chance to correct any statements or comments that you see written down.

Visit 3

The third, and final, visit will take twenty to thirty minutes. During this visit you will be asked to read some statements based on the written interviews of other study participants. You will not know the identity of the other study participants, and they will not know your identity either. You will also have another chance to look at what you said in your interview. You will be able to make additional comments or corrections to your answers.

Possible risks and benefits from this study

Loss of privacy is a possible but small risk. Information from this study will be kept confidential as described below. This study will not help you directly. The principal investigator hopes that the information learned from this study may be helpful to health care professionals who treat people in the future.

Costs / Payments

There is no cost to you for being in this study. No health care will be provided as part of the study and you will not be paid for your participation.

Right to refuse or withdraw

Your participation in this study is completely voluntary. You are free to refuse to participate in this study. Your decision will not affect your medical care. If you decide to participate, you can change your mind at any time without any effect on your medical care or eligibility for future care or membership in the Kaiser Foundation Health Plan (KFHP).

Confidentiality

The principal investigator will keep information about you obtained for this study confidential and will not disclose it without your written permission. However, your personal information may be disclosed if required by law. In addition, the Kaiser Permanente Hawaii Institutional Review Board (a formal committee that reviews research studies to protect the rights and welfare of participants) and other regulatory agencies may look at and/or copy your research records, for quality assurance and data analysis.

The audiotapes of the interviews will be kept in a locked drawer, and will be destroyed one year after the completion of this study. If quotations or statements from the tape recordings are used in public or in future publications, they will not have your name, initials or other identifying information attached. These quotations will be anonymous. All information obtained about you for this study will be identified only by an identification number.

Injury

No injury is expected as a result of participating in this study. Any injury or condition experienced by a member of KFHP as a result of being in this study will be treated in accordance with the member's Health Plan coverage, as described in the Evidence of Coverage.

Questions or Problems

Study-related questions or problems may be directed to the principal investigator. Questions about your rights as a research participant, comments or complaints about the study may be directed to the University of Hawai'i, Committee on Human Studies (CHS), Spalding Hall 253,

2540 Maile Way, Honolulu, Hawai'i 96822, Telephone: (808) 956-5007 and to the Kaiser Permanente Hawaii Institutional Review Board, 501 Alakawa Street, Honolulu HI 96817; Telephone (808) 432-4757.

Voluntary Statement

I certify that I have read the above information, or it was read to me. I understand the risks and benefits involved, and that any questions I have about this study have been or will be answered.

*I understand that **by signing below**, I hereby give consent to participate in this study; and that my consent does not take away any of my legal rights in case of negligence of anyone who is working on this study. I understand that I can withdraw from this study at any time and that my decision will not make a difference to my care in any way or cause a loss of benefits to which I might otherwise be entitled.*

*I understand that I have the right to refuse participation in this study **by not signing below**; and that this refusal does not affect my benefits to which I am entitled as a health plan member.*

I consent to participate. I have been given a copy of this signed consent form with a copy of the "Medical Research – Rights of Candidate" statement to keep.

(PRINT)

Name of Participant	<u>Signature</u>	Date
*Name of Witness	<i>Signature</i>	Date
Name of Investigator/Designee	<i>Signature</i>	Date

*Witness to signature only

Attachment: "Medical Research – Rights as Candidate"

Appendix E – Part II
AUTHORIZATION
TO USE AND DISCLOSE PROTECTED HEALTH
INFORMATION
INFORMED CONSENT

Why is this authorization required?

The US Government has issued a new rule, called the Privacy Rule, effective April 14, 2003. This rule requires Kaiser Permanente to safeguard your Protected Health Information. Protected Health Information includes information about you that could be used to link your identity to your health information. It also includes the information in your medical record.

The purpose of this section is to explain to you how Kaiser Permanente researchers propose to use your health information for the purpose of this study. None of your health information will be used without your written permission.

Must I agree to this authorization to participate in the research?

To participate in this research study, you must agree to authorize the use of your health information as described below. If you do not approve this use, you cannot participate in this study. This also means that you will not have access to this experimental treatment through this study.

Why will your health information be used for this study?

Kaiser Permanente researchers will use your health information to conduct the study, monitor your health status, measure effects of the use of technology in the home, and determine research results.

Your health information will not be disclosed outside Kaiser Permanente as part of this study.

Who will use my information, and what is the purpose of this use?

If you sign this authorization, Kaiser Permanente researchers and the research team may use your health information. They will use your study research record and information from your medical record. This includes laboratory tests and both clinical and research observations made during your participation in the study.

As we have explained, Kaiser Permanente researchers will not allow your health information to be seen by or sent to anyone outside Kaiser Permanente.

Your medical record may also be reviewed by Kaiser Permanente to monitor this study or others as otherwise required by law.

When will this authorization expire?

This authorization will expire at the end of this research study.

Can I withdraw this authorization?

At anytime during this study, you may decide that you no longer want to have your information used or disclosed as part of this study. If so, you must write a letter stating that you withdraw your authorization and send it to:

*Michelle Marineau, , Principal Investigator
Infectious Disease Department
Kaiser Permanente Moanalua Medical Center
3288 Moanalua Road
Honolulu, Hawaii 96819*

If you withdraw your authorization, you may be required to end your participation in the study.

Kaiser Permanente researchers may continue to use your health information that was obtained before you withdrew your authorization.

Even if you withdraw your authorization, Kaiser Permanente researchers are required by federal law to record and report anything that relates to your safety and the safety of others.

Can I see the information collected about me in this study?

You will be allowed to review the information collected about you during this clinical trial and after the study is over.

Will I get a copy of this authorization?

The researcher who is obtaining this authorization from you must give you a copy of this form after you sign it.

Authorization signatures

My signature indicates that this authorization has been explained to me, all of my questions have been answered, and I agree to allow the use and disclosure of my health information for the research as described above.

Signature of Participant

Date

Signature of Personal Representative, if
participant cannot give authorization

Date

Personal Representative's authority (e.g., Power
of Attorney, spouse, etc.)

Appendix E – Part III



KAISER PERMANENTE

Honolulu Hawaii
Medical Research - Rights of Candidate

Provide a copy of this document to each candidate at the time of interview

Every research study such as an interview, survey, investigation, treatment, or experimentation conducted in Kaiser Permanente (KP) facilities and/or by KP employees in the Hawaii Region will entitle each candidate to rights and privileges as appropriate to the specific research including the following, as applicable:

- **Informed** of the nature and purpose of the research to be conducted;
- **Given** an explanation in simple language of the procedures to be followed in the research; a description of any drug or device to be used; and confidentiality of all information collected.
- **Informed** of any related discomforts and risks that can reasonably be expected from participation;
- **Given** an explanation of any benefits that can reasonably be expected from participation;
- **Advised** of any appropriate alternative procedures, drugs, or devices while participating in the research that might be advantageous; and the relative risks and benefits of these alternatives;
- **Informed** of the availability of medical treatment after the medical research, should complications arise;
- **Given** an opportunity to ask any questions concerning the research, or about the procedures involved;
- **Given** the option to consent or not to consent to participate in the research without the intervention of any element of force, fraud, deceit, duress, coercion, or undue influence upon the decision. The same options will be provided to a minor, with full support (of selected option) by the parent or legal representative;
- **Given** a copy of this form and the written informed consent form for the research;
- **Instructed** that once the candidate becomes a participant, consent to participate in the research may be withdrawn at any time without prejudice.

If you have questions about your rights as a research participant, comments, or complaints about the study, you may contact the Kaiser Permanente Institutional Review Board, 501 Alakawa Street, Honolulu, HI 96817, telephone (808) 432-4757.

Appendix F TELEMEDICINE PROJECT

TELE-HEALTH SURVEY (VIDEO VISITS)

STUDY # _____ DATE & TIME SPENT ON VIDEO VISITS _____ TOTAL # OF DAYS _____
 TO RECOVER _____

DATE & TIME SPENT ON VIDEO VISITS _____

Background Information

_____ Age _____ Male _____ Female _____

Date of Birth _____ / _____ / _____ Ethnicity -you relate to: _____

Phone hm _____ wk _____

_____ Caucasian _____ Filipino
 _____ African _____ Japanese
 _____ Hawaiian _____ Chinese
 _____ Other _____ Korean
 _____ Other Asian _____

Home Living Situation Highest Level of Education Completed

_____ Lives alone _____ some High School _____ High School Graduate
 _____ Lives with _____ _____ 2 yrs College _____ College Graduate
 Time caretaker spends w/you _____ _____ College Graduate +

Do you have a computer? Y / N What kind of hook-up do you have? Dial-up / DSL / Road Runner / Other _____

Diagnosis: _____
Comorbidities

<p>1 point: _____ Myocardial Infarction (MI) _____ Congestive Heart Failure (CHF) _____ Dementia / CVA _____ Peripheral Vascular Disease (PVD) (cellulitis only) _____ COPD / Asthma _____ Age 50 – 59 yrs Other _____</p>	<p>1 point: _____ Connective Tissue Disease(CTD) _____ Ulcer Disease _____ Diabetes Mellitus _____ Mild Liver Disease _____ Smoker (CAP only)</p>	<p>2 points: _____ Moderate/Severe Renal Disease _____ Diabetes w/ End Organ Damage _____ Malignancy _____ Neurogenic bladder or indwelling foley (UTI only) _____ Obesity (cellulitis) only _____ CVI (cellulitis only) _____ Age 60 – 69 yrs</p>	<p>3 points: _____ Moderate/Severe Liver Disease (e.g., cirrhosis w/ ascites) _____ Age 70-79 yrs Other _____</p> <hr/> <p>4 points: _____ Age 80-89 yrs</p>	<p>6 points: _____ Metastatic Solid Tumor _____ AIDS _____ Steroids >125 mg pred _____ Kidney stones (UTI only) Other _____</p>
--	---	--	--	--

Comorbidity Score total _____

Outcomes

1) Clinical outcome: ___ Cured ___ Improved ___ Not improved

2) Adverse Events (if any): _____

3) Did you feel safer at home being treated w/ video visits as opposed to being treated at the hospital? (**circle one**)

1	2	3	4	5
Much Safer in the Hospital		Neutral		Much Safer at Home

4) Did you feel more comfortable recovering at home as opposed to being in the hospital? (**circle one**)

1	2	3	4	5
More Comfortable in the Hospital		Neutral		More Comfortable at Home

5) How quickly did you return to your normal activities of daily living? _____ (No. of days from entering study)

VIDEO VISIT Questions

6) Confident in provider's ability to assess health condition by using remote video system (**circle one**)

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

7) Comfortable discussing problems w/provider by using video visits (**circle one**)

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

8) Received appropriate level of care and attention from provider using video visits (**circle one**)

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

9) The video visits compared to direct face-to-face contact with the nurse was (**circle one**)

1	2	3	4	5
Far less desirable		Equally OK		Preferable

10) Video visits allowed timely access to provider (**circle one**)

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

Appendix F (cont.)

11) The telemonitoring equipment was easy to use (**circle one**)

1	2	3	4	5
Strongly disagree	Disagree	Neutral	Agree	Strongly agree

12) Overall, how do you feel about your video visits? (**circle one**)

1	2	3	4	5
Very Poor	Poor	Neutral	Good	Excellent

13) Did you feel being at home as opposed to being hospitalized speeded your recovery? (**circle one**)

1	2	3	4	5
Home did NOT speed recovery		Neutral		Home speeded recovery

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