Older Adults' Views on Their Ability to Express Their Needs in the Hospital Setting

by

Thomas P. Blickle

A Master's Research Project

Presented to
Oregon Health Sciences University
School of Nursing
in partial fulfillment of
the requirements for the degree of
Master of Science
April 30, 1999

Approved:

De[redacted]h.D., Assistant Professor

[redacted]

Christine A. Tanner, R.N., Ph.D., Professor

[redacted]

Theresa A. Harvath, R.N., Ph.D., Adjunct Professor

[redacted]

Beverly Hoeffer, R.N., D.N.Sc., F.A.A.N.

Associate Dean for Academic Affairs, School of Nursing

Acknowledgments

I would like to thank the six older adults who were willing to contribute their wisdom and insights to this research study. I must also acknowledge the help of Gry Melleberg, R.N., B.S.N., in locating participants for me. In addition, I would like to thank the following nurses for the support and insights that have enabled me to complete both this study and my master's degree.

my research committee	Deborah Messecar, R.N., Ph.D
	Christine Tanner, R.N., Ph.D
	Theresa Harvath, R.N., Ph.D
my academic advisor	Linda Felver, R.N., Ph.D
my mother	Ann Blickle, R.N.
my friends	Shannon Anastasiadis, R.N.
	Theresa Meeks, R.N.
and especially my life partner	
	Ron Larsen, R.N.

I am grateful that this study was partly funded by the Beta Psi chapter of Sigma Theta Tau.

Abstract

Health care workers commonly believe that older patients frequently do not express some of their needs in a hospital setting. Nursing research centering on older adult autonomy and empowerment tends to focus less on investigating the causes of this phenomenon than on strategies to reverse it. The literature that does seek to ask why this problem exists is often based on established concepts rather than on the lived experiences reported by older adults. This phenomenological study used in-depth individual interviews to examine older adults' perceptions of their own ability to express their needs while in the hospital. The interviews were largely unstructured, with general, broad-based questions designed to encourage the older adult to reflect on his or her recent experience as a patient. Qualitative methods as described by Van Manen (1990), Lincoln and Guba (1985), and Taylor and Bogdan (1984) were used to analyze the data.

Many themes emerged during the interviews addressing how older adults viewed their ability to express their needs in the hospital. They can be grouped into four main categories. These are 1) finding excuses for the staff, 2) the older adult's view of his or her relationship with the staff, 3) the older adult developing and implementing his or her own agenda, and 4) self-appraisal of needs.

Many issues surrounding the question of older adults and their expression of needs have not been fully explored or explained. It is hoped that this study into the lived experience of hospitalized older patients will cast additional insight into this area.

Research Advisor: Deborah C. Messecar, R.N., Ph.D

Table of Contents

List of Tables

Chapter 1: Introduction

Many health care workers are concerned about the ability of older patients to express their needs in the health care setting. Often they believe that older adults in particular are more dependent (Thomasma, 1984), and more amenable to authority than younger patients (Rice, Beck, & Stevenson, 1997). Researchers have addressed this issue under numerous different topics. The literature abounds with concepts such as empowerment, autonomy, advocacy, decision-making, self-determination, wellness motivation, consumerism, compliance, beneficence, and voluntariness. This problem extends further into specific issues such as advance directives, competence, restraints, and discharge planning.

The consequences of this problem seriously impact the personal well-being of older adults and the delivery of health care. Older adults can be cajoled, persuaded, or intimidated into accepting care or treatment. The plan of care may come to reflect the physician's or nurse's health care beliefs, rather than the patient's. Often this means increased numbers of tests and procedures, a prolonged hospital stay, and inflated costs. More importantly, the older patient may look back upon his or her role in the health care system as that of a pawn, and feel ashamed and demoralized.

Most literature on this topic follows a fairly predictable track. The authors define terms, discuss the problem and its relevance, and perhaps develop concepts based on a review of previous literature. They may conduct a deductive experiment or use a formally accepted instrument to test a hypothesis. Finally they draw a conclusion and recommend strategies to increase the older adult's independence. This "independence" is often defined by the researchers.

The focus of most of this literature is on the actions of the nurse or other health care workers. Independence and empowerment are traits that the authors encourage us to deliver, ensure, foster, encourage, or provide. They recommend strategies for the health care worker and warn us against pitfalls. The very titles of these articles often include phrases that remove the locus of control from the patient: "how to foster self-determination", "ensuring self-advocacy", "strategies for patient empowerment", "promoting autonomy in your elderly client", etc. These phrases represent a laudable and necessary attempt to confront real issues about patient independence. However, they fall prey to the same problem they seek to address. If we health care workers focus on ourselves as the means to organize and orchestrate our patients' independence, we may wrest power from them.

Of course it would be foolish to discount the valuable information and strategies that the research on empowerment and autonomy has yielded. Nurses can and do promote independence and autonomy in their patients. Without such efforts many patients would experience poorer health outcomes and increased dependence. But when striving to encourage patient independence, nurses may walk a finer line than they realize. Consider the phrase "promoting autonomy". On one hand, it signifies a pragmatic and beneficial intervention, one that we would all expect to improve patient outcomes. On the other hand, "promoting autonomy" is an oxymoron. The truly autonomous need no promotion, and the promoting of another renders them no longer autonomous. Paradoxically, the "empowerment" of patients may actually empower the health care worker more than the patient.

In looking at how older adults view their ability to express their needs in the hospital, this research project focused on their perceptions and meanings of asking for help. Therefore a qualitative approach was indicated, rather than a quantitative. This study attempted to set aside "common sense", preunderstanding, suppositions, and existing research and theory to learn from patients themselves (Van Manen, 1990). Because I chose to focus more on the individual experience and was not attempting to generalize any findings to a larger number of patients, I used a phenomenological approach.

This study is certainly not intended to repudiate the vast body of research concentrating on empowerment, autonomy, independence, or any of the other issues surrounding patient self-expression of needs. Rather I hope to complement such research with a phenomenological study of how older adults view their own ability to express their needs in the hospital setting. Although its causes are yet to be fully determined, inadequate expression of needs remains a major problem with older patients. Hopefully, research based on their own perspective will help to shed light on this phenomenon.

The specific aims of this study were:

1. to discover new insights into how older adults describe the lived experience of expressing their needs in the hospital setting, and

2. through the description of this lived experience, to discover new insights into what older adults consider attributing factors and consequences of their ability to express their needs.

Chapter 2: Review of the Literature and Conceptual Framework

Introduction

Belief that older patients frequently do not express their needs is prevalent throughout our health care system. The recent literature is made up mainly of studies that demonstrate how that this is true, but do not focus on why this problem exists. Most of the authors reviewed write from the assumption that many elderly patients in our health care system are inherently disempowered, and then progress from this assumption to discuss how this problem can be managed. The literature thus tends to concentrate on nursing and medical strategies to increase empowerment among older adults. In most of this literature, the hospital staff rather than the older patient becomes the locus for change. Several authors question whether it is effective to "empower" older patients without taking into account each older person's individual mindset.

Discussion

Health care workers (including myself) commonly believe that older adults frequently do not express their needs in the health care setting. Decreased expression of needs is perceived by health care workers as a problem particularly common among older patients. Researchers consider this problem relevant to various health care settings, including hospitals (Hewison, 1995), outpatient settings (Davison & Degner, 1997), long-term care facilities (Nystrom & Segeston, 1994), home health nursing (McWilliam et al, 1997), and physician offices (McCann & Weinman, 1996). This reticence by older adults engenders miscommunication, decreased coordination of care, decreased quality of care, increased illness, and increased costs. In a study attempting to determine if a new intervention promoted patient participation, McCann and Weinman (1996) demonstrate that older adults ask fewer questions and have shorter consultations than their younger counterparts. Furthermore, Sharpe (1995) refers to previous research indicating that older health care consumers are less likely than younger consumers actually to challenge physician authority.

Only a few authors attempt to ascertain with any depth the reason why older patients would behave in a passive, acquiescent, and unquestioning manner. According to Rice, Beck, and Stevenson (1997), older patients have been socialized not to question authority. Other authors even consider old age a state of dependency per se. Thomasma (1984) makes the unsupported claim that "once people reach the age of 80 or so, some severe limitations on their quality of life and a high degree of dependency set in"(p. 907). Based on their observational study, Nystrom and Segeston (1994) conclude even more gloomily that "The older person has developed personal habits and preferences, has an experience of autonomy in personal matters, and has no hope of growing abilities and changes toward autonomy in the future"(p. 131).

Although most health care workers are hopefully less fatalistic than the last two sources quoted above, most accept the passivity of the older patient without questioning its source in any depth. Most authors simply base their statements on accepted research and theory, and proceed directly from these to conceptualize the problem further and to recommend strategies. The literature thus tends to focus on treating the unequal power shift rather than on investigating its cause. The strategies usually center on increasing patient choices (Tolley, 1997), enhancing personal control (Meddaugh & Peterson, 1997), improving staff interventional skills (Kubsch & Wichowski, 1997), expanding staff education, and shifting to greater individualization of nursing care (Davies, Laker, & Ellis, 1997). Cox (1996) notes "Although there is much rhetoric about choice and empowerment, the degree of choice offered to elderly people is often very limited; in many cases the only real choice being to refuse the services offered"(p. 3). Hewison (1995) more succinctly summarizes findings from her observational study of nurse-patient interactions, "The decision has been made, and the patient is invited to agree"(p. 78). It would be tempting to retort to some of the empowerment literature by changing the above quote to "The decision has been expanded and the patient is invited to choose". Cox, in the article mentioned above, describes very interestingly how the applied concept of empowerment was met with suspicion by a group of older clients. A program designed to "empower" them was viewed by elders as unnecessary and as possibly a hidden agenda to cut costs.

Some authors do question the limitations in the current concept of encouraging patient independence. Davison and Degner (1997), measuring the results of an intervention designed to increase the empowerment of men newly diagnosed with prostate cancer, point out that "this [the current] model of care consists of providing patients with information and choices, but it is not clearly understood whether this is what these consumers really want"(p. 189). Social workers Mok and Mui (1996), in their qualitative assessment of an empowerment intervention in a Hong Kong home for the aged, conclude that "it is questionable if another person can really be empowered by another person...Empowerment is not something to be given to others, but it is something to be discovered within people"(p. 34).

Not surprisingly, a number of authors view the older patient as a victim of an unsympathetic or malfunctioning system. Sharpe (1995) and Browne (1995) review previous studies and discuss the negative effects of sexism and ageism in the lives of older women. A stratified survey by Blackhall et al (1995) revealed that some ethnic groups (in this case Korean-American and Mexican-American) tended to place family harmony above individual patient autonomy when dealing with end-of-life issues. Sully (1996) offers an interesting opinion on how empowerment can become a struggle between health care workers, the patient, and the family. During their analysis of a case study, McWilliam, Brown, Carmichael, and Lehman (1994) aver that "Current health promotion models and models to promote patient autonomy take a similar perspective, focusing on the professional's, family's, or community's behaviour [sic] in mobilizing resources, and on factors which facilitate or impede such behaviour. These models overlook the individual's mindset and sense of purpose in life as factors which may impede or facilitate resource mobilization. Our findings suggest that professional approaches to health care must consider such factors" (p. 336).

Browne (1995) states "Empowerment is thus viewed as both the possession of control, authority, or influence over others, and as the help provided to assist a person to gain control over his or her life" (p. 359). Most nurses probably use the second definition of empowerment when caring for older patients. However, in light of the first definition, by focusing on nursing strategies rather than on the patient's input, we nurses may be empowering ourselves more often than we do the patient.

Chapter 3: Methods

Overview of Study Design and Purpose

The aim of this proposed study was to understand further, from the older adults' perceptions of lived experience, their views about their ability to express their needs in the hospital setting. The study used a phenomenological approach to data collection and analysis, because a goal of the study was to learn from the lived experience of older adults, rather than to ascertain if their experience correlated with a previously established tool, philosophy, or research.

Setting and Sample

Six patients recently discharged from VA Medical Center, Portland or from an Oregon Health Sciences University Hospital satellite ward located at the VA Medical Center were recruited for the study. The subjects were between 65 and 87 years old, comfortable communicating in English, currently medically stable, and oriented to person, place, and time. The participants had been discharged from the hospital from ten days to four months prior to the interview. In each case their hospital stay had been for at least several days, and the admitting diagnosis reflected a seriously acute situation or chronic condition. This served to exclude participants whose hospital stay was too brief or whose reason for admission was not debilitating enough to make expressing their needs a moot issue. In order to procure rich information, patients were purposefully selected along two extremes of demanding behavior. These were patients noted by staff either for their demanding or "needy" behavior, or for their passivity or agreeableness. Demographic sample characteristics are displayed on the next page.

Table 1

Demographic Characteristics of Sample

Age	Gender	Ethnicity	Marital status	Level of education	Admitting diagnosis
76	Male	Caucasian	Divorced	8th grade	Pneumonia, Dysrhythmia
71	Male	Caucasian/ Native American	Widowed	4th grade	COPD
73	Male	Caucasian	Widowed	10th grade	Wound resection, cancer
78	Female	Caucasian/ Native American	Widowed	12th grade	Gastrointestinal adhesions
65	Male	Hispanic	Divorced	12th grade	Gastrointestinal bleeding, liver failure
87	Female	Caucasian	Widowed	Some college	Gastrointestinal bleeding

Three interviews occurred in the participants' homes. The other three interviews occurred in a Veteran's Affairs Nursing Home. One participant resided there permanently, another planned to return home after residing there for several weeks, and the third planned to return home although he had been residing in the nursing home for over a year. The participants were interviewed in these settings rather than in the hospital so as to avoid the interruptions that might occur, and to provide the participant with an environment that felt safe, familiar, and not pressured. It was intended that the "natural setting" described by Lincoln and Guba (1985) would not only decrease the participant's stress but decrease research bias as well. Because the entirety of each participant's experience would be clearer to him or her after the hospital stay had ended, and because Van Manen (1990) describes phenomenology as retrospective rather than introspective, I chose to conduct these interviews after discharge from the hospital. The participants were at least ten days post-discharge, to have allowed them time to recuperate and to reflect on their experience, and not more than four months post-discharge, so that they could more easily recall details about their day-to-day interactions.

This study represented a phenomenological approach to glean information from the lived experience of older adults. There was no attempt to establish theory or to claim that any findings would necessarily be relevant to a larger population. Therefore I believe that a sample size of six was sufficient to achieve saturation.

Selection

I selected participants in the two following ways.

1. At Oregon Health Sciences University Hospital, Gry Melleberg, R.N., identified from the hospital census potential participants who met the inclusion criteria mentioned above. She brought these names to my attention. I then approached them to explain the study, to assure confidentiality, and to inquire if they were interested in participating in the study. Although not followed verbatim, these conversations roughly followed the outline in Appendix A. The potential participants were given a letter describing the study (Appendix F) and the postage paid postcard that they could use to decline being contacted (Appendix G). In no case was the postcard returned. I then telephoned each potential participant as described in Appendix H.
2. Theresa Harvath, RN, Clinical Nurse Specialist at the VA Nursing Home in Vancouver acted as my liaison to recruit residents there who met the inclusion criteria. She identified from her patient census potential participants who had been discharged from the hospital from ten days to four months. The patient selection process was then unchanged from that mentioned above, except that Theresa Harvath acted as my liaison.

As much as possible, I attempted to select potential participants, interview them, and analyze the interviews iteratively. I used what I learned from the interviews to refine the selection process itself. Although in the interests of time I occasionally selected a potential participant before interviewing the previous selection, I did not recruit a group of individuals, and then interview them.

A total of seven potential participants were approached and asked if they would care to participate in the study. Only one person refused, stating that he felt too ill to participate. The other six agreed to be in the study.

Protection of Human Subjects

The names and phone numbers of each participant were written and coded on one piece of paper. This one paper was the only recording of participants' identities. Only I had access to this list, which I kept in a locked file cabinet and destroyed at the end of the study. At no time did I share a patient's name or identification with any other person, nor did I record that information elsewhere, either on paper or into a computer data base. When first contacting the participants and before each interview I ensured each participant of confidentiality and anonymity.

Interviews

At the start of each interview I clarified with the participant the purpose of the study (i.e. to discover how older adults view their ability to express their needs in the hospital setting). At the start of the interview, I told all participants that they had the option to reconsider participation, discontinue the interview if and when they chose, and that they could withdraw from the study at any time.

I then asked the participant if he or she had any questions. The written informed consent (Appendix B) was then reviewed and signed. Included in the consent form was an agreement for the interview to be tape recorded. I repeated to each participant that his or her identity would be kept anonymous.

Interviews were tape recorded. It was not a requirement that participants be interviewed alone, but each participant did choose to be interviewed alone. Questions asked throughout the interview were general in nature. The intent of the questions was to encourage and maintain the participant's flow of conversation, and to minimize my own input. Examples of questions that I asked were ""What stands out about your experience in the hospital?", "Were there times when you felt particularly anxious?", and "Were there times when you felt too overwhelmed to ask for something you needed?". For the fifth and sixth interviews, I added several questions that focused on themes previously mentioned in earlier interviews, such as "Everyone I've talked to so far has brought up getting other people in trouble. Did you wonder what would happen to others if you complained about something?" and "Did you feel like you had other options if you complained?" (Further examples of interview questions are in Appendix C.) Demographic data (see Appendix D) was obtained at the end of each interview, after gaining rapport with the participant.

Four interviews lasted about one hour. One interview lasted 35 minutes, simply because the participant felt he had no more to say. One interview lasted 45 minutes, partly because the participant felt he had said everything he could think of, and partly because he began to fatigue from his COPD. However at the end of the interview, and when I happened to meet him some weeks later, he expressed satisfaction and a sense of completion about the interview. All six participants were thanked. Five thanked me for the opportunity of being able to tell their stories.

Data Analysis

In each case, I endeavored to put all expectations and bias aside when analyzing the data. After each interview was completed, I gave the tape to one of two professional transcriptionists who signed a strict confidentiality statement, shown in Appendix E. I then listened to each tape, read each transcript repeatedly, verified each transcription, and reformatted it so that all the transcripts shared a homogenous line-numbered form. Data analysis was in five stages, as advised by Christine Tanner (C. Tanner, personal communication, December 15, 1998). They progressed as follows:

1. I read the first interview, wrote notes, and selected episodes that reflected the participant's central concerns.
2. I repeated the same process for the second interview, then looked for commonalties and differences between it and the first.
3. I repeated the process for the third interview, writing notes and comments, and looking for commonalties and differences. I recoded all the data gathered thus far, identifying some recurrent themes.
4. I continued the interview process described above for all subsequent interviews. I added several new questions in order to pursue themes that had emerged in previous interviews. I continued to recode data, pulling out excerpts that were representative of the themes mentioned in 3.
5. The findings were collected and written in a final report.

The data analysis also addressed the study aims as follows. I endeavored to reduce bias as much as possible by employing the qualitative research principles outlined by Taylor and Bogdan, 1984. These include but are not limited to the belief that qualitative research is inductive, holistic, and humanistic, and that the qualitative researcher must understand persons from those persons' own frame of reference, be sensitive to his or her effect on the participant, and attempt to set aside his or her own beliefs, perspectives, and predispositions. Bearing these philosophies in mind, I hoped to discover emerging themes from the interviews, themes serving to shed light on each individual perspective rather than serving to generalize into a theory.

Trustworthiness was attained by 1) conducting the interviews until sufficient data was obtained to provide a thick description of each participant's view, 2) debriefing with advisory faculty who were expert in qualitative research, 3) maintaining a distinct audit trail by storing all raw data, coding processes, advisory memoranda, lists of resources, theoretical outlines, and forms used during telephone contact and during the interviews, and 4) maintaining a chronological journal of the study.

Benefits, Risks, and Protection of Human Participants

The benefits to the participants of this study were potentially an opportunity for self-reflection, self-perception, and growth, and possibly a satisfaction in adding their voice to a body of scholarly knowledge. The risks were minimal. One participant became briefly tearful as he described personal health problems, but calmed himself almost immediately and at the close of the interview expressed satisfaction with it and with the opportunity to be of help in a study. Assurances of anonymity, confidentiality, and of the right to withdraw from the study were reinforced regularly. The only recording of the participants' names and phone numbers were on the single sheet of paper that I maintained in a locked place, shared with no one, and destroyed at the study's end. Any names or personal identification was deleted during the transcription process. Only I had access to the tapes, and only the three members of my MRP committee and I had access to the transcriptions. After the study was completed, the tapes were destroyed.

Chapter 4: Results and Discussion

Analysis of the interviews yielded many themes, over 20 of which were shared by two or more participants. These themes converged into four major themes: 1) finding excuses for the staff, 2) the older adult's view of his/her relationship with the staff, 3) the older adult developing and implementing his or her own agenda, and 4) self-appraisal of needs. This section discusses each of these four themes in turn.

Excusing the Staff

General Praise with Few Examples. When all six participants described the staff generally, they referred to them in glowing terms, such as "they were wonderful", "he's one of the best", "everyone was just as nice to me", and "they are all pretty darn good". However, when asked to describe in detail how the staff were good, they could provide few concrete examples. On the other hand, all six participants related detailed stories of how staff did not meet their needs. The interviews thus largely consisted of unsubstantiated statements that the staff were "good", "excellent", or "nice", followed by descriptions of how needs were not met. The following responses from three different participants show this. The first was from an older man who disliked the food throughout his hospital stay but never complained directly to staff about it.

> Well, the nurses and doctors were very good. Excellent, you might say, but, uh, one thing I didn't like was the food. I just didn't, some of it was okay, and some I just couldn't eat.

An older patient with COPD described the emotional discomfort of being confined in one room:

> They treat you nice. Not that they don't treat you nice, they treat you nice. But you're in the room, you don't get out. You're just in that one room, you don't circulate, and I like to circulate.

A participant hospitalized for a gastrointestinal bleed initially praised the staff, but immediately went on to discuss the physical pain and discomfort of his treatments.

> Well, they were all--like I've always said--they were all so nice to me, you know, the doctors that attended to me, and of course, I had to go through a lot of pain, you know, because they run two or three different kinds of instruments in my body, you know, into my rectum, to check where the blood was coming from, and one in my throat, and then one in my nose, and all the shots and all that.

Although all the participants quoted above spoke highly of staff in general terms, they immediately glossed over this to describe very specific examples of needs being unmet. Several participants declared at the onset that the staff were above reproach. The man recovering from cancer surgery described the staff as follows:

> Well, everybody was just as nice to me.....I've never been anyplace where the nurses were nice as they were in here. And that's the God's truth as far as I am concerned, other people might differ with you on anything, but I have found them to be exceptionally, they seem kind.

However, the only time that he mentioned an individual member of the nursing staff was when he described how a medication aide poorly timed his pain medication, which caused him significant pain. One woman , when asked what part of her hospital stay stood out most in her mind, immediately praised the staff in general terms.

> Oh the most memorable thing?....Everybody, everybody was so good to me. I just can't state myself any more that I appreciated everything that they did.

Although her comment above was enthusiastic with praise, when reflecting upon her lived experience in the hospital she tended to focus on how the staff failed to meet her needs, and was in fact quite critical of the staff. For example, she stated how she had complained to a nurse who had then ignored her, and described the encounter as "talking to a wall".

Concrete examples of the staff being good beyond general "niceness" were few. Mostly they consisted of the simple fact that basic care was provided. Staff was "good" or "nice" because they offered a meal, a blanket, a bath, or a medicine. One man thought that the staff was nice because they asked him if he was allergic to any medicines. When they were asked to expound on how the staff was good or nice, several older adults would describe how one particular individual stood out as good. As one man put it, "She was one of the nice ones". One woman described how a nurse was good because she was the first to adjust her pain medicine effectively and the only one who provided her with a decongestant so she could breathe. She focused more on this than on complaining about the other nurses who had not given her adequate medication previously. Several others referred to the staff during their recent hospital stay as far better than others in the past, but were unable to provide details that described how those inferior doctors and nurses encountered in the past were different.

Excusing the staff as "overworked". A frequent excuse offered for the staff was that they were overworked and understaffed. They were often described as too busy, running back and forth, and having "no time to stand". Several participants tailored expressing their needs based on this observation. One participant said:

> They left me sitting in a wheelchair for 13 hours...they were short of help and everything, so I was having a hard time getting a nurse down anyway so, to help me back to bed, so I just, 13 hours, and the next day 6 or 7 hours.

Another described how her belief that the nurses were understaffed led her to consider complaining as pointless.

> If you needed something for pain or if ah, like your IVs when they had you on a monitor and they would just let that thing go ding, ding, ding, ding, ding, ding, ding, before they would ever come and put on another bottle of IV...I think they were understaffed at night. As well as in the daytime. Really...I didn't [complain] because I just thought well what is the use? What is the use of complaining, just go ahead and take what you can get.

One participant felt that the staff would be too busy to attend to his emotional needs.

> I couldn't sleep at night. I just worried and worried...because I'm just by myself and I said I hope I don't die here and all this...I'm talking about when I was in there at night, I couldn't sleep...I never did tell nobody...they were too busy...this would happen at night...and everyone would be asleep, and I guess they would be short-handed.

This led to a related theme, not making work for others. Several participants stressed how they tried not to be a burden on the doctors and nurses while in the hospital. Comments like "they have enough stuff to put up with" and "they are doing the best they can" surfaced in most interviews. One man pointed out how he tried to do everything for himself. He described himself as "easy to get along with", and explicitly stated that if the staff thus saw him trying to be independent, they would be more likely to help him when he did need it. Another man who was hoping to be approved for a liver transplant took care not to rock the boat, but to do whatever he was told to do by staff. A third participant measured getting his needs met, paradoxically, by the fact that staff rarely felt that they needed to intervene.

> Interviewer: So, [it] sounds like you are able to ask for what you need?
>
> Participant: Oh yeah. Yeah, they pretty much leave me alone, they don't bother me too much.

As the interview progressed, it became clear that this participant, slowly recovering from cancer surgery, prided himself on making as few demands as possible. He also described himself as "easy", and as taking his pain medicine "whenever someone tells me". Attempting to decrease his own reliance on the staff may have been his way of believing that his prognosis was improving.

Excusing the staff as "learning". Another excuse frequently made for the staff was that they were learning. The participants (all selected from the same teaching hospital), tended to view themselves as an educational experience for medical and nursing personnel and students. One man described his role as that of a "guinea pig":

> But I didn't feel hurt about it, 'cos I knew they were learning, they were just beginners, beginning and they had to have somebody and we're the guinea pigs...It's not the greatest thing. But you know if you use it right, it is...You get something good come out of it, then it's good...Something...that would create something to happen down the road.

One participant coped with his situation by looking at his rare cancer as a learning experience for the staff. Another woman forbore to complain about new staff members who she thought were uncaring because she perceived them to be in the process of "thawing out", or improving. She felt that the student doctors were tired and overworked and that the student nurses were given too many patients to deal with. The participant with liver failure put up with the humiliation of being exposed in front of a group of medical students by telling himself it was a necessary learning experience for them.

Not getting staff in trouble. The final topic that emerged as a reason for excusing the staff was the desire not to get others in trouble. Several participants explicitly stated that they wouldn't complain if it would lead to a doctor or nurse getting in trouble. The woman who received a nasal decongestant from one nurse refused to ask for it from subsequent nurses, because she believed that the first nurse would get in trouble for giving her an unprescribed medication. She also believed that a patient complaining would reflect badly on a nurse's job performance, and might lead to the nurse being fired. The participant who was under-medicated by a medication aide had in fact carefully explained to her beforehand his rationale for why he needed it. Although he then experienced significant pain, he dismissed her action as "a natural little mistake".

Another participant experienced two cardiac dysrhythmias, both exacerbated by the staff not initially believing him. First a doctor had summarily discharged him, brusquely ignoring the participant's stated concerns that a new medication might create a dysrhythmia. His fears were realized before he reached home, and the paramedics rushed him back to the hospital. After he had been readmitted, several nurses responded to his complaint of rapid heart palpitations by incorrectly telling him to take a nitroglycerin tablet. The delay then precipitated a code for ventricular tachycardia. He complained to a patient representative about the doctor, but not the nurses:

> "I didn't want to get them [the nurses] in trouble either. But the doctor, I didn't care if I got him in trouble or not".

This participant did not say why he differentiated between who to get into trouble and who not to. It is possible that it was because the nurses eventually listened to him and believed him whereas the physician did not. However, there is not enough data from the interview to corroborate this supposition.

Discussion. The aforementioned describes how the older adults focused on excusing the staff; it does not entirely say why they do. It is probably basic human nature to believe that others are good and would help us if they could. Another universal reason to provide excuses for another is that it avoids conflict. Older patients may find excuses for staff inadequacies to reprieve themselves from the uncomfortable position of having to fight for what they want. This may be seen as good manners, making the best of a bad situation, or "rising above the fray". Additionally, avoiding getting others into trouble probably stems from a basic human instinct to watch out for one's fellow human beings.

Another reason that older adults may find excuses for hospital staff is their own self-image. Although discussed more fully in the "Self-Appraisal of Needs" section farther along, it is pertinent to this discussion as well. Older adults may see being "easy to get along with" as part of their role in the hospital setting. One man said that he made few requests because it is important "to work together". No longer in the work force, retired people may feel guilty adding to the burden of someone they see as overworked. They may refuse to say anything that could land someone else in trouble because they do not want to see themselves as a "snitch". Possibly they might put up with discomfort silently, believing that their role as "guinea pig" is necessary for others' learning experience. And as in the case of the man recovering from cancer surgery, they may equate minimizing their requests to staff with minimizing their dependence on the medical system.

Perceived Relationship with Staff

The older adults' perceived relationship with the staff led to a number of issues affecting how they felt they could express their needs while in the hospital. These issues can be divided into three groups: the older adults' and staff's knowledge of each other, power conflicts, and communication issues.

The older adults' and staff's knowledge of each other. Whether or not the older adults perceived the staff as "knowing" them was a major criteria for several of the participants. By "knowing", I do not mean that the staff was necessarily acquainted with them prior to admission. Rather the participant usually conveyed a sense that the staff had or had not developed a meaningful relationship with them. The man awaiting a liver transplant praised the doctors who had worked with him for months:

> And they have worked with me...they know all my story...And they told me it wasn't too late....They know--they know that I'm trying and I've suffered to get off of that stuff, because you don't realize how I did drink...We talked just like, you know, old friends from a long time.

He went on to say he could talk to his doctor as if she was his own daughter, and described how she knew his needs well enough to let him go outside and smoke during a visit. The participant recovering from cancer surgery described how he had his favorite nurses, referring to them as his "pets". On the other hand, most of the participants pointed out that the staff during their last hospital stay were too unfamiliar with them. One woman noted that modern doctors compared unfavorably with the old family physician of her past, who knew his patients well enough to know that something was wrong "just from looking at you." Almost all the participants described the nurses as flying in and out of the room, not spending enough time with them to deliver meaningful care. One older woman who was a retired nursing assistant said:

> "[I feel] like they are not nurses. They are not nurses. I was always taught that you take care of the ones that you are assigned. If you are assigned to the four people you stay in that room and you do for those four people your eight-hour shift. And you take care of those people. Go out and make your report, but when the light come on, go see what is the matter. That is a big problem. Those lights are never answered when they need to be answered.

Several participants complained about a lack of one-on-one care. This in turn led to a feeling of confusion as to who was responsible for what aspect of care. One woman simply did not know who she could complain to. One participant described feelings of frustration that arose when a group of doctors entered her room during rounds:

> They are called the blue group and they would be about four of them in there. One would talk...just one and the others would just stand there just like a statue. [Mimics thrusting them away.] "Get out!"...they are not acting like they are any interested in any of it. You know they stand there with their hands crossed like this or their hands in their pocket. They may

> be studying you, but why can't they say something?...It just crowds in...four and five that was in there and one talking and bombarding you with questions.

This feeling of bombardment was described by another participant detailing a conversation with one of his peers in the hospital:

> He said "I've been here three months, do you know I've had three primary doctors in three months?" He says "One comes in and asks of me a whole bunch of questions, hounds me, checks me, does all this and pretty soon he's gone, and here comes someone, same questions, same hounding, and pretty soon he's gone. And then here comes another one", he's going on like, "nobody's taking care of me".

This last quote also exemplifies another way that older adults showed a decreased rapport with the staff. Most participants, when asked to describe their lived experience in the hospital, proceeded to relate one or two stories describing the negative hospital experiences of friends and acquaintances. This could simply indicate the disinclination to directly confront staff mentioned earlier. In other words, it would be easier to criticize hospital staff vicariously than directly. Arguably it also shows a decreased rapport with the staff, in that the participant felt unable to confront them directly.

Power Conflicts. All six participants identified or described a power struggle between themselves and the staff. One man with COPD discussed how he had to confront staff to be allowed to sit up in order to breathe better during procedures. He stated that many staff members dislike interference and need to show that they are in charge. One nurse told him "if you don't like it, you shouldn't be here". He went on to describe how staff responded to his requests with a disgusted look on their faces, to which he countered by "biting his lip" and remaining silent. Two participants described how staff would express their disagreement with their requests by looking at them disapprovingly.

Two participants chose not to complain because they were testing the staff to see if they would do what was expected of them. One woman, seeing a piece of crumpled paper on the floor, waited all day for someone to pick it up. She never asked anyone to pick it up, nor drew anyone's attention to it, because she was waiting to see "if they would do their job". Another man carefully noted the dates on his water pitcher and urinal, then waited to see when they would be replaced. Even after weeks had gone by, he chose not to tell them that they needed replacement, but waited to see if the staff would do their job. He even made hatch marks on bed linen, one each day, to note how long the staff went without changing the sheets. When asked why he didn't just tell the staff that it was time to change these things, he said:

> I don't think the patients should have to...No I really don't...That's their business, they are in this trade. This is their trade and they should know their trade and they should do their trade.

The other participant explained why she refused to point out to staff that some waste paper had been lying on the floor all day.

> Participant: It was lying on the floor, and everybody walked around it, all day, all afternoon, and it was bothering me, because I pick everything up. I

> was being patient to see who would pick it up. Whether it would be a nurse, someone visiting, you know. That's it. I was testing her.
>
> Interviewer: Why were you wanting to test them?
>
> Participant: [To see] how observant they were. Yeah and to see how they were trained.

Two participants considered the staff to have carried the power struggle to the point of subterfuge. One woman with previous nursing aide experience overheard a doctor say "She knows a little more than we realize she knows". She noted that they were careful not to speak in front of her after that. One man with arthritis in his back believed that a staff person's query "How's your broken back?" was an attempt to entrap him. Because he knew his back was not broken , he believed that if he responded to the question he would be accused of attempting to make a fraudulent benefits claim.

All six participants related a story in which they complained to staff, and then had their complaint discounted by staff. The most dramatic was the story mentioned earlier by the participant who had been coded twice for cardiac events, largely because the staff discounted his input. The man who felt humiliated by being exposed in front of medical students asked the doctor if she was using him "like in a freak show". The doctor made a laughing response and did not acknowledge his embarrassment. Three participants related stories in which the staff person pointedly ignored them or walked away. The participant with COPD discussed how the staff did not follow up when he related that a confused roommate had trouble eating. A later dental exam proved that the roommate had a broken tooth. The same participant noted the repetitive use of the term "be right back" by the staff to shelve his requests:

> Participant: It's kind of hard to express them [my needs]...People won't listen. You tell something, [imitates a ghostly howl and flutters his hands in the air] ooooooh!
>
> Interviewer: They float away?
>
> Participant: Yeah. "Be right back". Four hours later--"Bye"...When sometimes they say "I'll be right back", I say, "Yeah, I'll be right back too".

Communication Issues. Communication issues were mentioned less frequently as a problem in the relationship between staff and participant. All six participants acknowledged times in the hospital when they were too painful, sick, tired, confused, or medicated to express their needs. Perhaps because they were also too impaired at the time to realize they had needs or to remember afterwards, few participants dwelt on this. Four participants discussed this, but only one to any degree. This was a woman who remembered being too tired to care about anything else but sleep. One man remembered being too painful to talk, but focused more on the experience of pain than on his inability to communicate. One woman dismissed the experience of feeling too sick to express needs as "I just thought what will be will be, and the Lord will take care of it". One man described being too breathless from COPD to express his needs as "You hope and pray...it [help] usually comes".

Only one participant spoke English as a second language. He was unfamiliar with some English medical jargon, and was at a loss to understand some of what the doctors said during rounds. However, he expressed confidence that the doctors knew what was best and satisfaction with his understanding of day-to-day hospital conversation. He went on to describe resources that he relied on for translation. Nobody else stated or described a scenario where they couldn't understand what the staff said.

Two participants discussed how they used indirect communication with the staff. When faced with an unappetizing breakfast and a carton of rancid milk, one man did not confront the staff directly to ask for a new meal. However, he did pour the rancid milk over the pancake, then stuck a sign on it that said "Try and eat this yourself". One man described how he used silence to retaliate against the staff:

> Well it all depends who it is and you know they are having a bad day, you let them go...And if [they're] not having a bad day, you just look through them and pass them on the hall, look right through 'em, don't say nothing. And pretty soon maybe you'll hurt one.

Discussion. The older adults' and staff's knowledge of each other, power conflicts, and communications issues all emerged as themes as the participants discussed their relationship with the staff. The first, knowledge of each other, seemed particularly related to how the older adults viewed the quality of care that they received from the staff. Often the participants measured the quality of care by its continuity rather than just by the sheer number of interactions and interventions. Thus having a single doctor or nurse spend time with them was more meaningful than being "bombarded' or "hounded" by a large number of staff.

Conversely, too few interactions with the nurse "flying in and out of the room" left them feeling deprived of care. This lack of meaningful interaction with the staff led to the staff and older adult not "knowing" each other. This lack of intimacy in turn probably led to the older adults feeling less comfortable expressing their needs. None of the participants had observable cognitive impairments, so the feeling of "bombardment" was probably not due to cognitive aging deficits causing inability to adjust to a new situation. Considering the woman who praised the physicians of the past who "knew" their patients, it is possible that some older adults are silent when confronted with the modern medical system, not because they implicitly trust it but because they do not believe that they matter as individuals in it.

The topic of power conflicts sheds an interesting light on how the participants viewed their ability to express their needs. Here the participants sometimes viewed themselves as adversaries of the medical system rather than as its beneficiaries. The older adults who tested the staff by silently waiting to see if they would "do their job" may have assumed the role of monitor as a way of taking control of their hospital stay and of their disease process. The participants who saw the staff as exercising subterfuge carried this one step further. Here their perceptions may not have been completely accurate. The health care worker who asked the man with arthritis "How is your broken back?" was, in my opinion, probably just making a rather clumsy joke, and not attempting to entrap him into making a fraudulent benefit claim. However, the accuracy of this participant's belief is beside the point. The salient issue is that his belief that the staff member was deceptive was real to him, and this in turn reflects upon the poor relationship between older adults and staff.

That communication issues played a limited role in how the older adults viewed their relationship with the staff was very surprising. Of course an older patient temporarily cognitively impaired from sickness or medication may be too impaired to be aware of those needs at the time, or to remember the experience later. Issues dealing with the needs of unconscious or semi-conscious patients obviously are not the province of a phenomenological study. The man for whom English was a second language trusted the system without understanding all that was said to him, but did not view this as a problem. The responses of "what will be will be" and "you wait and pray" clearly demonstrate some unmet needs. This study does not conclude that communication issues were not important in the care of older adults. It does seem, however, that the older adults interviewed in this study did not view them as important.

The Older Adult Developing and Implementing His or Her Own Agenda

When asked to reflect on their hospital experience, all the participants discussed how they developed different ways of getting their needs met other than relying on the system, or conversely how they used the regular channels of the system to get unspoken needs met. What these two actions had in common was that the older adult essentially maneuvered the system to suit his or her needs. Specifically, the older adults talked about choosing self-action, tricking the system, looking out for others, fear of retaliation, and focusing on returning home.

Choosing self-action. All six participants discussed scenarios in which they chose self-action rather than submitting to the staff. One example is the participant who disliked the food but assumed that since others must have complained about it, it would be pointless for him to. He simply left his trays untouched and bought his meals in the hospital cafeteria. The same man argued with the nurses who disbelieved that his self-perceived heart dysrhythmia was serious enough to warrant a code intervention. Not until he persisted in calling them on the intercom three times, and threatened to walk to the emergency department himself, did they pay attention to his needs. At that point they followed his suggestion and sent him to the emergency department. Earlier, when a physician misdiagnosed his pneumonia as anxiety and then ordered an anti-anxiety medication that in turn caused a serious dysrhythmia, he submitted despite his fear that the physician's actions were wrong. As he reflected on the two situations, he based his decision whether or not to assume self-action upon his knowledge of the situation. He describes his interaction with the nursing staff as follows:

> "Oh', they said "take a nitroglycerin". I said "A nitroglycerin is not going to slow my heart down...you have got to get me down to the emergency room". "Oh, take another nitro". I tried to explain to them that nitro is not going to slow your heart down and I got to get down there pretty darn quick. And, so I got on the intercom again and told them "I am gonna go down to the emergency room and if I make it down there alive why, I'll

> sure get after you girls when I come back up here, if I come back up here". Well, then they put me on the gurney.

On the other hand, he was not comfortable enough with his own knowledge level to override the physician's decision to administer Vistaril.

> Well, I thought [the physician] was doing the wrong thing. But I didn't know the side effects of the Vistaril, I thought well maybe if it will calm me down.

When he encountered the same physician after the medication he had prescribed caused a serious dysrhythmia, the participant refused his care. Another participant, after enduring two large bore nasogastric tubes in rapid succession, said that she would refuse a third now that she knew what they were like. One older woman overrode a physician's plan to discharge her, because she knew she was developing a fever. The participant with liver failure endured nightly anxiety attacks in the hospital without informing the staff. He partly based his decision not to tell on his familiarity with similar attacks at home. Another man refused to let physicians firmly squeeze a toe during assessments, because he knew from experience that it would be painful.

On the other hand, the participant recovering from cancer surgery allowed a medication aide to medicate him too early for pain, even though this ran counter his knowledge about his own reaction to medication:

> Now some people I know medication will react real fast and others it takes a long time, well I'm the one it takes quite awhile to, you know...Well I go

> along with them and see maybe they *are* right and I could be wrong. I don't believe in making a big issue out of it, you know.

This was the same participant mentioned earlier, who may have equated decreasing his requests to the staff with improving prognosis.

Tricking the staff. Several participants discussed tricking the staff to get their needs met. One example is the man who sneaked down to the cafeteria in order to drink coffee and thereby raise his blood pressure:

> "Don't get up now" [the nurse] said, "because your blood pressure's awful low"...so when she wasn't looking I got in the elevator and went down to cafeteria and had about three cups of black coffee...Then I come up there and got in bed again and then about half hour or little bit later she come up and checked my blood pressure..."Hey", she said "were you up?"... Then I said I went down there and drank three cups of black coffee. Cos I remember that black coffee gets the blood pressure up. She said, "You've done a very good job."

The same participant admitted lying to the nurses that his physician had prescribed a nightly back rub. Another example of a patient trick was the man mentioned earlier who made daily hatch marks on his linen to prove that the nurses were not changing the sheets. One elderly woman, when asked by physician to hurry to an exam room, intentionally scared the physician by pretending to sprint down the hallway. One participant intentionally did not speak to one health care worker because he did not want to prepare him for the fact that he planned to sue.

Fear of retaliation. Three participants brought up the subject of retaliation. In other words, they were concerned that if they were perceived as disruptive, their care might suffer. As one man put it,

> I'm easy to get along with...I learned a long time ago that...'Take a horse to water, but you can't make him drink", you know. There's a lot of truth to that. No use to push things out of bounds, out of proportion. You try to push, that can be pointless sometimes ,you know. I think you hurt yourself more in the long run than just try to work best and try to work together and everything else.

One woman stated that if she complained too much, they would "put her out the door". She felt that with budget cuts, staff would eliminate those patients that were too demanding. The participant with liver failure believed that if he did not follow the physician's orders, they would stop seeing him as a patient, and he would then not receive the liver transplant.

Looking out for others. Only one participant focused on the care received by other patients during his hospital stay. He thanked staff for providing care for those more impaired than himself, and saw his role as that of an advocate for those who could not speak. One other participant mentioned briefly curtailing her requests because she did not want to detract staff from those who might be sicker than she. However, as she pointed out, she was alone in one large hospital room, and had no idea if there was in fact anyone out there who was sicker. She described being alone in a four-bed room as being in "isolation". Other participants denied that this was a consideration. One pointed out that other patients were either very sick or curtained off, so that she had no opportunity to become familiar enough with them to be concerned about them.

Focusing on returning home. Four patients brought up the subject of wanting to go home. During two interviews, this response came unexpectedly when the participants were asked why they had not complained about something to the staff. One participant mentioned home when asked why he had not complained about an unappetizing meal:

> Interviewer: Did you talk [complain] to anyone directly?
>
> First Participant: No, I didn't I, hurry to get home, I never did talk to anybody while I, I guess I should have.

One woman brought up the subject of home when asked why she did not complain to staff about her meals being served too close together:

> Interviewer: Did you complain [about the meals] further?
>
> Second Participant: No, no I didn't. Because I wanted to come home and come home and be able to have somebody to take care of me that knew what they were doing.
>
> Interviewer: Do you think complaining would have made a difference about your coming home? I don't quite see the connection.
>
> Second Participant: Well I don't know. I really, I really don't know its ah, maybe I was just thinking too negative. I don't know about all of it.

It is interesting that neither of these participants could explain very clearly how wanting to go home affected their ability to complain. In fact, at some point of their hospital stay, both of them had attempted to persuade physicians not to send them home because they felt themselves still at risk. The second participant quoted above described later in the interview a dread of coming home too soon. Although she is quoted above as wanting to come home and have "somebody to take care of me that knew what they were doing", in point of fact she lived alone and was relying on home health at the time of the interview. A third participant admitted that he forbore to complain during his hospital stay because he wanted to go home, but then proceeded to describe home as depressing and lonely. Another man discussed how he refused to ask for pain medicine, because the sooner he was weaned off it the sooner he could go home. A fifth participant said that she had no particular desire to go home from the hospital until she felt that her problem was fixed. The sixth participant, who resided permanently in a VA long term care facility, made no mention of home.

Discussion. It has long been accepted, in theory, that patients should be empowered and take control of their health care as much as possible. In the actual practice of medicine and nursing this is probably not encouraged as much as we would like to believe. Certainly it is a positive and heartening sign that a number of older adults in this study chose to take charge of their own care. Less heartening is the fact that on some occasions, as the participant with cardiac dysrhythmias learned, the staff actively opposed such independence. When the participants took control of their care, the interchange with staff often sounds more pugilistic than consensual. Such an atmosphere is unlikely to produce optimal problem solving, because staff and patient have in essence set their agendas against each other's. This supports the participants' concerns mentioned earlier about power issues among the staff. The old adage that "a little knowledge is a bad thing" may be being applied to older patients by staff who do not want to give up the control that goes with that knowledge.

There is also the issue that some situations in which the older adult took control were done secretly, in essence tricking the staff. In a positive light, we can construe this as a sign of effective coping skills and survival techniques. On the other hand, it makes for less effective and certainly less efficient care when the older patient and the staff operate on two separate agendas, one (or perhaps each) of which is hidden from the other. Obviously, it reflects poorly on the health care system if older adults feel they must approach it as a secret adversary. Patients who do so are often given the stigmatizing label of "manipulative".

More concerning yet is the theme of fear about retaliation that emerged in some interviews. Although it is tempting to dismiss such a reaction on the part of older adults as ungrounded, there may indeed be a measure of truth in such fears. It is not unreasonable to suppose that older patients who are perceived by staff as demanding will receive less care. In my clinical nursing experience, physicians still routinely refer to undemanding older patients as "pleasant" in their written assessments. Nurses and physicians are likely to want an early discharge for patients not considered "pleasant", and there is no reason to assume that older adults have not figured this out for themselves. The woman who feared "being put out the door" if she complained mentioned the hospital's limited budget as one source of her concern. With both the media and hospital staff openly discussing the prevalent focus on cost containment in our health care system, some older adults may well attempt to be "pleasant" in the narrowing competition for health care dollars. The man awaiting approval for transplant may have been realistic in his concerns that an indigent patient viewed as noncompliant would be denied a liver transplant.

It was surprising that only one participant focused to any degree on the concerns of other patients. However, all six participants were hospitalized for serious illnesses, and they may have been simply too concerned with their own serious complaints to have time to think of others. With the present focus on cost containment, by and large patients are only admitted to hospitals for serious illness. As the one participant described, her roommates were so sick that they tended to isolate themselves behind curtains. She thus had no way to develop a relationship with them, and therefore had no reason to be concerned with them.

Also surprising was the emphasis on not complaining so one could go home. Ideally, expressing one's needs should engender more efficient care, so that from a strictly rational viewpoint, expressing one's needs would lead to going home sooner. Of course complaining about illness or symptoms might lead to staff deciding to keep a patient longer in the hospital for treatment. But the complaints that these older adults kept to themselves because they were focusing on "home" were about meal times, food quality, and wanting a cigarette, not about symptoms or illness. None of the older adults interviewed expressed themselves clearly about how wanting to go home had any bearing on not complaining about these items. Paradoxically, they were quite articulate later in the interviews about not wanting to go home until they had completely recovered, or in describing their particular home situation as unable to provide for their physical or emotional needs. One reason for this discrepancy may be that home is a psychological concept as well a physical reality. Stressed by their experience in the hospital, these older adults may have escaped into the fantasy of going home, temporarily forgetting what the reality of going home would mean.

Self-Appraisal of Needs

Self-appraisal of needs also emerged as a theme as the participants discussed their ability to express themselves in the hospital. This issue centered on the older adults' appraisal of their own knowledge level of the situation, on judging whether their needs were important enough to warrant voicing them, and on an ethic of not relying on others.

Viewing their own knowledge. How the older adults viewed their knowledge of their own health needs played a widespread role in whether or not they felt they should express those needs. Most of the stories mentioned above about older adults developing their own agenda involved a self-appraisal of knowledge. One example is the man who knew that nitroglycerin would not slow down his tachycardia, and so was able to stand his ground against the nurses who were discounting his symptoms. Because he had no knowledge of Vistaril and its side effects, he eventually gave in to the doctor who prescribed it. Similarly, he sneaked down to the cafeteria to raise his blood pressure by drinking black coffee, "'cos I remember that black coffee gets the blood pressure up". Another example is the woman who planned to refuse future nasogastric tube insertion after she had gone through the learning experience of having two placed. Two participants, one a former CNA and one a former hospital supply requisitioner, relied on their past knowledge of working conditions to judge the reasonableness of the care they now received.

Other examples included participants repressing expression of needs because they did not trust their own knowledge base. The man recovering from cancer surgery accepted the judgment of the medication aide to give him his pain medicine too early because he rated her knowledge base as higher than his. In comparing his knowledge base to the staff's, he displayed an equivocal attitude:

> Well, I really don't offer any opinion for the type of treatment to use for it because I really don't know. If I feel that maybe try this or try that would make [it] easier on me I'll mention it...they may come out and say "Well, okay well let's try this first, and then we can do that if you want to". I say "Whatever, it doesn't make any difference. I'm easy to get along with".

One man forbore to ask the physicians questions during hospital rounds, not so much because he had no knowledge of the situation, but because he had no knowledge of the physicians themselves. He said he would have been more comfortable expressing his needs to his primary physicians, whom he knew.

> I've been with them so many times, you know, that I feel more comfortable...they have been dealing with me so long...and he was just new to me and I didn't want to make a monkey out of myself, by asking [questions].

Four participants, looking back on their experiences, used expressions indicating they had learned from their recent hospital experience. These were typically brief comments like "maybe I should have" or "I didn't remember. Maybe next time". No participant elaborated on this theme.

Judging importance of their needs. Three participants discussed their needs as trivial or as unworthy of being noticed. One woman summed it neatly by saying "you got to take what you can get". One man, giving the example of wanting fresh water as a need too trivial to bother the staff about, used the statements "no big deal" and "it wasn't a matter of life and death". He stated that there was no point in "making an issue" out of his needs.

A poignant example of trivializing needs came from the Mexican-American participant who was awaiting liver transplant approval:

> I thought it wasn't nice for me to ask them [to let him smoke a cigarette], cause I wasn't nobody special, you know...I wasn't the president of the United States, or...some executive, or some important person, you know...a movie star or something...I go there for free, you know.

Adding to his reticence may have been the fact that part of traditional Mexican American culture is to trust physicians implicitly. He also believed that a request for a cigarette, coming from someone as sick as himself, might be enough to get him labeled as "crazy" by the staff.

Not relying on others. A final aspect of self-appraisal of needs that blends in with previously mentioned ones is the ethic of not relying on others. All six participants either stated this view of themselves or demonstrated it in their actions. One woman pointedly differentiated between herself and "hypochondriac" patients whom she described as wasting the staff's time. "When

I'm sick, I'm *sick".* The man with COPD took care only to make requests from the staff for things he could not do himself. He believed if they saw him as self-reliant they would then be more favorably disposed to him. One participant took care to stress how she asked for a commode only because her IV lines made it impossible for her to ambulate as independently as she would like. For one participant, his view of himself as self-reliant complemented the already mentioned theme of the staff being overworked:

> I've had 'em come up and go "Ring that bell, ring that bell. You old hard-head, ring that bell more"...I said "Well I watched you go past that door, you are always running all the time to people". She says "Yeah, they overdo it, some of them overdo it, and the thing of it is you don't do enough of it". They say to me I should call and get more and ask for more. But I figure well, they've go a lot to do, they are short-handed and there's no use making it harder on them than you have to.

Discussion. The themes in the "Self-Appraisal of Needs" section of this analysis are strongly linked to themes in other sections. But I do not believe they represent mere repetition of what has gone before. Rather they are a justifiable and necessary appraisal of the interviews by looking at them from a different aspect. Self-appraisal of needs and one's actions have a mutual cause and effect relationship. Analyzing the same material from this focal point produces new insights into how older adults view their ability to express their needs in the hospital.

Probably the most salient aspect of self-appraisal of needs was the level to which older adults viewed themselves as knowledgeable or not of their situation. Certainly self-appraisal of their knowledge of the situation played an integral role in every instance of an older adult choosing or not choosing to express needs. This leads to an important question. In this era of rapid technological advances in the health industry, how feasible is it for an older adult to maintain enough knowledge in order to feel comfortable taking an active role in his or her care? Another important issue, in these days of fragmented care and HMO's, is how well older adults feel that they know their health care providers. A lack of continuity of care may well be leading to decreased expression of needs.

The expressions "maybe I should have" or "maybe next time" were not elaborated on by any of the participants. This brevity may be insignificant, or may indicate a level of shame from seeing themselves as passive or "wrong". Seeing oneself as ineffective can be doubly humbling for older adults who are already dealing with the deficits of aging.

The participants who belittled their needs as trivial may be reflecting American culture's trivialization of the elderly. This may also be a comment on the downsizing of staff in today's cost-centered health care environment. Staff who now must prioritize patient needs in an increasingly overworked environment may be sending older adults the message, deliberately or unconsciously, that some their needs are too minor to be answered. The indigent man awaiting transplant approval who was grateful for any kind of attention and saw his needs as unworthy provides another insight. He may have feared that if his requests made the staff see him as unreasonable or "crazy", he would be denied a liver transplant.

Self-reliance is accepted as an integral part of the American cultural ethic. A belief in one's self-reliance is obviously important to many older adults as they face the consequences of aging. Several of the participants clearly attempted to bolster their self-image by showing the staff self-reliant behavior. This may have provided them with the feeling that they were a "part of the team". Because hospital staff tend to view less demanding patients with approval, this in turn might serve to reinforce self-reliance as an important part of how an older patient appraises needs. Thus hospital staff may actually be encouraging older adults not to express their needs.

Chapter 5: Summary and Conclusions

Summary

Although most interviews began with general praise of the nurses and physicians, the bulk of each interview consisted of how participant needs were not met. All participants related stories of not expressing their needs or of encountering difficulties when they did. The four major themes that emerged form the interviews were finding excuses for the staff, the older adult's view of his or her relationship with the staff, the older adult developing and implementing his or her own agenda, and self-appraisal of needs.

That older people frequently do not express their needs in the health care environment is assumed in most of the current literature on empowerment and autonomy. Why this occurs is generally not addressed in these articles. In my clinical experience, most nurses assume that hospitalized elderly tend not to express their needs because they implicitly trust nurses, physicians, and the health care system in general. But trust in the health care system was not a salient theme in these interviews. Although participants did relate stories in which they deferred to the staff rather than express their own needs, they usually did not base this decision solely on their perception that the staff was trustworthy. Rather they chose not to express their needs because they saw doing so as pointless, unjustified, uninformed, ungrateful, creating a burden, likely to worsen rather than improve their situation, or simply not as expedient as taking matters into their own hands. Participants who did express their needs frequently encountered opposition from the staff.

Limitations of the Study

There were several limitations to this study. Generalizability is not a goal of phenomenology; therefore it is uncertain whether the themes that emerged from this sample of six older adults could be assumed relevant to the experience of a larger population. All six participants were recruited from either a VA hospital or from a university hospital satellite ward at that same hospital. Therefore the staff and environment which they encountered there may reflect a limited view of the health care system in general. All participants were either widowed or divorced, and none described an experience of having adult children or family members heavily involved in their hospital stay. It is unclear if the experience they related of expressing their needs could be applied to older adults who have families actively involved during their hospitalization. Although one participant was Mexican American and two had some Native American ancestry, clearly no six adults could adequately represent all cultures in any large population, and so the findings of this study could not necessarily be applied to all groups.

Theoretical Implications and Future Research Recommendations

Any phenomenological research bases itself on "turning to the lived experience" (Von Manen, 1990). Although all the older adults interviewed did reflect on their lived experience during their recent hospital stay, they also spent significant portions of each interview summing up their experiences and offering the investigator their opinions as to the significance of that experience. This process of internal review and integration of events, which Butler (1963) refers to as the "life-review" process, is an essential need for elders as they attempt to establish meaning in their lives by reflecting upon the lessons of their past experience. Older adults often find meaning in their lives by summarizing their experiences in order to teach younger generations. Further research into how these traits affect the phenomenological approach to retrieving the lived experiences of older adults would provide useful insights.

Much of the reason that this topic was chosen for a research project is because the recent literature on empowerment and autonomy of the aged does not address in any detail why older adults do not express their needs while hospitalized. The literature tends to focus on pragmatic solutions to empowerment issues and not on questioning why such issues exist. The hope of this study was not to disprove or support earlier studies, but to illuminate new aspects of this issue by listening to the voices of the older adults themselves.

The interviews in this study offer a fruitful source of future research. We need to study further how the older adults' self-appraisal of their health care knowledge affects their ability to express their needs. Which requests that older adults deem reasonable and unreasonable to make in the hospital also bears closer scrutiny. The relationship between expressing needs and fear of retaliation, particularly as it relates to the older adult's struggle to maintain an ever-diminishing piece of the health care pie, is another subject worthy of future research. Future studies on the adversarial role that older adults may adopt towards staff, as well as their views on power issues in the health care system could shed additional insights. Whether or not staff indeed "train" older adults not to express needs would be another interesting field to explore. Several of the hidden motives to not expressing one's needs in the hospital, such as a belief that self-reliance leads to improved chances of recovery or that being non-demanding increases the likelihood of successful transplant candidacy would be of particular interest. Finally, understanding how the concept of "going home" affects one's ability to express one's needs may also be of great benefit to gerontological nursing.

Clinical Implications

One of the most obvious clinical implications that can be derived from this study is the importance of questioning more deeply the assertion commonly made by older adults that they are completely satisfied with their hospital care. As stated earlier, almost every interviewee began with such assertions, but then spent most of the interview describing how needs were not met. It is likely that most older patients, and perhaps most patients of all ages, feel more comfortable expressing their needs once a measure of time has passed and they have established a meaningful rapport with the hospital staff.

That many nurses and physicians fail to establish such a meaningful rapport with older adults is clear from the interviews. An increased rapport will obviously lead to a greater number of significant interactions between older adults and hospital staff, and hence lead to a more comfortable expression of needs. A key element suggested in the interviews is the amount of time spent with the older adult. Restructuring staffing more towards a more primary nursing pattern of care would provide less fragmentation and greater continuity of care. Similarly, changing the structure of resident physician-patient interactions from the current "bombarding" medical team rounds to more one-on-one encounters would decrease older adults' feelings of intimidation. Many elderly persons identify with an era when people developed an intimate relationship with one family physician. Faced with the current mode of HMO's and doctor shuffling, they may not now have the opportunity to develop enough trust in their physician.

The patient who described her roommates as curtained off and too sick to interact with brought up another clinically significant issue. With the current trend for more home health and outpatient care, the average patient in the hospital tends to be sicker than before and the average hospital stay is shorter. This reduces the chance for the older patient to bond with peers while hospitalized. The lack of "ward camaraderie" may further an older adult's sense of isolation in the hospital, and lead to decreased expression of needs.

The issue of power is one that many health care workers are uncomfortable to face. Nurses and physicians like to see themselves as beneficent and to view the older patient as the receptor of that beneficence. Clearly, however, a number of the older adults in this study thought that the hospital staff at times engaged them in a power struggle. Health care workers need to realistically determine their own agenda when delivering care. At the same time, it is important for nurses and physicians to assess the older patient's agenda, which may be quite different from their own. The older adults in this study who developed adversarial roles, sometimes secretly, testify to the fact that unexamined and unresolved power issues can seriously impede effective expression of needs in the elderly. It is also important for health care workers not to overly reward "easy to get along with" behavior, and to help older patients discern the sometimes rather fine line between repression of needs and self-reliance.

The recurrent theme of knowledge that emerges from many of the results in this study leads to another important clinical implication. The older adults in this study often used their self-appraisal of their knowledge of their health care situation in determining the extent to which they voiced their concerns to staff. With the rapidly advancing technological changes in today's health care scene, maintaining a high level of knowledge may become more and more difficult for many older adults. Nurses and physicians need to support older adults in their attempts to remain knowledgeable about their own health care. Older adults need to be told when their fears of retaliation are unreasonable and are impeding their ability to ask for what they need. Sadly, some fears of retaliation may be quite reasonable, but the health care worker will be unable to act as a patient advocate in these situations if the older adult does not feel comfortable voicing his or her concerns. Older adults should be reassured that they will not automatically get someone "in trouble" if they raise a complaint. Nor, like the man awaiting a liver transplant, should they fear that a simple request will lead to a cessation of care. Older patients in teaching hospitals should be assured that they are not "guinea pigs" whose needs are subservient to the furtherance of medical science. Probably the most important clinical implication to arise from this study concerning how older adults feel comfortable expressing their needs can itself be best expressed in the words of one of the participants:

References

Blackhall, L.J., Murphy, S.T., Frank, G., Michel, V., & Azen, S. (1995). Ethnicity and Attitudes Toward Patient Autonomy. Journal of the American Medical Association, 274, 820-5.

Browne, C.V. (1995). Empowerment in Social Work Practice with Older Women. Social Work, 40, 358-64.

Butler, R.L. (1963). Life Review: an Interpretation of Reminiscence in the Aged. Psychiatry, 26, 65.

Cox, J. (1996). An Unwanted Concept. Nursing Standard, 10, 24-5.

Davies, S., Laker, S. & Ellis, L. (1997). Promoting Autonomy and Independence for Older People within Nursing Practice: a Literature Review. Journal of Advanced Nursing, 26, 408-17.

Davison, B.J. & Degner, L.F. (1997). Empowerment of Men Newly Diagnosed with Prostate Cancer. Cancer Nursing: 20, 187-96.

Hewison, A. (1995). Nurses' Power in Interactions with Patients. Journal of Advanced Nursing, 21, 75-82.

Kubsch, S. & Wichowski, H.C. (1997). Restoring Power through Nursing Intervention. Nursing Diagnosis, 8, 7-15.

Lincoln, Y. S. & Guba, E.G. (1985). Naturalistic Inquiry. Beverly Hills, CA: Sage Publications.

McCann, S. & Weinman, J. (1996). Empowering the Patient in the Consultation: a Pilot Study. Patient Education & Counseling, 27, 227-34.

McWilliam, C.L., Brown, J.B., Carmichael, J.L., & Lehman, J.M. (1994). A New Perspective on Threatened Autonomy in Elderly Persons: the Disempowering Process. Social Science & Medicine, 38, 327-38.

McWilliam, C.L., Stewart, M., Brown, J.B., McNair, S., Desai, K., Patterson, M.L., Del Maestro, N., & Pittman, B.J. (1997). Health Promotion International, 12, 111-23.

Meddaugh, D.I. & Peterson, B. (1997). Removing Powerlessness from the Nursing Home. Nursing Homes, 46, 32-4, 36.

Mok, B. & Mui, A. (1996). Empowerment in Residential Care for the Elders: the Case of an Aged Home in Hong Kong. Journal of Gerontological Social Work, 27, 23-35.

Nystrom, A.E.M. & Segeston, K.M. (1994). On Sources of Powerlessness in Nursing Home Life. Journal of Advanced Nursing, 19, 124-33.

Rice, V.H., Beck, C., & Stevenson, J.S. (1997). Ethical Issues Relative to Autonomy and Personal Control in Independent and Cognitively Impaired Elders. Nursing Outlook, 45, 27-34.

Sharpe, P.A. (1995). Older Women and Health Services: Moving from Ageism Toward Empowerment. Women & Health, 22, 9-23.

Sully, P. (1996). The Impact of Power in Therapeutic Relationships. Nursing Times: 92, 40-1.

Taylor, S. J. & Bogdan R. (1984). Introduction to Qualitative Research Methods: the Search for Meanings. New York: Wiley.

Thomasma, D.C. (1984). Freedom, Dependency, and Care of the Very Old. Journal of the American Geriatrics Society, 32, 906-14.

Tolley, M. (1997). Power to the Patient. Journal of the American Gerontological Nursing, 23, 7-12.

Van Manen, M. (1990). Researching Lived Experience. London, Ontario, Canada: State University of New York Press

Appendix A: Initial Contact Form

Mr. (Ms.) X, my name is Tom Blickle. I'm a nurse getting a graduate degree at Oregon Health Sciences University. I'm working on a study looking at how people view their experience as a hospital patient. I believe .... spoke to you about me. So I'm looking for people to meet with and interview about that. Does that sound like something you'd be interested in?

[If "no"],

Thank you, anyway. I'm sorry to have taken up your time. Good-bye.

[If "yes"],

That's great, thank you. First let me tell you that this study is kept confidential, and that your name is never used at any time or printed in the study. The study looks at how people view their ability to express their needs when they're in the hospital. I'm doing this study as part of the requirements to get my master's degree. And it would involve my meeting with you about two weeks after you're discharged from the hospital and listening to you describe your experience for an hour or at the most two. Are you still interested?

[If "yes"],

Great. Thank you. I need to be able to tape record the interview. Would that be a problem for you? We could meet in your home unless there's someplace else you'd prefer. I'll call you in about two weeks after you're discharged to see if you're still interested, and to set up a time when we can meet. Here is a letter describing the study, and a postcard you can send me if you decide not to participate in the study. Thank you very much. Good-bye

Appendix B: VA/OHSU Research Consent Form

TITLE: OLDER ADULT'S VIEWS ON THEIR ABILITY TO EXPRESS THEIR NEEDS IN THE HOSPITAL SETTING

PRINCIPAL INVESTIGATOR: Thomas Blickle, R.N., M.S. Student

RESPONSIBLE VA STAFF MEMBER: Theresa Harvath, R.N., Ph.D.

PURPOSE and INCLUSION CRITERIA:

You have been invited to participate in this interview because you have been an inpatient at the VA Medical Center or at Oregon Health Sciences University Hospital within the last four months, and are 65 years or older. The purpose of this study is to learn how patients 65 or older view their ability to express their needs while in the hospital. The study involves an interview with the researcher that lasts two hours or less. Duration of participation will not exceed this 2 hours.

PROCEDURES:

If you agree to participate in this study, you will be interviewed at a time and place agreed to by yourself and the researcher. The interview will be tape recorded. It will last 2 hours or less. I will ask you questions about your experience communicating your needs while a patient in the hospital. I will ask you to supply some additional information about yourself, including your age, how much education you have had, and your ethnic origin.

RISKS AND DISCOMFORTS:

Some part of the interview may touch on experiences that may be upsetting to you. You are free to decline to discuss any topics that may be uncomfortable for you. You may choose to stop your participation in the interview at any time. Some people become uncomfortable and nervous when they answer questions about themselves, their thoughts and their feelings. If you become upset during the interview, the interviewer will stay with you if you choose until you are no longer upset. If you would like counseling to discuss the problems or feelings raised during the interview, the investigator will help you arrange this.

BENEFITS:

You may or may not personally benefit from participating in this study. However, by serving as a participant, you may contribute new information which may benefit other caregivers in the future.

ALTERNATIVES:

You may choose not to participate in this study.

CONFIDENTIALITY:

The interview will be tape recorded and written notes will be kept. The tapes will be transcribed, with all personal identifying information deleted in the transcription process. The audio tapes will be stored in a locked file. After the study is complete, the tapes will be destroyed. Personal identifying will be deleted from the written notes. The information you share will be kept confidential. Only the investigators and the faculty consultants will have access to your responses. Any publications will take necessary precautions to protect your identity. These include deletion of personally identifying information. Neither your name nor your identity will be used for publication or publicity purposes. According to Oregon law, suspected child/elder abuse must be reported to the appropriate authorities.

COSTS:

There are no costs involved in this study.

LIABILITY: VA Medical Center

There is no treatment or compensation offered for injury incurred during this study. However, you have not waived your legal rights by signing this consent form.

LIABILITY: OHSU Hospital

The Oregon Health Sciences University, as a public corporation, is subject to the Oregon Tort Claims Act, and is self-insured for liability claims. If you suffer any injury from the research project, compensation would be offered to you only if you establish that the injury occurred through the fault of the University, its officers or employees. However, you have not waived your legal rights by signing this form. If you have further questions, please contact the Medical Services Director at (503) 494-6020.

PARTICIPATION and RIGHT TO WITHDRAW FROM STUDY:

Participation in this research project is completely voluntary and you may refuse to participate and may withdraw from this study at any time without prejudice to yourself or to any future medical care with the VA Medical Center, the Department of Veterans Affairs, or Oregon Health Sciences University Hospital. If you have any questions about this research, or your rights as a research participant, you should first contact Thomas Blickle at (503) 293-3252, or Deborah Messecar at (503) 393-3573. Any patient participating in a study at the VA Medical Center is encouraged to contact Dr. Dennis J. Mazur, Chairman, Subcommittee on Human Studies, to discuss any issues related to their research study participation. Dr. Mazur can be reached through the Research Service, (503) 220-8262, extension 56620.

Your signature below indicates that you have read the foregoing and agree to participate in this study. You will receive a copy of this consent form.

RESEARCH SUBJECT'S RIGHTS: I have read or have had read to me all of the above.

Thomas Blickle has explained the study to me and answered all of my questions. I have been told of the risks and/or discomforts and possible benefits of the study. I have been told of other choices of treatment available to me.

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

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

In case there are medical problems or questions, I have been told I can call Dr. Theresa Harvath at 220-8262 during the day. If any medical problems occur in connection with this study, the VA will provide emergency care.

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

______________________________ ____________

Signature of Subject Date

____

Signature of Witness

____

Witness Name (please print)

____

Signature of Investigator

Appendix C: Sample Interview Questions

1. Why were you in the hospital?

2. What stands out about your experiences in the hospital?

3. Were there times when you were particularly anxious?

4. Can you recall a time when you were in pain? anxious? had to get out of bed? What happened then?

5. What was it like when the doctor came in? When the nurse came in?

6. Were you able to ask for what you needed?

7. Did you feel like you had a say so?

8. Were there times when you felt tongue-tied? too overwhelmed to ask for something you needed?

Probes

9. What was that experience like for you?

10. Can you explain what you mean by that?

11. How did that make you feel?

12. Please continue.

13. So if I understand you rightly, (paraphrase)

Questions Developed as Study Progressed

14. Everyone I've talked to has brought up getting other people in trouble. Did you wonder what would happen to you / to others if you pushed this further?

15. Did you feel like you had other options if you complained?

Appendix D: Demographic Data

Age________

Gender_______

Ethnicity African-American____ Asian-American____

Native American Indian____ Hispanic_______

White_______ Pacific Islander______

Other__________

Marital Status ______

Educational Level_________

Appendix E: Transcriptionist Confidentiality Form

Confidentiality Standards:

1. All information collected on a research participant, including the fact that a person is included in the study, is confidential and shared only with others as appropriate in the conduct of the study.
2. When not in use, all data should be stored carefully in appropriate storage areas.
3. When data are being used in the more public areas of an office, the individual using the data will be careful to protect it from unnecessary exposure.
4. Qualitative data such as transcriptions should not be left on the hard disk of a computer that unauthorized individuals may have access to.
5. Printed copies of such transcriptions should not be left unattended in public office areas.
6. Unusable copies should not be discarded into public area waste baskets or recycling bins, but should be given to the investigator for shredding.

I have read this policy, I have discussed any questions or concerns I have about it with the investigator, and my signature below indicates my agreement to observe it.

Signature ____________________ Date ____________

Appendix F: Potential Participant Contact Letter

OHSU & VA Medical Center, Portland

DATE

Thomas Blickle, a masters student in the School of Nursing at OHSU is doing a study on how patients 65 years or older view their hospital experience. Specifically, this study focuses on how patients view their ability to express their needs while in the hospital.

The researcher mentioned above would like to learn more about your experience while in the hospital. He believes that your experience as a patient can help nurses and other healthcare workers understand how they can better help patients in similar situations.

The purpose of this study is to better understand, from the patient's point of view, his or her experience expressing needs while in the hospital. Volunteers who agree to participate and who meet the criteria of the study will be interviewed once about their experience. The interview will last from one to two hours. All information will be treated confidentially.

About two weeks after you receive this letter, Thomas Blickle will call you to see if you have any further questions and to find out whether you would be still willing to participate. If, after having your questions answered, you want to participate, he will ask you to set up an appointment for an interview with you at a time and location that is convenient to you. If you do not want to be contacted, please return the enclosed postcard.

While the researcher hopes that you will choose to share your story with him, he has assured me that he wants you to feel perfectly free to say no.

With all best wishes,

Patricia Southard, RN, MS

or

With all best wishes,

Theresa A. Harvath, RN, Clinical Nurse Specialist

Appendix G: Potential Participant Postcard for Refusal

A masters student in the School of Nursing at Oregon Health Sciences University is currently seeking volunteers for a study on how patients 65 or older view their hospital experience. Specifically, this study will focus on how patients view their ability to express their needs while in the hospital. Thomas Blickle would like to call you to briefly explain the study and determine if you are interested in it.

If you decide you would not like to participate, please return this postcard within two weeks and no further contact will be made. Thank you.

_______ I do not wish to be contacted.

Signature________________________ Date____________

Agreeing to be contacted does not imply consent to participate in the study. If you agree to participate, you may change your mind at any time without jeopardizing your care from the VA Medical Center or from Oregon Health Sciences University.

Appendix H: Telephone/Initial Contact Script

Hello, may I please speak to Mr. (Ms.) X?

Mr. (Ms.) X, my name is Tom Blickle. I spoke to you in the hospital two weeks ago. I'm a nurse getting a graduate degree at Oregon Health Sciences University. I'm working on a study looking at how people view their experience as a hospital patient. So I'm looking for people to meet with and interview about that. Does that still sound like something you'd be interested in?

[If "no"],

Thank you, anyway. I'm sorry to have taken up your time. Good-bye.

[If "yes"],

That's great, thank you. First let me tell you again that this study is kept confidential, and that your name is never used at any time or printed in the study. The study looks at how people view their ability to express their needs when they're in the hospital. I'm doing this study as part of the requirements to get my master's degree. And it would involve my meeting with you and listening to you describe your experience for an hour or at the most two. Are you still interested?

[If "yes"],

Great. Thank you. I hope you don't mind if I record the interview on a tape recorder. We could meet in your home unless there's someplace else you'd prefer. What would be a good time for you? If you change your mind, here is my phone number-----------. Thank you very much. Good-bye