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GOING HOME: AN ETHNOGRAPHIC STUDY OF PATIENT SUPPORT  
NEEDS DURING THE TRANSITION FROM LONG-TERM HOSPITALIZATION  
TO HOME

THE UNIVERSITY OF ARIZONA

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GOING HOME: AN ETHNOGRAPHIC STUDY  
OF PATIENT SUPPORT NEEDS  
DURING THE TRANSITION FROM LONG-TERM  
HOSPITALIZATION TO HOME

by  
Melinda Staveley

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A Thesis Submitted to the Faculty of the  
COLLEGE OF NURSING  
In Partial Fulfillment of the Requirements  
For the Degree of  
MASTER OF SCIENCE  
In the Graduate College  
THE UNIVERSITY OF ARIZONA

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July 2, 1984  
Date

To JB and her family whose courage and love of  
life are an ever present source of inspiration

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## ABSTRACT

This exploratory study was designed to discover the cultural knowledge which persons with a change in body function use to interpret their experience during the transition from long-term hospitalization to home.

The technique of ethnographic interview was used with three informants to identify their support needs during the first four days post discharge.

Analysis of the data yielded eleven domains of meaning. The domains were analyzed for cultural themes and three were identified: 1) Going home is not "going home;" 2) It just takes time; 3) Helping is being there. The findings suggested that the going home transition is a complex one necessitating an understanding of the concepts of culture, body image, and care. Recommendations for nursing practice and further research are discussed.

## CHAPTER I

### INTRODUCTION

"Going Home." These two words evoke a full gamut of emotional responses and meanings. This simple expression is used by everyone, sometimes more than once a day.

"I'm going home; see you tomorrow," might be said to a colleague leaving the work setting. Or, "I'm going home now. I've had a great time," a form of salutation after sharing an evening with a friend. Or, "No thanks, no more tonight. I'm going home and get some sleep."

This innocent phrase, "going home," rolls easily, so unself-consciously off the tongue. In the context of the examples above, the implied meaning of "going home" includes safety, comfort, acceptance, relaxation; an entity, an environment, a space both physical and emotional without threat or energy drain. In common, everyday usage, "going home" connotes the known, a given, a relatively dependable variable in lives which are often scattered and discombobulated.

Does the use of "going home" differ in the context of a patient being discharged from the hospital? Use of the words by the professional staff or the patient and his family doesn't vary significantly. The nurse, the physician, the physical therapist, the patient's wife all say the phrase with positive intonation, with a smile, with the suggestion of hopefulness. The implication that going home will be safe and comfortable, that home will be a space without threat or

energy drain imbues the words "going home" and surrounds the discharge event with expectation and hope.

Is this realistic? Do the positive reassuring references to "going home" set the stage for a smooth transition from hospital to home? Or can this usage, no matter how well intentioned, become a set-up for disappointment, frustration and possibly failure?

A brief case outline illustrates the problem: BC has been a patient in the rehabilitation unit for 2-1/2 months. "Seventy-five, almost 76 days," he is quick to say. He arrived at the hospital Emergency Room via ambulance one month prior to transfer to the rehabilitation center. A motorcycle crash on the interstate, from which he was fortunate to survive, resulted in severe head trauma and burns causing the loss of one leg, both hands, both ears, grafting and scar tissue over 65% of his body.

Two hours before his accident, BC was a 25 year old construction worker, husband and father of one small child. His reported self-assessment was that of capability, energy, virility and determination. He had felt himself to be on the right track; set in his vocation, financially stable, making a decent place in this world for himself and his family.

Today he is being discharged. The hospital staff is excited. Their jobs have been well done from Emergency Room, through intensive care in the Burn Unit, through long weeks in the Rehabilitation Center. With the miracles of modern medical technology and the competent work

of many health care providers, BC is alive and ready to leave the hospital. He is going home.

What does this phrase mean now, in BC's context? Will home be home? Will it be the same physical space, the same emotional climate of almost four months ago when BC had both legs, hands, ears, full memory and use of his thinking processes? Will home be a safe, comforting place for BC who is learning to live with constant pain and new ways of doing even the simplest of daily activities?

How can home be home if the person is different? The environment is physical, concrete: a chair is a chair; a doorway is a doorway. Or is it? How much of the reality of environment is dependent upon the perception of it and the ability to function within it? What is really known about the "going home" experience?

#### Statement of the Problem

What cultural knowledge informs the behavior and determines the support needs of a person with a change in body function during the transition from the hospital to home after long-term hospitalization? The individual's perception of this event, as relayed by words and actions, was an account of what was learned from the experience.

#### Significance of the Problem

Much has been written recently in the bio-psycho-social literature on the issues and concepts of discharge planning, continuity of care, and patient/family education. Indeed, these are three of the tasks with which nurses are specifically mandated by JCAH, state boards



of nursing as well as professional standards of care. From the patient's day of admission the nurse is charged with providing continuous care, ensuring that the patient and family learn everything necessary for self-care, and for planning for the patient's release from the hospital.

Although articles have been published and the mandates are clear, much of what is done on the practical, clinical level is haphazard, uncoordinated, underfunded and unevaluated. Frequently, discharge plans or teaching programs demonstrate little connection to what the patient's or family's expression or perception of need may be. The nursing profession has embraced the notions of discharge planning, continuity of care and patient/family teaching but, as often happens, the lag time is great in effecting practice. There exists a gap between what is assessed as need by the profession, what actually happens, and what is reported by the informant to be needed.

This study takes the perspective that the person experiencing the "going home" transition is the expert. The goal of the study, which has grown out of the investigator's work in discharge planning and patient/family teaching, is to "grasp the native's point of view, his relation to life, to realize his vision of his world" (Malinoski, 1922:25).

What is the basis for discharge planning and patient/family teaching? If the mandates are to be fulfilled and the patient's needs met, more precise knowledge and understanding of the patient's experience during the transition from hospital to home are essential.

"Going home" must be seen through the patient's eyes. No longer can assumptions be made for it is clear that failure rather than success is sometimes the outcome.

The significance of this study lies in the identification of themes which will provide insight into the needs of patients being discharged from long-term hospitalization. This information will be available to nurses and other health care providers to be used as a basis for planning teaching strategies and discharge.

#### Statement of the Purpose

The purpose of this study was to discover the cultural knowledge which persons with a change in body function use to interpret their experience during the transition from long-term hospitalization to home and to identify their support needs.

Three major objectives were:

1. To describe the cultural experience of going home as lived by the informants.
2. To identify the support needs during the first four days post discharge.
3. To inform a theory of relevant and effective patient/family teaching and discharge planning based on the actors' point of view.

#### Conceptual Orientation

The concepts of culture/going home, body image/change in body function, and care/support needs constitute the conceptual framework of this study. Their meaning for the study and the possible relationship

between levels of abstraction are explored. Figure 1 is a visual model of the concepts to be discussed.

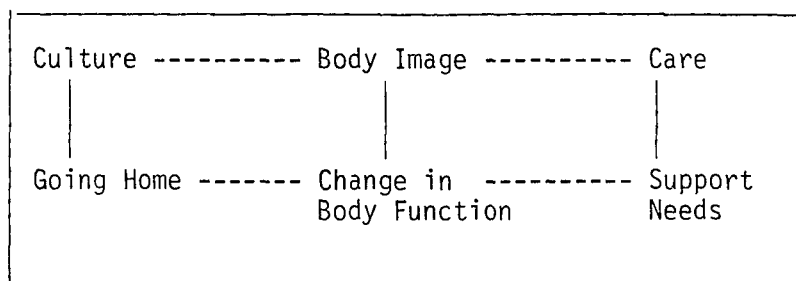


Figure 1. Conceptual Model of Going Home

The vertical planes in Figure 1 represent levels of abstraction with concepts of similar abstraction but different ideas organized horizontally. The broken lines represent possible relationships. There is no causality implied in the framework.

#### Culture/Going Home

The conceptual orientation is founded on the premise that the going home experience can be viewed and studied in cultural terms. Some approaches to culture focus on artifacts, others concentrate on rituals or center around the study of traditions. Goodenough has restricted his concept of culture to the cognitive realm:

As I see it, a society's culture consists of whatever it is one has to know or believe in order to operate in a manner acceptable to its members, and do so in any role that they accept for any one of themselves. Culture, being what people have to learn as distinct from their biological heritage, must consist of the end product of learning: knowledge. . . By this definition, we should note that culture

is not a material phenomenon; it does not consist of things, people, behavior, or emotions. It is rather an organization of these things. It is the forms of things that people have in mind, their models for perceiving, relating and otherwise interpreting them (Goodenough 1957:167).

Spradley's definition of culture is in the same vein as Goodenough's, and is more succinctly stated: "Culture. . . refers to the acquired knowledge that people use to interpret experience and generate social behavior" (1979:5).

For the purpose of this study, culture is viewed as the embodiment of knowledge. Cultural knowledge is a complex system which provides experience and behavior with cultural meaning. It is the knowledge which not only informs the behavior of the individual, but that also allows for the understanding and interpretation of the behavior of others. Cultural knowledge includes specific terms and symbols, but is more than a mere collection of information.

Anthropologists traditionally studied simple, self-contained societies, which are increasingly rare in today's world. Modern, complex societies are composed of many diverse subcultures. Subcultures operate in a variety of cultural scenes, and overlap, interrelate, coordinate, and conflict with each other while forming society as a whole. Examples of subcultures are ethnic groups, professional groups, and social and economic classes. Going home is a subculture operating within the hospital experience setting within the health care system of a society, but is also a distinct culture in and of itself, and is approached as such.

To paraphrase Spradley (1979), going home is not a material phenomenon; it does not consist of objects such as prescriptions and wheel chairs, or people like nurses, doctors and patients, or actions such as getting on the commode or doing one's own catheterization, or emotions like fear of rejection and grief. Going home culture is rather an organization of these things. It is the form of the meaning of things that persons going home carry in their heads, their models for perceiving, relating and interpreting experiences, their guides for determining their support needs.

The cultural framework for this study is the culture of going home. Within this context, the investigator was interested in discovering and describing the cultural knowledge of persons going home, that is, the cognitive apparatus of categories of information, patterns of associations and attitudes, rules for assessment, and guidelines for needs which are appropriate and specific to the culture of going home.

#### Body Image/Change in Body Function

A second concept for the foundation of this study is that of body image. Norris defines body image as follows:

Body image is the ever-changing total of conscious and unconscious information, perceptions and feelings about one's body as different and apart from all others. It is a social creation, developed through reflected perceptions of the surface of one's body, investments one makes in parts or the whole of the body and responses to sensations originating at the inner regions of the body as the individual experiences a kaleidoscopic variety of activities. The body image is basic to identity and has been referred to as the somatic ego (1978:5).

Image of self or self concept is in large measure dependent upon the individual's feelings about and acceptance of the physical body. Body image evolves slowly through the process of growth and development. It acts as a frame of reference for the ability to perform and influences the ways in which a person perceives self, measures continuity in life and identifies mastery of the world (Carlson and Blackwell, 1978).

Body image is unique to each person. Different people value different parts of their body differently. One may be pleased with the shape of the neck. Another may derive a positive sense of self from hair color. A logical extension is to apply body image awareness to the overwhelming threat to self that a change in body function may precipitate.

The phrase "change in body function" is used deliberately in contrast to disability, trauma, or body dysfunction. Use of such "loaded" or weighted terms, as disability or dysfunction risks the creation of self-fulfilling prophecies which lead to unnecessarily handicapped people. What a person is or is not able to do or be is only debilitating or handicapping to the extent that the person views it to be so. Thus, the informants in this study have experienced a change in body function. The change may or may not be perceived by them to be a threat to their functional ability or adequacy.

In addition, loss of functional control can affect loss of customary control of self, physical environment, time and interpersonal relationships (Ullman, 1964). Thus, the interaction between the concepts of change in body function and going home depend significantly

on the individual actor's perception and interpretation of the cultural scene.

#### Care/Support Needs

Care is the third concept providing a context in which to discover support needs of the informants for this study.

"To heal does not necessarily imply to cure. It can simply mean helping people to achieve a way of life compatible with their individual aspirations - to restore their freedom to make choices - even in the presence of continuing disease" (Dubos, 1978:82).

Leininger says in her foreward to Watson's Nursing: The Philosophy and Science of Caring that "the concept of care is probably one of the least understood ideas used by professionals and nonprofessional people, yet it is probably one of the most important concepts to be understood by human groups" (1979:xi).

Watson makes the distinction between "curative" and "carative" factors. She says "whereas 'curative' factors aim at 'curing' the patient of disease, 'carative' factors aim at the 'caring process' that helps the person attain (or maintain) health or die a peaceful death" (1979:7).

In this same vein, Benoliel distinguishes between the concepts of care and cure:

Cure centers on the diagnosis and treatment of disease. In contrast, care is concerned with the well-fare and well-being of the person. Cure deals with the objective aspects of the case, whereas care is concerned with the subjective meaning of the disease experience and the effects of treatment on the

person. Cure has many origins in science and instrumentation and 'doing to' people. Care has its roots in human compassion, respect for the needs of the vulnerable, and 'doing with' people" (1976:10).

While the above quote comes from the context of the terminally ill patient and the cultural scene of death and dying, the concept of care and the distinction drawn between care and cure are relevant to the cultural scene of going home and the identification of the support needs within the transition process.

Change in body function is usually permanent, that is the ability to regain total pre-injury or illness function is rare. Spinal cord injury, stroke, head injury are not curable. However, curative measures can increase independent function and improve quality of life. The crucial factor is that care be consistent with the particular needs of the individual person. Successful going home lies in the enlightened interaction between the concept of care/support needs and its application on the functional level. Doing with rather than doing for proves to be an important distinction as reported by the informants. Doing with attends to specific, stated support needs of the patient creating an environment for positive body image and adaptation to the change in body function affording the going home transition a significantly higher success rate.

Aamodt, in her studies of the Papago and Norwegian-American neighbors, advances the idea of care as a culturally relevant domain (1971, 1982). She says, "the concept of cultural solutions as a support system is common knowledge. The specific ways in which a cultural system provides support for health care problems, however, is



not well understood. . .The patterns of the critical behaviors are, of course, culturally specific and as such provide a support system because of their cultural boundedness" (1982). Cultural boundedness means the rules, or customs or traditions, which guide the pattern of behavior.

The conceptual orientation comes full circle through the concept of the culture of going home with a revision of body image due to change in body function which requires care based on support needs arising within the individual's interpretation of the going home experience.

#### Definitions

Ethnographic design involves discovery of meanings inherent in the way people use their language. The goal is to elicit the informant's own definition of terms. However, it is appropriate to define three terms used by the researcher in order to provide clarity:

1. Support needs - those carative activities people need or want to have done with or for them.
2. Change in body function - a physical alteration of the body which precipitates a change in the function of that part or the body as a whole. For the purposes of the study the change is as extensive as quadraplegia and as invisible as memory loss.
3. Long-term hospitalization - at least six weeks of continuous experience as an in-patient in a hospital setting.

which need not be on the same unit or in the same hospital for the entire period.

#### Assumptions

The following basic assumptions were made:

1. Persons going home after long-term hospitalization with a change in body function will have support needs.
2. Going home is a cultural scene.
3. Persons going home will be willing and able to communicate with the researcher about their support needs.

## CHAPTER II

### REVIEW OF LITERATURE

The concepts which form the conceptual orientation guided the investigator to review the literature in the areas of Going Home, Change in Body Function and Support Needs. Research findings to be useful must build on previous knowledge as well as guide future study and practice.

Chapter two presents a summary of basic studies and pertinent literature concerning the three concepts. Unfortunately, few nursing or allied health studies exploring the specific phenomenon of going home were found.

#### Going Home

According to Johnson, "one of the major responsibilities of the rehabilitation nurse is patient and family teaching relative to discharge planning" (1980:222).

While there have been numerous articles written, especially in the last five years, on discharge planning and patient teaching, very little formal exploration focused on the patient leaving the hospital and experiencing the transition of going home has been done or even proposed. One study took place in London and is reported by Gay and Pitkeathley in a small volume entitled "When I went home. . .a study of patients discharged from the hospital." This is an account "of how 275 patients got on when they went home" (1979:1).

The study grew out of concern with the work of volunteers in the health care setting. The methodology involved open ended questions on a questionnaire during a single interview two or three weeks post discharge. Conclusions focused on the extended family as a primary support system. To the original question, "Is there a need for voluntary care in the community for discharged patients?" there was an emphatic "yes," particularly during the first 48 hours post discharge (Gay and Pitheathley, 1979:62).

Several follow-up projects funded by the Office of Rehabilitation Services of the Department of Health and Human Services have been conducted. The primary goal of these studies was to identify the ongoing needs of rehabilitation patients and to design and effect an economically feasible system of care to meet these needs. Some of the factors assessed in these studies were discharge to home vs. to an extended care facility (Granger, 1975); involvement of Visiting Nurses personnel during the follow-up period (Granger, 1975); reasons clients return to a state vocational rehabilitation agency (Goldberg, 1975); and establishment of content consistency between patient goals and rehabilitation staff goals in the discharge planning process (Hamilton, 1975).

In February, 1980, an ongoing project was reported by Sadlick at the Annual Meeting of the Association for Rehabilitation Nurses. She, along with two other colleagues, is studying the therapeutic relationship between nurses and clients leading to optimal rehabilitation and achievement. Her as yet unpublished report is entitled, "Bridging the

Gap From Hospital to Home." Self image and help are two of her central concepts.

The idea of "going home" or "coming home" as a culturally relevant domain has been addressed in both the academic and popular literature surrounding wartime and return from war. The movie "Coming Home" combined the complex dynamics of long-term absence as a result of involvement in a war of dubious merit with the factor of change in body function experienced by the hero. Another study was published in 1944, by Pratt, Soldier to Civilian: Problems of Readjustment. The parallel drawn between returning from battle and going home following long-term hospitalization fits particularly as concerns the heavy emotional weighting in each case of the terms "going home" or "coming home." In both contexts to know how to be caring; to know what curative measures to provide, the caregiver must be receptive to and respectful of the personal expression of need.

While Spradley asserts that "medical theories of health and disease can be informed by careful ethnographies of folk medical theories" (1979:12), searching the vast literature addressing culture for specific references to discharge from the hospital reveals few entries. Denny (1974), using the ethnographic design, studied the social culture and health of quadriplegics.

Aamodt (1982) examined the use of ethnography for nurse researchers, emphasizing the validity of viewing the cultural scene of health care from the view, through the language, of the actor.

Bauwens' (1978) collection of statements on the Anthropology of Health serves to emphasize that health and health care delivery cannot be separated from the culture in which it takes place.

The person-environment fit (Coulton, 1979) is a challenging concept considered in the context of going home. Person-environment fit refers to the degree of congruence between the individual's needs, abilities, and aspirations and the demands, resources, and opportunities of the environment. Stress results where there is a lack of fit between the individual and the situation. The concept recognizes that an environment quite suitable for one person may be incompatible for the needs of another. Or, more relevant to this study, an environment appropriate to the needs of the occupant may no longer be compatible for the same person with a change in body function. The home may no longer provide the previously successful person-environment fit.

#### Change in Body Function

Many facets of body image and alteration in body function have been addressed in the literature. Ullman (1964) examined the disorder of body image after stroke. Dyk and Sutherland (1956) discussed the effects of colostomy and the perception of body image by both the spouse and family members of the patient. Weininger, Rotenberg and Henry (1972) focused on handicapped children and the effects of their altered body function on body image. These were children with both congenital and acquired disabilities. Arnhoff (1963) looked at the concept of

body-boundaries and what happens when a person is immobilized as in paraplegia.

Murray suggests that alterations in body image necessitated by changes in body function place the person in a "situation which is stressful to the degree that the usual pattern of responses, behavior and coping mechanisms is inadequate to handle the present feelings resulting from this event" (1972:697-698).

Two of the classic authors in the field of body image, Schilder (1950) and Fisher (1968), advocate the relationships between body image and personality. Patterns of body awareness provide the basic framework through which personality is expressed. Thus, if body image is challenged or threatened as with traumatic change in body function, the organization of self is disturbed.

Schontz (1975) makes the point that people ordinarily learn to accept limits that their bodies place on their actions. They become consciously aware of limitations only when they are suddenly altered, when there is a real change in body function. Even then, the immediate reason for frustration does not appear to be the illness or injury but the inability to function as before. He cites the person with aphasia who becomes angry because he cannot speak, not because he has damage to the brain. In an interesting study by Parkes (1972), 46 amputees were interviewed and asked, "Do you miss your limb?" While they all answered "yes," further probing revealed that what the people actually missed was not the limb itself but the functions it performed.

Krueger, discussing the extent of functional change in spinal cord injury, writes that "such drastic functional loss may trigger fear and confusion over the sense of disorientation with the body" (1984:26).

Trieschmann (1981) also considering the psycho-social issues of spinal cord injury emphasizes that the process of learning to live with disability begins at the moment of injury and continues through life. The change in body function affects change in body image which essentially restricts the person's whole environment: physical, social, emotional and spiritual.

#### Support Needs

Aamodt (1978, 1979), Benoliel (1976), Burnside (1979), Hyde (1975, 1976, 1977), Leininger (1979, 1981) and Watson (1979) are the authors found in the nursing literature who have addressed the concept of care and identify the support needs or the "things people do to care" within their cultural scenes. Their work has been discussed in the section in conceptual orientation. The relationship between support needs and care is inferred from these authors to mean the carative activities needed or wanted by the individual requesting them.

Aamodt asserts that the ways in which human beings care for each other reveals something very essential about the human experience. She says:



How human beings care for themselves and others is an essential field of inquiry for serious students of quality health care delivery because of: 1) the humanistic dimension the concept of care brings to the health care experience; 2) the practical need for health specialists to understand patterns of care already in use by their patients; and 3) the need to learn how to utilize the cultural dimension to enhance the quality of life for all people" (1978:37).

These studies and reports present persuasive support for the notion that caretaking is what most individuals are looking for as they express their support needs. These investigations focus both on the formal, professional system of care taking, i.e., the Health Care System, and the informal networking expressed by Aamodt's phrase, "what neighbors do for neighbors" (1980).

Studies (or even a study) discussing the support needs of patients immediately post discharge, with or without a change in body function were not found.

#### Summary

The search of the literature revealed that there are no studies on the support needs of persons with a change in body function during the transition period from long-term hospitalization to home. While there are numerous articles addressing the broad concepts of Culture, Body Image and Care, the pertinent ones have been reviewed in this section. Striking is the fact that with the exception of Aamodt (1978, 1979) and Gay and Pitkeathley (1979), all of the studies and articles read discussed the concepts analytically from the investigator's viewpoint. The lack of information in the actors' language of the going

home experience establishes the need for a study which focuses on the viewpoint of the patient.

## CHAPTER III

### METHODOLOGY

This study, utilizing an exploratory design with an ethnographic methodology is an attempt to determine the meaning of the going home transition to a specific group, persons with a change in body function who have been hospitalized for a long period.

One requirement of ethnographic research is that the investigator become immersed in the process. Because of the involvement of the investigator in the data collection and analysis it is important to provide information about the person who has conducted the study. This chapter on methodology, therefore, discusses the investigator, the informants and the research design.

#### The Investigator

The going home experience has been an event of interest and concern to this investigator over the past 5-1/2 years. As a student I had the opportunity to follow several patients home either on their weekend passes or at the time of discharge from a local rehabilitation unit. During these home visits, I played the role of participant observer (Spradley, 1980). I came "to a social situation with two purposes: 1) to engage in activities appropriate to the situation and 2) to observe the activities, people and physical aspects of the situation" (Spradley, 1980:54).

These experiences were informative, moving, eye-opening and challenging. The challenge evolved from my observations that both the patients and families were frequently overwhelmed by feelings of anxiety, fear and unrealistic expectations, coupled with lack of self-care knowledge and/or capability. In short, they appeared to be experiencing reality shock (Kramer, 1974).

Reality shock is a term used to describe the phenomenon and the specific shock like reactions of new workers when they find themselves in a work situation for which they spent several years preparing and for which they thought they were going to be prepared and then suddenly find they are not" (1974:viii).

Reality shock is similar in concept to culture shock which Kramer defines as "a state of anxiety precipitated by the loss of familiar signs and symptoms of social intercourse when one is suddenly immersed into a cultural system markedly different (1974:4).

I observed and provided care to these patients coming into their homes for the first time after, in some cases, as long as two or three months in hospital. A vivid combination of reality and culture shock were evident. One person, wheel chair bound, found himself unable to fit through the bathroom door. Later he sat with a perplexed look on his face staring at the television high on a top shelf, remote control was not available. Another woman sat in her favorite easy chair, shaking her head, tears flowing. She was both aphasic and alexic. An impressive stack of books and her reading glasses were neatly arranged on the table next to the chair. Reading has been this woman's favorite past-time. Her countenance and body

body language communicated shock and sadness. Surely she had become aware during therapy sessions or while trying to fill out her menu on the nursing unit, that she had suffered reading deficits? Certainly she had. She had been prepared and had even begun to make small improvements. Suddenly, however, she is home and home creates the expectation of familiarity, of resuming long held habits. The reality of her change, of her deficit hit home at home. She had been prepared but was not prepared.

It is this paradox that has led me to continue to explore, consider and, in my work, search for ways to plan and implement a realistic transition from hospital to home. The challenge has been to meet the needs of real people as they perceive them.

Discharge planning is an ever growing area of nursing practice with protocols, guidelines and forms. Do these tools and approaches meet real needs? All too frequently one hears the nurse accompanying the discharged patient to the car bubbling, full of smiles and reassurance, "You're going home. How wonderful! We're so happy for you." It wasn't until one of my informants in this study blurted out with resentment and conviction, "Well, it's not great; it's not wonderful. I don't want to be here. I can't do anything that makes this home;" that I began to fully realize the impact of following procedures and protocols that are based almost exclusively on care givers' assumptions. JB's declaration validated the essential need to discover the meaning of the going home experience from the actor's point of view.

There are dangers which accompany ethnographic research. Research driven by personal investment can be contaminated by bias,

subjectivity and preformed ideas. Familiarity with the cultural scene can cause the investigator to take things for granted or be insensitive to variation of meaning. I have tried to be aware of these dangers thus avoiding possible invalidating pitfalls.

### The Informants

Three informants were chosen as participants for the research study. The following criteria were used in selection of the convenience sample:

1. The informant will have a change in body function.
2. The informant will have been hospitalized for a minimum of six weeks.
3. The informant will have been discharged from the hospital the day prior to or of the first interview.
4. The informant will be willing to share what he or she knows about his/her going home support needs.
5. The informant will have enough time to fulfill the interview requirements of the study.
6. The informant will be able to communicate verbally in English.

Persons who met the above criteria were identified through the investigator's experience and interactions as a staff nurse in a hospital rehabilitation unit. After possible informants were selected, rapport was established via informal discussion. In sharing the purpose and process of the study, five informants were selected. Three informants completed the study. The fourth participant was no longer

appropriate when he was discharged to his daughter's home in another state, and therefore not accessible. The fifth informant withdrew himself from the study after the first day's interview session. He called the investigator to explain that his "wife didn't like him telling so much to a stranger." This instance of withdrawal from the study based on family pressure raised the question of the advisability of discussions and/or consent being entered into with family members as well as the informant prior to initiating the research process. This issue should be addressed before undertaking future ethnographic exploration.

The three participants who met the criteria were chosen from the general population of a 20 bed rehabilitation unit in a southwestern community hospital. Written consent to participate in the study was obtained prior to the person's discharge from the hospital (Appendix A).

### The Research Design

An exploratory design utilizing the ethnographic method was used to answer the following research question: What cultural knowledge informs the behavior and determines the support needs of a person with a change in body function during the transition from hospital to home after long-term hospitalization?

The ethnographic approach seeks to discover meaning and define variables for further, perhaps quantitative study. It has as its goal the understanding of another way of life from the native point of

view (Spradley, 1980). Ethnography is used to generate hypotheses rather than to test them.

### The Setting

Interviews with all three informants were accomplished in their homes. The study question necessitated that the home be the data collection setting. Indeed, the relationship between the informant and the home was a crucial factor in the study.

The informant was encouraged to choose the particular room or area for the interviews. As the interviews were being audio-taped, there was a need for relative quiet. The investigator also urged the informants to select a place with a minimal risk for interruption and which would provide the maximum level of confidentiality for the informant.

In all three cases, other family members were present in the house during the interviews, but seldom in the same room. As was indicated earlier a fourth informant withdrew from the study based on the spouse's objections to the confidential material being shared.

### Human Subjects Consent

The study was approved by the University of Arizona College of Nursing in accord with established research criteria. It was also approved by the Human Subjects Committee of the University of Arizona (Appendix C).

Access and approval to conduct the study was obtained from the Medical Director of St. Mary's Hospital and Health Center Regional



Rehabilitation Center (Appendix D). The informants received a written explanation of the study with their rights and privileges outlined prior to participation via the Human Subject's Consent Form (Appendix A). In addition to the written explanation, informants were given a verbal explanation and assured that withdrawal was possible at anytime and that confidentiality would be maintained.

#### Ethnographic Data Collection and Analysis

The audio-taped ethnographic interview was used to discover how the three informants described and defined the support needs they had during the first four days at home post discharge from long-term hospitalization. The interviews took place in the informant's home. A total of four interviews on four consecutive days were conducted with each informant. The interviews varied from seventy-five minutes to over two hours in length.

Part of the interview time was used in establishing rapport. Spradley (1979) discusses the importance of the investigator-informant relationship. Trust is essential in this relationship, particularly with respect to the reliability and validity of the study (Aamodt 1979).

The unique characteristic of the ethnographic interview is that information is gathered from the informants, not about them. The information is relayed in the form of folk terms, cultural symbols that give an investigator access to cultural meaning (Spradley 1979). Because of the central function of the verbatim language of the

informant to the purpose of the study, each audio-tape was transcribed in the day(s) following the interview. The complete transcription combined with field notes facilitated analysis which assisted in the development of questions for the subsequent interview. Thus, in the ethnographic method data collection via interview and analysis are done concurrently. The responses provided by informants are used to discover other relevant questions. This pattern of "building" the data reinforces validity and reduces the opportunity for bias or selective awareness on the part of the investigator.

Three broad types of questions were used to facilitate data collection (Appendix B). First general or "grand tour" questions were asked. These descriptive questions were used to elicit a language sample and identify the relevant areas of exploration.

The second type of question used, structural questions, was grounded in the language of the grand tour questions. The structural questions evolved from the organization of the information attained in the grand tour questions. Contrast questions assist in discerning differences among folk terms and thereby discover less explicit relationships (Spradley 1979).

The three types of questions were used interchangeably throughout the twelve interviews. The data collection and analysis process continued until all the informants were no longer contributing new information.

Spradley (1979) considers ethnographic analysis a tool for discerning cultural meaning. He refers to the systematic examination

of the information from the informants to determine its parts, the relationship among the parts, and their relationship to the whole "as conceptualized by the informants" (Spradley 1979:93).

Domains are the first units of analysis in ethnographic research. All the members of a domain share at least one element of meaning. Domain analysis must be repeated as new data is collected through the interviews.

Taxonomies are the next step in this hierarchical analytic process. A taxonomy is an organization of the terms used by the informants into sub-sets usually based on a single semantic relationship, for example X is a kind of Y (Spradley 1979).

On the next level is componential analysis which searches for contrast sets or components of meaning. Finally, domains of meaning and relationship between domains that are linked to the culture come together to form cultural themes. Cultural themes, recurrent expressions of the informants may be explicit or tacit and, as such, are frequently inferred from the data by the investigator.

In conclusion, the interviews were designed to focus on the knowledge and meaning that the three informants used in their going home experience. The informants' communicated their knowledge in the form of folk terms which were subsequently organized into categories of meaning. The data collected and analyzed in this study are presented in Chapter four.

### Limitations

There are two limitations inherent in the ethnographic method. If viewed within the framework of the study problem and purpose, neither limitation is of serious significance.

1. The information obtained from informants during the ethnographic interview is limited to what the informant is willing and able to discuss.
2. Information elicited from informants in the ethnographic process lacks generalizability. Results cannot be considered representative of a larger group. However, the ethnographic approach is suitable to a description of the whole, to the identification and definition of variables, and to the generation of theories.

## CHAPTER IV

### PRESENTATION AND DISCUSSION OF DATA

In this chapter characteristics of the sample, including descriptions of the informants and their families, the researcher-informant relationship and interview procedures are presented. Domains of meaning and cultural themes are identified and discussed in terms of the ethnographic interviews.

#### Characteristics of the Sample

The informants for this study were selected according to the criteria from the in-patient population of a physical medicine and rehabilitation unit of a southwestern community hospital. The persons were approached by the investigator approximately two weeks prior to their discharge to explore their interest and willingness to participate in the study. Several short interactions between the investigator, informant and family took place during this period prior to the signing of the Informant's Consent Form (Appendix A).

The resultant sample consisted of five persons: two women and three men. Two of the male participants withdrew from the study as previously mentioned. Therefore, the sample is considered to be three: two women and one man. The data and findings are based on the taped interviews with these three individuals: JB, LH and JA.

After obtaining permission to audio-tape the sessions, a total of twelve interviews were completed, four with each informant. All of the interviews were conducted in the informants' homes.

### The Informants and Their Families

Each informant is described in this section based on the taped interviews and field notes of the investigator. Initials are used to protect identity. Table 1 provides self-reported demographic data for each informant relevant to the study including date of birth, sex, age, occupation, years of formal education, ethnic group, religion, etiology, primary disability, date of onset, date of admission to the rehabilitation center, date of discharge, total number of days hospitalized, and primary caretakers at home. The right of refusal to give any information and the fact that all information was considered confidential were emphasized.

JB

JB was a 27 year old woman, unmarried, living with two female friends prior to her hospitalization. JB had an eleven year history of systemic lupus erythematosus although after the initial diagnosis and a six month period of exacerbation had experienced few symptoms. JB was on the rehabilitation unit having suffered a severe right hemisphere cerebral infarction while undergoing a craniotomy for removal of a leiomyosarcoma of the right parietum and inhibition of an intracerebral bleed. JB remained comatose for almost one month post surgically. Although glassy-eyed, with reduced spontaneous affect and an obvious

Table 1. Demographic Data of Informants

|                                      | JB   | JA                            | LH                                      |
|--------------------------------------|--|-------------------------------|---|
| DOB                                  | 2/7/53   | 12/7/54                       | 6/26/1898                               |
| AGE ON ADMISSION                     | 27   | 27                            | 82                                      |
| SEX                                  | F  | M                             | F                                       |
| OCCUPATION                           | Paralegal  | Carpenter                     | Housewife                               |
| YEARS OF EDUCATION                   | 18   | 14                            | 8                                       |
| ETHNIC GROUP                         | Caucasian  | Caucasian                     | Caucasian                               |
| RELIGIOUS AFFILIATION                | Unitarian  | Catholic                      | Mormon                                  |
| ETIOLOGY                             | Brain cancer<br>Stroke post<br>craniotomy          | Gun shot<br>wound             | Brain stem<br>infarct                   |
| PRIMARY DISABILITY                   | Left hemiplegia<br>cognitive/<br>language deficits | T <sub>11</sub><br>Paraplegia | Bilateral<br>plegia                     |
| DATE OF ONSET                        | 5/1/80   | 12/30/80                      | 2/13/81                                 |
| DATE ADMITTED TO REHABILITATION UNIT | 7/8/80   | 1/13/81                       | 3/3/81                                  |
| DATE DISCHARGED                      | 10/3/80  | 3/21/81                       | 3/27/81                                 |
| TOTAL NUMBER OF DAYS HOSPITALIZED    | 156  | 81                            | 45                                      |
| PRIMARY CARE-GIVER AT HOME           | Mother<br>Brother<br>Boyfriend                     | Mother<br>Girlfriend          | Nurse Aide<br>Daughter<br>Granddaughter |

level of discomfort, JB, when able to focus and concentrate, was alert, involved and witty. Her personality and communication skills lead quickly to the awareness that she was a bright, educated and assertive young woman. Indeed, she earned a Master's Degree in Business Communication. Her smile was radiant, if infrequent. This young woman, despite her discomfort, her deficits and her bleak prognosis, never let go of a beautifully developed *joi de vivre* and commitment to the productive struggle.

JB's interest in this research project was both emotional and intellectual. She seemed to thrive on the opportunity to share her feelings as well as the challenge to express her ideas. Her responses were always considered and thoughtful although frequently the interview sessions brought episodes of profound emotion. Her crying was at times uncontrollable, this being both an organic component of the stroke as well as an outlet for her grief and frustration. Of the three informants, JB was the most communicative and seemed to invest the most of herself in the interview process. She had a flare with words, seemingly without awareness of the significance of their meaning. Her most memorable contribution found expression on the first day post discharge. The discussion was about leaving the hospital. JB blurted out with disbelief and indignation, almost as a child who couldn't believe that such a trick has been played: "Why didn't anybody tell me that to go home I had to leave the hospital?" She was equally resentful on the third day post discharge when she denied that it was good to be home.

"Everybody said, 'Oh, how wonderful! Oh, how marvelous! You're going home.' Well, it isn't marvelous and it isn't wonderful because



it's not home. It's not the same, because I can't do anything here any more."

JB's primary caregivers were her mother who had been living out of state and returned to the city at the time of JB's initial hospitalization; her brother, one year her junior, a local resident married although separated from his wife. JB's sister-in-law was a very close friend and support to her also. In addition, JB's boyfriend of 1-1/2 years duration remained close, providing support, humor, and encouragement. All these members of JB's support system were open and receptive to the investigator. They assisted in planning interview times, provided privacy during the sessions and shared an interest in the project. Their contribution to JB's well-being was immeasurable and inspiring to observe.

LH

LH was an 82 year old grandmother who, prior to her brain stem infarct, had been living alone in her home of some 30 years. LH's health history was generally unremarkable for major disease or injury. Arthritis had begun to limit her activity over the past five years, although she reported "tolerable" relief with aspirin. LH's stroke had been a relatively minor one affecting primarily fine motor coordination, strength and endurance. LH dealt with crossed and blurry vision brought on by the brain stem insult by wearing a patch alternately on each eye. LH participated in the study and the interviews with a gentle forbearance and minimal curiosity as to the purpose of the investigation. On the second day post discharge, she assured me "It just takes time. Little by

little it's, my vision, is getting better. I don't think it's going to take me too long to do for myself again."

LH was particularly happy to be home. "I was ready to leave the hospital. I like to be in my own surroundings. I'm an old lady and I like things the same." In the fourth interview on the fourth day post discharge, however, she modified the statement above from her first day home: "I'll be glad, you know, when this little place with all my stuff really does feel like home again. I guess I'll really be home again when I don't need that gal to be here and when I can go out to the mail box alone."

LH took great pleasure, before and after the taped interviews and once right in the middle of an interview, because the urge overcame her and she didn't want to forget the "lines," of reciting verses to the investigator. She shared with pride her 10 plus albums of poems, songs, sayings and short stories clipped from newspapers and magazines.

LH's speech, which was routinely monotone, and very slow during the interviews, became expressive, rhythmical and quite speedy as she recited from memory a particular hymn or poem while the investigator followed the piece in the album. She explained that these albums represented one of her favorite pasttimes during her younger years when she was "raising my family and helping my husband make ends meet." She had raised three children, outlived two husbands, and had been a widow for 15 years. LH enjoyed recounting stories from the "hard days" and "early times" in Arizona. She considers herself somewhat of a pioneer: stubborn, independent and able to take care of herself. On the third

day post discharge, in the context of what help she needed and wanted, she described herself in this manner: "I feel I take pretty good care of myself. I know myself. I know what I can stand. I know what I can't stand. I take my time. I do what I can and I don't let anyone try to hurry me." LH's caregivers consisted of a nurse's aide who received pay for her care of LH. She was a close friend of LH's daughter and LH reported she was "like family." LH's daughter and granddaughter were the other primary caregivers for LH, although the investigator had little direct contact with them. The granddaughter brought cookies on the third day post discharge during an interview session. She was friendly, respectful and indicated she knew who I was and what was going on. The nurse's aide also was quite cooperative and friendly although each interview session from the first through the fourth began with an awkward scene in which she had to be invited not to respond to the questions. She would eventually leave the room and occupy herself with chores in another area of the house. Her disappointment was clear each time, however, and each time the investigator experienced a pang of guilt as if depriving a child from staying up for the party.

JA

JA was a 27 year old man whose work history and hobbies included carpentry, auto mechanics and gunsmithing. JA's T<sub>11</sub> paraplegia was the result of a gun shot wound received when he surprised a burglar late at night in the room of his parents' home where he had been living for ten months prior to the assault. The motive for the shooting was never clear

nor was the assailant apprehended. JA felt certain that he had met the person before and that his valuable gun collection was the cause. It was to this room that JA returned at discharge and where the interviews took place. JA's prior health history revealed an atheletically oriented young man who, while taking his health pretty much for granted, had avoided serious illness and/or injury.

JA's educational background consisted of 14 years of formal education but "no earned degrees." He emphasized frequently during the interviews that he considered himself "amazingly intelligent and astute." His approach to the study was one of controlled indifference although he also expressed dichotomous feelings throughout the four days, alternating between making sure his statements were understood and backing off from sharing his thoughts at all. His modus operandi was to answer any questions with an immediate, "I don't know," or "I've never thought about that." Given time and silence, he would pick-up on the theme or folk term and carry on spontaneously for several minutes.

JA's anger infiltrated all of the interviews and must be viewed as a backdrop for his responses. He appeared reluctant to own the anger and communicated clearly his dislike at being asked about it or having the anger brought into the discussion at all. "I'm not angry. Why should I be angry? Nothing I can do about it. I didn't feel I deserved to be shot in the back. But so what? It happens." He did, on the third day post discharge, report that "I got more depressed yesterday. I lay around feeling sorry for myself; wanted to shoot my legs and things like that. But I didn't. Logic prevailed." This admission was an example of

the paradox present throughout his interview sessions: the desire for control coupled with denial on the one hand, and the urge to be self-revealing on the other. "I'm basically a private person. I'll answer questions but I'm not one to initiate conversation about my feelings."

JA's going home "surprised" him. He had not expected to be discharged when he was. His re-telling of the discharge and coming home revealed again the complexity of his combined bravado and sensitivity.

JA's humor, caustic and witty, constituted one of his major coping strategies. He used humor frequently to diffuse the conversation or express his anger. It was often as if by communicating the idea or feeling with humor, he could avoid responsibility for it. An example of this came on the fourth day post discharge in response to being asked to explain what "learning to be a cripple" meant: "You must lead a limited life. When was the last time you got shot in the back? Try it you might like it."

JA's principal caregivers were his mother and girlfriend. While both were polite with the investigator they seemed neither interested in nor supportive of the study. Frequently, even though interview appointments had been scheduled carefully to fit into JA's social and self-care schedule, the investigator was asked to wait while either mother or girlfriend finished a particular task. Phone calls were not diverted nor were visitors asked to wait.

According to JA's account his girlfriend "worked real hard" although sometimes she wasn't "efficient enough." He begrudgingly acknowledged the importance of his mother's and girlfriend's help

although he emphasized "I could do it all myself if I had to." His relationship with his mother was an open struggle for control. Each of them discussed the other's "stubbornness" during the third interview session.

### Researcher-Informant Relationship

The importance of the researcher-informant relationship lies at the heart of the ethnographic method (Spradley, 1979). Spradley says, "It is best to think of ethnographic interviews as a series of friendly conversations into which the researcher slowly introduces new elements to assist informants to respond as informants" (1979:58). The goal of the interviews is always to elicit the language and meaning of the informant. To reach this goal a level of trust and rapport must develop. If mutual respect is not present the process can easily deteriorate into interrogation or testing in which the informant tries valiantly to give the "right" answers. The validity of the information gleaned from such an interview is seriously compromised.

Rapport with the three informants in this study developed over time beginning approximately two weeks before the first interview was conducted. It proved very helpful that the investigator and informant had a prior history within the context of the injury or illness. Although an outsider in the person's home, the investigator was not an outsider within the context of experience. The investigator's role as a nurse added to the informants' acceptance of the investigator's willingness and ability to see things from their point of view.

Serious concern and attention were given to validating the informant's role as expert and minimizing the investigator being viewed as judge or teacher. All three informants at some point in each interview sought confirmation of the investigator's role however indirect. JA would say "Right, teach? This isn't the way we did it at the hospital. But it's OK, right?" LH apologized for the dust and disarray in her home as if checking to see if her housekeeping were important to me. JB because of her lability and emotional outbursts needed frequent reassurance that she was not being judged negatively for her tearfulness.

All interviews took place at the convenience of the informant. Appointments were made which respected their schedules. The location within the home was selected by the informant. In JA's case all four interviews took place in his room. LH sat in the same favorite chair throughout her four sessions. JB preferred more variety, meeting the first day in the living room, then two sessions in the kitchen and the last in her bedroom.

The length of each interview varied but were in all cases at least 1 hour 15 minutes or 15 minutes longer than the contracted time of 1 hour. The interview was usually terminated by the informant except in one instance when the investigator had a prior commitment and ended the third interview session with JB after two hours.

#### Domains of Meaning

Through the use of ethnographic interviews domains of meaning that represent the informants' view of the going home experience were confirmed. The domains include data collected from and validated by

all informants. The domains of meaning are discussed in this section in chronologic organization according to first, second, third and fourth day post discharge. While data were added from each day of interviews to the existing domains and new categories developed from Day 1 to Day 4, the final analysis of the data from all 12 interviews fell into this pattern over time.

The following domains of meaning were identified:

First Day Post-Discharge

1. Leaving the Hospital
2. Being at Home

Second Day Post-Discharge

3. Activities I Need Help With
4. Characteristics of a Good Helper
5. Aspects of Being Home

Third Day Post-Discharge

6. People Who Help and What They Do
7. Helpful Attitudes

Fourth Day Post-Discharge

8. Things That Make it Easier to be Home
9. Getting Well is a Full Time Job
10. Contrasts Between Hospital and Home
11. Ways to Make the Transition From Hospital to Home Easier



### The First Day Post Discharge

The first interview took place for each informant on the first day home post discharge. It is not surprising that the grand tour questions which initiated these interviews were focused on the broad issues of Leaving the Hospital and Being Home. It would have, indeed, been difficult to have brought the informants' attention to any other topic. JB had been hospitalized a total of 156 days, more than 43% of a year's time; LH for 45 days; and JA for 81 days, or almost 1/4 of a year. Because the informants talked about actions and feelings on leaving the hospital this domain of meaning has been divided into two sub-sets, with the sub-set Actions further divided into Mine and Others (Figure 2). The findings were consistent among the three informants as regards the action sub-sets, with the exception of crying. JB reported lots of tears. LH said she felt like crying but didn't.

JA denies crying, "I can count the number of times I've cried on one hand. It's just not an outlet I've used." Importantly, however, he did not reject the validity of this category.

Looking at the data in terms of actions of others, the others for the most part were the persons taking the informant home. The only phrase that implied the hospital personnel was "say goodbye to me." This plus JB's inclusion of "saying goodbye to the nurses" were the sole indications that hospital personnel were part of the person's awareness of leaving the hospital. Does this mean that the nursing staff and other rehabilitation team members' interactions are not relevant at this point? Or does it imply that what was done was not

|                          |               |                               |                             |                  |
|--------------------------|---------------|-------------------------------|-----------------------------|------------------|
| LEAVING THE HOSPITAL     | Actions       | Mine                          | Say Goodbye                 | To Roommate      |
|                          |               |                               |                             | To Nurses        |
|                          |               |                               |                             | To Other Friends |
|                          |               |                               | Leave Friends               |                  |
|                          |               |                               | Cry                         |                  |
|                          |               | Think about what happens next |                             |                  |
|                          |               | Others                        | Say goodbye to me           |                  |
|                          |               |                               | Wheel me out                |                  |
|                          |               |                               | Put me in the car           |                  |
|                          |               |                               | Load up the car             |                  |
|                          | Push me out   |                               |                             |                  |
|                          | Bring me home |                               |                             |                  |
|                          | Feelings      | Abandoned                     |                             |                  |
|                          |               | Scared                        | Falling                     |                  |
|                          |               |                               | Not being able to do things | Feed the cat     |
|                          |               |                               |                             | Water the plants |
|                          |               | Wash the dishes               |                             |                  |
| Surprised                |               |                               |                             |                  |
| Sad about leaving people |               |                               |                             |                  |
| Ready to leave           |               |                               |                             |                  |

Figure 2. Domain of Meaning for Leaving the Hospital

helpful? Or that the support from hospital personnel is as it should be behind-the-scenes and unremarkable?

The sub-set of language organized in the category designated "Feelings" includes two folk terms which may reflect attachment to or relationships with staff: feeling abandoned and sad about leaving people. All three informants reported these feelings naming various therapists, nurses, other patients as well as their doctors and counselors. They expressed feelings of dependence on the hospital setting which was translated into being "scared" about leaving. As JB put it, "It's like going from the known to the unknown."

In Figure 3, two sub-sets for the domain of meaning for Being at Home are featured. Again "Feelings" are prominent as well as "Things Needed to be at Home." The informants' confusion and complexity of response during the transition from long-term hospitalization to home was clearly communicated in this set of data. Feelings ranged from "unhappy to be at home" to "good to be at home." The fascinating finding here was that the chronology of these statements was not the same for all three informants, nor were they all consistent particularly during any given interview. For example, LH on Day 1 talked about how good it was to be in her own home, with her own belongings while during the same interview session she reported feeling more dependent and helpless. She attributed the increased dependency to the fact that at home she had to "impose" on people to help her while at the hospital it was their job.

|   |          |                                  |
|---|----------|----------------------------------|
| B<br>E<br>I<br>N<br>G<br><br>A<br>T<br><br>H<br>O<br>M<br>E | Feelings | Unhappy to be home               |
|   |          | Helpless                         |
|   |          | Not my home                      |
|   |          | More dependent                   |
|   |          | Defiant                          |
|   |          | Crippled                         |
|   |          | Anger at loss of control         |
|   |          | Glad to be alive                 |
|   |          | Good to be at home               |
|   |          | More secure at home              |
|   |          | More religious                   |
|   | Needs    | More control                     |
|   |          | Honest people                    |
|   |          | Be able to walk alone            |
|   |          | Have my left arm doing something |
|   |          | Things to be the same            |
|   |          | Have help                        |
| Not be changed  |          |                                  |

Figure 3. Domain of Meaning for Being at Home

JA's defiance and anger at loss of control, although he refuted the term anger even after using it himself in two instances, were strong feelings he communicated particularly in terms of his "surprise" discharge. JA had gone on a 24 hour pass over the weekend. When he returned to the rehabilitation unit he found he was considered discharged, not having signed a Pass Release. In addition, the physician had not written an order for his leave of absence. JA claimed to feel "more secure at home," "ready to be at home," yet "more aware of being crippled." JA's complexity, indeed, made him at once a challenging and fruitful informant.

The "more religious" feelings were also reported by JA.

"It happened in intensive care. It felt like energy floating above me. Maybe He did this to straighten me out or make me more religious. If you pray long and hard enough, even if your body is f----- up, maybe something will happen. I pray every night. I get annointed. I'll probably go to Mass."

JB did remain consistent throughout the four interviews, the four days immediately post discharge. She was 'unhappy to be home' and didn't budge from this stance. Her feelings grew primarily out of the second sub-set of this domain wanting to have more control, wanting people to be honest in acknowledging her sadness, anger and fear. She felt strongly that she should not have been discharged to home until she could "walk alone" and "have her left arm doing something." LH expressed the wish "that things be the same" at home and JA asserted that what he needed to be at home was to "not be changed." A universal finding was that the change experienced by the informants in their

abilities, their body function, was chiefly responsible for their other problems and difficulties during the first four days at home.

#### The Second Day Post Discharge

Three domains evolved during the interviews taking place on the second day at home: 1) Activities I Need Help With; 2) Characteristics of a Good Helper; and 3) Aspects of Being Home. Each domain categorizes responses from all three informants. The data are more explicit, more detailed and functionally oriented than Day 1. The informants had had time to resolve the immediate "parting" issue of the first day home and away from the hospital. Now they seemed ready to register the actual steps - problems, needs and accomplishments - of everyday life.

"Activities I Need Help With" (Figure 4) describes the details of five major activities: taking a shower, getting dressed, moving from one place to another, getting things for me, and doing things for me.

"Taking a shower" was a multi-step activity - one that was of importance to all the informants. They expressed relief that they could even take showers. JA particularly had assumed he would have to have a bed bath. They agreed that one of the reasons that they felt they needed more help at home than at the hospital was that the hospital staff were more knowledgeable and efficient. In addition, as LH said, "At the hospital it's their job." This finding was somewhat curious as she was, indeed, paying for the services of the nurse's aide. Being in an institution and being home are perceived, experienced very differently despite the parity of activity.

|                             |                                  |                            |                                      |
|-----------------------------|----------------------------------|----------------------------|--------------------------------------|
| ACTIVITIES I NEED HELP WITH | Taking a Shower                  | Walk to shower             |                                      |
|                             |                                  | Get into shower            |                                      |
|                             |                                  | Get seated in shower       |                                      |
|                             |                                  | Wash my arm and back       |                                      |
|                             |                                  | Wash my hair               |                                      |
|                             |                                  | Shave my leg               |                                      |
|                             |                                  | Get out of shower          |                                      |
|                             |                                  | Dry me off                 |                                      |
|                             | Getting Dressed                  | Get out clothes            |                                      |
|                             |                                  | Put on shirt               |                                      |
|                             |                                  | Help me balance            |                                      |
|                             |                                  | Button and zip             |                                      |
|                             | Moving From One Place to Another | Push wheel chair sometimes |                                      |
|                             |                                  | Get in and out of car      | Walk beside me                       |
|                             |                                  |                            | Put my legs in                       |
|                             |                                  |                            | Steady me                            |
|                             |                                  |                            | Put walker and/or wheel chair in car |
|                             | Getting Things For Me            | Water                      |                                      |
|                             |                                  | Clothes                    |                                      |
|                             |                                  | Telephone                  |                                      |
| Catheterization stuff       |                                  |                            |                                      |
| Kleenex                     |                                  |                            |                                      |
| Books                       |                                  |                            |                                      |
| Food                        |                                  |                            |                                      |
| Mail                        |                                  |                            |                                      |
| Doing Things For Me         | Turn off and on TV               |                            |                                      |
|                             | Reposition me                    |                            |                                      |
|                             | Cook                             |                            |                                      |
|                             | Wash dishes                      |                            |                                      |
|                             | Hand me pills                    |                            |                                      |
|                             | Clean up my mess                 |                            |                                      |
|                             | Wash clothes                     |                            |                                      |
|                             | Help me eat                      |                            |                                      |
| Fix my hair                 |                                  |                            |                                      |

Figure 4. Domain of Meaning for Activities I Need Help With.

"Getting dressed" data as with "taking a shower" highlighted the "taken-for-granted" elements in the informants' daily lives. They shared their surprise and, at times, frustration, with the numbers of "little, insignificant things," as JA put it, that required assistance of another person. Not being able to "get things" from shelves or cupboards or the mail box created a dependency that introduced a time factor. JB lamented that "I can't go to bed when I want to or turn on the radio or even go to the bathroom. I have to wait until my mother is off the phone or comes in from the back yard. My life has to be all planned out. I liked being spontaneous and impulsive." JA shared these frustrations: "I don't eat when I'm hungry. I eat when my girlfriend is ready to feed me."

Mobility is an obvious deficit for a person with hemiparesis or paraplegia. Getting from one place to another often necessitates another person's assist to negotiate the wheel chair over a sill or into a closet size bathroom. JA was confined to his own room in his parent's house because it was on a different level from the other rooms. He was "wheel chair independent" in the hospital but his house was 90% inaccessible to him. Even if a person is ambulatory on discharge as were JB and LH, seldom is endurance achieved for long distances nor are safety awareness or balance sufficiently intact to allow independent walking.

"Doing things for me" as a sub-set functioned as a catch-all for activities reported by the informants. Those mentioned paint a picture of the most common steps a person takes through any 24 hour period. All informants were preoccupied with daily tasks investing them with unusual importance and thought.



The Domain of Meaning for Characteristics of a Good Helper was established based on complex reports and data from the informants (Figure 5). In two cases, JB and JA, a primary caregiver was the mother. The parent-child relationship between mother and adult child can manifest during the best of times as a power struggle. Parent is often unwilling to give up parenting and child frequently seeks the best of both worlds: the help and security of childhood, and the freedom of adult status. A change in body function, long-term hospitalization and the renewed need for actual physical care combine to exacerbate the power struggle. The issues were often insignificant: cranberry juice, vitamins, arrangement of clothing on the bed, for examples. All informants reported, however, weighty issues of disagreement between themselves and the caregivers. For LH the most important characteristic was patience. She resented being "hurried along" or having something done for her that she could do for herself given the time. As LH so poignantly put it: "What else do I have to do? Where else am I going? Why should I rush through brushing my dentures? Why have her do everything for me just to sit around and do nothing?"

Another significant finding which brought emotional responses were the two folk terms "asks instead of just doing" and "suggests instead of tells." Similar to the power struggle issue just discussed, these statements focus on the informants' sense of control over their environment. While JB did experience minor memory and problem solving deficits, all three had incurred primarily motor damage. Thus, they were cognitively able to direct and control how they were helped and what they were helped with - if the helper was open and receptive to their

|                                  |                             |
|----------------------------------|-----------------------------|
| CHARACTERISTICS OF A GOOD HELPER | Is patient                  |
|                                  | Gives help but not too much |
|                                  | Reads my needs              |
|                                  | Lets me struggle            |
|                                  | Has a sense of humor        |
|                                  | Is fast and efficient       |
|                                  | Asks instead of just doing  |
|                                  | Suggests instead of tells   |

Figure 5. Domain of Meaning for Characteristics of a Good Helper

directions. The IF was a major factor from the informants' view. In their language, there were helpers and there were people who tried to help and ended up being trying instead of helping. JA was the most expressive about this distinction. He had the minimum of patience, demanding "fast and efficient help."

"Has a sense of humor" was a universally reported finding. "I love to laugh at myself and at the situation. If I don't laugh, I cry and that bothers me and everybody else," shared JB. "If you lose your sense of humor, you might as well be dead," said JA. LH named her nurse's aide's sense of humor as one of her best qualities for being helpful. All three informants responded to the investigator's attempts at providing humor in the interviews. They would relax and become more open if humor was a part of the opening few minutes of each session. For one informant humor was an obvious coping mechanism with the use of a sometimes sarcastic, indirect humor.

The last domain of meaning established on the second day post discharge but added to over all four interviews is "Aspects of Being Home." These folk terms include global and specific concerns; both orientations were clear in the data. The informants were able and wanted to be quite pragmatic in their statements at times. While at other moments they took a more philosophical stance. Figure 6 illustrates the terms included in the domain. "Feel not at home" and "feel like home" are sub-sets using interesting colloquial phraseology.

As illustrated in the introduction, going home, coming home, feeling not at home, feeling like home bring to mind certain characteristics

|                       |   |                                 |
|-----------------------|---|---------------------------------|
| ASPECTS OF BEING HOME | Things That Make Me Feel <u>NOT</u> At Home | Can't wash dishes               |
|                       |   | Can't work on cars              |
|                       |   | Can't keep things in good shape |
|                       |   | Can't come and go alone         |
|                       |   | Can't take care of pets         |
|                       |   | Can't water plants              |
|                       |   | Can't reach phone               |
|                       |   | Living room is inaccessible     |
|                       |   | No longer safe here             |
|                       |   | My albums                       |
|                       | My bed                                      |                                 |
|                       | My mother                                   |                                 |
|                       | Food  |                                 |
|                       | Bathroom                                    |                                 |
|                       | Plants                                      |                                 |
|                       | My cat                                      |                                 |
|                       | All my junk                                 |                                 |
|                       | My friends                                  |                                 |
|                       | Radio                                       |                                 |
|                       | My guns                                     |                                 |
| No P.A. System        |   |                                 |
| Just me and my family |   |                                 |

Figure 6. Domain of Aspects of Being Home

or expectations. As the data were reviewed and brought back to the informants, it was reinforced that these phrases are not clear conveyors of assumed meaning when changes of body function, cultural parameters and care needs are present.

"Things that make me feel not at home" include mostly "can't" statements or limits of function. Inaccessibility and safety were two additional terms, particularly for JA. LH focused less on feeling not at home than on what made her feel at home. Her albums, plants and radio were important items for feeling at home in her environment. JB focused on "can't" items on the first and second days at home but became more willing to consider factors that made it feel like home by Day 3 and 4. Resentment, loss, grief, anger as well as a sense of growing comfort accompanied these discussions. Being home was neither easy nor simple for any of the participants in this study.

#### The Third Day Post Discharge

The evolution over time of the ability to cope, to adapt and to establish workable routines and patterns was a significant finding from the collected data. The informants suffered problems, frustrations, disappointments during the transition from hospital to home but they progressed and adapted noticeably even during the first four days, a relatively short time. During the interviews this third day focus came around to the helpers: who they were. The Domain of Meaning for "People Who Help and What They Do" identifies specific people providing support and the activities they do (Figure 7).

|                                  |                                  |                                   |
|----------------------------------|----------------------------------|-----------------------------------|
| PEOPLE WHO HELP AND WHAT THEY DO | Brother                          | Respects me                       |
|                                  |                                  | Keeps things in perspective       |
|                                  |                                  | Takes care of my mother           |
|                                  | Mother                           | Supports me when I walk           |
|                                  |                                  | Arranges things for me            |
|                                  |                                  | Helps me in and out of bathroom   |
|                                  |                                  | Checks on me                      |
|                                  |                                  | Helps me in and out of the shower |
|                                  |                                  | Tells me what to do               |
|                                  | Boyfriend/<br>Girlfriend         | Helps me walk                     |
|                                  |                                  | Transfers me                      |
|                                  |                                  | Gives me affection                |
|                                  |                                  | Keeps me from being depressed     |
|                                  |                                  | Is sensible                       |
|                                  |                                  | Is there for me                   |
|                                  |                                  | Helps me solve problems           |
|                                  | Daughter                         | Cares                             |
|                                  |                                  | Puts things away                  |
|                                  |                                  | Fixes supper                      |
|                                  |                                  | Comes by                          |
|                                  |                                  | Calls                             |
| Nurse's Aide                     | Sits with me                     |                                   |
|                                  | Shows me how to draw up medicine |                                   |
|                                  | Takes me to church               |                                   |
|                                  | Cooks                            |                                   |
| Sister-in-Law                    | Cleans up                        |                                   |
|                                  | Talks                            |                                   |
|                                  | Comforts                         |                                   |
| Granddaughter                    | Laughs                           |                                   |
|                                  | Talks to me                      |                                   |
|                                  | Keeps me young                   |                                   |
|                                  | Makes me smile                   |                                   |

Figure 7. Domains of Meaning for People Who Help and What They Do

In the section describing the informants and their caregivers and on the demographic data table the primary helpers are identified for each informant. Several points of significance evolved from the data: two, or at the most three, people formed the CORE support system for any one informant, all of the caregivers were women with the exception of JB's boyfriend and brother; with one exception, LH's aide, all caregivers were family members or boyfriend/girlfriend status.

The importance of the caregiver is paramount. None of the three participants in this study could have been discharged to home without at least one full time caregiver available. Despite the descriptions of frustrating interactions with the caregivers the informants acknowledged their contribution. The negative feelings towards the caregivers evolved in the most part from the informant's own frustration with dependency and change in body function. Needing a caretaker involved a new role, one for which none of these three people were well prepared. JA perhaps had the most difficult time yet he was able and willing to describe his girlfriend appreciatively and identify the ways in which he was supported by her. He was at his most open on an emotional level when he discussed her and their relationship. On the other hand he was equally as uncomfortable crediting his mother with positive contributions. He rather faulted her for "telling me what to do" and "arranging things."

In contrast, "arranging things" was a folk term used by JB but with a positive connotation. She was grateful to her mother for

establishing routines and seeing to details which were no longer within JB's capability. She felt cared for by being "checked-on" as well as with the physical support given with the everyday activities of daily living.

It is interesting that many of the folk terms included in this domain are not measurable or functional but rather more emotional level supports, more abstract. "Checks on me," "is there for me," "gives me affection," "respects me," "keeps things in perspective," "comforts," "makes me smile" are examples. These findings lead easily to the conclusion that it is the unique capability of the close family and friends in the person's support network who provide the emotional nourishment which allows adaptation, transition, indeed, rehabilitation to occur.

Also on Day 3 post discharge the informants spent a fair portion of the interview time praising or bemoaning the attitudes of their helpers. Again, the more secure the person began to feel at home, the safer it became to complain, suggest, find fault or let out some of the frustration and fear. The more dependent one is the easier it is to develop a strong resentment towards the source of support. Each informant criticized but they also found much positive description to acquaint the investigator with the attitudes which they considered helpful to them (Figure 8).

These attitudes are not surprising. They are straight forward and simple. Perhaps it will be the simplicity itself which will one day improve the transition experience. "Being there," "be honest," "don't be upset when I cry," as examples, are easier said than



|                   |                              |                                |
|-------------------|------------------------------|--------------------------------|
| HELPFUL ATTITUDES | Being there                  | Doesn't expect a lot of me     |
|                   |                              | Comes by                       |
|                   |                              | Is just around                 |
|                   |                              | Is there when I need something |
|                   | Is honest                    |                                |
|                   | Doesn't get upset when I cry |                                |
|                   | Talks to me                  |                                |
|                   | Roots for me                 | Hopes I will get better        |
|                   |                              | Encourages me                  |
|                   | Respects my preferences      |                                |
|                   | Doesn't take control         |                                |
|                   | Gives me time                |                                |

Figure 8. Domain of Meaning for Helpful Attitudes

accomplished on many occasions, particularly those that are high level stress. "Talk to me" sounds so obvious, so simple. It's not. One of JB's greatest sadnesses was her perception of how quickly her friends began to feel uncomfortable with her. She found long before she left the hospital that people often had nothing to say to her.

"Gives me time" was essential to LH and very difficult for her busy, task orientated caretakers to actually accomplish. JB summed it up well, "It's not that what they do for me is so different. It's the attitude. One person makes me feel useless and bothersome. The other has different attitudes. She really respects my needs."

#### The Fourth Day Post Discharge

The last day of interviews combined a summing-up and verification of data; a contribution of new folk terms and perspectives; and leave-taking of the investigator. The latter proved a more complex "good-bye" than anticipated. The temptation, in at least one instance, to take on a more active role in the person's post hospital course was difficult to resist. As Spradley (1979) describes, the ethnographic method involves emersion into the culture and knowledge of the actors. Perhaps in a subsequent volume it would be timely of him to discuss the process of extraction from the studied world that has become personalized and real. Both the informants and the investigator needed closure. Fortunately, the data collected and the circular aspect of the ethnographic interview encourage organization of the information, a satisfying step for all participants in the study.

The domain of "Things That Make it Easier to Be Home" (Figure 9) gives insight into the adaptive process of the three informants. For JB "slight start of a routine" was most important. To be able to count on getting-up, doing her exercises, having a shower, eating breakfast and writing letters increased her security and comfort at home. In the first interview, JB had grieved for the loss of routine and known structure of the hospital. By the fourth day she had begun to fulfill this need for herself, with the help of her caregivers. For LH getting "a little bit stronger" was the central issue. She wanted to be able to walk to the mail box through the gravel, an act she described as "premature" on days 1 - 3. On day 4, with her aide at her side, she reported walking to the mail box, "in my own good time; but, I did it." Her sights were even more optimistically set on making enough improvement to resume living alone. LH did a great deal of reminiscing on this last day of interviews. She appeared motivated to inform the investigator of her background and earlier experiences in her life. It was almost as if she were truly "at home" now and could take-up one of her favorite past times, reviewing the past.

JA's transition became easier as "people do normal things with me," a folk term used also by JB. JA didn't want to see himself as a "gimp" or "crip" - his words. He resented the idea of people feeling sorry for him or thinking him to be any different. With a sense of relief, JA described "riding around town," "going to the movies," "drinking beer." He made the point that home was a place to come back to for short periods of time, in between activities. He felt like a

|  |                                    |                  |
|--|------------------------------------|------------------|
| THINGS THAT MAKE IT<br>EASIER TO BE HOME | Slight start of a routine          |                  |
|  | Getting a little bit stronger      |                  |
|  | People do normal<br>things with me | Go to movies     |
|  |                                    | Go out to dinner |
|  |                                    | Ride around town |
|  |                                    | Visit            |
|  |                                    | Drink beer       |

Figure 9. Domain of Meaning for Things That Make it Easier to be Home

prisoner just like in the hospital during the first two days because he didn't go out of his house, or even his room.

One of the most interesting domains was "getting well is a full time job" (Figure 10). The information and categories of meaning collected around this phrase were significant for all the informants. They emphasized the energy and concentration required not only to do specific functional tasks but to not panic or become overwhelmed with sadness. To give in, or give up, was always a temptation. This domain was couched in two feelings: resentment and relief. Resentment was expressed in terms of "no time for anything else." JB wanted to get back to her job - yesterday. JA's catheterization schedule, and limited sitting-up time, "cramped his style." On day four, JA's predominant emotion was resentment of the changes, the restrictions. For LH and JB relief dominated. They seemed comforted by their acceptance of "getting well" as a job. They needed justification for how they spent their time. Viewing their day's activities in the light of "being a job" validated them, gave them meaning.

JB was the first informant to draw contrasts between hospital and home (Figure 11). She did this on each day of interviewing; JA and LH validated the categories of meaning but only focused on the contrasts on Day four. For them, being at home had been positive from the outset. For them it was only in looking back that some of the secure aspects of hospitalization came to mind. The significance of the contrast for all three informants lay in the element of surprise. Each expressed surprise and, in JB's case, disappointment, in the realization that

|                                    |                              |                  |
|------------------------------------|------------------------------|------------------|
| GETTING WELL IS A<br>FULL TIME JOB | No time for<br>anything else | School           |
|                                    |                              | Job              |
|                                    |                              | Hobbies          |
|                                    |                              | Therapy schedule |
|                                    |                              | Messing around   |
|                                    | Uses all my energy           |                  |
| Takes all my concentration         |                              |                  |

Figure 10. Domain of Meaning for Getting Well is a Full Time Job

| CONTRASTS BETWEEN<br>HOSPITAL AND HOME | HOSPITAL           | HOME                       |
|--|--------------------|----------------------------|
|  | Environment I know | Everything seems different |
|  | Help knows more    | Quieter                    |
|  | Routine            | Get more tired             |
|  | Easier             | More secure                |
|  | More people        | Smells better              |
|  | Boring             | Not enough room in shower  |

Figure 11. Domain of Meaning for Contrasts Between Hospital and Home

home was not all positive, that in some ways being in the hospital had been easier, more known, provided more people for support. Even on Day four it was clear that home was not home as it had been previously known.

Figure 12 illustrates the domain for "Ways to Make the Transition From Hospital to Home Easier." The transition clearly consisted of two entities, leaving the hospital and going home. This distinction is an important finding. A combination of the three types of ethnographic questions resulted in the findings associated with this domain. "Tell me about leaving the hospital" was a descriptive question. An example of a structural question was "What needs do you have today?" "What things could have been done to make you more ready to be home?," a contrast question, helped LH, JA, and JB to focus on the transition.

Whether it was the way the questions were asked or the orientation of the participants, or a combination the data revealed a singular focus on what others could do to make the transition easier. Indication that the informant could have done anything to improve the situation was absent. This is an interesting finding analyzed in view of the emphasis in rehabilitation on "doing with" rather than "doing to."

"Be more honest" referred to the much resented tendency of staff, friends and family to be joyful, jolly, optimistic and encouraging in the face of the patient's own more negative attitude. JA and JB shared a similar frustration that people were not "calling a spade a spade," in JA's language. Both shared the feeling that their own



|  |  |                        |
|--|--|------------------------|
| WAYS TO MAKE THE<br>TRANSITION FROM<br>HOSPITAL TO HOME EASIER | Talk more often about leaving the hospital                             |                        |
|  | Help me be more realistic  |                        |
|  | Be more honest   |                        |
|  | Help me realize the difference between going home and the 24 hour pass |                        |
|  | Prepare me for not being able to do some things at home                | Get around easily      |
|  |  | Cook                   |
|  |  | Knit                   |
|  |  | Read                   |
|  |  | Write letters          |
|  |  | Feed the cat           |
|  |  | Take care of my plants |
|  | Don't pretend going home is happy when it isn't                        |                        |
| Spend time with me and my family for the little things         |  |                        |

Figure 12: Domain of Meaning for Ways to Make the Transition From Hospital to Home Easier

feelings had been unacceptable to others and thus ignored or negated attempts made to "talk me into being happy."

"Talk more often about leaving the hospital" and "help me be more realistic" represent a plea for being prepared emotionally. None of the informants were able to recall discussing the actual leave taking from the rehabilitation unit prior to its happening. For JA the discharge was a "surprise," certainly no time to prepare for leaving. LH knew she was going home but didn't really know when or how. And JB communicated the most traumatic response to leaving the hospital: "Nobody told me that to go home I had to leave the hospital."

"Prepare me for not being able to do some things at home" is a task-specific corollary to "help me be more realistic." The finding from these data is the request that realistic acknowledgment be given to the deficits that have significance to the person rather than emphasizing only remaining abilities. It appeared that the informants were saying, as did LH, "Let's face it, I can't knit now. The therapist keeps trying to cheer me up by telling me maybe someday I will. But the thing is I can't now and I've got to face it."

"Spend time with me and my family planning for the little things" related another aspect of the going home transition which proved frustrating. Little things mentioned were where to buy catheters; how to position the affected hand to prevent swelling; how to get the wheel chair into the trunk easily; what to do if the suppository doesn't work; how to do the leg exercises and rolls in bed without bed rails? Aspects of care taken for granted by the hospital

staff became barriers to self-care in the home setting. The informants communicated a need for all the details to be consciously discussed and considered prior to discharge.

### Cultural Themes

A cultural theme, as defined by Spradley, is "...any cognitive principle, tacit or explicit, recurrent in a number of domains and serving as a relationship among subsystems of cultural meaning" (1979:186). Based on the work of Opler (1945), the cultural theme represents the investigator's view of the structure which organized the informants' cultural knowledge which is used to interpret going home and inform behavior.

Three cultural themes were discovered from this study, evolving from emersion in the data in the domains of meaning:

1. Going Home is not "going home"
2. It just takes time
3. Helping is being there

#### Going Home Is Not "Going Home"

The underlying theme for the participants in the study was that home was not as they expected it to be, either emotionally or physically. They didn't derive the same sense of comfort, safety, or ease as they returned to home after long-term hospitalization as they had prior to their change in body function. The domains that particularly related to this theme were "Being at Home," "Aspects of Being at Home," "Things That Make it Easier to be Home," "Contrasts Between

Hospital and Home," and "Ways to Make the Transition From Hospital to Home Easier."

All three informants expressed surprise, disappointment, frustration and even argued that home was not home. Going home had become an all consuming goal as many hours of hard work were devoted to the various therapies. Going home, resuming a "normal" lifestyle, getting back to normal routines, activities, was, during the first four days post discharge, an unattained promise for these three participants. What they had been working so hard for turned out to be not real and still beyond reach.

JB admonished during the fourth interview (Figure 12) "not to pretend that going home is happy when it isn't." Yet "going home" definitely, as used by hospital staff and families, implies a happy occasion and a successful next step. The three informants agreed that "being honest" was another strong priority. Combining honesty, encouragement and positive role modeling is a challenge to all caregivers.

#### It Just Takes Time

The second theme connects with the time factor of the first four days post discharge and the evolutionary quality of the experience. This theme was both explicit within the categories of meaning as well as implicit in the general discussions surrounding each activity or plan. The related domains include "Activities I Need Help With," "Characteristics of a Good Helper," "Helpful Attitudes," "Getting Well is a Full Time Job," and "Ways to Make the Transition From Hospital to Home Easier."

"Spend time with me," "talk more often about ...," "...realize the difference between going home and a 24 hour pass," "no time for anything else," "gives me time," "is patient," "is fast and efficient," are folk terms included in the domains which draw attention to the collective concern of the informants for the element of time.

This theme also represented the underlying hopefulness of the informants. "It just takes time" is a reassuring statement, yet not relinquishing its ambiguous nature which provides the justification for admitting the reality of continuing deficits without giving up to defeat.

The "it" referred to is getting well, feeling back to normal, able to function fully once more. "Time" can't be pushed or modified or halted. Somehow the nebulous concept of time - getting well takes time - no matter its imprecision, was an underlying theme and one providing comfort and encouragement to the informants.

#### Helping is Being There

Several of the domains include categories and terms which describe the support needs of the informants and the ways in which they preferred to be helped. The cognitive principle organizing the cultural knowledge evolved from these domains is "Helping is Being There." Many specific support needs are listed as well as qualities of caregivers, particularly in the domains of "Activities I Need Help With," "Characteristics of a Good Helper," "People Who Help and What They Do," and "Helpful Attitudes." Yet all three participants continued to come back to the idea of the caregiver "being there," in

the emotional as well as physical sense. Availability, trust, competency, respect, compassion - all were implied as components of "being there."

#### Summary

This chapter has included characteristics of the sample, descriptions of each informant and their caregivers, and an account of the researcher-informant relationship. Interviewing procedures were outlined as well. Data were displayed in eleven domains of meaning and presented in narrative form. Three cultural themes were extracted and relationships of the themes with the domains of meaning were discussed.

## CHAPTER V

### CONCLUSIONS

This chapter presents the research conclusions with the following sections to be included: the relationship of the findings to the conceptual orientation, recommendations for nursing practice and recommendations for future research.

The problem investigated by this research was the individual's perception of support needs during the transition from long-term hospitalization to home. The specific question addressed was: What cultural knowledge informs the behavior and determines the support needs of a person with a change in body function during the transition from hospital to home after long-term hospitalization? The method of ethnographic interview was used with three informants to discover culturally relevant domains. Conclusions were drawn based on the investigator's organization of this data into three cultural themes: 1) Going home is not "going home," 2) It just takes time; and 3) Helping is being there.

#### Relationship of the Findings To The Conceptual Orientation

The concepts used in the conceptual orientation for this descriptive study were culture, body image and care on the most abstract level with going home, change in body function and support needs on the lower empirical level.

A founding premise of the study was that the going home experience could be viewed and studied in cultural terms. The cultural knowledge of the informants would inform their behavior during their transition from hospital to home. Going home was proposed to be not a material phenomenon but rather an organization of the meaning of the things and people within the going home scene.

The first cultural theme, "Going home is not 'going home'" affirms the premise that the transition from hospital to home or the going home experience is indeed a cultural event. Throughout the domains, "Being at Home" (Figure 3), "Aspects of Being at Home" (Figure 6), "Things That Make it Easier to be at Home" (Figure 9), "Contrasts Between Hospital and Home," (Figure 11), and "Ways to Make the Transition From Hospital to Home Easier" (Figure 12), there are terms supporting the conclusion that "going home is not 'going home'" and is a legitimate sub-culture of going home as was described in the introduction and is the commonly understood meaning of going home. The informants communicated pre-conceived notions for going home. Expectations were informed by their cultural knowledge of the experience.

The second cultural theme to emerge from the data was "It just takes time." This finding connects with the concept of change in body function and evolution of body image over time. The informants' use of folk terms in the domains relevant to this theme revealed a sense of hopefulness, justification for remaining disabilities with associated need for support as well as a source of comfort and encouragement.



The related domains include "Activities I Need Help With" (Figure 4), "Characteristics of a Good Helper" (Figure 5), "Helpful Attitudes" (Figure 8), "Getting Well is a Full Time Job" (Figure 10), and "Ways to Make the Transition From Hospital to Home Easier" (Figure 12).

Change and the adjustment to change "just takes time." The informants varied in their capacity to tolerate the factor of time but were in agreement both explicitly and tacitly that the transitional period "just takes time."

"It just takes time" has implications for the person's expectations of the going home experience. The care giver's expectation must also be in tune with those of the informant. It is in this relationship that unmet needs can evolve and care that is inappropriate be offered.

The final theme was "Helping is Being There" which relates to the concepts of care and support needs. Despite the fact that the informants had been independent, self sufficient people prior to the accident or illness, they were able to recognize their need for care and to describe the support needs they had and how they wanted them met. They didn't readily accept the care, however, and were clear in the data that the sooner the care was not needed the better. The domains which categorized the data supporting this cultural theme were "Activities I Need Help With" (Figure 4), "Characteristics of a Good Helper" (Figure 5), "People Who Help and What They Do" (Figure 7), and "Helpful Attitudes" (Figure 8). Support needs ranged from the very

specific "wash my arm and back" or "hand me pills" to the more general "arranges things for me" or "comforts." The functional areas of care are delineated, as well as the more elusive factors such as "keeping me from being depressed" or "respects me" - the emotional domain. "Helping is being there" suggests the recurrent theme found in the data and serves as an organizing cognitive principle for the concepts in the conceptual orientation and folk terms included in the informants' reports.

Figure 13 is an illustration of the relationship of the cultural themes to the conceptual orientation.

#### Recommendations for Nursing Practice

Nursing is concerned with the care and well-being of the person. Nursing involves teaching and adaptation. Nursing relates to the whole person including the person's family and support network. Nursing embraces the missions of discharge planning and patient/family education, two activities of utmost importance to the person hospitalized over a long period of time with a change in body function. Professional nursing care incorporates the cultural aspects of a person's interpretation of experience as well as the biological, psychological and sociological components of their experience.

Increasingly we are realizing that long held assumptions of what the needs of patients are and what the going home process really is may not be as well understood as once thought. Respect for the patient's knowledge and expression of need is growing. The health care

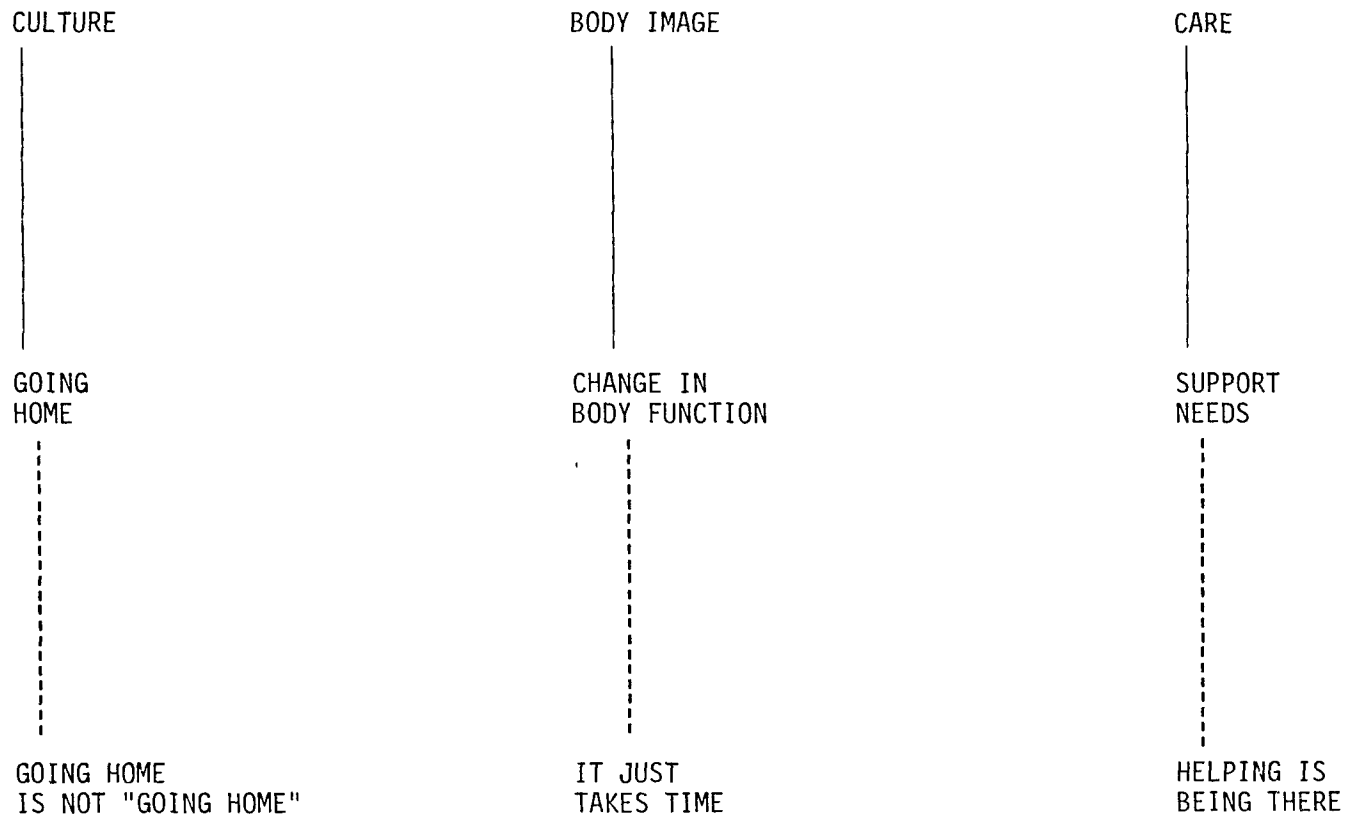


Figure 13. Relationship of Cultural Themes to the Conceptual Model

consumer is being encouraged to speak up and the health care provider is realizing the wisdom of listening.

The purpose of this study was to discover the cultural knowledge which persons with a change in body function use to interpret their experience during the transition from long-term hospitalization to home and to identify their support needs. The kind and quality of care based on the informants' experience of needs is well delineated in the data of this study. There is important information to be heeded by nurses and family members who play a key role in achieving a successful transition from long-term hospitalization to home. Nurses begin to intervene and prepare the patient for discharge and home self-care even on the first day of admission, utilizing attitudes, skills, communications and knowledge.

Nurses have the option of functioning according to task orientation following the tenets of long unreviewed, unquestioned traditions. Or we may listen to the person, relating specific needs to a wide range of possible interventions, selecting the best approach for the individual.

Figure 12, which illustrates the domain of meaning for Ways to Make the Transition From Hospital to Home Easier, provides clues for developing care plans and interventions which will meet real needs. We may choose the less comfortable route of honesty, realism, and individualization; or we may continue to ignore the "little things" and "pretend going home is happy when it isn't," sending our patients off with a cheery, but meaningless "You're going home. How wonderful."

The nursing process includes assembling a data base of information relevant to the person's life outside the hospital setting. Much of the information gathered in this study during the first four days POST discharge is information that would be useful and productive in preparing the person FOR discharge. If patients' home care needs are identified before the fact, not after it, the transition from hospital to home can be much smoother. Our ultimate goal is to enable the patient to function within society, not within the hospital.

The cultural theme, It Just Takes Time, and the domains of meaning which amplify this theme provide nursing with creative alternative ideas for how to deliver useful care within the institutional setting. If the adaptive process and the transition from hospital to home take time, then the facilitator and the caregiver must have the time to give. In pragmatic terms, this means nurses need the structural support to practice what is written in journals and protocols and spoken of at conferences and workshops. Nurses need to prioritize discharge planning and become the advocate for the patient's individual needs. Planning with the patient and family for the acquisition of home care supplies, teaching treatments, bowel and bladder programs, or a successful communication approach for the aphasic person are examples. Staffing patterns which reflect the teaching and discharge planning needs of each patient will contribute to the successful going home event.

Nurses who reflect in attitude and behavior their respect for the knowledge and wisdom of the individual patient and family are better

resource persons. Such nurses are able to assess the unique needs of the individual and search for the appropriate caregivers and care techniques to meet these unique needs. The three informants' requests for honesty, realism and time indicate important aspects of how nurses provide quality care.

In summary, the experiences shared by the three informants in this study support the premise that nurses function in an exciting environment in which we may learn from our patients as well as care for them. With the long-term hospitalized person, the opportunity for learning how to deliver relevant nursing care becomes more clear over time.

Keeping in mind the findings of this study, the following specific recommendations for nursing practice are offered:

1. All nurses have the opportunity to conduct ethnographic research to enhance their ability to understand patient needs from the actors' point of view.
2. The health care unit in which nurses deliver care provide the supports, particularly of time and personnel, which allow nurses to prioritize and complete discharge planning and patient/family teaching.
3. Nurses incorporate in the discharge planning process the technique of keeping a notebook by the patient and/or family. The notebook would facilitate identifying and projecting needs for going home.

4. Nurses be encouraged to experience a continuous inner dialogue focusing on the values, priorities and needs of self in relation to others. Increased self-awareness will contribute to the nurse's ability to recognize others' needs as valid and will minimize subjective judgments.
5. Nurses assume the role of patient advocate. Nurses are the ideal health care providers to play this role because we have the skills and opportunity to assess the whole person, to learn from the person and to respond to the person's individual expression of need.

#### Recommendations for Future Research

The following recommendations for further study based on the cultural themes as well as the rich material developed by the ethnographic approach are suggested:

1. Describe the cultural experience of the patient with permanent change in body function within the institutional setting during long-term hospitalization.
2. Explore the cultural knowledge and experience of the caregiver for persons with permanent change in body function during the transition from hospital to home.
3. Explore the needs of persons with a change in body function six months post discharge from long-term hospitalization.

4. Utilize a diary kept by the informants and participant observation as data collection tools to explore the going home event.
5. Explore the cultural experience of patients being discharged from long-term hospitalization to an extended care facility rather than to home.
6. Explore the needs of persons with a change in body function during the going home experience controlling for variables such as sex, age, ethnicity or etiology of disability.



APPENDIX A

INFORMANT'S CONSENT FORM

GOING HOME: AN ETHNOGRAPHIC STUDY OF PATIENT SUPPORT NEEDS DURING THE  
TRANSITION FROM LONG-TERM HOSPITALIZATION TO HOME

INFORMANT'S CONSENT

I understand that I have agreed to participate in a study exploring the support needs I may experience during the first four days after I leave the hospital. I have been chosen for this study because I meet the objective criteria outlined to me by Melinda Huie, and I am willing to share my knowledge and awareness of my support needs with her.

I understand that I will meet with Melinda Huie in my home for four or five interview sessions of approximately one hour each. These sessions will begin the day after I am discharged from the hospital and will follow on the three or four consecutive days thereafter. The meetings will be tape recorded and the contents of the interviews will be reviewed by the researcher. I understand that my name, address and other identifying characteristics will be kept confidential and never be used.

I understand that I will not be paid for my participation, nor charged for the same. I understand that although I may not have any immediate benefits, this study may be useful to health care professionals in planning for the most productive transition process from long-term hospitalization to home.

Melinda Huie agrees to answer any questions I have concerning the study. I know that I am free to decline to respond to any specific

question as well as to withdraw from the study at any time, and that my nonparticipation will not affect my health care in any way.

I understand that if questions or problems arise relating to my health needs that Melinda Huie will refer me to my primary health care provider.

I understand that excerpts from the interviews may be presented in reports, speeches, text books, or other educational materials.

I understand that the results of the study will be available to me upon request. I understand that after the final report of the study is produced that the tapes will either be given to me for my permanent possession or destroyed. The transcriptions and notes will be retained by Melinda Huie for possible future research.

I have read and understand this consent form, and know that a copy is available to me. I understand that this consent form will be filed with the Human Subjects' Committee of the University of Arizona, and that access to such will be limited to the researcher or her authorized representative, and myself.

The nature, demands, and benefits of this study have been explained to me.

\_\_\_\_\_  
Date

\_\_\_\_\_  
Informant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness' Signature

APPENDIX B

DATA COLLECTION TOOLS

## DATA COLLECTION TOOLS

Grand Tour Questions

1. Tell me about leaving the hospital.
2. Tell me about your first day at home.
3. Tell me about coming home.

Structural Questions

1. What are things people do to help you physically?
2. Were there ways you didn't want to be supported?
3. What needs do you have today?

Contrast Questions

1. Is there a difference between leaving the hospital and going home?
2. What things could have been done to make you more ready to be home?
3. What are the qualities of a helper?

APPENDIX C

HUMAN SUBJECTS APPROVAL



THE UNIVERSITY OF ARIZONA  
TUCSON, ARIZONA 85724  
HUMAN SUBJECTS COMMITTEE  
ARIZONA HEALTH SCIENCES CENTER 2305

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1 October 1980

Ms. Melinda Huie  
3401 North Columbus Boulevard  
Apartment #5N  
Tucson, Arizona 85712

Dear Ms. Huie:

We have received your project entitled, "Going Home: An Ethnographic Study of Patient Support Needs during Transition from Long-Term Hospitalization to Home", which was submitted to the Human Subjects Committee for review. We concur with the opinion of your College Review Committee that this is a minimal risk project. Therefore, approval is granted effective 1 October 1980.

Approval is granted with the understanding that no changes will be made in either the procedures followed or the consent form used (copies of which we have on file) without the knowledge and approval of both the Human Subjects Committee and the College Review Committee. Any physical or psychological harm to any subject must also be reported to these Committees.

A university policy requires that all signed subject consent forms be kept in a permanent file in an area designated for that purpose by the Department Head or comparable authority. This will assure their accessibility in the event that university officials require the information and the principal investigator is unavailable for some reason.

Sincerely yours,

Milan Novak, M.D., Ph.D.  
Chairman

MN/jm

cc: Ada Sue Hinshaw, R.N., Ph.D.  
College Review Committee

APPENDIX D

ACCESS AND APPROVAL TO  
CONDUCT RESEARCH





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*St. Mary's*  
HOSPITAL & HEALTH CENTER

1601 WEST ST MARY'S ROAD  
P.O. BOX 5386  
TUCSON, ARIZONA 85703  
PHONE (602) 622-5833

Dr. Katherine Young  
College of Nursing  
University of Arizona  
Tucson, Arizona

March 20, 1981

Dear Dr. Young,

I have read and reviewed Melinda Huie's thesis proposal entitled "Going Home: An Ethnographic Study of Patient Support Needs During the Transition from Long-Term Hospitalization to Home." I have also reviewed the Informant's Consent Form which her informants will each be asked to sign.

As the Medical Director of St. Mary's Physical Medicine and Rehabilitation Center, the department from which Melinda will be obtaining her informants, I would like to assure you of my approval of the study in general, and the proposal and consent form in particular.

I look forward to following Melinda's progress through the project and am hopeful that some relevant information will come out of the study. In this regard, I have agreed to serve as a Consultant to Melinda for this investigation.

Sincerely,

*Stuart Holtzman M.D.*  
Stuart Holtzman, M.D.

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